Putting ‘Sugar Diabetes’ on the Table: Evaluating “The Sugar Plays” as Entertainment-Education in Appalachia

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of the requirements for the degree
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This dissertation titled
Putting ‘Sugar Diabetes’ on the Table: Evaluating “The Sugar Plays” as Entertainment-Education in Appalachia

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Abstract

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Putting ‘Sugar Diabetes’ on the Table: Evaluating “The Sugar Plays” as Entertainment-Education in Appalachia (418 pp.)

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I began this research with a desire to understand the narrative performance of diabetes in Appalachia and the degree to which entertainment-education, specifically theater, can be used to reveal and reshape this performance. First, I wished to understand the pedagogical effects of plays which were comedies that aimed to entertain and educate the audience about type 2 diabetes. Second, I explored the role of the family in negotiating issues around type 2 diabetes. Third, I analyzed how audience members narratively constructed diabetes and ways their personal constructions coincided, collided or merged with the staged narratives; and finally, how social and cultural forces (re)shaped the narrative performance of diabetes.

This study examines diabetes through the lens of social construction and with an interpretivist orientation. My results are gleaned from a variety of qualitative research methodologies which included in-depth interviews, participatory sketching, open-ended questionnaires and informal focus group discussions. These methods were executed after the participants had viewed two plays, Sugar Bear and Lucille, which had storylines about the lived experience of type 2 diabetes in Appalachia. Over an eight week period, a total of 30 in-depth interviews were conducted with residents of six Ohio counties, which formed part of Appalachian Ohio. My findings are based upon the responses and the narratives from the interviews, which were complemented by the participants’
explanations of their personal sketches and open-ended questionnaires. Additionally, responses from focus group discussions were incorporated.

My findings illuminate much about the narrative performance and the social construction of diabetes in southeast Ohio. Among the lessons learned were the importance of family support and healthy eating, one of the seven self-care behaviors advocated by the American Association of Diabetes Educators. Additionally, the narratives from the participants reveal the social construction of diabetes or how the participants perceived diabetes. These stories ranged from narratives of fear to narratives of resistance, among others. The findings indicate that social and cultural forces influence the lived experience of diabetes. The examination of the narrative reality of diabetes must be holistic, incorporating the impact of poverty, tradition and other important cultural factors influencing rural southeast Appalachia. This dissertation positions theater as a viable alternative to be explored in the field of entertainment-education because it is inherently performative and narrative. Essentially, this medium creates the space for learning, narrative telling and reflection. Finally, as scholars, this project reminds us of the centrality of language in communicative interactions.

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eternally grateful because I think I have found a niche after three years of searching. Additionally, both you and Dr. Harter have modeled a love of cooperation between fields of knowledge that I hope to exemplify in the future. Thank you for opening doors and providing information about a culture with which I was unfamiliar. You all rock!

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Prologue

My correspondence with Dr. Sharon Denham began in June 2007. Dr. Sharon Denham of the School of Nursing, Ohio University, was excited about her research on diabetes in Appalachia and was hungry for innovative ways to reach at-risk audiences or persons who were already experiencing diabetes personally, within their families or within their communities. A classmate of mine, Marie Thompson, informed me that Sharon was interested in entertainment-education and would love to have the assistance of a graduate student who specialized in this area. Marie passed on my contact information to Sharon and this was where our correspondence began.

During our first meeting on June 15, 2007, she outlined her overarching plans to work with diabetes educators and community volunteers in Appalachia. One project she was keen on completing within the next year was the writing of at least three plays with storylines on diabetes prevention and management. I recall mentioning that while I had no special playwriting skills, we could contact the University’s School of Theater as a means of assistance. What if we could commission students from the School of Theater to write these plays? We could get them to unleash their creative ideas and we would receive quality work at a level at which we would not have been able to accomplish if we wrote the plays ourselves. With that idea birthed, Sharon immediately made contact with the Head of the Professional Playwriting program at the School of Theater, Professor Charles Smith. From this contact grew a fusion between two Schools that has marked the first part of this project. For the next two quarters, I was assigned to a graduate assistantship at the School of Nursing to help in the completion of this project.
Dr. Denham and I had our first meeting with Professor Smith and several graduate students from the School of Theater in the second week of September, 2007. Sharon eagerly pitched her ideas for the plays to the students, while informing them of the current state of diabetes in Appalachia and the role the plays would accomplish in educating audiences within the region. Eight students were present and most were eager to contribute in some way to helping arrest a health issue which was becoming increasingly out of control within the area. Questions about the disease, the characteristics of the people and the specifications for the play were asked. Sharon made it clear that only three playwrights would be commissioned for a total fee of $1000 each, with $500 being presented upon selection and the rest when the play was completed. Each play needed to have no more than five cast members, minimal props, be no more than 20 minutes in length and have a central theme of family support as the issue of diabetes unfolded. When the plays were completed, they would be placed on a website which would be made available to diabetes community volunteers and diabetes educators. The hope is that the volunteers and the educators would download the plays and regard the plays as alternative activities for educating their targeted audience and for starting a discussion on diabetes and the role of family support. Interested playwrights submitted a portfolio which included their resume and a sample of previous work.

After careful evaluation, based on advice from Professor Smith, Sharon selected three playwrights by mid-October – Dana Lynn Formby, Nicholas Sgouros and G. William Zorn. All three promptly started to conduct research about the disease and the area, and to pen a narrative on diabetes in Appalachia. Each presented three plays –
Sugar Bear (Dana Lynn Formby), A Family Affair (Nicholas Sgouros) and Lucille (G. William Zorn). Over a period of six months, beginning winter quarter 2008, the authors presented their drafts in a total of three open sessions. The scripts were read by acting students in front of a mixed audience. Each play received specific feedback after each reading. Sharon focused on ensuring that the information on diabetes and aspects of the plots were culturally relevant and accurate. The revisions included correcting the number of carbohydrates named in eggs in a draft of Lucille, discussing the fact that taxis sometimes do not operate in rural areas and that a child with a pet turtle may not be likely in rural Appalachia in the first draft of Sugar Bear, and correcting the mention of social security in A Family History which was a play located in the early 1900s.

Finally, in late May, at the end of the spring quarter, during the Playwrights Festival which was organized by the School of Theater, the playwrights had their final reading. This time, they conducted the readings in front of an audience comprising not only their fellow students, both also other students and faculty members from within the Ohio University community, as well as in front of several accomplished Guest Artists in Residence. Among the comments from the artists was the conflict they experience regarding balancing their own creative flow with the requirements from commissioning agencies. Other discussions included the fact that one of the plays, Lucille, was actually an adapted story from the real life experience of its author, G. William Zorn. Right after he had been commissioned to write one of the plays, the project became more personal for Bill, as he found himself literally entering the world of diabetes. During the winter break from school, Bill was diagnosed with type 2 diabetes and as such, penned most of
his experience into the story of the 70-year-old, Lucille. Lucille, like Bill, entered the hospital, almost without her sight and with a high blood glucose reading of 982, a reading which meant she (he) was almost in pancreatic failure. Bill wrote about his interaction with his nurse, who was also named Candy and displayed a witty ability of meeting him toe-to-toe with regards to knowledge about English Literature.

The final presentations of the plays marked the end of a one-year journey. Sharon had now successfully received completed plays which focused on diabetes management and family support (see Appendices A and B for scripts of Lucille and Sugar Bear). Now that the plays were completed, it was time to conduct step two which involved determining the effectiveness of the plays’ messages and evaluate the degree to which the audience could relate with the characters and their narratives. After the plays made their final presentation during the Playwrights Festival, I focused most of my summer on trying to locate a director who would be responsible for selecting cast members and guiding them through rehearsals. A series of emails were sent out to members of the local theater community. I got an enthusiastic response from an alumna of the School of Theater, Merri Biechler. She was instrumental in organizing auditions, locating local actors, organizing rehearsals and providing general guidance on the development of the characters. While there was minimal response from actors to the auditions, this hurdle was soon solved through Merri’s networking savvy within the community. As soon as the actors were selected, rehearsals were conducted and then we proceeded to present the plays to various venues with the hope that the audience would be able to connect with the
characters and that the messages will also resonate with them. And this was how my
dissertation story began.

The rest of the story unfolds with Chapter One, an examination of the extent of
type 2 diabetes in southeast Appalachian Ohio and the rationale for pursuing this study.
Chapter Two provides a two part section which first provides a definition of the disease,
its symptoms and complications, and second, a description of the cultural aspects of
Appalachia with particular attention paid to the value on family. In Chapter Three, I
present the theoretical foundation upon which this study is grounded by reviewing extant
literature and justifying the three broad research questions posed at the end. Chapter Four
highlights the epistemological lens guiding the specific methodological strategies I
employed in this study. In Chapter Five, I present the results from my study. Finally, in
Chapter Six, I address the theoretical and practical implications of the study, drawing
attention to what communication scholars can learn from the findings, explaining the
importance of culturally relevant initiatives and the role of narratives in rural southeast
Appalachian Ohio.
Chapter One: Introduction

The Thompsons were from southeast Ohio. Jerry, the father, was a logger and the breadwinner of the family. He delayed going to the doctor because he could not afford to miss work and since diabetes runs in his family he thought nothing could prevent it from developing. Since the diagnosis, he has worried about the cost of medication, strips for the glucose monitor and diabetes education workshops. Neither he nor his wife, Sarah, a day-care assistant, had health insurance. Sarah knew changing their meals would be difficult since they could mostly afford only canned food which the doctor warned against. “Eat more fresh vegetables,” he said. But fresh vegetables were expensive. For Sarah, her last check-up revealed she had pre-diabetes, that is, blood glucose levels that were high, but not high enough to be diagnosed as diabetes. She could reduce this by changing her diet, but, she did not want to be a burden to her family, so she decided to maintain their usual meal plans. The doctor also told them to talk with their family about diabetes and its complications, such as depression, which Jerry had started manifesting. However, this will be difficult as it had never been a habit to talk about diabetes in their family, even though everyone was aware of its presence. Jerry recognized that for some of his aunts and uncles, diabetes was a thing of shame and for other family members, like his cousins, it was simply too private a matter to talk about.

This fictional and realistic composite story of the Thompsons from rural Appalachia highlighted several areas of concern. First, the narrative emphasized the need for communication initiatives that address the cultural uniqueness of communities in Appalachian Ohio. Second, their story indicated the role of illness narratives and their
potential ability to generate dialogue. Finally, the story illustrated the manner in which an illness, particularly diabetes is perceived and imbued with social and cultural meanings.

As the prologue indicated, three plays were produced in an effort to present diabetes educators with an alternative and culturally appropriate medium through which they could educate at risk audiences about diabetes. These plays targeted residents of Appalachia, with an aim of urging them to interrogate their own narratives of diabetes personally and through dialogue with others. In essence, through the combined work of the School of Nursing and the School of Theater, we now have a means of addressing the three aforementioned concerns: the need for culturally appropriate initiatives, dialogue about health issues and the impact of culturally imbued health narratives. As such, this dissertation explored, through the presentation of two of The Sugar Plays, how diabetes was narratively interwoven into and characterized within the Appalachian Ohio culture and the ways in which the health narratives surrounding this disease construct the perceptions about the disease.

In this section, I outline the current state of diabetes in the United States, looking specifically at the prevalence, the implications for the economy, the family and the individual. I also discuss the current state of the disease in Appalachia and end with a statement of the objectives of the dissertation, the theoretical standpoint I use and the research questions guiding this study.

*Outlining the Problem*

According to the World Health Organization (WHO), approximately 180 million persons have diabetes throughout the world and this number is expected to double by
2030 (World Health Organization, 2006). The WHO goes on to state that approximately 2.9 million deaths per year are attributable to diabetes. The highest prevalence rate across the board is within the 50 years and above age group. In fact, about half of the deaths occur in persons between the ages of 50 and 70 years, with half of this number being women (World Health Organization, 2006). The WHO also warned that if urgent action is not taken, the number of deaths will rise by 50 percent in 10 years.

Diabetes is of a national concern within the United States. Over the years, the prevalence of diagnosed diabetes has increased significantly in the United States (Cowie et al., 2006), in fact, nearly doubling over the past 10 years according to the Centers for Disease Control and Prevention (Kirtland, Li, Geiss, & Thompson, 2008). According to Kirtland et al. the age-adjusted annual incidence of disease between 2005 and 2007 was 9.1 per 1,000 adults, an increase from 4.8 per 1,000 between 1995 and 1997. The same report found startling increases in diabetes in several states throughout the country, mostly in the south, where the incidence rates doubled over the last decade, currently averaging 10.5 per 1,000. West Virginia, for instance, the only state classified as completely Appalachian, had the highest incidence of new case rates, 12.7 per 1,000. The lowest incidence rates were found in the mid-west states, with an average of 7.4 per 1,000. Alarmingly, in some southern states, such as Texas and Florida, the new incidence rate soured by 200% over the 10 year period (Kirtland et al., 2008). However, while there may be concern for the south, there are still other states outside of this region with incidence rates as high as 10 per 1,000, such as Indiana and Arizona. These new
developments are disturbing, because it speaks to the fact that diabetes is not regionally bound, but has a strong connection with lifestyle as well.

The number of diagnosed persons and persons who may have pre-diabetes is cause for alarm. Reports from 2007 indicated that nearly 24 million persons in the United States now have diabetes, which presented an increase of nearly 3 million over the previous two years (Centers for Disease Control, 2008b). At present, that means about 8% of the U.S. population has diabetes and the percentage is growing (Centers for Disease Control, 2008b). This number includes persons who have been diagnosed (17.9 million people) and the estimated undiagnosed (5.7 million people). In essence, about 11% of all persons over the age of 20 in the United States have diabetes. In fact, in 2007 alone, 1.6 million new cases of diabetes were diagnosed within the 20 years and older age group. More specifically, persons with diabetes represent 23% of the 60 years and older age group. This representation also highlights the high incidence of type 2 diabetes, which represents 90 to 95% of all diagnosed cases of diabetes among adults in the United States (Centers for Disease Control, 2008a). This dissertation focused on narratives of type 2 diabetes or in most cases, non-insulin dependent diabetes mellitus.

Indeed, the effects of the disease are extensive. A look into the future should create some cause for alarm for health officials and members of the public. Researchers project that due to the increase in national diabetes incidence, by 2050, there will be approximately 48 million persons diagnosed with diabetes in the United States (Narayan, Boyle, Geiss, Saaddine, & Thompson, 2006). In essence, this means that without any intervention, the country will see a large portion of today’s toddlers and teens merge into
middle-aged persons with diabetes unless there is a health care intervention within the next few years. As such, continuous efforts need to be made toward increasing awareness about the condition, especially within the groups of persons who are at a high risk.

For instance, there is an alarming prevalence in the age group under 20 years and this should draw concern about the possible future of the country. Approximately, 186,300 persons under the age of 20 years, have type 1 or type 2 diabetes (Centers for Disease Control, 2008a). Based on 2002-2003 data, the rate of new cases for type 1 diabetes among youth was 19.0 per 100,000 and for type 2, 5.3 per 100,000. This translates to about 15,000 youth diagnosed with type 1 diabetes yearly and 3,700 youth for type 2 diabetes. Non-Hispanic whites had the highest rate of type 1, with minority youth having the highest rate of type 2 diabetes (Centers for Disease Control, 2008a).

However, of graver concern is not only the increasing number of persons with diagnosed diabetes, but also the number of persons with pre-diabetes, with a majority of these reported cases lying above the 60 years and older age group. In 2006, 26 percent of the population had impaired fasting glucose (IFG) or pre-diabetes, a condition in which persons have above normal levels of blood glucose, which are not high enough to be diagnosed as diabetes (Cowie et al., 2006). In 2008, these numbers were recorded at approximately 57 million (Centers for Disease Control, 2008b). As a result, medical practitioners and health communication scholars need to be sensitive not only to the needs of the diagnosed, but also to those who are on the cusp of developing the disease and are too comfortable with their status.
It is not just the diagnosis which should command our attention, but also the fact that the disease opens the door to a number of complications and accompanies other diseases. For instance, persons with IFG are at a high risk for developing heart disease, stroke, and type 2 diabetes if they do not engage in an alternative lifestyle which allows them to reduce their blood glucose level. The effects of diabetes and its complications are far-reaching, with mortality and morbidity rates recording diabetes as a major contributing factor to deaths in the United States. On death certificates in 2006, diabetes was listed as the seventh leading cause of death in the United States. In 2005, the latest date for which such information was collected, about 234,000 death certificates identified diabetes as a contributing factor (Centers for Disease Control, 2008a). However, researchers still believe that diabetes, as a cause of death is underreported, because persons with diabetes have twice as high a risk of death than persons their own age without the disease.

A great cause for concern is the contributing role of diabetes on the management and emergence of other illnesses. Adults with diabetes, have heart disease death rates two to four times as high as those without diabetes (Centers for Disease Control, 2008a). Also, persons with diabetes have a risk of stroke two to four times higher than those without. In 2003-2004, 75% of those diagnosed with diabetes reported that they take medication for hypertension and possessed blood pressure readings higher than those without diabetes diagnosis. Other complications include diabetic retinopathy which accounts for a majority of new cases of blindness within the 20 to 74 age group and ranges from 12,000 to 24,000 persons annually (Centers for Disease Control, 2008a).
Diabetes accounted for 44% of new kidney failure cases in 2005. In fact, in 2005, the United States and Puerto Rico had approximately 179,000 persons with end-stage kidney failure due to diabetes, living on chronic dialysis or a kidney transplant (Centers for Disease Control, 2008a). Persons with diabetes also suffer from mild to severe forms of nervous system damage. About 60% of those diagnosed with diabetes will suffer from impaired sensation or nerve damage which affects their hands, stomach and even sexual performance (erectile dysfunction). According to the Centers for Disease Control (CDC), about 30% of those with diabetes above the age of 40 years can identify one place on their feet which lacks feeling (Centers for Disease Control, 2008a). This impaired sensation in the feet is the cause of the majority of non-traumatic amputations in the country. In 2004, this number amounted to approximately 71,000 persons with diabetes. Other complications for those with diabetes are periodontal disease, pregnancy complications and diabetic ketoacidosis. Finally, persons with diabetes above 60 years report more difficulty in mobility and in the completion of daily activities, such as household chores (Centers for Disease Control, 2008a).

Based on the complications described above, we find that diabetes is not only costly to the individual, but also to the society in general. In 2007, diabetes cost the country about $174 billion, “including $116 billion in excess medical expenditures and $58 billion in reduced national productivity” (Dall et al., 2008, p. 596). These costs are up from figures posted for 2004 when diabetes cost the country $132 billion annually. In 2004, $92 billion went to direct medical costs, while $40 billion to costs incurred from loss in productivity due to sick days taken or missed days of work (Centers for Disease Control, 2008a).
Control, 2005). Actually, the total cost of diabetes may be more than was estimated and may not be calculable. The figure does not include intangible costs, such as pain and suffering, non-paid caregivers and medical costs associated with undiagnosed diabetes. Then there are the expenditure categories of health care system administrative costs, over-the-counter medications, training programs for clinicians, research and infrastructure development, higher insurance premiums for employees and employers and reduced overall quality of life for family and friends (Dall et al., 2008).

According to the American Diabetes Association, a breakdown of the medical expenses in 2007 revealed that, “medical costs attributed to diabetes include $27 billion for care to directly treat diabetes, $58 billion to treat the portion of diabetes-related chronic complications that are attributed to diabetes and $31 billion in excess general medical costs” (Dall et al., 2008, p. 596). The largest components of medical costs come in the form of hospital inpatient care (50%), diabetes medication and supplies (12%), retail prescriptions to treat diabetes complications (11%) and physician office visits (9%) (Dall et al., 2008). On the federal level, one dollar in every five health care dollars is spent on caring for someone with diabetes, “while $1 in $10 health care dollars is attributed to diabetes” (Dall et al., 2008, p. 596).

While there are direct costs created by diabetes, we also need to be aware of the indirect costs that diabetes incurs on the labor force and the productivity of the nation. Indirect costs include, “increased absenteeism ($2.6 billion) and reduced productivity while at work ($20.0 billion) for the employed population, reduced productivity for those not in the labor force ($0.8 billion), unemployment from disease-related disability ($7.9
billion), and lost productive capacity” which is caused by early death ($26.9 billion) (Dall et al., 2008, p. 596). At the micro-level, the seventh leading cause of death in the U.S. (Centers for Disease Control, 2008a) has a very expensive impact. Persons with diabetes incur medical costs up to 2.3 times higher than what the patient’s costs would have been without the condition. Yearly, individual expenditures amount to $11,744 per person, with $6,649 attributed to diabetes (Dall et al., 2008). Diabetes is a compromising factor in a person’s health, especially if the person is obese or suffers from hypertension (Dall et al. 2008). According to the American Diabetes Association, because of the compromising nature of the disease, persons admitted for general medical conditions, but who list diabetes as a secondary illness, will have slightly longer hospital stays than others without diabetes. These statistics have informed us that diabetes is becoming increasingly prevalent and could indicate a growing familiarity with the disease that may lead to complacency in the preventative and management efforts.

Apart from the general society we also have to investigate how the disease impacts on the micro-level and how this impact is performed and presented. Diabetes affects not only the individual, but also social relationships. One of the most important groups affected is the family which often experiences an immediate effect after the diagnosis. Several researchers have argued for the importance of not ignoring the influence of family processes when a member has type 2 diabetes (Denham, 2003; E. B. Fisher et al., 2002). It is important that we take a look at dietary habits in the home, since disease management generally takes place in this setting and the family plays a large role in the management of chronic diseases (Rolland, 1994; Trief et al., 2003). As the person
with diabetes begins to institute changes, the family is often required to play a supportive role. This comes in the form of accompanying them to diabetes educational seminars, and supporting and participating in dietary changes, monitoring the blood glucose level of the person with diabetes, even also, checking for possible areas of sensation impairment. The disease becomes a part of grocery shopping and meal preparation, even decisions about participating in social activities. The effect is also emotional, as some family members are fearful and endure the mood swings of loved ones who suffer from fluctuating glucose levels (White, Smith, & O’Dowd, 2007).

Family members also impact how the person with diabetes manages the disease (Jones et al., 2008). Studies that have looked at type 1 diabetes found that positive interventions by the family were cost-effective, improved blood glucose levels and overall quality of life (Anderson, Brackett, Ho, & Laffel, 1999; Hanson, DeGuire, Schinkel & Kolterman, 1995). However, while family members can be helpful, they also can create some problems for the person with diabetes. First, they can negatively affect self-management due to a lack of education about the disease (White et al., 2007). Some family members are willing to help, but may not have been able to attend education seminars with their family member. Family members might not be able to help adequately due to a lack of access to understandable information about the disease and its management (White et al., 2007). On the other hand, some family members may be unsupportive and unwilling to access additional information about the disease. In both scenarios, family members can create tempting environments for the person with diabetes, thus making it harder for them to manage their diet or make healthy choices. In
effect, this lack of support and knowledge can result in confusion, ineffective dietary changes, and ultimately, the poor management of the disease. Furthermore, research on diabetes within the family has revealed another disturbing trend which could hinder preventative efforts and compromise the health of non-suspecting family members who are at risk of developing diabetes. There appears to be little discussion of family screening for diabetes (White et al., 2007). While this may be due to a lack of understanding of the hereditary nature of the disease, it also may be due to the fact that some families simply accept the diagnosis as an inevitable development within their families. What this literature (Anderson et al., 1999; Hanson et al., 1995; Jones et al., 2008; White et al., 2007) points to is a need for an analysis of the types of stories of support and lack of support from the family and how the person with diabetes narratively makes sense of this involvement.

At the individual level, for some persons with diabetes, self-management is an immense challenge, as the disease is perceived as hard to control and one causing adverse effects on the physical, psychological and social aspects of life (Debono & Cachia, 2007; Jones et al., 2008). At the heart of this perception is the discomfort with the maintenance of a strict dietary regimen which may be expensive and overwhelming at times and perceived as a loss of control over one’s life. Indeed, the individual’s successful management depends on things such as how much is known about diabetes management, the previous eating patterns, self-efficacy, degree of social support and time management skills (Savoka & Miller, 2001). Nevertheless, a majority of persons with diabetes experience a great deal of psychological distress, such as depression out of a fear of never
being able to fully function independently again due to physical complications (Debono & Cachia, 2007; Gregg et al., 2000). For some persons with diabetes, the coping mechanism has come in the form of faith and family and friends (Jones et al., 2008). Others have taken a laissez faire attitude toward the disease, much to the chagrin of their family members who are concerned about possible complications (White, et al., 2008).

The demands of self-management may lead to frustration over the treatment regimen (Debono & Cachia, 2007). Some of the frustration may even be brought on by the effects of the medication. For instance, a person on a strict insulin regimen may feel restricted and avoid socializing or driving all together, because of the recurrent hypoglycemia which may develop while on insulin (Debono & Cachia, 2007). The effects of hypoglycemia could endanger the life of the person with diabetes especially when driving. Additionally, the frustration could be brought on by family members who push for self-care changes that may be overwhelming. Unfortunately, these demands could lead to a sense of loneliness where the person with diabetes believes that no one else understands the experience totally, because if it were understood, such a tedious self-management routine would not be encouraged. Ultimately, this frustration could also lead to inadequate control, which further heightens the emotional distress of the individual and family. However, what is required is a better understanding of how persons with diabetes organize these experiences and make sense of the diagnosis and the disease, compared with how persons not diagnosed with diabetes perceive this disease and make sense of the needed modifications.
The many concerns linked with diabetes draw attention to the important role of diabetes education in self-management. Education influences not only the prevention of the disease, but also its physical and psychological management. Certified Diabetes Education focuses on the patient’s everyday management of the lived experience with diabetes, emphasizing autonomy and independence (Debono & Cachia, 2007). However, unfortunately, self-determined goals may be compromised by diabetes-related distress which hinder the person with diabetes from feeling empowered enough to address the problem. Additionally, current strategies would have to be rethought before being applied within Appalachian Ohio which has a group-oriented culture, which will be elaborated on later (Denham, 1996; Isserman, 1997).

Various groups of persons throughout the U.S. are at high risk for developing diabetes. Among these are African-Americans, Hispanic-Americans and Native Americans (Centers for Disease Control, 2008a). Apart from these ethnic groups, persons in the Appalachian region also face high risks. About 24 million persons live in the 420 counties in the Appalachian region. This 205,000 square mile region runs from New York to northern Mississippi, with 42% of the population being rural compared to the national average of 20% (Appalachian Regional Commission, n.d.a). With regards to chronic illnesses, Appalachia has the third highest overall death rate in the United States. The CDC goes on to state that 25% of the deaths from chronic illnesses in the region could have been avoided if persons had adopted healthier lifestyles. The region has the ninth highest obesity rate in the country. Heart disease as well, which is a major
consequence of diabetes, is also consistently higher than the rest of the country (Appalachian Rural, 2006a; Centers for Disease Control, 2001).

The high prevalence rate in Appalachia did not go unnoticed in the latest findings from the CDC (Centers for Disease Control, 2008b). In fact, while mention was made of the south, CDC researchers also pointed to the fact that prevalence in the Appalachian region has increased over the years (Centers for Disease Control, 2008b). West Virginia, for instance, the only state that is completely Appalachian records the highest rate of new incidence throughout the entire country.

While the Mid-west recorded the lowest levels, several counties in Ohio, the site of this dissertation research, recorded levels that were higher than the national prevalence rate (Centers for Disease Control, 2008a, 2008b). A healthcare needs assessment survey conducted in 2006 by the Appalachian Rural Health Institute found that there was an average 11.3% prevalence in counties serviced by this organization and this rate was higher than the state and national prevalence rates which are about 8% (Appalachian Rural, 2006b). Within Appalachian Ohio, all the counties, except for one, Athens (6.9%), recorded prevalence rates higher than the national average. Some rates were as high as 10.6 percent (Mahoning County) (Centers for Disease Control, 2008a). A disquieting finding is that the likelihood of diagnosis within Appalachian Ohio increases as age increases (Appalachian Rural, 2006b). While only 6% of persons with diabetes statewide and nationally were diagnosed before the age of 21, within Appalachian Ohio, this rate rose to 13%, with the rate almost tripling to 25% in Morgan County (Appalachian Rural, 2006b). A startling correlation is the fact that as the rate of obesity increased in the
region, so did the rate of diabetes. Indeed, the region is in need of special attention before the situation becomes unmanageable.

One cultural value to take into consideration is the role of the family. Purnell and Paulanka (2005) observed that family ties were so valued in Appalachia that elders often live close to children and grandchildren. Because diabetes management is most likely to take place within the home, it is important that we investigate how intergenerational dietary patterns are perceived and even challenged by family members. In some families, existing intergenerational stories often perpetuate unhealthy eating habits (Denham, Manoogian & Schuster, 2007).

Educational initiatives need to address the challenges of balancing a healthy diet with the needs of the family in the Appalachian region. As previous research indicated, paradoxical family relationships arise due to the disease (White et al., 2007). While family members have been found to be invaluable in reminding persons with diabetes about medication and monitoring levels, they can also be a source of stress and worry (White et al., 2007). Persons with diabetes in this region also confront the temptation to indulge and overeat, when family members bring in treats high in sugar, such as cookies and sweets. However, some learn the importance of self-accountability and self-efficacy in these situations as was revealed in a study on how women with diabetes in Appalachia manage low glucose levels (Magness, 2007). This reliance on the family requires that we investigate communication initiatives that incorporate this group and their narratives. As this section indicated, diabetes is a growing concern for the economy, the family and the individual. The prevalence of the disease has grave implications for self-management,
prevention and the perpetuation of intergenerational stories. In the next section, the implications for communication scholars and health practitioners are examined.

Implications for Communication Scholars and Health Practitioners

Despite these startling figures and socio-cultural information, some good news is on the horizon. Education about diabetes has been growing and the effects are tangible. The CDC reported that the percentage of persons who do not know that they have diabetes has decreased from 30% to 25% between 2006 and 2008 (Centers for Disease Control, 2008b). Additionally, for those with diabetes, there has been a decrease in the number of hospitalizations, in the rate of cardiovascular disease, and in the prevalence of visual impairments (Centers for Disease Control, 2008a). This information speaks well of the effectiveness of public education programs about diabetes. This could mean that more persons are becoming aware of the symptoms of diabetes and are seeking medical assistance in diagnosing the disease earlier and learning how to better manage the disease. While this dissertation acknowledges these strides, still more needs to be done as some of these public education initiatives are not appropriate for all cultural populations.

A need for more consistent promotion of specific lifestyle interventions especially within the population of persons who are at great risk of developing diabetes still exists. Special attention needs to be paid to the predictors or instigators of diabetes, particularly of type 2 diabetes. For instance, a major predictor of diabetes within the United States is obesity (Kirtland et al., 2008). Therefore, among the messages needed are the importance of weight loss, coupled with moderate activity and a balanced diet (Centers for Disease Control, 2008a). Research has also pointed to the heavy reliance on foods high in
carbohydrates and sugars as one of the sources of the problem. However, we also need to be mindful that human health develops in an interdependent and interactive ecosystem which comprises physical (abiotic), biological (environment) and cultural components (McElroy & Townsend, 2004). Therefore, if there is a change in one component of this ecosystem, the other components will also be affected. That is, if something happens within the culture within which an individual resides, for instance, the development of a busy schedule or the lack of convenient shopping or the acquisition of a sedentary job, then this will affect the other aspects of life that are connected to his or her physical health. In essence, the health communication practitioner cannot ignore the presence of social and cultural forces which surround an individual’s life, as these impact how that person will perform health sometimes (Denham, 2003). Indeed, these factors must be addressed in any initiative dealing with diabetes education. If not, we will be doing a disservice to Appalachians and persons with diabetes in general.

The CDC has issued a call for programs that demonstrate that diabetes is both preventable and controllable. Several messages need to be disseminated. Research findings indicate that simple lifestyle changes can reduce the onset of type 2 diabetes by 58% among persons with pre-diabetes (Knowler et al., 2002). These changes can include losing about 7% of one’s body weight, and conducting at least 150 minutes of physical activity weekly (Knowler et al., 2002). Another message is that disability and death are not expected outcomes of the disease (Centers for Disease Control, 2008a), especially when the patient is working in collaboration with a strong support system, like the family and a medical practitioner who help monitor proper glucose levels. Proper control of
these levels can reduce the risk of the development of complications like kidney disease by 40% (Centers for Disease Control, 2008a). However, literature on diabetes management infers that these messages must be complemented by other messages on self-efficacy (Serrano, Leiferman, & Dauber, 2007) and family support (Denham, 2003; Purnell & Paulanka, 2005).

In essence, communication initiatives which focus on diabetes must be clear and culturally-fitting. While the messages and the effects disseminated must be correct, the portrayal of the cultural and lived experience of the target audience must also be correct or appropriate and not appear illogical or culturally out of place. The message must be complete, providing the total picture of the illness, the prevalence, the effects and the possible treatment options. The information must also be concise enough that it is not overwhelming. And finally, the information needs to be compelling and capable of holding the attention of the audience and possibly instigating dialogue, a change in perception and even a call to action. While the aforementioned strategies are important in the presentation of information on diabetes prevention and management, they are also all qualities needed for a successful entertainment-education product (de Fossard & Riber, 2005), which was the communication framework used in this study to explore narratives of diabetes performance. Additionally, theater is an alternative context suggested for the presentation of diabetes information in communities.

**Theoretical Standpoint**

An examination of the current state of diabetes in the United States reveals two types of stories: those of proper care and management and those of failure and
resignation. Diabetes educators and institutions like the CDC are realizing that while they have succeeded in disseminating stories of success, other stories exist that hinder efforts for prevention and proper care. It is within this paradoxical narrative environment that this research is based.

Over the years, increasing attention has been give to the role of narrative within the field of communication and especially within the area of health communication. In fact, Bruner (2002) exhorted us that, “we should not write off this power of story to shape everyday experience as simply another error in our human effort to make sense of the world…” (p. 7). Essentially, he argued that stories should not be trivialized but recognized for their role in lived experiences, especially with regards to illness. In fact, it is through narrative that we understand later life experiences, referring to “events and things and people by expressions that situate them not just in an indifferent world but in a narrative one…” (Bruner, 2002, p. 8)

According to Babrow et al. (2005) “…a narrative approach [to understanding illness] privileges the particularities of individuals’ lives and attempts to understand how specific persons in particular times and places describe their experiences of living their lives.” (p. 33). Therefore, by privileging the narrative, we focus on the individual experience and his or her understanding of that experience at a given time. The emphasis is on the meaning associated with the experience and the implications of that meaning on one’s health and interactions with others. It is this understanding that helped to guide this dissertation and to evaluate the meaning associated with diabetes within Appalachia.
This dissertation illustrated that by focusing on the “meanings that people attribute to their experiences as they construct narrative accounts,” (Babrow et al., 2005, p. 34) we have to shift our attention from universal truths about an objective reality of an illness and embrace the “subjective experiences of individuals” (Babrow et al., 2005, p. 34). By taking this stance, we find that by embracing these subjective experiences, we begin to understand the varied interpretations and performances of diabetes. As such, this assertion forces us to consider the relationships individuals form between separate events, which may not be linear in nature and how these relationships affect the perception of a disease and its management (Babrow et al., 2005; Bruner, 1996; Leondar, 1977; Mishler, 2006). We can see that these relationships are usually described in a narrative form. Additionally, a narrative framework is useful because of its sense-making utility in understanding what happens “…when unexpected, unpleasant, ambiguous, or uncertain bodily experiences challenge what had previously been taken for granted or when we experience our body in significant new ways” (Babrow et al., 2005, p. 45). Unfortunately, it is sometimes the unpleasant experience of illness, whether personally, or through a loved one that brings into perspective our interpretation of our reality and the illness and it is at this juncture that this dissertation begins its interrogation.

Several reasons exist for utilizing entertainment-education as the narrative medium through which diabetes is explored. First, narrative builds a complex mix of realities or spacialities. Within this mix, the text creates a world within which the teller, the reader and the characters live (Babrow et al. 2005), and it is this world that will be at the heart of the research. Second, the plays are also able to depict narrative progression
over time. The narrative helps to share the person’s own reconciliation, if any, with the disease over a period of time. The narrative indicates change, from resistance to embrace, as was depicted in the plays.

Finally, this dissertation utilized the narrative standpoint as a means of locating communication within the discourse of diabetes. The narrative standpoint draws our attention to the centrality of language (Berger & Luckmann, 1989; Brumett, 2000; Burke, 1968) and the performative narrative of illness narratives in particular (Conquergood, 2004; Peterson & Langellier, 2006). It is hoped that the plays may instigate the authoring of new stories about diabetes and thus, a new understanding of the disease (Babrow et al., 2005). Furthermore, the acted-out, performed narrative has the ability “to express ideas concealed in the everyday conventions of thinking and telling about things” (Bruner, 2002, p. 22). In essence, narrative opens up possible worlds within the mundane.

Objectives of the Study

In sum, with all this information on the state of diabetes provided, it is clear that health educators and health promoters need to develop strategic interventions for stemming the rising tide of diabetic diagnosis. One way to do so is to carefully examine and evaluate health behaviors in the cultures in which they work to determine how rooted are these behaviors in the cultural values and beliefs of the people (Airhihenbuwa, 1995). A lack of knowledge about these behaviors can hinder or sabotage the effectiveness of any planned health promotion or health education campaign. Sometimes the blame for the failure of a health initiative is placed on the target community. However, the health promoter bears the responsibility for determining culturally sensitive ways to meet the
needs of the target community (Conquergood, 1988). Of interest to this dissertation was the way in which the culture of a society affects the narrativized health of an individual, families, and ultimately, a community.

This dissertation outlines a plan to explore a particular cultural initiative within the Ohio Appalachian region. This cultural initiative is the presentation of two plays, *The Sugar Plays*, which each have central storylines on diabetes pertinent to residents of the Appalachian region. Originally written as tools for diabetes educators, the intent of this study is to determine whether this initiative, which caters to the storytelling nature of the culture (Caldwell, 2007), will potentially be an effective stimulus for initiating dialogue about diabetes. Overall, the dissertation seeks to draw a coherent thread between culture, health, perceptions of illness and the use of narratives to address diabetes in southeast Ohio. As such, this research was guided by an overall question – How can a creative, yet traditional communication initiative spur narratives and dialogue and potentially effect changes in the perception of diabetes?

Specifically, this study focused on (1) the messages the audience recalled from the plays and how they acted as a means of entry into the discourse on diabetes; (2) the kind of narratives that emerged from the audience after viewing the plays; and, (2b) how these narratives connected with those in the plays and demonstrated a construction of diabetes; and, finally (3) how the audience perceived the lived experience with diabetes in the culture of the region.

This study utilized interpretivist and participatory methodologies to uncover the three aforementioned areas of focus. The findings were based on audience responses
gleaned from presentations of two of the plays, *Lucille* and *Sugar Bear*, at five venues in southeast Ohio, during the fall of 2008. The research was based on qualitative methodology, including, in-depth interviews, participatory sketching, open-ended questionnaires and focus-group discussions. The study was also grounded in social constructionist theory, specifically focusing on the narrative construal of reality and the intersections of narrative and performance. Based on the theoretical standpoint of the centrality of language in our lives, this study presented the use of theater as a means of exploring and challenging the narrative discourse on diabetes and the construction of diabetes in southeast Ohio.

*Summary*

This chapter provided a brief description of the current state of diabetes in the United States and Appalachia, with an overview also provided of the state of diabetes in southeast Ohio, which falls within Appalachia and serves as the focus of this study. Overall, this section provided a rationale for the study by outlining the problem and providing research which called for specific strategies to address the prevalence of diabetes. Also, attention was drawn to the theoretical and epistemological orientations which will guide this study.
In this chapter I describe in detail two main areas of focus for this study. First, I provide an overview of the discourse on diabetes at the national level as well as within Appalachia. Second, I provide an overview of the culture of Appalachia, covering its geography, stereotypes and how these have been challenged. Finally, I end with the impact of diabetes in Appalachia and the discourse on this disease within the region.

_Introducing Diabetes: Discourses on an Epidemic_

In this section, I focus attention on discourses of diabetes, starting with a description of the illness, its development and current concerns about its state in the nation. Then, I highlight the state of the disease in the region of Appalachia. As I move through this section, I illustrate how this discourse calls us to explore how the social and narrative construction of reality within a certain culture frames individual narratives of diabetes. These theories will be more extensively explained in the next chapter.

According to the Centers for Disease Control and Prevention (2008a), diabetes is “a group of diseases marked by high levels of blood glucose resulting from defects in insulin production” (p. 1). There are three main types of diabetes: type 1 diabetes, type 2 diabetes and gestational diabetes. Type 1 diabetes, previously known as insulin-dependent diabetes mellitus (IDDM) or juvenile-onset diabetes occurs when the body destroys pancreatic-beta cells which are the only cells in the body capable of producing insulin that regulates blood glucose. Usually prominent in children and young adults, this type will require that persons have insulin delivered through an injection or a pump. Type 1 diabetes accounts for 5% to 10% of all cases of diabetes in adults.
Gestational diabetes is diagnosed during pregnancy and is a form of glucose intolerance. This type occurs most frequently among obese women and women with a family history of diabetes (Centers for Disease Control, 2008a). During pregnancy, women diagnosed with gestational diabetes must have their glucose levels regulated to avoid endangering the infant. Immediately after pregnancy, 5% to 10% of the women will usually have type 2 diabetes, with 40% to 60% more likely to develop type 2 in the next 5 to 10 years.

Type 2 diabetes, which is the form on which this study focuses, is also called non-insulin-dependent (NIDDM) or adult-onset diabetes. Type 2 diabetes accounts for 90% to 95% of all adult cases of diabetes. The disease begins as an insulin resistance, “a disorder in which the cells do not use insulin properly” (Centers for Disease Control, 2008a, p. 1).

The following is a brief description of what happens in the development of diabetes. Each time we eat, our bodies react by releasing insulin to provide glucose with access to the cells that are in need of energy. However, due to the surplus of glucose in our system, the cells begin to transform and reduce the number of insulin receptors on the surface of the cell (Boaz, 2002). So, the amount of glucose entering the muscle or fat cell decreases because of this change in the cell. This action makes the cells become insulin-resistant. As a result, the amount of glucose entering the cell is reduced, meaning that more glucose remains in the blood. As the need for insulin arises, the pancreas gradually loses its ability to produce it and eventually, the individual has to rely on insulin injections in order to maintain a glucose supply to the cells.
Diabetes is caused by a combination of factors which result in elevated blood glucose levels (Cypress & Gleeson, 1992; Eaton, Shostak & Konner, 1998). Among these conditions are genetic predispositions. Several populations at risk for this disease: older persons, persons with a family history of diabetes, and those of certain race/ethnicity. Among those most at risk are African-Americans, Hispanic/Latino Americans, American Indians, some Asian Americans, and Native Hawaiians or other Pacific Islanders (Centers for Disease Control, 2008a). Other conditions are more as a result of biological conditions and life choices. For instance, women with a history of gestational diabetes are at a high risk for developing diabetes and persons who are physically inactive or obese are more likely to develop an impaired glucose metabolism (Boaz, 2002; Centers for Disease Control, 2008a).

A majority of persons with diabetes have type 2 diabetes. As the person ages, their insulin deficiency becomes progressively worse (Cypress & Gleeson, 1992). There is a strong genetic link among persons with type 2 diabetes. However, excess weight and the sedentary lifestyles of modern civilization have played important factors in the occurrence of diabetes. Researchers have found a growing number of links between obesity and diabetes (Centers for Disease Control, 2008a; Eaton et al., 1998), resulting in a greater promotion of weight loss through diet or exercise as one of the strategies for beating diabetes. However, even after a diabetes diagnosis, while weight loss can restore insulin secretion, it does not fully restore insulin sensitivity.

Several symptoms are associated with diabetes. A list provided by the American Diabetes Association names the following as the main signs – frequent urination,
excessive thirst, extreme hunger, unusual weight loss, increased fatigue, irritability and blurry vision (American Diabetes Association, n.d.a). Some of these symptoms seem harmless, but early detection can prevent the development of serious complications. After the diagnosis, several complications usually accompany diabetes, because of the progressive effect of abnormal glucose levels in the blood stream. Among the complications are heart disease and stroke, kidney disease, eye problems, nerve damage, foot and skin complications, gastroparethesia (abdominal bloating and heartburn are some signs), depression and Charcot’s syndrome (joint damage) (American Diabetes Association, n.d.b, n.d.c) Insulin is the most popular treatment used to control glucose levels. However, new treatments such as pramlintide and inhaled insulin are being introduced to the market to maintain blood glucose levels (American Diabetes Association, n.d.d). As the newly diagnosed begins to learn about the condition their perception of themselves and how others perceive them undergoes several changes.

Progressing on to diabetes is not an inevitable fate for persons with pre-diabetes. Diabetes can be delayed and prevented by implementing certain lifestyle interventions, such as, increasing exercise, and changing one’s diet (Knowler et al., 2002). This intervention becomes even more important because according to Narayan, Boyle, Thompson, Sorensen, and Williamson (2003), one in three Americans born in 2000 will develop diabetes in their lifetime. This raises concerns for the effects on the future population, the labor sector, and the health care system of the country, as, diabetes is the leading cause of adult blindness, lower-limb amputation, and kidney and nerve damage,
with about two-thirds of persons with diabetes dying from heart attack or stroke (Centers for Disease Control, 2008a).

In this section, I presented an overview of diabetes and the current discourse surrounded the diabetes. In the following section, I introduce Appalachia, the nuances of its culture and how this culture impacts the understanding of diabetes.

*Introducing Appalachia: Connecting Culture and Health*

Appalachia is a Native American word meaning “endless mountain range” (Appalachian Regional Ministry, n. d.). For years, the region has been bombarded with unfair stereotypical portrayals and these have been reinforced with the scholarly and popular culture realms. Within this section, I reflect on the geographical placement of the region, the portrayal of the region over the years and the attempts made by scholars to correct that depiction. I also review the effect of the economy of the region, the presence of poverty and illiteracy and the impact these have on the health of the people. I also briefly introduce the culture of the region and finally, present a brief overview of Appalachia in Southeast Ohio.

*Geography and Cultural Overview*

Appalachia includes all of West Virginia, and parts of 12 other states: Alabama, Georgia, Kentucky, Maryland, Mississippi, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Tennessee, and Virginia (Appalachia Regional Commission, 2002). Appalachians range in ethnicity, including Native American, Irish, Scotch, English, German and Pole (Appalachian Regional Ministry, n. d.).
The wide geographic nature of the region indicates that the region is heterogeneous in nature, contrary to past portrayals. This area hosts a variety of locales, including the rural townships of West Virginia and the bustling metropolitan county of Allegheny which houses the Steel City of Pittsburgh. Over the years, the media, as recorded in issues of the *Appalachian Journal*, research scholars (Cattell-Gordon, 1990; Caudill, 1969; Fischer, 1989; Weller, 1965) and popular culture have deemed that the geography has isolated the region from the influences of other forces. However, other scholars (Eller, 1982, 2001; Tice & Billings, 1991; Wilhelm, 1977; Williamson, 1995) have refuted this claim, stating that while the mountains may have played a role in the type of culture that developed, the people are no more separate or distinct from other regions and other groups of people within the country.

Furthermore, the region has a rich culture that is characterized by a sense of “Appalachian pride” (Denham, 1996). With this pride comes a sense of self-sufficiency which is a validated need to take care of self and family. With regards to health this self-reliance can be a constraining factor, as some persons would prefer to wait and self-medicate before visiting the doctor. In fact, as part of this self-medication, persons may use prescriptions from other family members (Denham, 1996). This is especially true for persons with diabetes, where this sense of self-sufficiency could lead persons to refuse the help of others or loved ones who could serve as accountability partners as they embark on the road to recovery or management of a disease.

Other cultural themes related to family health, such as the role of the mother and the extended family will be discussed later in this introduction. An examination of the
cultural fabric of the region has also revealed a strong connection between health and faith, religion or spirituality (Coyne, Demian-Popescu, & Friend, 2006; Denham, 1996; Lowry & Conco, 2002). Health and illness were described in relation to God and faith was considered beneficial for healing (Coyne et al., 2006; Denham, 1996; Lowry & Conco, 2002). Indeed, God was seen as a source of good health. However, as the interwoven and colorful fabric of Appalachia has been outlined above, the region has struggled with and is still contending with stereotypical representations of the region.

Representations of Appalachia

Over the years, the view of the peoples of this region within popular culture, within the academy, and within the arts has often been monolithic, pejorative, and has largely gone unquestioned. There have been generalized and abstract assertions and descriptions of the region in everyday writing and publishing over the years. For instance, in describing the state of West Virginia, Headley (2007) stated that, “older cultural, social, and economic conditions tend to survive – even thrive – in the mountains” (paragraph 25).

Other representations have appeared in the fictional literary world as well. For instance, Chuck Palahniuk (2007), author of the novel, turned movie, Fight Club, released another narrative recently, Rant, where the main character is Rant Casey, “a hillbilly of extraordinary charisma” (Colvile, 2007, paragraph 4). Palahniuk writes that Rant spends his time looking for creatures to get bitten, rather than sleeping with girls and moms, as normal Appalachians do. This example demonstrates that stereotypes of
Appalachia and the behaviors of the people of this region continue to be perpetuated well into the twenty-first century, especially if the characterization leads to profit.

The same stereotypical treatment has been observed within academia. Cattell-Gordon (1990) described Appalachia as a “traumatized culture” (p. 55). The effects of the culture, he asserted has produced a “culturally transmitted traumatic stress syndrome” (p. 47) which is passed down through the generations, creating a group of persons who were withdrawn, depressed, indifferent, and resigned.

Also, one of the most controversial and highly criticized cultural representations of the region in the arts world was the production of Robert Schenkkhan’s Pulitzer prize-winning play, *The Kentucky Cycle*. Appalachian scholars have taken offence to the fact that the author, after conducting very little research in Kentucky, created a composite of characters within three interrelated families that illustrated the extraordinary poverty of the economy and the environmental abuse within the region. The play has been faulted for its inaccurate historical recollection of the development of Kentucky and the demeaning representation of the Appalachian people.

*Challenging those Representations of Appalachia*

Several responses have been made to the stereotyping of Appalachian peoples, particularly as represented in Schenkkhan’s play. Documented in the text, *Talk back Appalachia: Confronting stereotypes*, several authors have decidedly presented their own lives and varied identities as Appalachians as a refutation to the play. They attempt to challenge overt and implicit regional stereotyping and to “provide insight into the operations of cultural power and ideology in America that such stereotyping signifies”
(Billings, 2001, p. 4). The writers within the text addressed stereotypes ranging from a
description of the people as mountain-people, unexposed, who engage in inter-family
marriage, greedy and as savages, the most primitive forms of American life.

The representation of Appalachia began through early writings of missionaries,
local colorists, educators and social reformers and industrialists in the late eighteenth and
early nineteenth centuries (Lewis, 2001). Lewis stated that an examination of nineteenth-
century Appalachia will reveal that the area was not any more economically isolated or
homogenous than the rest of the country. However, literary writing has portrayed this
region in a certain manner over the years, insisting that the reality of which it writes is
true. Early fiction gave preference to rural and remote sections of Appalachia, resulting in
these sections being declared as representative of the whole and as such providing the
picture that the region was homogenous in nature. Unfortunately, this tradition remains,
as can be seen the play, *The Kentucky Cycle*. Ledford (2001) also examined the early
writings of the settlers and noted that even though the first inhabitants were upper class,
propertied explorers, as soon as they began to recognize the value of the land and its rich
resources, the images of a wild and untamed region were also transferred to them.

Several scholars have used their voices to talk about their own personal
experiences in Appalachia as a means of dispelling stringent stereotyping. Giardina
(2001), a native of eastern Kentucky, in sharing the story of her family’s entrance and
presence in Appalachia noted no form of abnormality after reflecting on their stories and
photographic images which were passed down over the ages. Instead, she found a
dignified and hospitable people who welcomed strangers, a sharp contrast to the lurid and
violent stories told by writers over the years. S. L. Fisher (2001) also talked about the shame he felt by being labeled an Appalachian in his youth, and how, as a result of that shame, took part in costume parties as an undergraduate where he reinforced the stereotype of the hillbilly in drunken stupors, in order to be accepted by his peers. However, as he grew older and began to listen to others from the land of Appalachia speak with pride of their heritage and achievements he too began to embrace the identity. Hall (2001) refutes the stereotype of hillbilly-as-victim as she recounts her own rise from poverty and institutions of dominance in the region. Regarding the portrayal of health in Appalachia, Anglin (2001) noted that the tales that are often told resonate with centuries old representations of the region as being “broken,” and in dire need of fixing. Anglin argued that these perceptions, sometimes mixed with sympathy and stereotype, may be told by medical practitioners and writers who are not native to the region and often go unchallenged because of their clinical experience.

In other academic work, anthropologist, Kathleen Stewart (1996) attempted to move away from stereotypes of Appalachia in her documentation of her two-year stay in West Virginia in the 1980s. While she acknowledges that her account can in no way be regarded as completely representative of the total reality of Appalachia, she offered a narrative space to the people, recounting their stories and their experiences. While her work honors the everyday narratives of these people, there is still a sense that the region is placed as an ‘other,’ a contrast to the American mainstream. Nevertheless, while scholars work to eliminate misrepresentations of Appalachia, unfortunately, their efforts may be hampered by the region’s economy.
Economy in Appalachia and Appalachian Ohio

In order to gain a better understanding of why diabetes may be of such grave significance in this region, it is important to look at the economy and the effects on the income of the people. According to Isserman (1996), inadequate job opportunities are part of the region’s problems. In the past, the region was heavily dependent on industries such as mining, oil, coal, and timber (Appalachian Regional Ministry, n. d.) which provided the bulk of employment. However, changes in the mining and agricultural industries nationwide in the 1950s began to impact those industries in the region. Whole coal mining counties, for instance, lost almost half of their populations over a 20 year period (Isserman, 1996). In the late 1970s and 1980s, the situation in the industries was even more exacerbated by international economic restructuring (Isserman, 1996), thus resulting in more decline in the industries and ultimately a loss in jobs.

Today, industries such as the coal mining industry have suffered a continuous decline due to the emphasis on alternative more environmentally friendly fuels (Appalachian Regional Commission, n.d.b). Now, the economy is diverse and increasingly more dependent on service industries such as tourism, retailing and government. This diversity in economy is evident throughout the region. For instance, within the coal-rich mountains of eastern Kentucky, there is an enthusiastic exploration of the possibility of implementing adventure tourism (Jafari, 2007). This new income generator hopes to take advantage of the rough terrain of the region by marketing such activities as whitewater paddling and rock climbing within economically depressed counties in eastern Kentucky. In essence, over the years, some counties have adjusted to
the changing demands of the national and local economies and have diversified their industries. On the other hand, some are still adjusting, while others are still severely distressed and suffering from a lack of basic amenities (Appalachian Regional Commission, n.d.b). The lack of or the poor quality of income generating activities within a community, can adversely impact the health of its members, especially if the community is plagued by poverty. Without adequate income, for instance, individuals will not be able to maintain good quality health.

According to 2000 Census reports, the poverty rates in Appalachia had begun to converge with that of the nation, moving down to 13.6% in Appalachia, in comparison to 12.3% for the rest of the country at that time (Lichter & Campbell, 2005). In fact, within the 1990s, a majority of counties in Appalachia reduced their poverty rates. These numbers indicate a decline in poverty rates throughout the 1990s. However, there is a geographical difference within Appalachia, which further highlights the plural and non-monolithic nature of the region. The northern and southern sub-regions have significantly lower poverty rates (12.8%) than central Appalachia (21.1%) (Lichter & Campbell, 2005). In essence, central Appalachia had a poverty rate of nearly twice that of the national average. Still, Lichter and Campbell noted that poverty within the region cannot be defined solely on the income. Within distressed communities, poverty is manifested “in dilapidated and crowded housing, lack of plumbing and clean running water; limited access to public utilities, social services and medical care; geographic isolation born of poor transportation systems; and inadequately staffed and poorly funded schools” (p. 5).
A similar situation can be evidenced in parts of Appalachian counties in Ohio. Ohio has 32 counties that are classified as being in the Appalachian region (Appalachian Regional Commission, n.d.a). Each displays unique and similar characteristics that have been impacted by the economic situation within the counties. Southeast Ohio, specifically, has struggled with economic challenges and poverty. The U.S. Census Bureau figures from 2007 indicated that these counties had poverty rates (Athens, 29.4%; Scioto, 20.6%; Morgan, 20.2%; Meigs, 19.8%; Vinton, 18.9%; Hocking, 16.0%; Noble, 16.4%) that were higher than the overall state average (13.1%) and national average of 13.0% (U.S. Census Bureau, 2009).

Poverty has a far-reaching effect throughout Appalachia. The health of the residents is one of the areas most gravely affected, with residents in Appalachian Ohio experiencing less access to various health care facilities in comparison to other Ohioans (Denham & Rathbun, 2005). Perhaps the most striking observation is the fact that four of the counties in Appalachian Ohio (Athens, Hocking, Pike and Vinton) have been declared by the Health Resource Service Administration (HRSA) as health professional shortage areas in primary and mental health care. Each of these counties, except for Hocking County, also has shortages in dental health care. Noticeably, two of these counties are located within southeast Ohio (Denham & Rathbun, 2005). This status means that within these counties there is a population to primary care physician ratio of 3500 to 1 or higher. As such, the primary care physicians are either overused or inaccessible to the population. Fewer health care programs are available to the children and other residents in comparison to the rest of the nation (Denham & Rathbun, 2005). As a result, more
residents of Appalachia in comparison to the rest of the nation have poorer health practices, limited health care opportunities and little or no preventative care. Therefore, the high prevalence of chronic diseases, such as diabetes, within these counties should not be surprising (Denham & Rathbun, 2005).

Connected to poverty in Appalachia are high levels of oral and written illiteracy. Research has found that low levels of literacy are a strong predictor of a person’s health (Foulk, Carrolli, & Wood, 2001). A low literacy level compounds an individual’s ability to make informed decisions about health and health care for themselves and their family. This is especially crucial for persons with chronic diseases, such as diabetes. Persons with diabetes need to know how to modify their lifestyle, alter diets, and monitor blood glucose levels. Therefore, the treatment process and compliance will be hampered if the patient cannot read, understand or act on the information provided about the disease. In a 1996 survey conducted by the Ohio State University Agriculture Extension Agency, 50% of persons in Hocking, Pike and Vinton Counties had reading Levels 1 and 2, and are considered functionally illiterate by the National Adult Literacy Survey. Denham and Rathbun (2005) noted that, a Level 1 reader has difficulty reading printed materials and will regard themselves as a poor reader. A Level 2 reader has low test scores, but may not always regard themselves as poor readers. In Athens County, less than 45% of those surveyed were Level 1 and 2 readers. However, these numbers for Athens County may be skewed due to the high numbers of residents acquiring post-secondary degrees in the county. Therefore, printed information in the form of medical brochures, medical
instructions, and pharmacy handouts may prove very difficult to understand for those with chronic illnesses.

While researchers of diabetes prevention and care in Appalachia have uncovered findings that have been unique to the region, there have also been findings that are not exclusive to the region, thereby countering the perception that the area is completely homogenous and different from the rest of the nation. Indeed, Appalachians who fall within the lower-income bracket may face additional challenges with regards to the lifestyle changes that they have to make when diagnosed with type 2 diabetes in comparison to the rest of the region (Lohri-Posey, 2006). According to the Appalachian Rural Health Institute (2006b), 12.7% of persons with diabetes in counties serviced by the Institute admit that cost is at the heart of their irregular visits to a physician. The Institute also reports that cost impacts the purchasing of medication, the checking of glucose levels with test strips, and attendance to educational seminars. Furthermore, Appalachians are more likely to have no health insurance coverage, lower high school graduation rates, and limited finances. The utilization of health resources could be hindered by cultural barriers, as well as the simple lack of access, in the form of transportation (Lohri-Posey, 2006).

Indeed, poverty can prove to be an indicator of the status of one’s health. Unfortunately, persons who knew that they were at a high risk reported “lower rates of full health insurance, being less active and running out of food more frequently” (Serrano et al., 2007, p. 121). The disease can also affect an individual financially. In some
instances, persons with diabetes have also had to modify their employment, either by missing work or changing jobs altogether due to low energy levels and dizziness.

Without a doubt, health initiatives in Appalachia need to recognize that persons with diabetes have many of the same fears as other persons with diabetes in the rest of the nation. Therefore, before any educational initiative on diabetes prevention and management is undertaken, diabetes educators and health communication scholars need to first, incorporate the lived experiences of diabetes in Appalachia, which also include some cultural idiosyncrasies (Lohri-Posey, 2006). Along with the challenges of the economy, poverty and abiding stereotypes, we also need to be mindful of the role of culture and family in the prevention and treatment of disease.

*Culture and Discourse*

Now that we have defined diabetes and the status of the disease in the United States and Appalachia, it is important an examination is made of how the culture of a region could affect the health narratives that emerge from that region. At the heart of culture is language and in this section, we will examine several social and material discourses that can hinder the effective treatment or prevention of diabetes. Culture provides us with a means through which we can examine the performative nature of illness narratives. Helman (2007) defined culture as “a set of guidelines (both explicit and implicit) that individuals use to view the world and tell them what behaviors are appropriate” (p. 2). These guidelines are passed on to the next generation through symbols, language, art and ritual (Helman, 2007). Helman noted that culture can be viewed as a lens through which “the individual perceives and understands the world that
he inhabits and learns how to live within it” (p. 2). He noted that this shared perception is important if the cohesion and continuity of a human group is to survive.

Witte and Morrison (1995) noted that culture shapes how we interpret and transmit messages. As a result, health educators and providers must realize that “culture is the lens through which we view the world” (Witte & Morrison, 1995, p. 219), because our interactions are culturally based. Therefore, from their observations of others, persons with diabetes will learn the set of behavioral guidelines associated with diabetes. Their observations will also tell them how to view the world, how to experience it emotionally and how to behave in it as a person with diabetes.

Harter, Japp & Beck (2005) define culture as having a set of “normative meanings” (p. 20). Therefore, in order for a person to operate within a culture he or she must know the significance of these meanings and symbols. Our lives are shaped by these discursive parameters (Harter et al., 2005) and as such, we will view our illnesses through the lens constructed by these storied elements. Next, we will examine the unique lens of the Appalachian culture through which persons both encounter and story their lives.

Home to 1 in 12 Americans, Appalachia touches various states along the Eastern, Midwest, and southern portions of the United States (Appalachia Regional Commission, n.d.a) and comprises mostly Caucasians with pockets of representation of African-Americans and Native Americans. Researchers of Appalachian culture have argued that behavior change initiatives that target persons who live in the region should present those initiatives through traditional cultural beliefs and practices, rather than those that are within a professional frame of reference. This is because persons in this region learn
health beliefs and practices within a cultural context that is unique to their upbringing and region (Denham, Meyer, Toborg, & Mande, 2004). For instance, among the cultural beliefs is a strong value for place, connection to family (including extended family), and religion within the region (Denham, 1996; Isserman, 1997). Greenlee and Lantz (1993) identified family and friends as the most important and common social support network for Appalachians. Research has reported on the importance of kinship (Denham, 1996) and the roles of mothers and women (Denham, 2003; Rosswurm, Dent, Armstrong-Persily, Woodburn, & Davis, 1996). With such a strong influence of kinship, it goes without saying, therefore, that the dietary habits will be similar, having been passed down from adults to the next generation, thus perpetuating eating habits that can lead to diabetes and heart disease. Nevertheless, while we acknowledge the effects of these habits, they cannot be regarded as the sole contributors to diabetes development.

Therefore, it can be argued that in order for us to effectively study the discursive beliefs and health practices rooted in the Appalachian culture, we need to include the discursive communicative nature of the family (Denham et al., 2004). It is fundamental that members of the health care system understand that the lives of persons with diabetes are “embedded within larger narrative landscapes, times and spaces that shape our lives and the stories we tell of them” (Harter et al., 2005, p. 21). We should not view individual health choices and narratives of the care of life with diabetes outside of the larger narrative of Appalachian culture, or outside of the narrative of their families.

Research has substantiated the importance of the family unit in the health of family members within Appalachia (Denham, 2003). The findings within focus group
discussions revealed that when it came to health, the participants referred to health in connection with their family more than they referred to health in connection with school, work or friendships (Denham et al., 2004). The researchers also found that an understanding of disease, community environment and prevention of disease were all drawn from experiences of familial life. The health problems of family members also provided the participants with a frame of reference to describe their own understanding of disease and unhealthy behaviors. Hutson, Dorgan, Phillips and Behringer (2007) in their research on cancer stories in Appalachia confirmed that perceptions about cancer, including a distrust of doctors, were passed down to the next generation, for instance. This was done through traditional oral storytelling, which, within Appalachia played an important role in making sense of illness (Caldwell, 2007). In fact, Hutson et al. added that it was storytelling within families that helped to clarify the existence of cancer disparities within the region.

The role of the family cannot be ignored within Appalachia. The home was a significant locus in the production of disease and well-being. In fact, the behavior of individual family members, such as older family members, was pivotal in determining the overall health and well-being of the entire family. In fact, Denham et al. (2007) found that persons with type 2 diabetes generally received support from individuals in the family who act as the main support, such as spouses and children. Therefore, since diabetes management is most likely to take place within the home, it is important that we pay attention to the narratives that develop concerning “cultural food preferences, family traditions, and intergenerational dietary patterns” (p. 36).
A strong sense of kinship and family signals a strong sense of collectivism within the Appalachian culture. Hofstede (1980) identifies individualism-collectivism as one of the most important dimensions that influences behaviors in cultures. According to Hofstede, this dimension explains the degree to which the person’s identity is shaped by either our personal choices or group to which they belong. Collectivism, in particular, occurs within societies in which persons are integrated, from birth and throughout their lifetime, into strong cohesive in-groups which require unquestioning loyalty in exchange for protection (Hofstede, 1980). According to Samovar and Porter (2001) collectivism has deep historical roots with one of the characteristics being when “individuals trust group decisions even at the expense of individual rights” (p. 79). This sense of loyalty and cohesion may provide a better understanding of the reasons underlying the perpetuation of certain family routines within the Appalachian culture (Denham, 2003).

The role of the family in Appalachia is integral, particularly for persons suffering from chronic diseases, such as diabetes. Researchers (Denham, 1996; Denham et al., 2004) have pointed to the fact that optimal health is maintained when the patient has the support of friends and family (Denham et al., 2007). In fact, many persons would willingly seek advice from family and friends before seeking professional help about a health issue (Nations, Camino, & Walker, 1985). We also find that once the diagnosis is received, persons with diabetes also turn to family members with diabetes for information on how to self-manage. Unfortunately, some of these family members have not managed their disease well, have lost limbs and suffered other complications, but still remain role models (Lohri-Posey, 2006).
Forms of support can include adopting new dietary routines and even preparing the meals of their loved ones (Trief, Britton, Wade, & Weinstock, 2002). Family support helps to minimize the difficulties and complications associated with type 2 diabetes (Denham et al., 2007). This support becomes integral when attempts to change dietary routines failed or when a poor blood glucose report is given by the doctor. Within the Appalachian region, when these difficulties occur, feelings of shame, anger and frustration sometimes emerge, responses that can be compounded by physical complications from diabetes.

The primary responsibility of supporting the person with diabetes or maintaining a diabetic diet within the family is usually performed by the woman, even if she is the diagnosed; essentially, she routinely performs the role of initiator and conservator of the family’s health (Denham et al., 2004; Rosswurm et al., 1996). However, this role is characterized by tension and conflict, especially when the meal plan is resisted by other members of the family (Denham et al., 2007). Sometimes women cannot effectively implement the changes even though they have control over the family’s dietary routines. Some women will yield to family pressure and defer to the food preferences of others without implementing healthy choices (Denham et al., 2007). However, in general, researchers found positive responses to changes in food preparation and meal plans in the family (Denham et al., 2007).

However, research on family support for persons with type 2 diabetes revealed the presence of constraining and enabling factors (Denham et al., 2007) and the contrasting ways in which families deal with these factors. Essentially, within the Appalachian
culture, “cultural food preferences, family traditions, and intergenerational dietary patterns [have] influenced behavior changes related to dietary patterns” (Denham et al., 2007, p. 49). For instance, there is an apparent conflict between the healthy dietary standards required of persons with diabetes and the traditional eating patterns within families (Denham et al., 2007). The encouragement to refuse gravy or even limit the amount of bread and butter was viewed as constraining. Denham et al. found that some Appalachians observed that their eating patterns probably started as far back as the Depression, where their elders learned to eat a lot of potatoes, bread and beans, and that diet was perpetuated and possibly helped to create the current health status. Meal preparation habits (cooking a lot) and eating habits (never leaving anything on their plate) were learned from elders.

Another constraining factor that can be coupled with the traditional eating patterns of the family is the valued special family event, such as birthdays, anniversaries, Thanksgiving, Christmas and potlucks, which helps to foster kinship within the culture. Denham et al. (2007) noted that these occasions prove difficult for persons with diabetes, as they are plagued with guilt and shame, such as when they refuse certain food choices prepared by loved ones because they know it could compromise their diabetes management. By doing so, they face alienation from family members who may not be educated about diabetes care, but who instead see the refusal to eat as a social slight against them and other members of the family. However, guilt and shame occur when they do comply and compromise their diabetes care.
In actuality, some persons have taken a very proactive approach to their health needs as a means of coping, even when the family circumstances, which may be compounded by the aforementioned constraining and enabling factors, are less than desirable (Denham, 1996). While some persons might believe, based on discourse with and observation of family members, that it is their fate to develop diabetes since other members in their family have the disease, research (Denham, 1996) has found a sense of optimism among Appalachians. Instead of an overwhelming sense of predetermination regarding poor health, individuals have articulated that they live in the present, exercising caution, embracing modern healthcare, while not being tied to folklore or home remedies. In actuality, many persons are very sensitive to the hereditary nature of the disease and have become especially watchful of their children, seeking instead to screen and reject health-related intergenerational stories or treat their health needs daily to properly manage or prevent the disease (Lohri-Posey, 2006).

It appears that family education about diabetes in Appalachia needs to take a holistic approach, as family routines are embedded in the discursive cultural and ecological contexts of the families (Denham et al., 2007). Since family routines (patterned behaviors) shape the health outcome of the individual (Denham, 2003), health education interventions will need to incorporate the family by inquiring about how the family talks about diabetes, diabetes management, how they perform eating rituals and address other mediating factors such as time management (Savoka & Miller, 2001).
Summary

This section first focused on defining diabetes, the different types, the symptoms and complications which often arise from developing the disease. This was followed by a description and evaluation of the current state of diabetes in the United States and particularly in Appalachian Ohio. This information served to draw our attention to the need for health interventions which aid in stemming the tide which threatens the future of the nation’s economy and labor. Second, the section focused on Appalachia, starting with representations of the region over the years and how these stereotypes have been addressed by scholars in the region. These representations introduced us to the fact that Appalachia is complex and diverse, impacted by both economy and culture. Of particular interest to this study was the value placed on the family, and especially that of the woman, as a performative unit within Appalachian culture and life with diabetes. Dietary routines and traditional patterns of family life can hinder and enhance the health of the person with diabetes. In moving forward, therefore, it is important that we recognize these cultural patterns, such as the role of the family, and utilize them as entrances into discourse about diabetes.

After reviewing this literature, several questions arise: Since we know that the family and oral storytelling are valued within Appalachia, how do we explore the value placed on these cultural elements in seeking to reduce the prevalence of diabetes? What role do these cultural values play in perpetuating and challenging discourses of diabetes in the region? How can we utilize these cultural values to evaluate and challenge the
narrative reality of diabetes in Appalachia? I also wonder about the actual perceptions of
the constraining factors for diabetes and how individuals narratively address these.

These questions pave the way for the next chapter which reviews literature on
theoretical orientations which will help us understand the perpetuation of these discourses
and the manner in which these discourses shape our treatment of diabetes and persons
with diabetes. Now that the context of the study has been elaborated upon, it is
imperative to explore the communication theories and concepts which will guide this
study on the impact of a disease that has laid root within the region.
Chapter Three: Literature Review

Specifically, in this chapter, I situate discourses about diabetes in Appalachia in reviewed literature on (1) the centrality of language in communication; (2) the theory of social construction; (3) discourses of illness to demonstrate the narrative construal of reality and narrative as ontology; (4) the theory of performance to help us understand the enactment and interpretation of illness; and (5) the role entertainment-education can play in influencing diabetes discourse and performance. In essence, the study allows us to view narrative as performance, as a means of expressing our construction of knowledge, transformation and resistance. With this focus to help me understand the research setting, I posed the following research questions which I revisit in the end:

RQ 1: What messages did the audience recall from the plays and how did these act as a means of entry into the discourse on diabetes?

RQ 2: (a) What kind of narratives emerged from the audience after viewing the plays? (b) How did these narratives connect with those in the plays and how did the participants demonstrate a construction of diabetes?

RQ 3: How did the Appalachian audience perceive the lived experience of those with diabetes?

Using the Centrality of Language in Communication

Within this section, I will present a theory of language grounded in the works of several scholars who have contributed to the field of communication. Guided by these theoretical presentations, I will present a definition of language and then focus on the
purpose of language in everyday life and its value. Then I will focus on the implications of grounding my research in this theory, thus linking theory to praxis.

Classical theorists, such as Plato and Aristotle provided us with some of the earliest philosophies of language. By examining language, they began to inquire into the nature of meaning, what speakers and listeners do with language in communicative interactions, how language is interpreted and how language and meaning relate to the world and what we perceived as truth (Brumett, 2000).

Later, additional scholars built on these foundational explorations into language, providing several definitions of language. For instance, Berger and Luckmann (1989) defined language as a “vocal set of signs” (p. 36-37) which was crucial in the “understanding of the reality of everyday life” (p. 37). As such, they began to center our attention on the symbolic nature of language which allows us to represent a concrete and objective reality which consists of things and objects, as well as ideas. Burke (1968) also defined language as symbolic, nothing “but a set of labels, signs for helping us find our way about” (p. 5). He continued by elaborating on man’s role in the definition as “the symbol-using, symbol-making, and symbol-misusing animal” (p. 6), thus highlighting our role in the construction and (mis)interpretation of language. Gadamer (1989) extended this definition by providing a more optimistic view of language as the “site of human understanding, consist[ing] of events of discursive engagement in the to-and-fro play of question and response between Thous” (p. 36). Therefore, Gadamer argued that we can identify language as we examine the mutual interaction between persons, where both seek to understand each other. He further clarifies simply that language is “the
medium in which substantive understanding and agreement take place between two people” (p. 384). However, from the classical theorists to contemporary scholars the main critique of these definitions is that there is a bias toward accepting the verbal expression as the only means of communication or language.

With these definitions of language in mind, I will now examine various perspectives on the purpose and value of language in everyday life. Language serves to fulfill several purposes. Burke (1968) in fact quoted his colleague Edward Sapir’s view of language as “a collective means of expression” (p. 15). Burke felt more comfortable with this view of the purpose of language, which embraced language as serving more than just an instrumental purpose. With this in mind, we find an intertwining of the purpose and value of language from a personal perspective, as well as from the perspective of the researcher. From the personal perspective, language helps us to relate, but still remain distinct. From the researcher perspective, the study of language informs us of how we relate and balance individuality in a social reality that is distinct, yet similar.

First, language helps us understand how we act in social relations which are in turn influenced by language. Burke (1969a) would state that language illustrates that we are actors in this life which is drama in its totality. As actors, we engage in a discursive play, in which we seek to establish common interests with ‘the other.’ In focusing on how we relate to others, Burke would suggest that we have to examine the verbal, non-verbal, textual and non-textual language behavior, as we seek to establish these common interests or identification through language.
Identification is a function of social interaction (Berger & Luckmann, 1989; Burke, 1969b). As Burke noted, “A identifies with B in so far as A’s interests are identified with B” (p. 20). However, if A’s interests are not joined with B’s, he/she might still believe that they are joined if they presume they are. As symbol-using individuals, we are constantly attempting to connect with other symbol-using human agents. Language allows us to look at the manner in which we seek to connect with others in various communication contexts which are framed, such as when we are watching a play and we are hearing messages and then when we share those messages with others.

In essence, language is the means through which substantive understanding and agreement is reached between two individuals (Burke, 1969b; Gadamer, 1989). Gadamer stated that understanding is sharing a common meaning, while bearing in mind the presence of multiple interpretations. He terms this sharing of a common meaning as the ‘fusion of horizons,’ which is the substantive achievement of language. Gadamer’s theory is that as social beings, in seeking social relations, we are actually seeking understanding, which also brings transformation of the self and a communion with the other. He encouraged us to be open to all that ‘the other’ offers, and to acknowledge the possible truth of assertions made against our own prejudices and biases. As language seeks to achieve this, we begin to examine how we relate with others, including critically evaluating the meanings associated with our symbolic language. Bakhtin (1981) would support this notion, as for him, all social utterance or language, has an evaluative function. Therefore, language also helps us to understand how relationships are changed.
as we communicate our interests with each other. Using Burke’s own words we will use these symbols to form attitudes and induce certain behaviors from persons.

Second, apart from allowing us to identify attempts at relating with others, language also allows us to identify the dialectical tensions that arise in our social relations and within our reality. Bakhtin (1981) has pointed out that our reality is dialectical, filled with forces of unity and forces of difference. In fact, while we bear our own individualities, we are also present within a reality that is characterized by heteroglossia (Bakhtin, 1981). In other words, the researcher recognizes that while we have our distinct voices and stories, we are also impacted by multiple social and historical forces and stories. Thus, we are surrounded by tension-filled, contradictory forces with embattled tendencies and this affects our personal relations. In effect, the study of language or discourse within a certain communication context helps us to go beyond the individual emotions and behaviors to the larger social system.

To determine how people perceive the world, Burke (1969a) suggested that we examine people’s words, a group of motives, to determine how they interpret the world, why they interpret it in that manner and how they would want us to interpret it as well. He presented his theory of the pentad as the five perspectives through which persons speak and through which we can examine how persons view the world. Persons could speak through any of these perspectives separately or all together. He stated that persons speak through the perspective of the act (what was done), the agent (who did it), agency (how it was done), purpose (why it was done) and the scene (where it was done); he later added attitude, making it a hextad. Although not receiving an outright mention here,
Burke is in effect, laying the foundation for the validity of using the narrative, which usually encompasses all aspects of the pentad. So far, we have seen how language helps to inform us of how we relate to each other and how we perceive our social reality. Next, I will explain how this understanding of language affects the theoretical standpoints upon which I have chosen to ground this project.

These perspectives on language informed me of the need for us to be recursive, constantly revisiting, questioning, and reinterpreting assertions. Gadamer (1989) noted that we are to discursively engage in a to and fro (play) question-and-response with ‘the other’. For Gadamer, ‘the other’ could mean a person, tradition (history) or event. Gadamer took the ontological stance that we are in a constant struggle between the old and the new, constantly reevaluating and mediating between the past and the present, and reentering and revisiting decisions and truths which were agreed upon. As such, I sought to situate my research in theories that embraced the notion that people could use language to be recursive and as such, enter into a better understanding of their world.

These perspectives of language also informed me of the multiplicity of social reality or heteroglossia (Bakhtin, 1981). These multiple voices arise not only from interactions with ‘the other,’ but also with traditions and they converge and impact each other. This notion of multiplicity informs me that our reality is multidimensional and interpretive (Gadamer, 1989). Because I took this view of our world as being interpretive, I also embraced the notion of the importance of dialogue.

Within this section I introduced the lens through which I examine discourse on diabetes management and prevention in Appalachia. I addressed the purpose of language
and these perspectives guided the theoretical choices upon which this research is grounded. Therefore, the following is what I bring to research on diabetes in Appalachia: a central focus on language, with an emphasis on the recursive nature of language and the importance of appreciating multiple interpretations or multiple meanings. Essentially, as a communication scholar, I will utilize the plays to create a framework, take discourse on diabetes and demonstrate the centrality of language and how discourse of the past as well as the future potentially shape our language of the present.

Now, I will provide an overview of the theory of social construction. This will be followed by my perspective on narrative as ontology by looking at narratives of illness.

**Social Construction of Reality**

Within this section, I examine the role of language as argued by the main theorists of the social construction of reality and the implications of these assertions on this study. At the heart of this theory is the relationship between language and reality. In fact, the authors assert that, “everyday life is, above all, life with and by means of the language I share with my fellowmen” (Berger & Luckmann, 1989, p. 37) and without which, we (they) could not survive.

Berger and Luckman (1989) outlined a number of purposes of language. They began by declaring that as we interact with the other, language helps to reveal our own subjectivity which includes our biases and concerns. Additionally, language helps us refer to the cluster of meanings we have about aspects and experiences of everyday life, both in the present and in the future. The authors also explained that language helps us to typify our reality, by allowing us to place experiences under certain categories which
have not only personal meanings, but also meanings for our fellowmen. Furthermore, as persons share the meanings of those categories, language helps to transcend boundaries, by “bridging different zones within the reality of everyday life and integrates them into a meaningful whole” (Berger & Luckmann, 1989, p. 39). In other words, language can help to create a whole world, by creating spatial, temporal and social objects that are absent from the present. This capacity in particular creates an opening for understanding narrative as dialogue as with the ability of creating worlds, not currently present. Finally, the authors assert that language does more than just constructing symbols from everyday reality, but also, is also capable of “‘bringing back’ these symbols and appresenting them as objectively real elements in everyday life” (p. 40). Therefore, language has the ability of reinventing and reintroducing symbolic meaning.

One of the main assertions made by Berger and Luckmann (1989) was the fact that “society is a human product…man is a social product” (p. 61). This indicates a dialectical relationship where the producer acts on the product and vice versa. Undoubtedly, the means by which this occurs is through language. In essence, the authors remind us that, “the objectivity of the institutional world, however, massive it may appear to the individual, is a humanly produced, constructed objectivity” (Berger & Luckmann, 1989, p. 60). Therefore, while the institutionalized world, including its meanings and behaviors, may be perceived as the norm, it is actually a social product. In essence, as we enter into discourse with the cultural zone of Appalachia, it is important to recognize the agency of human beings, by noting that “man’s self-production is always, and of necessity, a social enterprise. Men together produce a human environment, with the
totality of its socio-cultural and psychological formations” (Berger & Luckmann, 1989, p. 51). This reminds us that people are active agents in the human environment they create, which include the socio-cultural environment, and the psychological orientations toward the environment.

An important assertion made by Berger and Luckmann (1989) was the role language plays in reinforcing knowledge. Language helps in the production of knowledge which is an ongoing production of our social reality. As it is legitimimized, knowledge orders our society, shapes the individual and is transmitted to the next generation. This statement helps to clarify such social phenomenon as fatalism, where meanings about a family’s or a community’s fate is passed on from generation to generation.

Another thread upon which the authors focused was the matter of performed roles in society and the manner in which language is used to determine whether these roles are reified and how they are performed. Both authors noted that “the institutionalized world is real only insofar as it is realized in performed roles and that, on the other hand, roles are representative of an institutionalized order that defines their character and from which they derive their objective sense” (Berger & Luckmann, 1989, p. 78-79). Therefore, when we examine performed roles, such as that of the mother, or that of the sick person, we are also receiving insight into the institutionalized world, whether it is on the micro level, such as within the family or on the macro-level, that is, in the wider society. For instance, Allen and Waks (2000) found that television and communication with others shape a normative view of the social roles of women and African-Americans.
There are several reasons for being mindful of the instrumental use of language to transmit meaning and construct knowledge. Berger and Luckman (1989) noted that “all transmission of institutional meanings obviously implies control and legitimation procedures” (p. 71). To make this concern relevant, over the years, several studies (Adoni & Mane, 1984; Allen & Waks, 1990) have utilized the social construction theory as a means of validating concerns over the power of the mass media. Therefore, as we look at discourse that surrounds diabetes, we examine the possibility of transmitted institutional meanings that seek to reinforce and reify negative meanings of diabetes and control discourse on diabetes. At the same time, this assertion reminds us that as humans, we too can assert control and change the meanings imbedded within a certain discourse.

The implications for the use of this theoretical framework for research on narratives in health are clear. Sharf and Vanderford (2003) argued that social construction theory enlightens scholarship in health communication by providing a gateway through which narrative inquiry can be used to approach health communication research. Several scholars (Frank, 1991; Japp, Harter, & Beck, 2005; Sharf & Kahler, 1996; Workman, 2005) have utilized this theory to evaluate the impact of language on illness. Kleinman (1988), after listening to the stories of several patients with chronic illness over the years, found that illness was a social construction and refers to the lived experience that includes symptoms and sufferings. Sontag (1978, 1988), by utilizing the diseases of tuberculosis and AIDS, argued that language shapes the identity of persons suffering from these illnesses. Beck (2005) also addressed how this construction can affect our relations with others, by noting that how we embody illness will impact how we construct
our self in relation to others. Frank (1995) also argued that we need to look at how illness stories are determined by the culture in which they are located, the social organization of health care and the bio-politics of the disease. But he also argued for activity, not passivity, by noting that the ill person can also take charge of his or her own story.

In this section, I described the centrality of language in social construction theory. Next, I focus on narrative, by first extending the work of Berger and Luckman (1989) and by addressing the use of language in constructing a narrative reality. After talking about how we have constructed this reality, I discuss how we engage this reality.

**Narrative Reality**

Stories are the route to understanding the world (Bruner, 1996). They are the means by which persons move from “what somebody said to what he meant, from what seems the case to what really is” (p. 131). With that said, Bruner outlined nine universals of the way in which narrative construals demonstrate how reality is constructed according to the rules and devices of narrative.

First, narrative constructs reality by representing it through time, a sequence of crucial unfolding events. This affirmed the prior work of Ricoeur (1990) who helped to unravel how narrative creates a relationship between time, events and experience. Ricoeur described this as ‘narrative time,’ or ‘humanly relevant time,’ when the narrator or the protagonist in the narrative gives meaning to the events. Second, narratives specialize in the particulars of reality with stories falling into certain genres or categories. This highlights the generative nature of stories, where genres generate stories causing us “construe certain events according to their generic prescription” (Bruner, 1996, p. 134).
Bruner concluded that some stories just sound like each other, reminding people of one just like it or a different version of it. Also, we find that stories take their meaning from the encompassing narrative structures or genres under which they fall. In other words, while the genre exists in the text, it also exists to make sense of the text or of another story. Bruner thus concluded that we cannot make sense of characters or events without knowing into which genre they fit. Therefore, genres “are culturally specialized ways of both envisaging and communicating about the human condition” (p. 136).

Third, narrative helps us construct reality by causing us to seek the reasons behind actions. This leads us to look at the setting and question why the physical events had such an effect on the actions of the protagonist. Fourth, a narrativized reality also is hermeneutic in nature, where the meaning of a story is dependent on the reading of its particulars or alternative expressions of its meaning. This introduces an interpretive nature of thinking which makes us willing to consider multiple narrative construals. Also, part of this interpretive nature is that we are also always looking for a voice, which will tell us why a story is being told in a certain way under particular circumstances. Therefore, fifth, a narrativized reality causes us to recognize that we engage in cultural negotiations, reserving the right to contest the narrative and the voice.

I have classified the next five universals presented by Bruner as exemplary of how a narrativized reality is also transformative. In his sixth universal, Bruner asserted that through language, a narrative reality helps us to make connections with the canonical, the expected, or the conventional. However, in this linkage, we are sometimes presented with deviations which we go along with because of the hermeneutical nature of
stories and the fact that the version is presented afresh. Furthermore, because of these twists and the interpretative nature of story, we recognize that seventh, the narrative nature of reality is very ambiguous and dependent on the reading. Eighth, using Burke’s pentad to explain, Bruner stated that when there is an imbalance in various elements of the story (agent, action, scene, goal and instrument), there is trouble. However, the construals of the story are transformative, capable of change that is not historical or culturally bound. This is a positive character of a narrative reality, in that a story may be said differently at another time, and a norm expressed in one circumstance, may be challenged in a next. Finally, in this reality, we find that plots, characters and settings continue to expand the same story, even though the circumstances may change. In effect, as we tell the story, it gives rise to the past and we act to make this past coherent. As a scholar-researcher, I felt drawn to determine evidence of these universals in everyday life and discourse. With this knowledge of what narrative imposes on our construal of reality, let us now turn to narrative as ontology.

**A Narrative Ontology: Implications for Health Narratives**

In this section, I focus on my perspective of narrative as ontology, a way of being in the world. In so doing, I look at why and how we enter into narrative and the implications on illness narratives in particular. Before I dive in too deep, I present several definitions of narrative. Chase (2005) stated that a narrative could be oral or written:

- (a) a short topical story about a particular event and specific characters, such as an encounter with a friend, boss or doctor;
- (b) an extended story about a significant aspect of one’s life such as schooling, work, marriage divorce, childbirth, an
illness, a trauma or participation in a war or social movement; or (c) a narrative of one’s entire life, from birth to the present (p. 652).

W. R. Fisher (1987) also identified narratives as any communicative account, such as conversations, arguments in scientific journals, and bedtime stories that have a beginning, middle, ending, and characters. In my view, a story must have a plot, central characters, and action sequences, which are bound in space and time and all organized around a specific theme or message.

Now that there is an idea of what a story is, I will now address the reasons for entering into a narrative. As we look at why persons enter into stories, we are at the same time presented with the purposes for narrative telling. Bruner, in presenting us with the universals of a narratively constructed reality, began to lay the foundation of narrative as ontology, allowing us to see the effects of that reality on our everyday lives. In this section, I will place the individual in more of a subject role, actively utilizing the narrative to fulfill several needs as he or she participates in this ontology.

First, narrative is utilized to make sense of symbolic interaction according to time. Ricoeur (1990) described this as humanly relevant time, where persons place human experiences according to the sequence of the episodes in which they unfolded and they also place the events, episodes or stories in categories to make them more understandable. With this knowledge we recognize the temporal and meaning-making quality of narratives. As such, we realize that as narratives create relationships between events, not only do past events gain a meaning, but also future events. As Williams (1997) stated, the narrative “imaginatively reconstructs the past so that it has meaning or
purpose for the present” (p. 16). Therefore, if we rearticulate the sequence of the events, we change their meaning and the meaning of the total experience (Babrow, Kline & Rawlins, 2005).

It is important that we are sensitive to the temporal nature of narratives, especially when we engage in discourses of health (Mishler, 2006). This approach is relevant in health communication contexts, because the patient or family helps us understand how events unfolded over a period of time, which is how patients are more inclined to approach their ailment, rather than in a chronological format. Narratives cause us to inquire about why certain events were selected as being pivotal for completing the story and what the teller perceives as the consequences of the story’s events (Mishler, 2006).

Second, our experiences are laden with narratives and people make sense of what has happened and what is happening to them by attempting to assemble and in some way to integrate these happenings within one or more narrative (Bruner, 2002). In a world of chaos and seemingly random and disconnected experiences, the narrative acts as an organizing tool aimed at bringing coherence. As Babrow et al. (2005) noted “narratives comprise the means by which individuals organize a host of random emotional, perceptual, physical, and social experiences into a meaningful account of their situation” (p. 34). These stories bear the meanings we use to construct and to better understand our lives and relationships (Murray, 1997). Thus, Sharf and Vanderford (2003) concluded, that the development of social and personal meaning is characteristic of a good story.

Bochner (1994) agreed that narrative is a means of knowing (understanding our world). He also noted as well that the narrative is a means of telling about our social
world and experience. Therefore, the stories generated from the audience after the viewing of the plays are simply their method of making sense of the communicative encounter, their episodes with others during this context, their interpretations of the current and past events and encounters, and the meanings of the actions of ‘the other.’ Polkinghorne (1988) stated that it is through narrative telling that people organize their own understanding of a human experience. If people are to put together why something happened, they have to sort through all their experiences, select the most significant and then arrange them into a sequence that leads to a logical ending, and a narrative helps them to accomplish this.

Several scholars have examined narratives as a means of knowing and understanding when illness enters. Frank (1995) talked about stories of quest and journey in which the suffering was interpreted as leading to a larger or greater purpose. He included his own narrative of understanding as a cancer and heart disease survivor. Ellingson (2004) reflexively examined her own experience and struggle with understanding her body when cancer was diagnosed.

While I hail the use of narrative to engage in sense-making, Sharf and Vanderford (2003) also draw our attention to the fact that sense-making can differ among people who shared similar experiences, especially persons who share the same illnesses. Vanderford and Smith (1996) provided us the conflicting narratives on illnesses which developed among a group of women who had conducted breast implants. In gaining the perspectives of the audience who watched the plays, it would be interesting to note how much they differed as they made sense of the stories, since they all had shared experience.
Also, we use the narrative because it acts as a map to guide others. Stories are “a special repertoire of instructions and norms of what is to be done and not to be done in life and what we can and cannot do in life” (Brockmeier & Harré, 2001, p. 51). The narrative has the ability to disseminate conventional wisdom, thereby advising us of “what can be expected, even (or especially) what can be expected to go wrong and what might be done to restore or cope with the situation” (Bruner, 2002, p. 31). This ability becomes true in discourse of illness when information is disseminated by the individual actor, the patient, or through the agent, such as the plays on diabetes. According to Frank (1995), “stories have to repair the damage that illness has done to the ill person’s sense of where she is in life, and where she may be going. [Therefore,] stories are a way of redrawing maps and finding new destinations” (p. 53). Specifically, this becomes even more recognizable when we hear persons tell the stories of the complications suffered by loved ones as a means of disseminating conventional wisdom to family ones of what will happen if the guidelines are not followed or they will tell that story to indicate the lesson they learned about what complications can be expected.

With that said, we enter into narrative to engage in dialogue with the other. Bochner (1994) stated that the best way to understand people is to understand their stories. It was Bakhtin (1981) who presented the concept of heteroglossia, the presence of multiple interpretations and meanings in our reality. Admittedly, with this multiplicity comes conflict and therefore, Bakhtin (1981) emphasized a collaborative construction of meaning which requires that we truly listen to ‘the other.’ Bakhtin noted that meaning
can only change through dialogue, but this only occurs when there is a willingness to engage in and welcome the other’s evaluation of the meaning assigned to a word.

Inherently co-constructive (Harter et al., 2005), narrative provides an opportunity to listen, empathize and participate in the stories of others. Narratives help us to make sense of other persons’ worlds, which members may have never personally experienced (Bruner, 2002; Garro & Mattingly, 2000). In fact, W. R. Fisher (1984) asserted that stories are meant to “induce others to dwell in them [stories]” (p. 7) establish some of commonality or to invite the person to have the same experience if but only for the time while the story is being told. Stories are always told from different perspectives and even Bruner stated that “the victor’s tale of triumph is the loser’s tale of defeat, though both were in the same battle” (p. 23). These alternative perspectives create the opportunity for dialogue (Bruner, 2002; Garro & Mattingly, 2001) and remind us of the multiplicity of the narrative reality. As we engage in dialogue with each other, we will recognize that there are alternative readings, thus signaling the hermeneutic nature of our world. As such, the plays may provide individuals with fictional stories through which relatives and loved ones will be able to enter into the world of diabetes and as such, better understand their experience.

Persons may use narrative to instigate dialogue about emotional issues brought on by illness. For instance, a family coping with the illness of a loved one can engage in co-construction as a means of understanding the changing identities and relationships (Adelman & Frey, 1997). Sometimes this co-construction can be entered into unwillingly when they involve painful decisions. Ellis (1995) wrote of the heart-wrenching
conversations she had with her life partner, Gene, who was dying from emphysema, about steps to take when disease would completely overtake his body. Butler and Rosenbaum (1991) also addressed co-construction as they examined the relationships between patient and loved ones, specifically the story of a surviving partner and a breast cancer survivor who wrote their own impressions of shared events. Co-construction can prove beneficial for a family with a member with diabetes as the family helps the individual deal with emotional issues, such as loneliness and depression, while he or she deals with the family’s own perception of the disease. Indeed, support from family members can result in improved health (Denham, 1996; Denham et al., 2007) and relational development can be enhanced by storytelling (Keyton, 1999). Cawyer and Smith-Dupré (1995) found that storytelling was an important and regular activity in a traditional non-residential support group for persons with HIV/AIDS. Indeed, co-construction is valuable as it allows us to construct new understandings and author new stories (Babrow et al., 2005).

In fostering dialogue, narratives also help to create a bridge between knowing and being in this world (Harter et al., 2005). Babrow et al., (2005) stated that “throughout our lives, experiences of our physical being call for the construction of (and, in turn, challenge) basic understandings” (p. 32). At the personal level, narrative helps to create a balance or reconcile the divide between the physical and the cognitive, even though it may be a struggle (Beck, 2005). At the interpersonal, narrative becomes dialogic as the person enduring the physical disruption seeks to bridge the divide between him or herself and the one who is not. Illness requires that we call into question our understanding of
our body, mind, self and relationships within others; therefore, our communication with
them is inherently geared toward making meaning.

The narratives helped to establish a common experience and emotion, while
enhancing relationships. Frank (1995) observed that family, friends, co-workers and
employers, and health-care providers all demand stories during times of illness. People
want to know what happened, what is happening and what will happen in the future and
the story helps them to make sense of it all, drawing them closer as well into sharing a
common experience. Beck (2005) in recounting the story of journalist, Cathy Hainer’s
battle with cancer, described health narratives as collaborative co-accomplishments,
which highlight the fact that even as persons engage in health care experiences, very
rarely do they do so in isolation. Along with readers of the newspaper article, Hainer’s
story is shared with her parents, who had to clean her, and her boyfriend, who learned
how to give her injections.

In fact, Bochner and Ellis (2000) noted that if we think in stories, see, hear and
read others’ stories, then we also attempt to induce others with our stories to achieve a
commonality. Perhaps, through dialogue, participants in the study may find ways to unite
and co-construct, along with the loved one and persons with diabetes, the meaning of the
lived experience with diabetes. Furthermore, as a researcher, I have found myself
intrigued by this co-constructed social life (Harter et al., 2005). Through this research, I
attempt to determine with participants how the human experience of diabetes is endowed
with meaning (Harter et al., 2005).
We also enter stories to evaluate. This is an expansion of one of Bruner’s (1996) construals of reality where he pointed to the hermeneutic nature of reality. Because of the multiplicity of our reality, Bruner noted that we are also always looking for a voice. In essence, while we are being told a story, we also ask why the story is being presented in a certain way and why we are being presented the story under certain circumstances. Once these align, we have a stronger reason to believe and to engage in the story. If not, we engage in a cultural negotiation, questioning the narrative and the voice.

Other scholars have also addressed our entrance through evaluation. Ryfe (2006) pointed out that authors of stories “intend to persuade hearers that the problems they [the authors of the stories] pose, and the manner in which they resolved them, are accurate reflections of the way the world is or ought to be” (p. 74). Schechet (2005) also noted that we must force ourselves to listen to the voice people use to tell the story. We must ask why they told the story in a certain manner and what is the actual story being told. She insisted that superficial reading of the story is not enough, but we must interrogate the story, lest we become complicit readers. The complicit reader accepts the story presented by the author of the story without question. However, the resistant reader examines the gaps between the real world and the presented story and the gaps between the story and the narrator. Hence, the closer the gaps are or their absence, the greater the compliance.

Nelson (1997) also repeated the same suggestions, ending with a firm reminder that when evaluating a persuasive story “if the stories refuse to mesh, then either we don’t know enough of the particulars of the situation or else we don’t have shared moral understandings at all” (p. xiv). Therefore, we need not only to be good storytellers, but
also good listeners of stories because all stories are incomplete and we are morally obligated to interrogate them (Hardwig, 1997). Frank (1995) rephrased this suggestion by stating that we should actually think with stories, thus demanding that “we attend carefully to how a story is being used when it is told, how different meanings or shades of meaning are assigned to the story as a result” (p. 160). This approach makes the listener more active and they decide whether they want the story to go in a certain direction. Now that we have to address why we enter into narrative and how we enter in.

The plays also bear their own narrative purposes which must also be interrogated in this section. They were written to enter into the narrative reality of the audience and to present an additional interpretation of the experience of diabetes. As a researcher, I am interested in determining whether the plays will fulfill a generative reaction (Bruner, 1996), that is, generating stories that create a space for dialogue about diabetes. If we agree with Frank (1997) and Bruner (1996) then they should do so because stories are evocative “resources that generate other resources” (Frank, 1997, p. 44). It will also be interesting to determine whether the audience placed the plays in a certain genre and created stories which they felt were similar to the genre.

The plays also enter into the narrative reality to fulfill a persuasive purpose. As a persuasive tool, the story is concerned with showing how a meaningful lived experience is also believable (Bochner, 1994). Within the telling of the story, there is an attempt to reinforce, shape, or change the audience’s attitude or behavior regarding the subject. There is an intent to communicate a reality (Cline, 1999) to an audience, with the hope that the members may share a similar perspective eventually. Cline found that this was
possible in social groups, where, through stories, the members shared “themes, visions, values, and meanings that constitute group ideology, which, in turn, provides the foundation for the emergence of connection and community” (p. 533). One of the main themes within the plays is the role of the family during illness and it would be fascinating to see whether the audience also eventually shares this value.

The stories in the plays may be persuasively effective simply because stories are “intuitively appealing to humans, as we are all essentially storytellers and avid story recipients” (Kopfman et al., 1998, p. 281). In fact, people are more influenced by concrete, emotionally interesting information, vivid case histories or personalized stories or narratives, than statistical data (Nisbett, Borgida, Crandall, & Reed, 1976). Researchers (Nisbett et al., 1976) have found that as people told their experiences, the stories engaged the imagination of the audience. This is all the more reason to examine the potential usefulness of theater as a means of storytelling, as storied evidence “evoke stronger mental images than abstractly presented information, are easier to access from memory, and are therefore more likely to influence attitudes” (Perloff, 2003, p. 183) during decision-making.

In sum, this section examined scholarship that focused on how we enter into narratives and the implications these methods have for narratives of health and illness. As a consequence of this review on narrative, I have been left with several lingering questions: I wonder about sensemaking, that is, how do persons make sense of diabetes? How do persons with diabetes reconcile their changing being with the identity they have
known all these years? Are there stories of co-construction and dialogue about diabetes within Appalachia? And, if yes, how will the audience evaluate the stories?

Since we have looked at narrative as ontology, a way of being, I now look at the contribution of performance studies and the implications this has for health communication research.

Linking Performance and Narrative

According to Conquergood (2004), “performance studies is uniquely suited for the challenge of braiding together disparate and stratified ways of knowing” (p. 318). He asserted that performance is aimed at closing the gap between theory and praxis, cutting across seemingly separate domains of knowledge. He noted that we can think of performance as an object of study, a method, or as a tactic of intervention, a space through which various theoretical struggles can be interrogated.

Goffman (2004) defined performance in everyday life as “all the activity of an individual which occurs during a period marked by his continuous presence before a particular set of observers and which has some influence on the observers” (p. 61). In this definition, Goffman spoke of the show, setting and the audience, thus inciting the language of narrative theory. Carlson (2004) also expanded on the use of theatrical terms, noting that it was possible for these to move from the stage into everyday life. He noted that there were several concepts of performance, but of interest to this study are the modes of behavior that are culturally coded and, as such, are performed before a cultural audience. Carlson introduces the role of culture in performance and the importance of this element is affirmed by Fabian (2004) who stated that “cultural knowledge is performative
rather than informative” (p. 177). Therefore, people perform their culture and they are able to illustrate this performance through their narratives if they have an audience.

Michel de Certeau (1984) stated that “what the map cuts up, the story cuts across” (p. 129). It is right in between this gap between the abstract, the objective (the map) and the embodied, the practical (the story) that we will be able to situate performance. According to Peterson and Langellier (2006) performance has helped to resituate narrative as an object of study, particularly emphasizing its embodiment in communication practices. The authors posited that performance could be located at the intersection of two ways of understanding narrative: narrative as both a making (poiesis) and doing (praxis). The turn to performance enhances our understanding of narrative as a making, which is the bodily ability to create a narrative, thus bringing into existence one more narrative. In the realm of doing, narrative is performative in that the bodily capability for narrating constitutes or realizes a narrative (what is done). Narrative is performative by nature, as soon as someone says, “let me tell you…,” they refer to the subject and begin performing the narrative. By looking at praxis and narrative, we are able to investigate what is meant by doing narrative; and by looking at poiesis and narrative, we are able to examine those cultural and inventive forces that make a narrative or are created by a narrative.

The inclusion of performance in understanding and studying narrative presents four consequences. First, we recognize that “narrative is embodied socially in communication practices” (Peterson & Langellier, 2006, p. 176). Also, we see the performance in the lived body and we recognize that the titles of storyteller, character,
narrator and audience can be taken on by one person, distributed in a group or told by an institution. Second, “narrative is constrained by situational and material conditions” (p. 176). Under this perspective, we receive a connection to Bruner’s (1996) final universal of transformation which addresses the imbalanced nature of the story. In one situation, someone may be free to tell a story, while constrained in another. Sometimes, some of these constraints are just performative norms, like gestures, or interpersonal relations.

The third consequence of the performative turn in narrative is that we find that “narrative is embedded in and ordered by fields of discourse” (Bruner, 1996, p. 177). In other words, external rules and systems of exclusion, that is, discursive practices and conventions, determine who tells the story, what is salient and what is not salient. Finally, and I think most relevant to this study is the fact that “narrative is strategically distributed to reproduce and critique existing relations of power and knowledge” (p. 178). This consequence reminds us of the constructive nature of the narrative, having the ability to reproduce, replace, to challenge existing discourses and relations. This consequence also speaks to the generative nature of narratives. Therefore, if narratives generate or reproduce or replace stories, the performances will also do the same. With this focus, we learn that the performative turn helps to situate narrative as making and doing, as attending to the bodies of participants as well as the bodies of knowledge, “the materiality and situationality in narrative practices” (p. 179), and the multiple discourses that are situated in multiple levels and strategies.

By including the performative in this study, I am challenged with several questions, which have implications for the study of performance in health narratives:
Which stories are thought to be important and why would they be selected to be told? How is narrative used to reproduce bodies of knowledge that serve to constrain? What material and situational practices impact the telling of stories? And most pertinent to this study, how are narratives of illness, particularly those of diabetes, performed?

While several scholars have identified different types of narratives of illness, little has been done to situate these narratives in performance. In working with support groups for epileptic patients, Arntson and Droge (1987) identified four functions of health-related storytelling: sense-making, asserting control, transform identities and social roles, and decision-making. Sharf and Vanderford (2003) added a fifth function which was community building based on similar agendas and a common vision. Later, Bosticco and Thompson (2008) reviewed the aforementioned functions and added a sixth: reinforcing and challenging dominant ideology. I posit that these functions are inherently performative in nature, since performance is any activity, such as the telling of a story, which is done in the presence of a set of observers (Goffman, 2004). It is at the intersection of understanding these narratives as both making and doing that we will locate performance (Peterson & Langellier, 2006). In that, if narrative is understood as praxis and poiesis, when the performative lens is applied we will be able to understand what it means to narratively perform sense-making or to narratively make or construct a dominant ideology. As such, another question emerged, how can I identify illness narratives and can performance be easily situated within them?

In this portion, I addressed the centrality of language, examined the theory of the social construction of reality and the narrative construction of reality. I also made a case
for narrative as ontology and the implications this would have for narratives of illness. Finally, I ended by situating the performative in narrative, as a means of understanding narrative as doing and making. With theory addressed, it is important to determine whether theory can be manifested, examined or challenged through praxis. In the next section, I focus on entertainment-education, the communication tool to be used to address the discourse and the narrative reality of diabetes in Appalachia.

Entertainment-Education as an Entrance

In this section, I present first, an overview of entertainment-education and the role it has played in health education. Then, I focus on the narrative nature of entertainment-education and why it fits with the theoretical lens used and the discourse phenomenon being explored. Entertainment-education (E-E) has been carefully defined by Singhal and Rogers (1999) as “the process of purposely designing and implementing a media message both to entertain and educate, in order to increase audience members’ knowledge about an educational issue, create favorable attitudes, and change overt behavior” (p. 9). Since the British radio soap opera, The Archers, broadcast messages on agriculture in 1951, the use of the strategy has grown. Over the years, developing countries have used E-E to address vaccination, family planning, HIV/AIDS and conflict-resolution (Singhal & Rogers, 1999; Singhal, Cody, Rogers, & Sabido, 2004; Tufte, 2005).

Entertainment-education was formally theorized by Mexican television writer-producer, Miguel Sabido. One of the key theories on which this model is grounded is Bandura’s social learning theory (Singhal & Rogers, 1999; Singhal, Cody et al., 2004). According to Bandura (1977), people learn how to act in society by observing and
modeling the discursive behaviors of role models in everyday life, television programs and in the movies. As individuals begin to match their actions with those of their role models, psychological change takes place (Bandura, 1977). It is within these psychological processes, that the personal and social narratives of audience members are challenged, and (re)defined.

Media effects studies have found that exposure to the message may lead to a change in attitude and behavior (Singhal & Rogers, 1999). For instance, the adoption of family planning methods by a couple indicates how an individual’s perception of the world and perhaps him or herself has changed. Singhal, Cody et al. (2004) present a number of cases which illustrate the effects of entertainment-education initiatives. One such case is the story of the small Indian village, Lutsaan. After continued listening to the radio drama serial, *Tinka Tinka Sukh*, citizens of Lutsaan vowed to disapprove of dowry marriages (Singhal, Sharma, Papa, & Witte, 2004). Essentially, what we are finding here is an emphasis on the generative nature of narratives, where the narrative from one presentation generates narratives within the audience. These narratives are new and promote change within the audience. As they interact with others, including institutions, such as the national media, we find that they engage in performing the stories, that is, they both ‘do’ the stories and ‘make’ new ones.

While the effects of E-E have been heralded, most of the research has focused on the soap opera as the technique of choice (Brown, 1991; Singhal & Rogers, 1999; Singhal, Cody et al., 2004). In fact, this technique has become increasingly commercialized with Hollywood, for instance, contributing to the discourse on health, by
including them in continuous episodes of daytime soap operas and sitcoms (Singhal, Cody et al., 2004). In 2002, *Communication Theory* published a special issue on E-E in which Singhal and Rogers challenged the field. They argued that theoretical investigations of E-E needed to explore how and why entertainment-education has effects, not just what the effects are. Singhal and Rogers (2002) asserted that communication scholars needed to investigate the attributes of different genres of entertainment-education, other than radio or television soap operas. This research seeks to evaluate a response to this call by positioning entertainment-education as performative and inherently narrative through the use of theater, an alternative area of E-E exploration.

Over the years, several scholars have positioned entertainment-education within narrative theory (Slater, 2002; Wilkin et al., 2007). Most of the research that has focused on entertainment-education as a narrative communication has emphasized the persuasive nature of the framework (Moyer-Gus, 2008; Salmon, Witte, & Lee, 2005; Slater, 2002; Wilkin et al., 2007). In fact, it is often the persuasiveness or ability of the product to instigate change which is used to determine the success of the product. According to Slater (2002), good “entertainment-education is intended to stand on its own in terms of narrative quality” (p. 175), thereby successfully attracting audience through its compelling drama, rather than its educational or persuasive content (Singhal & Rogers, 1999). In other words, for the narrative to be successful, the audience must not be overwhelmed by the persuasive content. The fact that E-E is used to persuade is in line with a previous assertion that the narrative is persuasive in nature (Bochner, 1994; Nisbett et al., 1976; Perloff, 2003).
E-E scholars have found that audience members can become very involved with the entertainment-education text or product, its characters and their relationships (Singhal & Rogers, 1999; Singhal, Sharma et al., 2004). In fact, some audience members may even draw connections or parallels between their own lived experiences and the stories and relationships in the text. From these connections emerged personal narratives which were silenced, overlooked or rejected (Singhal, Harter, Chitnis, & Sharma, 2007). Thus, this research points to the ability of E-E to engage us in understanding the difference between knowing and being, that is, providing the opportunity for comparing our own lived experience with that portrayed in the product. E-E, as narrative, helps us dialogue, helps us make sense of our reality, often acting as a map or as a model of social behaviors to be emulated. E-E can foster the formation of a common experience or co-construction between audience members, as well as between the form of E-E and the audience member. Also, these narratives usually call for additional discussion or mobilization on the issues at the community level (Singhal, Cody et al., 2004; Singhal, Sharma, et al., 2004). Slater (2002) argued that E-E was effective in generating dialogue and change because the persuasive messages were processed as narratives and the audience members responded to the messages in narratives.

Entertainment-education comes in various forms: comic strips, radio dramas, music, animated cartoons, television soap operas, photonovelas and even online soap operas (Singhal, Cody et al., 2004). One such form is theater or on-stage drama. Now that we have addressed E-E as a narrative form of communication and how the idea of using plays to disseminate messages about diabetes evolved (as was described in the Prologue),
let us now also position theater as a narrative form of communication capable of generating and challenging discourses about diabetes.

*Theater as Entertainment-Education*

In this section, I describe first, the purpose of theater in research. Then, I address the theories upon which theater as a communicative instrument is based. Throughout this section, I also weave the argument that this medium aids in connecting theory and praxis.

Theater has been used to fulfill many purposes, including entertainment, to inspire critical thought, reflection, emotional engagement, catharsis and personal transformation (Rossiter et al., 2008). Theater has even been used as a means of interpreting and even for enlivening the presentation of results (Rossiter et al., 2008). However, drama is not only entertaining, it is captivating. As entertainment-education, theater provides many possibilities, such as the extension of theory. Theory provides a framework through which communication strategies can be implemented. In the same manner, we can look at the production of these *Sugar Plays* and examine their impact through several theoretical perspectives. As such, I will present several drama theories to better understand the narrative nature of E-E.

Various entertainment-education initiatives have been grounded by a set of dramatic theories. According to Kincaid (2002) drama theory can be used to understand how emotion can change social relationships. Among the first drama theories is Eric Bentley’s dramatic theory (1991). Under this theory, Bentley outlined five types of drama: tragedy, comedy, tragicomedy, farce, and melodrama. One of the main contributions by Bentley is outlining the importance of forming both positive and
negative characters within various plots. This notion demonstrated that drama simply “presents human relationships” (p. 62), thus allowing the audience to see encounters on stage as we watch what people do with and to each other.

Kincaid (2002) argued that drama theory captures conflict and confrontation which occur in social relationships, as well as the cognitive and contextual aspects of drama. Upon watching dramatic presentations, the audience is motivated by their emotions and this causes them to reconceptualize their own problems in their lives and to resolve them in the same manner as depicted in the drama. In essence, in the same manner that emotions drive the characters, emotions drive the decisions, conflicts and finally the resolutions of audience. The aim, therefore, for any good drama is to ensure that the audience feels like a participant, understands the plot, empathizes with the characters and cares about what happens to the characters. Kincaid also asserted that drama, more than any other form of communication, has the most effect on an audience because “it tells an engaging story, it involves the audience emotionally, and it depicts changes in characters with whom the audience identifies” (p. 150). He also noted that for entertainment-education to succeed and to illicit social change, the characters, their relationships and their story must generate similar stories within the audience.

Theater has been employed across the world to make positive political and social interventions (Boon & Plastow, 1998), for instance in Africa and India as a means of informing persons about HIV/AIDS (Singhal, 2004). Most of the research has focused on participatory theater (Harter, Sharma, Pant, Singhal, & Sharma, 2007; Singhal et al., 2007) which is grounded in the work of Augusto Boal (Boal, 2000) and Paulo Freire.
Freire, 1993). Participatory theater is political in nature and aims to highlight the inequities within a society (Singhal, 2004). Building off the work of Freire, Boal discovered that theater encouraged audience members to become activated and fight the oppression themselves. Activated audience members can become positive role models for the communities in which they reside. The aim of participatory theater is to foster that activism, particularly through dialogue. In these presentations, the audience become ‘spect-actors’ who participate in solving the problems both on stage and within their community (Diamond, 1994). Through participatory theater, the audience receives an aesthetic space in which “the human being recognizes that s/he can see himself or herself (the function of the mirror); s/he recognizes who s/he is and is not; s/he imagines who s/he could become” (Feldhendler, 1994, p. 94).

Theater as a performance and as a cultural narrative has been explored by Conquergood (1998). Conquergood used popular development theater as a communication tool to reach Hmong refugees in the Ban Vanai camp in Thailand. As he sought to educate the refugees about the importance of vaccinating all dogs against rabbies, he too grounded his approach in the work of Freire (1993) and Boal (2000), considering as well Burke’s (1969b) rhetorical processes of identification and consubstantiality. The group was marginalized, persecuted and exiled from their homeland, but were still heavily reliant on oral tradition and cultural performance. Conquergood realized that their own culturally performed theater would be an effective means of not only reinforcing cultural beliefs, but also of empowering the Hmong to address their own health problems.
Theater can also be successfully used to address diabetes (Birdsall & James, 1999). Health practitioners in the United Kingdom found that storylines characterized by humor, in particular, were effective in helping persons living with diabetes. Research has found that drama was an interesting and creative means of delivering health-related messages to various client groups (Birdsall & James, 1999). In another instance, drama was used to help practitioners better communicate about erectile dysfunction which is one of the effects of diabetes (“GP turns to theatre,” 2004). Rossiter et al. (2008) also advocated for the used of theater in health education, noting that this is beneficial for health care providers because the strategy will allow them to “better understand, and therefore, cope with issues in practice that are complex, interpersonal, emotional and embodied” (p. 132).

So far, the research on theater has demonstrated that entertainment-education is an appropriate and theoretically grounded strategy which can effectively initiate dialogue and explore discourses on diabetes within a culture that honors oral storytelling. This social change strategy also extends our understanding of the centrality of language, the performative nature of social interactions and the narrative construction of reality.

Summary and Research Questions

In this chapter I reviewed literature on the centrality of language and on discourses of illness to demonstrate the social and narrative construal of reality and the implications for such research in health communication. Finally, I reviewed literature on the intersections of performance and narrative, thus embracing an understanding of the potential impact of entertainment-education, specifically the use of theater.
From this review emerged several key claims that naturally lead to the posed research questions. Running through these theoretical orientations is a distinct thread that focuses on the centrality of language in social interactions. It is through language, and more specifically, through narrative construction that we understand ‘the other’ and present our own version of the world. This stance informs us of the multiplicitous nature of our world and helps us understand how many individuals can engage in the same experience, but emerge with different interpretations. Also, language bears the potential to teach or model behaviors and herein emerges the desire to explore the pedagogical potential of E-E to enhance the recall of salient messages. From this understanding emerged the first research question which interrogates the messages persons gleaned from the plays.

Another assertion from the literature draws our attention to the temporal, sense-making and generative nature of narratives, particularly illness narratives, which attempt to bridge relationships between related experiences (being), while constructing an understanding of these realities (knowing). We find that the personal narrative interacts with historical and social narratives, such as those from loved ones, who try to understand the illness. Based on this knowledge claim, the second research question sought to uncover how this collaborative construction occurs by examining how the audience reconciles narratives from the plays, with their own narratives of personal experiences with diabetes. In essence, I ask, will personal constructions of diabetes be narratively constrained, reinforced, resisted, or extended?
Finally, another assertion made within the literature is the ability of language to reify performed roles in society. Through the lens of performance, and especially by utilizing entertainment-education, we recognize how embodied illness narratives are in social interactions. Finally, we also recognize the suitability of E-E by understanding that performance, fictional and real, can reflect and generate discourse, while being influenced by institutionalized discursive systems. Hence, the final question explored how discourse in broader social and material narratives (culture) determined the performed role of the person with diabetes and the person’s narrative of the experience.

Ultimately, this research sought to provide an understanding of how these theoretical orientations intersected when we examined narrative discourses and performance which emerged within the communicative framework of entertainment-education. With this theoretical focus, I posed the following research questions:

RQ 1: *What messages did the audience recall from the plays and how did these act as a means of entry into the discourse on diabetes?*

RQ 2: (a) *What kind of narratives emerged from the audience after viewing the plays?* (b) *How did these narratives connect with those in the plays and how did the participants demonstrate a construction of diabetes?*

RQ 3: *How did the Appalachian audience perceive the lived experience of those with diabetes?*
Chapter Four: Methodology

In this chapter, I outline the methodological orientation I took within this study and explain how the research methods I selected proved appropriate in exploring the theoretical and practical questions I posed. I begin by describing the plots of *The Sugar Plays* which provided the springboard for generating discourse on diabetes in Appalachia. Then, I explain why I grounded my research in a social construction and an interpretivist orientation, while illustrating how this combined epistemology guided my narrative inquiry stance. Then, I tell the story of how the process of executing the research unfolded. I then explain the methods of data collection I selected for this research study, ending each with the story of how it was executed and the lessons I learned. Finally, I present the ethical considerations I faced and addressed in the process.

*Description of The Sugar Plays*

*The Sugar Plays* are three 20 minute one-act plays (*Sugar Bear, A Family History* and *Lucille*) which focus on characters living with type 2 diabetes in Appalachia (see Appendices A and B for scripts of the plays). Ultimately, the plays will be part of a community outreach program and toolkit entitled, *Diabetes: A family matter*, for use in Appalachia, which will be directed by Dr. Sharon Denham, Professor in the School of Nursing at Ohio University. For this study, I acted as the producer of the plays and focused on ensuring the transportation, and payment of the actors and director, acquisition of props, recruiting of participants or audience members, and the booking of venues. While three plays were written as part of the commission, only two, *Sugar Bear* and *Lucille* were selected for review. This decision was based on the reactions of the
audiences to the draft readings, the difficulty in securing a venue and participants to watch all three in one sitting or to return on consecutive days to watch each play.

*Sugar Bear*, written by graduate theater student, Dana Lynn Formby, highlights the story of a family with two household heads who struggle with being compliant in managing their type 2 diabetes. Chickens killed by a coyote, a story about a bear, a hidden stash of sweets and confessions of undisciplined behavior create quite an atmosphere of tension and resolution in this play.

*Lucille* was written by G. William Zorn, a graduate theater student. This play focuses solely on the engaging conversation between newly-diagnosed retired English teacher, Mrs. Lucille Myers, and her transition nurse, Candy. Mrs. Myers is about 75 years old and now has to come to terms with her diabetes management and the importance of family support, even if it has to come from an unlikely source. Within these two scripts are stories of the challenges of illness, the impact of family and the discussion of health between intergenerational family members living in Appalachia. Now that the plays have been introduced, I will focus on the epistemological foundation used to explore the discourse created in the context of these plays.

*Narrative as Epistemology*

According to education philosopher, Thomas Schwandt (2000) qualitative researchers have participated in three alternative approaches, constructivism, hermeneutics and interpretivism for gaining and producing knowledge. I posit that narrative is a sub-type of qualitative social inquiry (Chase, 2005), which offers us an alternative lens for examining knowledge claims. In my literature review, I spoke of why
I viewed narrative as ontology. Here, narrative is an epistemology, a useful tool for telling us what we know, how much we know, and how and why knowledge is acquired.

Therefore, within this study, my central focus was on how participants grasped and gave meaning to their practices, understandings and language with regards to diabetes and how these had been constructed over time. My attention was peaked when they expressed and reinforced this knowledge and meaning through narrative telling.

Apart from the constructionist approach, I also ground my methodological practices through the interpretive lens. Through this lens, I recognize symbolic forms, such as rituals and artifacts, as being encoded with cultural meaning (Geertz, 1973). An interpretive researcher also sees the social action from the actor’s point of view; recalls that as humans engage in interpretive and expressive practices together, they collaborate in the social construction of their realities; and understands that realities are plural, with multiple voices and interpretations (Cheney, 2000; Lindlof & Taylor, 2002) even as each participant undergoes the same experience.

Both approaches are suitable for helping me explore, through the presentation of two of *The Sugar Plays*, the central question, which was how diabetes is narratively interwoven into and defined by culture, and the ways in which the health narratives surrounding this disease construct the perception of the disease and determine how it is performed. Through the social construction and interpretive lens I will be able to understand how meanings were constructed and evolved into objective symbols with encoded subjective cultural and personal meanings. Proposed as a cognitive way of
thinking or rationalizing (Schwandt, 1997), narrative would be a suitable means of inquiring as to how knowledge about diabetes is constructed and interpreted.

**Methodological Strategies**

So far, I have presented a case for why I took a social constructionist and interpretive standpoint for this project and why I chose a narrative inquiry approach to explore the research questions posed. Now, I will outline how the research got started and follow it with the selected methodological strategies which were used to analyze the discourses of diabetes in Appalachia after the presentation of the plays.

**Getting Started**

A major hurdle to tackle at the start was locating venues and attracting audiences who would act as participants in the study. I chose to focus on community groups and organizations with easy access to loyal patrons. The plays were presented at five venues.

The venues were selected based on access to participants (Table 4.1 provides an overview of each venue and number of participants). Each venue had a committed set of patrons who were willing to participate in the research and who would have no difficulty accessing the venue. All the patrons also had some exposure to diabetes or were currently diagnosed with diabetes. For instance, the director of the shelter for persons who were homeless thought that the Friday evening community dinner would be an ideal venue for presenting plays, since the context was food-based and most of the patrons were persons with diabetes or had family members or friends who had diabetes.
Table 4.1

*Description of Venues*

<table>
<thead>
<tr>
<th>Venues</th>
<th>Plays viewed</th>
<th>Target audience</th>
<th>No. of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. RHIO Conference, Ohio University, Athens County</td>
<td><em>Lucille &amp; Sugar Bear</em></td>
<td>Health practitioners working in Appalachia</td>
<td>Approximately 10</td>
</tr>
<tr>
<td>2. Shelter for the Homeless, Athens County</td>
<td><em>Lucille &amp; Sugar Bear</em></td>
<td>Homeless and Friends of the Homeless</td>
<td>Approximately 60*</td>
</tr>
<tr>
<td>3. Local community church, Athens County</td>
<td><em>Lucille &amp; Sugar Bear</em></td>
<td>Congregation members and non-members from the community</td>
<td>Approximately 40</td>
</tr>
<tr>
<td>4. Local living assistance home, Athens County</td>
<td><em>Lucille</em></td>
<td>Residents of the home</td>
<td>Approximately 12</td>
</tr>
<tr>
<td>5. Multicultural Center, Morgan County</td>
<td><em>Lucille</em></td>
<td>Members of the Center</td>
<td>8</td>
</tr>
</tbody>
</table>

*Note.*

* This number was an estimation, as it was difficult to determine, during the second presentation, which audience members who saw *Sugar Bear* had already seen *Lucille*. While four of the venues focused on accessing the local community, one venue addressed a group of diabetes educators and medical practitioners who specialized in diabetes. This group will be using the plays in the field and as such it was important to hear their reactions to the narratives, especially their potential effectiveness.
The procedures for execution at each venue were always the same:

*Step one*

This step involved introducing the occasion and reminding the audience that this was a research project, not just entertainment. At this time, I would also conduct a short raffle where one participant could win a $20 gift certificate.

*Step two*

This step involved passing out three forms: a consent form for participation in the play; open-ended questionnaires on which persons could write comments to the research questions I posed on the plays (see Appendix C); and a “contact me sheet” if they were willing to participate in an individual in-depth interview.

*Step three*

The respondents watched the plays and wrote comments on their questionnaires.

*Step four*

Step four involved giving the audience time to complete additional comments on the questionnaires, soliciting their verbal responses, engaging them in the participatory sketching activity, encouraging them to complete an interview form and completing another raffle. In venues where both plays were shown on the same day, this process took an hour and 45 minutes. In venues where only one play was shown, the process took 30 minutes to one hour. The wide difference here was due to time constraints; for instance, in one venue, I only had time to ask the audience two questions after they had finished watching the plays.
I chose the following strategies for collecting narratives and understanding perceptions: in-depth interviews, participatory sketching, open-ended surveys and focus group discussions. By doing so, I have ensured that the project was grounded in empirical data and embraced multiple voices and realities. Next, I will provide a brief description of each strategy, how each was executed and the lessons learned.

*In-depth Interviewing*

In-depth interviews were my primary source of collecting stories for this project. I agree with Lindlof and Taylor (2002) that they were well-suited for “understand[ing] the social actor’s experience and perspective” (p. 173). In order to determine this experiential knowledge, the interview proved to be beneficial in eliciting three forms of discourse: their stories, accounts and explanations.

In total, I conducted 30 in-depth interviews, with each lasting approximately 45 minutes. The longest interview was approximately one hour and 40 minutes, with the shortest being approximately 20 minutes long due to the fact that the participant had to leave to attend a meeting. Seven men and 23 women conducted interviews. Their ages ranged from 20 to 76 years. A majority of the participants were from Athens County (25), with 5 others each residing in Fairfield, Franklin, Meigs, Morgan and Perry counties.

This setting provides a space for allowing the participant to construct his or her own experience and their self according to the context, action and intentionality (Baumeister & Newman, 1994). Interviews also allow participants to provide accounts of their experiences, which sometimes come in the form of excuses or justifications of social conduct (Scott & Lyman, 1968). Additionally, in this forum participants receive the
opportunity to explain their behavior, that is, “…how they appl[ied] what they know in certain areas of their lives, how they negotiat[e[d] certain issues, how they moved from one stage of their lives to another, how they interpret[ed] certain texts, and so on” (Lindlof & Taylor, 2002, p. 174).

As an international researcher of a minority ethnicity, I knew that there were certain aspects of the social reality of diabetes that I would not be privy to. Therefore, the interview also acted as a means to “gather information about things or processes that cannot be observed effectively by other means” (Lindlof & Taylor, 2002, p. 174). I found that the interview was an excellent means of connecting with well-informed participants who described the social reality of diabetes in Appalachia and who provided “more reflective understandings about the nature of that experience” (Johnson, 2002, p. 106). Additionally, the interview provided insight into the three-fold present (Ricoeur, 1990), the collaborative existence of the past with the present and the future. Finally, I believed that the interview helped me achieve efficiency in my data collection. I used the interview to compare and expand on comments made in the informal group discussions and on the participatory sketches.

Rosenblatt (2002) stated that “interviewing produces a social co-construction in which interviewer and interviewee are both players” (p. 894). In essence, the interviewer does not hold complete control over the interviews, but that the interviewee also plays an integral role. With this understanding I developed a semi-structured interview protocol that had open-ended questions to probe the individual (see Appendix D). Additional questions emerged during the interview process, mostly for clarification, as well as to
probe the individual, for instance, about choices that were made. Sometimes persons eagerly responded, willing to share their experiences, but in other times, there was hesitation, uncertainty due to the belief that they did not have enough information to provide me and uncertainty with regards to whether they were answering me correctly, even though I assured them that there was no correct answer. Indeed, sometimes there were productive and unproductive digressions, which followed the participant’s interest and knowledge (Johnson, 2002).

Interestingly, I had no participant who was openly or covertly, at least to my knowledge, unwilling to share or participate in the interview once we got started. There was always a desire to “help me out.” I also learned about the vice of multiple interpretations, as questions that I thought were very straightforward would be ‘read’ completely differently from my assumptions.

After collecting the contact information sheets at the end of the plays, I contacted persons and arranged interviews. I recall that in one exhausting day, I did four interviews due to the fact that the academic term was ending and I wanted to reduce as much as possible the amount of time between when the patrons saw the plays and when the individual interview was conducted.

With the exception of two participants, who adamantly insisted that they did not need it, each was provided with a $20 gift certificate that was redeemable at several local businesses. I made it clear that this was not payment, but was simply a token of my appreciation for their time. I received funding for the gift certificates through an Original Research Grant from the Graduate Student Senate of my university. I met persons in
various venues including local Wendy’s, and McDonald’s restaurants, and even in their homes and offices. All were face-to-face interviews, with the exception of one telephone interview which I had to conduct with a lady who had watched the plays and lived seventy miles away, but who eagerly wanted to participate.

Acquiring interviews from the various venues in which the plays were presented proved to be a mixed bag for me. In one venue, the director of the shelter for persons who were homeless was reluctant to grant me permission to contact patrons of the Friday dinners and meet with them separately on alternative days. While he allowed me to meet with persons up to 30 minutes before the dinner started, this proved difficult, as sometimes persons would be late and by the time we got started as was the case with the 20 minute interview, it was time to end. While this was frustrating and disappointing for me, I respected his policy and understood his desire to protect the patrons from being subjected to being exploited and researched as they had been in the past. The majority of my interviews emerged from the patrons of the local church. I believe they were willing to participate because I had been a member of the church for the past five years and had cultivated a trust and abiding friendships (Johnson, 2002) with them.

The interviews were audio recorded and transcribed. Each interview was transcribed in chronological order and analyzed in chronological order.

*Participatory Sketching*

While I did not conduct a workshop, I used participatory sketching as another means of gathering knowledge about diabetes. Greiner, Singhal and Hurlbert (2007) stated that the use of participatory sketching as a research method has increased in
popularity over the years. Singhal and Rattine-Flaherty (2006) utilized this methodology to examine the effects of a radio soap opera in the Philippines and another in the Peruvian Amazon, which was organized by Minga, Peru. Later, Flaherty (2008) used participatory sketching as a research method to understand how dialogic processes in a Palestinian-Arab organization addressed sexuality and sexual health. These studies recognized that in “privileging the visual forms of expression, researchers position themselves to question the dominant hegemony of textocentrism” (Greiner et al., 2007, p. 244). In other words, this method does not privilege the text-based way of knowing as would be done in the open-ended surveys.

Participatory sketching offers another way of engaging the audience rather than through traditional surveys, placing the production of knowledge into the hands of the participant. As a result, the researcher becomes a co-learner, learning with and from participants (Flaherty, 2008). The methodology arose out of the work of Brazilian educator, Paulo Freire (Freire, 1993) who utilized the narratives of the persons he worked with as a means of having them critically examine their lives (Greiner et al. 2007). Participatory sketching, therefore, has been utilized as a means of accessing the rich narratives from persons from southeast Ohio.

The participatory sketching took place in two forms. At the end of each session, I presented the audience with a final question: “What does diabetes mean to you?” or “When you hear the word diabetes, what image comes to mind?” Using pens, which they had been provided with for the open-ended questionnaires, I asked them to sketch their responses. The participants were told to draw, using the blank sheet at the back of their
open-ended questionnaires, whatever they wanted to in response to the question(s) regardless of their sketching ability. Unfortunately, I had to provide them with a time frame, usually five minutes due to the time constraints already at hand.¹

After they received a few minutes to draw, I then asked several persons to orally share their image and explanation with others. I could not ask each audience member because of the constraints of time. In two instances, the audience had watched both plays in one sitting and had been at the venue for a little over an hour, and was clearly getting agitated after engaging in a brief discussion. For persons who signed up for interviews, I asked them to write their names beside their images which I collected at the end of the session. This approach worked best at the local church and with the health practitioners.

I found that this activity was received with some amount of excitement on the part of the audience. Many thought that it was fun and I heard laughter, and amidst the clamor, exclamations of “I don’t know what to draw!” Clearly, they were comfortable with each other as they shared their sketches and laughed at the art work and stories. I assured several that there was no right answer and that I anticipated seeing and hearing their interpretations.

At the interview, the first question I asked of the participant was for him or her to explain the sketch in detail and the reasons behind the interpretation. The sketch would remain in front of us throughout the interview and sometimes, the participants referred to

¹ According to Flaherty (2008) a participatory research activity such as this should not be time bound but participants should be allowed as much time as possible to complete the task. I was saddened by this constraint in the research setting and recognize the potential limitations it placed on participants.
it again, stating usually, that it reminded them of another narrative or they used it to clarify a point.

The other form of executing the participatory sketching activity occurred only in four interviews. These persons participated in three venues where time did not allow me to conduct the sketching activity. Therefore, at the start of the interview, I asked them the same research question presented previously and waited as they drew. We then began the interview session with their explanation of their drawings.

In the end, I ended up with 39 sketches. The additional sketches were from persons who participated in the activity, but did not wish to conduct an interview. As a result of losing their explanation of their sketches, I decided to focus only on the sketches provided by the interview participants.

The visual and narrative analyses that emerged from this study were the most enjoyable part of this study for me. As Flaherty (2008) had suggested, I ensured that the question was broad and refrained from giving more detailed directives even when I got blank stares at first. I found the activity a valuable complement to the in-depth interviewing, open-ended questionnaires and informal group discussion. This approach does not purport to be a ‘better’ method, but simply offers to participants an alternative way of knowing and expressing that knowledge which may not be possible in the interview and discussion (Flaherty, 2008). Flaherty (2008) continued to state that this activity “allows participants to include issues of emotion and imagination as part of the research process and by allowing participants the freedom to express themselves both visually and verbally, unique insights often surface” (p. 116).
The following participatory sketch (Figure 4.1) and explanation is only one example, but without a doubt, I found that the drawings offered an array of images, understandings, as well as emotions from the participants. The drawings certainly helped me gain a better understanding of how diabetes is perceived in the area, and the effect of the plays.

Figure 4.1. Kelsie’s representation of diabetes.

I drew that because, usually when I hear the word diabetes, I think that no sugar, like, so I would just put the “X” over it, cause “X,” usually just means “no,” when you put it over something and like I just know with my family like, I thought of them too, like all the things that they can and cannot have, so, like my little cousin, he has diabetes. And I just know with him, he can like, you can have it, he can have it, but it’s very limiting, so... (Kelsie)

The explanations of the sketches were audio recorded and transcribed. The drawings have been analyzed using the existing epistemological framework and in conjunction with the other sources of discourse collection. The analysis of the transcriptions of the
explanations of the sketches was also done in chronological order. A more detailed presentation of the analysis of these sketches will be provided in the Results Chapter.

Open-ended Questionnaire

The open-ended questionnaire, served two main purposes in this study. First, it helped acquire demographic information (Lindlof & Taylor, 2002) and then it served to as a means of recording immediate reactions to the plays. Open-ended surveys were handed out to the participants at the start of each event. The questionnaires comprised four main questions which they could answer during and after the presentations (see Appendix C). These questions were also asked in the in-depth interviews and participants were encouraged to refer back to their notes made under each. The questions required information on perceptions of the messages in the plays, portrayal of the family, perception of diabetes and the challenges persons with diabetes face in the region. I thought these were the most relevant and demanding responses needed after the viewing of the plays.

While I collected a number of open-ended questionnaires, only those used by the in-depth interview participants were examined. The others were either incomplete or not clear. The questionnaire was originally intended as a data source for participants I thought would have to leave the venue before the start of the group discussion. Instead the questionnaires proved to be integral in the in-depth interviews, they served as a means for the participants to take notes and record the information they gleaned from the plays. Since persons were asked to place their names under the images they drew on the back of
the forms, I found that many of the participants appreciated having the forms because they reminded them of stories, and other points they had not noted or remembered.

I do not think that their privacy was violated by placing their names on the forms; instead, they served to really enhance the in-depth interviews. I found that the participant appeared to fall into the role of the researcher as a result of these questionnaires, eagerly examining the text, that is, the plays, critiquing them, as well as enjoying the reporting of the themes they identified from their own examination. Consequently, I found that the participants unwittingly engaged in interpretive methodology, as they sought to interpret and understand the meanings behind the practices of the characters in the plays.

*Focus Group Discussion*

The final methodology used in the study was the focus group discussion. The focus group discussion, as a data collection method, is effective for several reasons. These discussions probe people’s understandings of mass communicated messages. We also find that expressed ideas and experiences stimulate other expressions from group members (Lindlof & Taylor, 2002). There is a chaining effect, that is, “talk links to, or tumbles out of, the topics and expressions preceding it” (Lindlof & Taylor, 2002, p. 182).

Since the research questions sought to explore the emerging discourse after the presentation of these narratives, then the group discussion was an appropriate method to stimulate discourse. The aim of having focus groups was to stimulate a chain reaction of discussion on the narratives presented in the plays, identifying how group members expressed their views; how they add their own interpretations; and how they theorize about their particular worldview. As Lindlof and Taylor (2002) observed, the focus group
is useful for “studying the production of interpretations, perceptions, and personal experiences” (p. 182).

Unfortunately, this methodology was not very well executed. My main constraint, once again, was time after the presentations of the plays. After the first presentation at the shelter for the homeless, I was able to hold a discussion for about 40 minutes with six persons who remained behind after the play had ended. Some of the responses from this discussion have been included in the Results chapter. However, at the second presentation, *Sugar Bear*, I was only allowed about five minutes to engage the audience in their response to the plays. The participants at the local church allowed me 40 minutes to talk about the plays. However, since the majority of the persons there signed up for the individual interviews, some of their responses from the discussion were repeated in the interviews. Some of the responses from this discussion have been included in the next chapter. Another issue which emerged in this discussion with the group at the church as well was that the group was too large for a traditional focus group discussion. There were approximately 40 persons present and as a result, all topics could not be addressed, neither could all participants be equally engaged. Only six persons remained for a discussion after the presentation to the health care workers and it was during this setting that the recording was low and sometimes indecipherable. The discussion at the multicultural center in Morgan County involved eight persons, but only lasted for about ten minutes. This was due to the fact that they had just ended a meeting that had lasted for one and a half hours and were already tired.
Nevertheless, I found that it is important to engage the audience in reflection after a text has been provided and it truly seemed that they were eager to share what they had learned. I believe the discussion served as a springboard for the in-depth interview. The participants were exposed to my personality, and they also got an idea of what the in-depth interview would be like. I believe that made them receptive to further participation.

*Ethical Considerations*

I agree with Stake (2005) who stated that, “qualitative researchers are guests in the private space of the world [of the researched]” (p. 459). I was always consciously aware of my manners and the code of ethics I had committed to through the Institutional Review Board of Ohio University. After an initial attempt at one of the venues, I decided to only administer informed consent forms during my interviews. The very first time the plays were presented, I found that I had too much paperwork and my observation of the audience informed me that the forms were making my participants agitated, impatient and unwilling to participate; most of them were just eager to watch the plays. In total, I had three forms at that first venue: informed consent forms, open-ended questionnaires, and a “Contact me for an interview” sheet, all of which I handed out to each participant at once and this proved too overwhelming for them. In addition, since I was also playing the role of hostess and introducing the plays, I found that the forms were cumbersome and did not allow me to concentrate well.

Therefore, I relegated to verbally reading the consent form and handing out only the questionnaires and the contact form. I believed that the interest of the participant was still honored. In two of the four venues, there were patrons under the age of 18,
however, I had previously informed the parents and leadership that these children could not stay and participate in the discussion which ensued after. At the shelter for the homeless, the children were taken away to play games by some of the volunteers of the organization, and at the church, the children were taken to adjoining classrooms to play.

Also before and after the presentation of the plays in each venue, I held an informal raffle drawing, where one participant was awarded a $20 gift certificate. This was once again, a show of appreciation for their patience and hopefully, it was a sign of goodwill on my part.

However, each interviewee was asked to sign an informed consent form. At that time, while I assured confidentiality, I did not ask for pseudonyms. I realized this mistake close to the end of my discourse collection process, where one participant, in telling me a personal story about being diagnosed with a sexually transmitted infection (STI) paused to receive assurance from me that his identity would not be revealed. It was because of his request that at the point of analysis of the transcriptions I decided to assign each participant with a pseudonym, thus, as Johnson (2002) insisted protecting a valuable person who had assisted me in the research.

Additionally, I recognized the impact of the epistemological lenses in the ethical decisions I made. I came to understand that I too did not enter these stories uninitiated, but with constructed views (Schwandt, 1994, 2000). For instance, I was struck by the fact that my entry into my final interview was much different from that of my first interview, because of my involvement in previous stories told by participants, as well as my own personal experience with diabetes. However, I agree, with Charmaz (2005) that “what we
know shapes, but does not necessarily determine, what we “find” (p. 310). Hence, I believe I honored the participants’ stories with the same respect as they presented them.

Analysis of Data Collection

I engaged in repeated thematic and close reading of the transcripts for the in-depth interviews, focus group discussions and the explanations of participatory sketches as part of my analysis. Therefore, during the transcription, I began to make my first notes of initial reactions to the interviews and interviewees. After the transcriptions were completed, I conducted a second reading and made clearer categories. The third and fourth readings later condensed and clarified the themes. The analysis for the open-ended questionnaires was actually done along with the in-depth interviews. The analysis of the open-ended questionnaires as a separate data source was not thought to be wise, since the participants actually verbally stated their responses on the questionnaires in the in-depth interviews and further elaborated on them in that interview setting. Only the questionnaires from participants of the in-depth interviews were analyzed.

I paid special attention to the stories and the themes emerging from these transcripts so that I could get a better understanding and a detailed, thick description of what diabetes meant to the participants, how the participants perceived their experiences with diabetes and how they ‘read’ the events in the plays.

Eventually, I knew I had reached a point of saturation when I began to notice by my 25th interview that I was receiving similar messages, concerns and interpretations of the text. This made me confident in and comfortable with the decision I made to conclude
my study. I believe that each methodological strategy helped to build the validity of the study and provide a better understanding of the communication context.

Ultimately, I found that I, along with the interviewee was involved in a process of narrative negotiation. Through the methodologies that I brought to the table, the interviewees were able to reflect on their own stories and interpretations of the stories presented to them. Through questions which probed and asked for further clarification, we both engaged in a co-constructive process where a clearer and a better understanding of diabetes emerged. Additionally, my close reading of the transcripts further engaged me in this process of negotiation and co-construction, as while the participants presented their stories, I afterwards, in the process of analysis, gave additional meaning to these narratives through the themes that I identified as emerging.

Summary

In conclusion, in this chapter, I have described the plots for the two plays which served to provide the communication framework and context in which the study is based. I have explained how the broad methodological orientation of narrative inquiry is guided by the intertwined epistemologies of social construction and interpretivism. I have provided the methodological approaches upon which this dissertation was driven. Finally, I provided, the narrative of how the methodological strategy was initiated, which specific methods were used and my experience with those, and the ethical conclusions I drew at the end (See Table 4.2 for a summary of the research process). In the next chapter, as I seek to answer the posed research questions, I present the themes that emerged from the responses to the executed methodological practices.
Table 4.2

*Research Design*

<table>
<thead>
<tr>
<th>Methods</th>
<th>Type of Data</th>
<th>No. of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Analysis</td>
<td>Male</td>
</tr>
<tr>
<td>1. In-depth Interviews</td>
<td>Thematic analysis involving first, second, third and fourth readings</td>
<td>7</td>
</tr>
<tr>
<td>2. Participatory Sketching</td>
<td>second, third and fourth readings</td>
<td>7</td>
</tr>
<tr>
<td>3. Open-ended questionnaires</td>
<td>introduced several themes with the</td>
<td>7</td>
</tr>
<tr>
<td>4. Focus Group Discussions</td>
<td>data.</td>
<td>3**</td>
</tr>
</tbody>
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*Note.*

* Some of the individuals for the participatory sketching activity did not reveal their sex. These were often persons who submitted their sketches, but did not sign up for an interview.

** The specific male and female participants were not taken due to time constraints. The number of participants in these groups ranged from eight to 50.
Chapter Five: Negotiating the Narrative Reality of Diabetes

In this chapter, I present the narrative reality of diabetes in Appalachia, organizing the responses from participants around the three research questions, which developed into three thematic areas of content. I have looked for patterns and themes to gain a better understanding of how diabetes is perceived and constructed within southeast Ohio, as well as how effectively theater can be used to entertain and educate an audience about diabetes thereby encouraging some form of behavior change. I paid close attention to narratives that paralleled those presented within the plays, as well as those that contradicted and extended the plots. Throughout this process I found a reflexive audience that was not only amused by the antics of the characters and intrigued by the conflict, but also disturbed by the prevalence of this disease in their society.

After reflecting on close readings of transcribed interviews, focus group discussions, participatory sketches and written responses to open-ended questions derived from the research questions, I posit that the reactions from the members of the audience can be placed into three domains which organize this chapter. The responses within the domains were guided by my three research questions:

1. *Educating through Entertainment: Engaging with the Messages in the Plays*

This section presents the messages which the audience members identified as they watched the plays. The identified messages indicate that some degree of learning occurred while the audience was entertained by the stories being depicted on stage. Within this domain, I explore how stories that were culturally-relevant and based in humor succeeded in teaching members of the audience several lessons about how to
prevent and manage diabetes. These messages included an awareness of the role of the family during illness, the importance of communicating not only with one’s family, but also with the medical practitioner and the effect of healthy eating, one of the seven self-care behaviors advocated by the American Association of Diabetes Educators (AADE7) (American Association, n.d.).

2. Using Narratives to (Re)Construct the Meaning of Diabetes

This area focuses on the narrative construction of diabetes. Within this realm, I explore the emergence of private narratives which emerged after watching the staged narratives on diabetes. Here, we see how members of the audience sought to reconcile their own construction of diabetes with that presented in the plays and they did so by telling narratives to explain these intersecting constructions. There were specific themes of narratives which emerged: narratives of fear, narratives of resistance (Frank, 1997; Schechet, 2005) and narratives of guilt and shame (Frank, 1995, 1997). The final theme which focuses on intersecting narratives, demonstrates how the audience made sense of the stories as they presented stories that were not related to diabetes but which explained their understanding of the illness further.

3. Culture and the (Re)Shaping of diabetes

This domain explores culture as a means of social construction. Within this realm I paid attention to the participants’ evaluation of the effects of poverty and the economy on the prevention and treatment of diabetes. Attention is also given to the effect of tradition on eating rituals within the family and how these rituals could hinder the management of the disease. A sub-theme under tradition is this sense of fatalism which
sometimes constrains attempts being made to curb the prevalence of diabetes within the family. This domain also highlights a call for social change or action at the community level, where audience members advocated for community support for persons with diabetes and dialogue about the disease.

Each domain is explored by first presenting the main themes which are followed by an examination of the sub-themes which emerged from the audience’s responses.

*Educating through Entertainment: Engaging with the Messages in the Plays*

Four themes or messages emerged under this first domain. The outline below provides a brief description of this section:

(1) ‘Family Dynamics’
   a. Support
   b. Lack of support
   c. Gendered caregiving

(2) ‘Dialogue’
   a. Lack of disclosure
   b. Communicating with the family
   c. Patient-Practitioner communication
   d. Communicative sensitivity

(3) ‘Healthy Eating’
   a. Control: Battling the urges
   b. Sugar as poison or death
   c. Alcohol and diabetes
(4) Facilitating the Reception of Messages: Using Humor and Cultural Relevance

   a. Humor as a medium
   b. Culture as a medium

Family Dynamics: Support, Lack of Support, Gendered Caregiving

A resounding observation made by most participants was the manner in which each play’s narrative centered on the important role the family played in the lives of persons with diabetes. It was clear that the family must act as a unit, recognizing that if one member had the disease, all members of the family had to adjust their lives and diet. In exploring this theme, I found that while most of the participants reflected generally on the message, they also reflected on their own relationships with family members with the disease and what this information meant for future interactions.

This theme addresses the role relatives and significant others play in helping to prevent and manage the development of the disease. This section highlights the nuances of family support by focusing on the need for relatives to act as accountability partners and the importance of cooperation from all parties involved. However, the theme also addresses the dark side of family support, such as the lack of such support, and the enabling and apathetic nature of relatives. Finally, this theme also examines gendered caregiving by looking at the role of the mother or women in a family with diabetes.

Support.

Undoubtedly, while other sources of support, such as friends, neighbors and co-workers, exist during times of illness, possibly the most consistent source will be family members. Their support and ability to command some degree of accountability during the
management of the disease is needed from the very start of the process. After watching both plays, local insurance agent, Darla, pointed out that the time of diagnosis would probably be accompanied by some amount of shock and therefore it was important to have someone there who would listen to the doctor and catch important messages that would not be heard by the patient. Another participant, a stay-at-home mother, Tonie, noted that the participants will be too preoccupied with a myriad of questions and thoughts (see Figure 5.1), and as such, it would be beneficial to have another set of ears present, so that the instructions are correctly followed:

When they hear that diagnosis, it’s like okay, so what’s next? Am I going to have to take pills? Am I going to have to take insulin? Is it, is this just a diet change? You know, ahm, how is this gonna affect the way I work, the way I live? Where I go, you know. All of those things, ahm, if you’re a woman and you’re young and unmarried, [clears throat] how’s this gonna affect me having children. That’s, I mean, diabetics and pregnancy, that’s a whole other realm of things, so, there’s a lot of questions, you, you just have no answers to right away and it’s I can imagine, it’s probably, really, really, terrifying.
There was also an expressed need for the presence of family members beyond diagnosis. Along with proper eating habits, exercise and any necessary medication, the family support system is the final piece of the puzzle in the move toward achieving a successful management of diabetes. Through the assistance of the family, the person with diabetes can realize that the disease does not have to have complete control and can be well-managed. In Lucille, we saw the medical expert, the transition nurse, Candy, carefully addressing the need for Lucille’s family to be involved in her recovery and the healthy management of the disease beyond the diagnosis. After listening to Lucille describe her relationship with her daughter-in-law and how her eating habits had not changed since the death of her husband, the nurse drew a somber conclusion:

CANDY

You know, Lucille. I can’t help but think that the biggest obstacle to your recovery might be your family.

LUCILLE

Continue.
Well, we see a lot of patients become lax in their efforts to keep up with their blood sugar readings or they might start to forget their insulin. But, those that have support from their families always do much better. Someone to ask if you’ve taken your insulin today or to encourage you to eat better. [Excerpt from *Lucille*]

The message was not lost on the audience members. A number of participants, persons with diabetes and persons not diagnosed with diabetes, began to realize the importance of having a loved one play the role of an accountability partner as the individual begins to learn how to live with the disease:

Just the dialogue between the nurse and, and, ahm, the patient, [in *Lucille*] it’s just showing the, them the, other side of it, “yes, this is very serious, but if you stick with these, with this plan, if you ahm, do the things that you’re supposed to do, keep up with your diet and you know, if you have the support in your family, you can manage this and it won’t, you know, it’s not as scary as, as it seems. (Tonie)

…and when we go to buy stuff, Jerry [her husband] kinda helps me a little bit, but he doesn’t, it’s not necessarily consistent. But when he does actually help me out, it’s like, “oh, should you, you probably shouldn’t eat that.” Like my sister, my sister made homemade buckeyes, “one’s fine, five is not.” And so, she’s, she’s like, “well, that does have a lot of powdered sugar in it,” and I said, “okay.” So, I had one as opposed to having two or three. Ahm, so to have that support, it’s kind of a
balance, checks and balance system, where, you know, they can kinda help you, you know, see what you’re doing and it’s kind of another set of eyes. (Tarah)

These words illustrated that there were a number of ways in which relatives supported persons with diabetes. Relatives can monitor a loved one by inquiring about or helping in the checking of blood glucose levels and insulin injections. They can also help shop for healthier food choices or recipes, help them to remain on schedule and even provide transportation to alternative sources of food which may not be present in the loved one’s current locale. Additionally, some participants mentioned the importance of having family members attend educational classes with the person with diabetes as a show of solidarity, as well as a means of becoming more educated about the disease and its imminent impact on the family. Local dietician, Erin, stated that diabetes was a family disease and that it is helpful for as many family members as possible to attend the sessions so that they can learn how to start working together:

…so when they go home together, somebody else knows that, “Hey, this is what we are supposed to be doing, here.” But if the, if the man just comes by himself and nobody from his family comes and he learns about the diet, when he walks out of the office and goes back to his routine at home with the routine foods, what chances are that he’s gonna make any changes at all, especially if it’s his wife, that’s the one that’s purchasing the food, bringing the food home, cooking the food?

Several participants willingly shared their own personal narratives about caring for loved ones with the illness. Kelsie recalled an incident while she was working at her father’s
office. She kept hearing her grandmother, who had diabetes, repeatedly stating that she
needed to take a break and eat something, but her father kept delaying the break:

I heard her keep saying that and I just got up, I’m like, ah, I’m like, “Dad, let me
see your keys.” I’m like, “Grandma what you want?” I’m like, “I’m gonna get
you something. Like Subway’s right down there, I’ll go get you something, now I
would be the one to go get it.” And I, I ended up like, I didn’t like tell my dad, but
I had to sorta tell my, tell my mom and she was like, “Kenny, you know you ‘pose
to, you should let your mom like, either provide food when you know you guys
are gonna be there after a certain time, you know she needs to eat at this time.”

Another respondent, Jennifer, recalled the times when she would rise early in the
morning to go over to her mother’s house to test her blood glucose level for her because
she did not know how to use the machine and was also not willing to learn. Inga also
talked about the fact that her brother relies on her for medical advice regarding his own
diabetes. She was also chosen to be her mother’s caregiver after she received her
diagnosis, even though she was very young at the time:

I was the one that had to see that this got done and that got done and then when
my Mom got sick, I was the one that washed her ass and cleaned it. I’m the one
that fed her. I’m the one that gave her her medicines. I’m the one that took her to
the doctor…I just took her, just like I would a kid…

There were stories of support from even the youngest members of the family, who are
sometimes able to clearly identify the needs of a person with diabetes, while still not
being able to articulate it well. For instance, Stefann pointed out:
But, as early as 4-years-old, I remember my son coming in from being outside with his dad and saying something like, “Dad needs a sandwich.” And I would say, “Would dad send you in here?” And he said, “Nope, but he needs a sandwich.” So, even at that very young age, he’s picked up on the lows, the personality change, and, my husband gets really short with us, you know, ahm, so, whenever they were going camping or fishing, or whatever they were doing, I was very comfortable when they were together.

Fifty-six-year old, Neil also recalled his father’s insistence that no one ate ice-cream in the presence of a young female cousin because she was ill and was on a special diet:

We couldn’t bring it at home. We had to eat away from home, so, so, it would be hard on her as a little girl, see, we would be sitting there eating ice-cream cone and she couldn’t have none. So, so, so when we have candy or ice-cream, it’ll be the family thing. My dad would get along Saturday, with the whole family, would eat some, and she would eat some. But we, we didn’t do things like that, to tempt her. See?

The need for support from the family was clear. However, while caregivers recognized this, several respondents also pointed to the fact that providing this support can be a challenge, especially when the person with diabetes does not comply willingly:

One thing we had we had a problem with, my grandmother on my father’s side, ahm, she was all, she’s always like the very busy, on the go kind of person and we like, we had to constantly, we would, me and my sister took it up on ourselves to call her at a certain time every single day or send her a text message, to remind
her like, ahm, “My lunch was good, what did you have?” or like, just trying to throw little hints to remind her like, “Oh I need to eat something,” and we did it at the same exact time every single day. (Kelsie)

So far, respondents have reflected on the role they played as support systems for loved ones with diabetes from the start of diagnosis and beyond. This support comes in various forms, ranging from the tangible to the emotional. In the next section on this sub-theme of support, we extend this perception further by incorporating the challenges that the family faces as they try to extend and receive support.

The lived experience of the person with diabetes is dependent on several mediating factors. Some respondents stated that among the factors that lead to effective management of the disease is the harnessing of cooperation and understanding among all members of the family, including the person with diabetes:

Like with Robert’s mom [her mother-in-law]…I know that’s a big problem with diabetic people. They don’t eat right. And, ah, like she’ll, she’ll just eat stupid like ‘cause she works a night shift and ah, she’s a baker, so she doesn’t sleep right either. So, she only gets 4 hours of sleep a night. So then, she’ll come home and eat like egg sandwich and that’s it for the whole time she’s up and I’m like, “You need to eat,” and then she’s wondering why she doesn’t have the energy. So I call her and bug her all the time and make her eat right, like when we lived there, I always made her food and made her eat correctly…(Jenise)

This cooperation needs to be fueled by transparency from each person regarding the management of the disease and its complications. Margaret noted that culture might
hinder adjustments to be made by members of the family, as would have been the case with her father:

Ah, he came from Germany, so he was very, you know, you got to do it, you gotta be very independent, you gotta, you know, and it wouldn’t fly for the whole family. He wouldn’t want to eat what they wanted to eat or wouldn’t, it wouldn’t work. He wanted mashed potatoes and gravy and meat [laughs] and that’s what we’re having [laughs].

Erin also reaffirmed the notion that successful management is based on the willingness of all parties. She laughed as she told me how nervous she felt as she watched Sugar Bear because the atmosphere felt very stressful with the tension among the members being very palpable. She noted that the tension within the family surfaced as they tried to cope with someone who was struggling with the disease, even as they sought to understand their individual roles in the process:

…there was so much conflict in the family, you know, the father wanted to do his own thing and he was, he was hiding when he was doing it from the others, and he was defensive, so he was blaming things that, that, that was his fault on his son, which caused more conflict and then there’s a conflict with the wife because she trying to help him and he doesn’t…

To further emphasize how illness can prevent cooperation within a family and ultimately compromise its management, Stefann provided a real-life narrative of a family who was clearly in conflict as they tried to learn how to manage their 13-year-old son’s diabetes:
…his family has done everything and now he has this stepmother and she just thinks it’s way too much trouble and, ah, you know, so this kid has lots of highs and lows, and they fight about, ahm, he doesn’t want to write them down in a book because the meter keeps the blood sugars in there, and the Dad wants him to write them all down. And, you know, and so, I’ve seen this battle with him and it’s like, you know what, the meter stores the numbers, don’t burden the kid making him write them all down, you just look into the, into the monitor, they’re there. So, and I, you know, I don’t know if that’s a control thing or what that is, but it’s like, let him be a kid. You know, he’s got enough to deal with, he’s, he’s willing to take his blood sugar well, then you take the meter every night and you write them down! [laughs] You know, I mean, you know, it’s a, [laughs] why stress the kid out more?

Under this sub-theme, I have addressed how the respondents reacted to the nuances of family dynamics. These included recognizing the need for providing support for the person with diabetes, even while acknowledging the challenges of providing and receiving the support. However, there are two sides to the coin with regards to family support. On one hand, the family can provide considerable assistance and encourage accountability on the part of the person with diabetes. On the other hand, there can be indifference and even cruelty from family members.

*Lack of support.*

There are various consequences which could arise from a lack of family support, with the most glaring being the possible death of the person with diabetes. However,
other potential outcomes from the lack of monitoring could include the increased complications and the development of the disease within other family members. There are several reasons behind this lack of support and these include lack of knowledge about the disease and the impact of culture on the family.

There could be a lack of vigilance over the health of a loved one even while family members are aware of the presence of the disease. For instance, sometimes, family members thought or chose to believe that since the person with diabetes appeared to have everything under control, there was no need for inquiries to be made. In reflecting on her grandmother’s management of the disease, university administrator, DJ, admitted, wryly, that no one in her family actually paid attention to her grandmother’s illness and neither did they change their own eating habits to accommodate her illness. DJ also recalled that, in fact, her grandmother often made two meals, one for herself and another for the rest of the family. She also stated, sadly, that this must have been frustrating for her grandmother, and even more so when her grandfather took a turn to cook the meals since he did not make any meal preparation accommodations:

…I thought about that in the play [Sugar Bear], you know, it was still, when we were talking about the roles and whose responsibility is it, and really she was the only one that kept up with it, we didn’t. You know, I can never recall my grandfather saying, “I’m gonna cook you this meal, this is what we’re gonna have and we’re all gonna eat it,” no. No, and I think that’s probably what, may have frustrated my grandmother’s, because we were all, I know I wasn’t conscientious
about, you know, what I ate in front of her and trying to eat the same thing that she was eating.

This lack of support becomes even more glaring at family gatherings where there is an absence of substitute dishes for someone with diabetes. Without options that are suitable for the diet of the person with diabetes, the individual either has to forego sharing in the eating ritual, eat just a limited amount, or indulge completely and risk harming the glucose levels in the body:

…oh, just for, the example with my grandma. We tell her, “You can’t eat this and this and that.” But then we don’t have other alternatives. So, it’s really not supporting her [laughs], ‘cause it’s like, “Well, you just can’t have a lot.” But I mean, but who’s gonna get full off of, “I’ll just have a little bit of every little?” You know. So, we need to do a better job of having different dishes and say, “Look grandma,” you know, “We made this, this new recipe, blah, blah, blah, and you can eat, you know, and you can eat it and I’ll be fine. It’s low in sugar. It’s low in carbs,” and you know, we don’t do that. (Shaniqua)

Apart from not providing other meal options, a lack of support can also come in the form of enablement which involves the avoidance of correction when poor meal decisions are being made or when persons with diabetes are encouraged to deviate from their prescribed diet. In essence, family members can become dangerous companions while one is trying to manage a disease. Fear of confronting the authority of the person with diabetes can also result in the absence of support. College student, Shaniqua, admitted that whenever she saw her grandmother making poor meal choices, she would always
feel afraid of chastising her, because she was her elder and having a younger person correct a senior is frowned upon within her family.

A major consequence of a lack of family support, whether from indifference or enablement, is the development of a sense of loneliness on the part of the person with diabetes. The absence of a caregiver or someone who will inquire about his or her current situation or offer encouragement after bad reports on the management of the disease can lead to depression which further compromises the health of the individual. Of the two plays, it appeared that Lucille captured this emotion most accurately:

That play hit home more than any body will ever know. Ahm, not just the diabetes, but it just, it was the concept of her being alone and not really having anybody there to take care of her or to listen to her or for her to understand, you know, to try to help her understand anything. Ahm, I’ve been there. I’ve done that. When I had the car wreck, I hate to keep bringing that up but, when I had the car wreck, my daughter comes up to the hospital, I’m lying in the hospital, they don’t know if I’m living or dying. They really didn’t. My daughter comes in and says, “Hi Mom, I love you. Goodbye, I’m going to Montana.” Now do you understand why I said that hit home for me probably more than anybody else? (Inga)

While I have focused so far on the support persons with diabetes need from family members and the reasons for the lack of support, it is important to note that the influence is a two-way street in the family, with persons with diabetes sometimes negatively impacting the health of persons not diagnosed with diabetes. Sometimes family members
with diabetes can act as poor role models for other relatives, who are at a high risk for
developing diabetes. Linda noted that her daughters have struggled with staying on track
ever since her mother-in-law who has diabetes moved in and brought with her the
practice of indulging in Butterfinger candy bars, soda, cookies and cakes to help regulate
her levels. This is a source of frustration for Linda, especially since her mother-in-law,
who is over the age of 70, is so set in her habits. Despite this frustration, Linda has found
ways to circumvent this familial influence:

She bought, she wanted to buy the syrup this time and I know why because
[laughs] the syrup that I had, because we do egg or waffles every once in a while,
is, is half-sugar-free, and half regular and so when it came time to get sugar, to get
the, ah, syrup again. She wanted to buy the kind she likes, so, and, I mean, she
uses it very liberally. So, as soon as it gets down a little bit, I will be buying the
other kind and filling it back up, so I think just, just little things like that, that
maybe I can slip things in a little bit of a time.

Darla added that there was a downside to having family members with diabetes who
continue to eat poorly but who live to an old age. These persons, sometimes unwittingly,
act as role models for younger family members who emulate the poor eating habits of
their elders, believing that while the quality of life may not be entirely desirable, it is still
be sufficient. Shaniqua observed this perception among her own family members who are
seemingly oblivious to the possible genetic nature of the disease and the future impact of
current eating habits. However, she understands that this indifference may be because her
grandmother has not manifested many complications:
I think people think “I, have that youth, I’m young, nothing’s gonna happen to me thing,” so…they don’t think about it, not that they just don’t feel like, “Oh, I’ll just get it one day,” but they just don’t think about it at all [laughs] and when they do get it, then it’s kinda like, “Oh well, I guess this make sense ‘cause grandma had it.” As opposed to, “Why did grandma have it? What was her diet like? When could I have changed?” So, I think it, maybe they just don’t think about it at all, you know, one way or the other and then when they’re older, it’s like, “Well, grandma had this when she was older,” you know, instead of thinking, “I’m now that I’m 22, what can I do to make sure that I don’t have it?”

Another element to be explored is the recurring role of the woman or the mother as the main source of support which was commonly commented on during the interviews.

*Gendered caregiving as a family dynamic.*

Even as the participants expressed the importance of support, and transparency and cooperation within the family, there was also an underlying sub-theme of women as caregivers. In both plays, women are presented with the role of keeping the family and the person with diabetes on track; sometimes this was conducted effectively or ineffectively. While one respondent observed that some women simply liked to feel needed and as such gravitated toward the caregiving role, most participants, including men, acknowledged that women were generally regarded as the task managers, organizers and nurturers of the home, and even more so when a child or an elderly parent is ill. The better enactment of this portrayal was in *Sugar Bear* where the mother, Marlene, was the one in charge of the family’s meal times and the general operation of
the group. However, for Leena, a united front from both parents is preferred especially in a family with diabetes:

…the mother’s always the one in that situation, she was always the one to, to force, enforce the like, “Here, we’re eating this, we’re eating this, we’re eating this, we’re eating at this time, we’re eating at this time, we’re eating at this time,” and like the Dad just, went along with it, instead of being the enforcer and taking control of his own, ahm, medical issues, like, “No, we have to eat at this time, because I need it and like it’s good for you too to eat at this time…”

The mother is usually regarded as the accountability person and is entrusted with the family’s health. Toward the end of Sugar Bear, for instance, the grandfather and the father pass a bottle of bourbon and a bag of sweets respectively to the mother. Elizabeth described this moment as an act of surrender, a turning point in the narrative, which had nothing to do with the fact that she was a woman, but more so with the fact that she was the only adult there with no problems and therefore, could be trusted.

Indeed, the mother’s actions in Sugar Bear received varied reactions. One of the more popular reflections was how important it was for the caregivers and support systems within the family to find a balance between supporting and nagging. Linda, a mother of two girls who had pre-diabetes, told me that she walked out of the room in the middle of the presentation of Sugar Bear in tears, because the mother’s portrayal was so similar to her own. She explained that it was very difficult to avoid being overbearing at home because she wants so much to improve her daughters’ health:
Because I thought, “Oh my gosh, is that how I sound? And they still don’t wanna do it, yet that’s how I sound?” You know, did I push too hard? And not, and, and they were just, they just didn’t wanna hear me anymore. They just didn’t wanna deal with it anymore. Did I push too hard because I am kind of a strong, I don’t sometimes know when to be quiet and lay off. Because I want this, I want them to get better. Then they don’t think there’s anything wrong. So it was really, truly, it was very difficult for me to sit there any longer, that’s why I got up and left. ‘Cause I couldn’t do it anymore. I, I couldn’t hear anymore. I was, I was done. ‘Cause it, ‘cause it’s hard, sorry.

Some participants thought that the mother was more of a nag and as such, was very ineffective in her attempts to keep the family on track. Ilene stated that the mother needed to be more creative in her approach and be less of a task master who cracked an imaginary whip over everyone each time she spoke. Lloyd noted that although she was the initial advocate and encourager in the family, the mother was overzealous and eventually evolved into a nuisance. In essence, at the heart of the relationship between the caregiver and the person with diabetes was communication:

…presentation influences interpretation and influences, receptivity. If you’re constantly being badgered about something it’s the presentation. It may not be the product that you’re trying to sell. It may not be the principle that you’re trying to get across but it’s, it’s constant, badgering, policing, and some things if you present them properly, some of the worse things you’ll be able to be more receptive if they’re presented properly. Sales is everything, and what I saw in the
play was the mother wasn’t selling and she was, she, she, she, she had ah one approach with, with the children and another approach with the husband and she didn’t sell the thing well, she, she, became a policeman, she became, ah, a cop for lack of a better term over, over the sugar.

Lloyd argued that the mother’s presentation in *Sugar Bear* was the reason her messages were misinterpreted and as a result, her husband viewed her as a controller and retreated, essentially insisting that the disease did not exist and did not need as much attention as she wanted. Shaniqua expanded on this description by stating that sometimes regarding the mother in a nagging role was actually expected within society:

> We have, just like we have mom’s a caregiver, we also have mommy as, caregiver, annoying, nagging caregiver. So, the whole, culturally, we think, “Mom is supposed to get on our nerves. She’s supposed to make us do things we don’t wanna do. She’s supposed to make us brush our teeth, longer than two seconds. She’s supposed to make sure we eat healthy,” and culturally we see it everywhere, on TV, kids are “Oh, we have to eat these vegetables,” so, it’s like, Mom has that role, you know as, as kind of like, the warden almost. It’s, like at the end of the day, you always love Mom and you appreciate it, but I just think our culture, that comes with the caregiver role. She’s the one that has to do things that we don’t like and it’s just, it’s just Mom. That’s what Mom does.

Elizabeth interpreted the situation differently and insisted that the family, as a whole needed to address the situation from another perspective:
…I don’t think I heard nagging, I, I feel, I heard a frustrated wife who loves and cares for her husband and is frustrated that she feels that she can’t do anything, well, there’s nothing she could do, until he actually owned up to it, as Henry [another participant] said. And so, the family just needs to be there, you know, and sometimes it’s time, the family needs to let that person go until they get to the point, and it’s not. I mean, if she is the caregiver in the situation in the play and she’s the one making dinner, well she can make right choices in the dinner. And if, if the husband wants to be stupid about it, stupid about it and say, “I don’t want that,” she’ll say, “Well, you need to make your own.” I mean, that kinda support. I mean, there’s tough love.

The climax in the story occurred when the father admitted his guilt and then promised to take better care of his diabetes to prevent it from being passed on to his children. It was a behavior change which was followed by a more positive attitude toward the prepared dinner for the evening which contained, ‘rabbit food’ (vegetables). As soon as he made this promise the entire family seemed to fall in line and eagerly approached dinner, a contrast to their attitude at the start of the play. In analyzing this scene, Ilene felt that the change in the family’s perspective had nothing to do with the fact that the father was the authority in the house, but instead arose because the mother’s voice had lost its shock value. She argued that the father’s voice was different. However, most participants surmised that this change in attitude within the other family members was due to the father’s authority in the home and was a response to the mother’s nagging attitude:
…when he spoke it out, he put authority behind the mother’s decision to have that kind of diet, then everyone went along with it. Yeah, mothers can be caregiver, but it doesn’t mean everybody’s always gonna obey her. People obey the father, you know what I mean, ‘cause I, think I’m little more scared of the dad maybe he’s the disciplinarian (Darla)

…but as soon as he claimed responsibility for his disease and the management of his disease, then they were all on the same page, moving together forward, you know, that’s kinda how I saw it. Maybe not so much as him taking the lead, but taking self-responsibility and then everybody saying, “Yeah, we can do this together.” (Erin)

However, there was a different reaction when the caregiving role was placed in the hands of the daughter-in-law in Lucille. Nurse Candy made the insightful conclusion that Lucille’s most frequent family contact was Judy, the daughter-in-law. Most audience members felt that Judy would be the most logical choice, not because she was the woman, but simply because she was the only family member who consistently visited. But some interviewees reiterated that Lucille’s successful adherence to the program, like any other person with diabetes, depended on three conditions: (1) whether she was willing to disclose her condition and complications; (2) whether the daughter-in-law (the family member) would actually consider herself as the main source of support; and (3) whether Lucille was willing to allow this young woman to get close to her and improve their relationship.
In the end, several participants agreed that the role of the caregiver does not have to fall solely in the hands of the woman, because men were just as capable:

Ahm, we have, in the dialysis unit have a, a, ahm, elderly patient that’s a female and her son is her caretaker. Usually you see it is the opposite, it’s the daughter that’s the caretaker, ahm, of the elderly father or even, of the, ahm, father-in-law. But in this case, the son was never married and ahm, he retired, he retired from the air force, so he takes care of his mother and he’s excellent, excellent, takes her to the bathroom, you know, bathes her, good with the medications, the diet, everything, cooks for her. So men can do it, but I think a lot of times, they don’t need to do it. So, they just don’t learn those skills, they prefer not to. (Erin)

In sum, the theme of ‘Family Dynamics’ addressed how participants interpreted the presence of support in the plays. A number of participants emphasized that this particular support system was one of the key elements in the bigger picture toward managing diabetes. As the theme emerged a number of persons highlighted aspects of the family’s involvement, including their lack of support, the need for cooperation and the role of the woman as caregiver. Essentially, there was a common thread of using the “we” language within a family with diabetes so that all parties shared in the blame and the rewards of managing and preventing the disease. Considering the importance of language, let us now focus on the respondents’ reaction to the significance of dialogue within the family as an emerging message.
Dialogue: Engaging Disclosure and Communicative Sensitivity

The theme of ‘Dialogue’ encompasses the need for open communication and greater sensitivity toward the needs of ‘the other.’ This theme addresses the implications of a lack of disclosure, the need for open communication between the patient and the medical practitioner and between family members and the patient, and the implications of these interactions. Finally, I was heartened by the number of audience members, especially those not diagnosed with diabetes, who began to express a greater sense of caring toward persons with diabetes after watching the plays. I witnessed the creation of a space where those not diagnosed with diabetes received the opportunity to enter into the world of diabetes and to experience, vicariously, the challenges that resided there. Under this sub-theme, I examine how several audience members engaged in self-reflexivity by identifying how they treated others with diabetes in the past and determining how they could ensure greater sensitivity in the future.

Lack of disclosure.

Dialogue is important and as some of the respondents highlighted, both plays emphasized that in order to receive strong family support the person with diabetes must feel comfortable in disclosing the illness, as well as any additional illnesses that emerge. For instance, in Lucille, Candy, the nurse, after recognizing that the patient lived alone, encourages her to talk with her daughter-in-law about the disease, especially if she wanted to manage the disease effectively. However, Lucille, like some persons with diabetes is unwilling to engage the assistance of this family member. The same is evident
within Appalachia where even though the disease is quite prevalent, there is a noted silence about diabetes and its complications:

No, not around this area, not like that. They don’t discuss it or talk about it, no…I don’t know, I don’t know why. There’s a lot of other things people don’t talk about around here. I think most of the people around here just wants to ignore it, talking, don’t want to even discuss it, I mean, ‘cause they know it’s ahm, it’s hardship…(Jennifer)

Jennifer, a resident of Athens County, in Appalachian Ohio, admitted that within her community, there was little dialogue about the disease which affected the lives of many persons. She noted that even her own family members did not talk about the disease willingly, especially her step-sister who had experienced several amputations as a result of the disease.

There may be several reasons for reticence in talking about the disease. For instance, nondisclosure could also be due to the lack of knowledge about the disease on the part of the person with diabetes. If someone does not know much about the disease, he or she may not be inclined to share any amount of information. Additionally, a lack of disclosure could be due to embarrassment of not knowing about or being exposed as not having a great understanding of the disease.

Also, the silence could be due to a culture of privacy which could be argued for in the case of Jennifer’s observation. Originally from Kentucky, Darla also noted that there was a lack of disclosure about the disease in the area in which she was raised. Especially, within her family, there was no mention of the disease. She said, “Boy in our family, it’s
almost like we didn’t want to talk about it because we knew it was a death sentence. That’s the way we took it.” In explaining this, Darla noted that her family was highly superstitious as was characteristic her community. They believed that if you spoke about something it would definitely develop in your life. She surmised that no one talked about the disease out of fear that by doing so, they would give the disease permission to develop in their lives. The thought was that if you spoke about the disease, you owned the disease; in other words, by speaking about it one could be sanctioning a curse.

However, within some families, nondisclosure or secrecy is maintained as a means of protection. For instance, in the play, *Sugar Bear*, we notice that the parents do not correct or stop the grandfather as he embarks on a tale about being attacked by a bear instead of honestly addressing his illness. The secrecy was maintained perhaps because they were exasperated by the grandfather’s history of storytelling, but also because they may have felt that they needed to protect the children from the knowledge of the disease:

…well they were secret[sic], certainly about the grandfather being, he’d been I guess, he’d been in the hospital a few days, but nobody wanted to say, why and they didn’t want the youngest child to, to know that at all. Aww, so there was a lot of secrecy, ahm, and obviously there wasn’t much support of, any support, they were sort of undermining, each other in every respect (Margaret).

However, another reason for the lack of disclosure and dialogue could also be due to the personality of the person with diabetes as Todd and Darla explained:

I think with my mom, it’s just, ah, part of her personality. She’s shy, doesn’t want anyone to be in her business like that, but at the same time, she doesn’t like to
sometimes share things with me or let me know about it, especially if it’s concerning her and her health in a negative light, because she doesn’t want me to have to be concerned about her. She wants me to be more focused on what I’m trying to do in my life and take care of my family. So, she doesn’t want to worry me I think with a lot of her own personal health issues. That’s one of the reasons I think that she keeps it to herself (Todd)

Darla agreed that lack of disclosure could be as a result of the personality of the individual. She recalled that while she was growing up, her paternal grandmother spoke openly about her diabetes because the effects of the disease were conspicuously evident as her fading eyes and leg amputation indicated. On the other hand, her maternal grandmother was very reserved about the disease and was described by Darla as being so prim and proper that she would exit the room to check her glucose levels privately.

Several consequences arise due to nondisclosure. Without a knowledge of the existence of the disease or the appropriate ways to treat it, family members will not make proper accommodations, as was the experience of Margaret, who only recently heard from her middle-aged son that he had been diagnosed with diabetes for several years. Even though they both had participated in several family events over the years, he had never mentioned this health development until recently. She regretted not having this information and hoped that none of the meals she had prepared had sidetracked him:

But ahm, and I, I believed was at least shocked, because no one, you know, in our family has had, that I know of or admitted it. So, yeah, and he, well, obviously is an adult, now when he’d discovered it, and when he admitted it. How long that
period of time was from when he’d discovered it, and when he admitted it, I don’t
know. And I haven’t paid any attention to notice ah, on, the, you know, the, ahm,
holiday meals and various things how, how he reacts to what I fix. I fix what I
normally fix and well it’s up to him to say, I can’t choose this.

Undoubtedly, support from one’s family cannot be gained unless there is disclosure. At
the same time this lack of disclosure can be due to the culture in which the person resides
and perhaps the personality of the individual. Under the next sub-theme I explore
reactions to instances of disclosure between the individual and the family.

*Communicating with the family.*

In the following section, I present the responses of some of the participants with
regards to the importance of maintaining communicative lines between the person with
diabetes and members of the family who are not diagnosed with diabetes. There are
several possible outcomes which occur after disclosure. One likely result is that
disclosure will facilitate dialogue. Furthermore, accountability for the management of the
disease will be shared by someone else apart from the person with diabetes.

Undoubtedly once members of the family are included in the information-sharing
process the path toward appropriate treatment becomes even easier. Not only does talking
about the disease lead to more dialogue about the disease, disclosure will also provide the
means through which persons receive additional support from family members and
thereby share the responsibility of managing the disease:

I knew what my grandma had, but it never really, our family, we never really
talked about it. We just knew it, but we didn’t really talk about it and I saw that in
the play [Sugar Bear]. Nobody really talked about it and then when they did, it almost made it, ahm, you know, it, it, almost made it ahm, seem as if it was something that was conquerable. You know, like you actually would, have a chance of surviving, whereas before when it’s not talking about, seems like it’s like, “Okay, well, let’s just, you know, let’s just really not talk a lot about it and hope that you at least see, live to see 70,” You know. (DJ)

Some respondents shared stories of the impact of complete openness about diabetes in their own families. Kelsie revealed that on her father’s side of the family diabetes was talked about as if it were any other regular topic. This approach provided a safe and supportive environment for persons with diabetes in the family:

I know like my aunt, she’s like the mom over everybody including my nana and she’s like, ahm, if she there, she checks on ‘em, she’s like, “What was your reading today?” And she, soon as they tell her, “Oh, that’s really good, I’m so proud of you,” da, da, da, da, dah. She’s a, she’s a real mom. But she’s just like, like that’s the only way, like she really just be anybody that brings it up, like “Oh, that’s good to hear. I’m glad your reading is doing good. I’m glad you’ve been staying on top of it,” like it’s next to nothing…

However, in contrast to Kelsie’s observation, Darla argued that there can be too much disclosure. She could hardly contain her amusement as she related the example of her mother-in-law and sister-in-law who excitedly share their experiences with diabetes. She believed that the women shared too much information and that this could become a nuisance in the family. She informed me that both women seemed to be very proud of
their management of the disease and publicly talked about their blood glucose readings and insulin shots. She described their behavior by stating that it was as though they both wore the disease like ‘a badge of honor.’ It appeared that Darla’s in-laws regarded being persons with diabetes as a new identity which they had eagerly embraced and which, perhaps, had given them an added sense of purpose. However, in Darla’s opinion, their openness was inappropriate and overbearing at times:

She [the sister] got the, gestational and it never went away. Oh my gosh, I can’t even go out to eat with her, every, I mean, she like pulls up her shirt and [demonstrates how this is done] and injects herself, like people all around the restaurant see, or she’s exposing herself and shooting up and testing her blood, like, like for everybody to see. It’s a big drama. I’m just like, “would you stop it?” you know, it’s too, me, it’s like she’s trying to draw attention to herself, like she’s wanting a pity party or something. And, it’s, and then Jimmy’s [her husband] mom is just diagnosed. But hers isn’t, hers isn’t too bad. But it’s almost like she was like, “Oh, I got sugar now! I’m gonna have to get a treadmill,” you know, almost like it gave her something to...to work for. It was a goal, to then get the sugar down which she did really, she lowered it, really well with the, ahm, with the treadmill, she lost a lot of weight, she did really good, but it’s like all she wants to talk about and I thought, once you get it lower, then what’re you gonna do? You know, stop exercising so it can go up and you can do it again, you know. But I think they just call each other and wanna compare blood sugar levels and it’s like “Oh, gimme a break. You guys make me sick!” [laughs]
Certainly, while disclosure often breeds additional dialogue and possible support, it is received in different ways. Sometimes it is eagerly embraced and encouraged and at other times, there is a desire to silence it.

However, another response is that family members may now be prompted to seek additional information about the disease to ensure that the illness is properly managed. Margaret remarked that this was particularly important in a culture where the term ‘sugar’ was predominantly used to describe diabetes. She noted that the use of the term could construct an incorrect perception of diabetes thus leading to improper treatment by ill-informed members of the family. Communication with the person with diabetes and with his or her practitioner could provide the needed impetus for the family to get correct information about the disease, so that the individual could lead a more healthy life.

Also, there may be a greater boldness to question the actions of the persons with diabetes and to demand inclusion in and disclosure of health-related decisions being made as DJ expressed with regards to her mother who recently started to check her glucose levels:

…so now, I, I see her every so often where it’s like she goes through these spurts, where she’s just like on a sugar high, you know, well, trying to get a sugar rush, trying to find something. And I’m just like, “What is wrong? Well you know what’s wrong with you, so, I, I, I don’t know.” Ahm, well she is, ahm, picking, test, testing, her sugar. She does do that. Ahm, but I don’t know what the doctors have said in terms of, I don’t think, to my knowledge, they haven’t diagnosed her as diabetic, yet…and like certain things like orange juice, she, she used to always
say like about a year or so ago, she always said, “I don’t know,” I, like she always had to have orange juice. “What? What is it with you and orange juice?”

However, the entire process of disclosure can be complicated sometimes with each party attempting to determine who should take the first step. Thinking from the perspective of a friend, Vannie remarked that persons who are not diagnosed with diabetes sometimes struggle with timing and determining when to encourage someone to talk about their condition. As a result, she advocates for leaving the initiative to disclose solely in the hands of the person with diabetes:

It’s just that I’m not sure if I start talking about it, what the reaction will be, so I wait for them to talk to me about it, you know, because you can talk, try to talk to people, “Gee I just heard that you got this, that and the other,” and they, they don’t want to talk about it, they don’t want you to mention it so, you can lose a friend that way too, so I said you just got to be careful about who you talk and what their attitude is, some people will take it very easily, others, it’s the end of the world, as far as they’re concerned and ah, I think, I think you kind of have to go slow and easy and see what their reaction is before you can take any steps.

Apart from dialogue and disclosure within the confines of the family and close friends, the communication between the practitioner and the patient is also worth attention.

Patient-practitioner communication.

Apart from communication between the family and the patient, there also needs to be open communication between the person with diabetes and the practitioner.

Unfortunately, oftentimes, this is the person with diabetes’ main and only source of
support, especially when the management of the disease becomes stressful as Erin explained through Figure 5.2:

*Figure 5.2. Erin’s representation of her role in diabetes education.*

I’m a dietician, I see my role as a cheerful advocate of, for the person with diabetes to change behaviors, so that they can take better care of their diet, you know, themselves with diabetes, and it’s hard to do and they often feel overwhelmed, that’s so that’s why I have the person kinda frowning and saying, “it’s too hard,” and then I’m smiling and saying “you can do it,” because I’m
trying to lead them in the right direction and ahm, but they’re the ones that have
to do all the work and I’m just holding their hand through it…(Erin)

Darla offered another perspective on the communicative interaction between the
practitioner and the patient. After watching Lucille she felt that there were times when the
nurse, Candy, was condescending and addressed the elderly lady as though she were a
child. She warned that in real life this could create a poor relationship between the patient
and the practitioner which could hinder the patient’s recovery. Nonetheless, she also
acknowledged that some older persons prefer that style because they feel cared for. At the
heart of it all she concluded that it was important for health care providers to carefully
consider and select an appropriate communication strategy for each patient. This final
lesson on the importance of mindfulness in communicative interactions introduces the
sub-theme of communicative sensitivity which several respondents verbalized as a lesson
they gathered after watching the plays.

Communicative sensitivity.

After receiving the opportunity to enter into the world of diabetes and experience
some of its challenges vicariously, some of the participants remarked that they felt a
greater need to be more sensitive:

…unless you are in a family with diabetes, like you would never see that
conversation happen, because those are things that you keep inside your house
and you just talk about it at home. So, since my parents don’t have it or none of
my siblings do then ahm, it was really interesting. I almost, while I was watching
[Sugar Bear], I almost felt like, “I shouldn’t be there, like, oh this family’s having
a fight, like I shouldn’t be watching.” But ahm, so that was interesting just to hear ahm how other families dynamics are…(Sydney)

Ahm, and I know, even with my wife, I mean, because I do like to eat, and I’m kind of selfish about that, that I try to be a little more sensitive, that I can’t really just sit and eat what I want in front of her, ‘cause that’s tough, you know, so I’ve tried to alter my diet a little bit, and so that’s what I really got from *Sugar Bear* [italics added]. Yeah, I probably need to be a little bit better. (Dennis)

Sensitivity and empathy are vital to the successful management of diabetes. Without it, not only does it hurt the relationship between communicating individuals, but it could also act as a setback for persons with diabetes. In the play, *Lucille*, the main character participated in a role-playing activity with the nurse and portrayed her daughter-in-law’s insensitivity:

CANDY

(Doing a crankier LUCILLE.)

Hello, Judy.

LUCILLE

(As JUDY.)

Oh good. You’ve got coffee on. I just didn’t have the time before I left. Rush, rush, rush. That’s all I do these days. My nails. My hair. I simply must spend your son’s money before he gets smart and divorces me. *Are you outta sugar? Oh that’s right! I’m sorry. Well, Equal will just have to do, I guess* [italics added]. How are you feeling?
CANDY

I’m feeling fine, Judy. Just fine. [Excerpt from Lucille]

In the italicized sentences, we recognize that the main character is bothered by Judy’s seemingly lack of tact in reference to her diabetes and the audience realizes that this may hinder Lucille’s own development by hurting her self-image.

The necessity of understanding was echoed by some respondents. In Seri’s opinion, there must be some amount of thoughtfulness exercised by loved ones during meal times. She explained that her family made changes after her husband was diagnosed with pre-diabetes. She stated that “I think you have to do it as a family, you can’t, say, ‘Oh, I’m going to eat this pie and I’ll keep it in front,’ because that’s cruel, you know, I mean, you have to…” Tonie also emphasized that while family members needed to exercise care in their own actions, the person with diabetes also needed to assess the actions of loved ones as part of the ongoing process in determining whether the disease was being effectively managed:

…ahm, how sensitive are your family members to what you’re going through? You know, the, the, not only are you frustrated because you can’t do what they’re doing, but how sensitive are they to what you’re going through? How, how are they helping you cope with that? How are they reacting to it, are they sensitive enough not to eat certain things in front of you, or is this, the, not that they’re trying to be mean, but they’re just not thinking about how it might affect you and how does that affect where you go?
Unfortunately, knowledge of the individual’s condition and disclosure on the part of the person with diabetes, whether to relatives or strangers, may not generate immediate sympathy, compassion or sensitivity. Darla recounted the story of a former colleague who had diabetes and who experienced difficulty balancing the demands of his disease with the needs of the clients at the workplace:

Like I worked in an accounting office where a man had very, very bad diabetes, I mean like he could pass out and he needed to eat, at a, you know, strict time, check his blood, eat his lunch, do his insulin, he needed very, very rigid, clients would walk in without an appointment, “hey, hey, I’m here, need you to do my taxes. I need you to look this up.” He said, “you know, I’ve gotta take care of this, I’m diabetic.” “Oh, it’ll just take a few minutes.” And you know how people stand and talk, next thing you know, half hours passed and he’s getting really dizzy. And you’d look at him like he looks like he’s gonna pass out. People, people are just rude, I think [laughs]. They don’t, some people, just like, “oh it’s just diabetes, it’s no big deal,” you know, they just act like it’s you know, like having a, you know, rash, or something, you know, it’s like, don’t realize it can be life and death for some people.

Indeed a lack of sensitivity could have grave consequences for the person with diabetes, especially if this thoughtlessness created a lapse in or the abandonment of the required treatment regimen. A consequence of this error could be the development of physiological challenges which Darla observed in the workplace experiences of her former colleague.
While not presented in great detail, both plays dealt with some of the physiological complications that could accompany diabetes. In *Sugar Bear* the audience watched as the father, Andrew Jr., had a near fainting spell and ‘the shakes’ which were brought on by low blood glucose levels. Even as his children observed this effect on their father with unease, they are also exposed to how he dealt with both complications as he drank liquid glucose and checked his blood glucose level using the blood glucose monitor. In *Lucille*, we are told that the main character was experiencing the loss of sight and near pancreatic failure upon her admission to the hospital:

CANDY

Well, Mrs. Myers, we’re finding out more and more about this disease everyday—

LUCILLE

Then maybe they’ll find out I don’t actually have it.

CANDY

Mrs. Myers, normal blood sugar tops out at about 120. Do you know what your blood sugar was when you were admitted to the emergency room?

LUCILLE

They told me it was high.

CANDY

It was 982. You were essentially in pancreatic failure.

LUCILLE

But, I didn’t feel that bad.
CANDY

Mrs. Myers, you couldn’t see. [Excerpt from *Lucille*]

The presentation of these incidents generated a sense of sympathy on the part of some respondents. Various participants began to commiserate with the characters and consequently with real-life persons with diabetes. The presence of these complications further emphasized for them the seriousness of the disease and the potential hazard it could bring to one’s well-being.

While this exposure educated them about the risks of improper care, the interviewees stated that the plays also informed them of the fact that the disease was manageable. It appeared that some members of the audience engaged in some form of transformative learning, moving away from a fear of the disease to a better understanding of the disease, which subsequently aided in the development of a greater sense of sensitivity. Some persons not diagnosed with diabetes articulated a better understanding of the emotions that could possibly emerge at the point of diagnosis, the fear of complications, but most importantly, the role they could play in being sensitive and reminding persons with diabetes of ways to control the disease:

Because, it’s very scary. I think in most people, that, that get a diagnosis of diabetes, I think one of the things that they think about is, “Is this eventually gonna kill me?” Because I know that’s one of the things that would probably cross my mind, because there are so many different complications that can take place, you know. Your kidneys can fail, you can lose your eyesight, you can get, have amputations. But, and you see the whole side of it during the play, because
you see that, ahm, you know, maybe you don’t necessarily have to have drugs, but if you need to have the drugs, you know, ahm, there’re people who can help you, ah, keep track of these things, and ahm, just having someone who is supporting you, I think this is the biggest thing, helping you keep track of your medicines, being an encouragement. (Tonie)

Essentially, I found that a number of respondents were more reflective about their own interactions with persons with diabetes and admitted that they had been lacking. In watching the plays, they were reminded of the importance of their support and as such, expressed a greater commitment to being more sensitive, especially in social gatherings where food was a central component. In essence, there was now a greater attempt to being more mindful of the needs of the other.

In conclusion, the theme of ‘Dialogue’ highlighted several significant areas which must be considered during communicative interactions with persons with diabetes. These include the need for an awareness of the reasons for a lack of disclosure during times of illness; the communicative relationship between patient and the family and the different ways in which disclosure is received by relatives and friends; the communication between the person with diabetes and the practitioner and the importance of finding an effective strategy for each individual; and finally, the importance of communicative sensitivity and understanding when interacting with persons with diabetes. The effect of open communication lines in the family becomes very apparent in the third theme of ‘Healthy Eating’ which will be explored next.
Healthy Eating

The theme of ‘Healthy Eating’ also emerged within my conversations with the participants. Here, I examine which of the learning points that focused on healthy eating habits were recalled by members of the audience and why these points resonated with them. Through their reactions and narratives we learn whether they believe these stipulations presented in the plays are achievable. Of note, the impact of alcohol on glucose levels was a sub-theme under ‘Healthy Eating.’ Even though this topic was addressed just briefly in the play, *Sugar Bear*, many audience members expressed surprise and appreciation about being presented with the information.

*Control: Battling the urges.*

The sub-theme of self-control or the lack thereof during meal times was also expressed or confessed as participants reflected on their behavior during eating rituals. There was a clear awareness of the need to eat in moderation or of the fact that at that certain point in time, the individual does not need to satisfy any degree of hunger. However, because of the occasion and due to the fact that another person was eating, it becomes even more difficult to avoid or stop the indulgence as Ilene noted in Figure 5.3:
Figure 5.3. Ilene’s representation of her perception of diabetes.

When I drew that? It meant to stop eating crap. That’s completely it, because I, I know for me, with my diet and everything I just don’t eat the right stuff (Ilene)

Ilene’s confession of her struggle and her weaknesses was not the only one expressed during the interviews. Interestingly, some of the respondents took the time to also laugh at themselves even as they conveyed amazement at their eating habits:

…like last night, I had, yesterday I had lunch, and I had lunch late. So by the time I picked up Elijah [her son], I was like, “Well, I’m not really hungry.” But we ran a few errands, but I had another meeting and there till 5:30, so I’m like, “Okay, we need to do dinner before, because otherwise, it’ll be too late.” Well, by I got, by the time I got to, I still wasn’t really hungry, but, you know, he was getting something, so when the waitress asked me, “What? Are you having something?” I ordered it anyway and I like, “This is gluttony. This is ridiculous,” because I, I can, you know, I can eat a little something, but I probably would have been very content with a glass of water. But what’d I do? Instead of just getting water, I
actually just got some, some food and that was just, utterly ridiculous. But again, it’s because they had the buffet. You know, it’s because it was buffet! [laughs].

(DJ)

DJ’s narrative addressed the matter of eating in moderation and thinking carefully about meal choices. Yet for DJ, a person not diagnosed with diabetes, the implications of moderate eating and changing eating habits may not be quite as critical as they would be for Inga who recalled how she too realized the need to change as she struggled with learning how to manage her diabetes. Under medical recommendation, Inga decided to undergo an expensive, $20,000 gastric bypass surgery to help her lose weight. While this helped to reduce the weight, it did not help to reduce her blood glucose level which was another main goal of the surgery. What she found instead was that she also had to change her eating habits, centering mostly on eating in moderation. Her secret, she informed me, was not to binge, but actually to eat whatever one wants:

You can set all the food out there that you want to set out there in front of me and I might think something’s really delicious. I might take one or two bites and be done. Ahm, when I first got to where I could ah, go out and eat with Sam, we’d stop at McDonald’s and get a Big Mac, and I’d take 1 bite and I was full. You understand what I’m saying, I mean I wasn’t eating enough to trigger anything, but the weight was coming off. But as far as controlling the diabetes, no, that’s not, that’d not what controlled the diabetes. It was the fact that I learned don’t overload your stomach. Just because you can eat it, doesn’t mean you should eat
it, ahm. I guess I had a better look at diabetes better than, different than you got a lot of other people.

Essentially, Inga found that there was a difference between self-deprivation and self-control. One can still have great self-control while indulging in favorite foods. She explained that while self-deprivation can be practiced to avoid some foods, it could still lead to detrimental consequences.

As the participants began recognizing that they also bore some amount of responsibility in shaping their own health, they also reflected on the diet and glucose monitoring tips mentioned in the plays. Most commonly discussed were the importance of counting carbs in determining the insulin ratio, the need to maintain the blood glucose readings within the normal range, and the importance of eating three times per day as techniques of control:

…I know this was from Lucille [italics added], ‘cause we talked about the, ahm…that, you can still eat the same foods, but just in moderation, depending on the carb level, ‘cause that’s what Marlo [the actress playing Candy] has, had mentioned. She was going over the chart, the list to talk about the different foods, and the carb levels, yes. Ahm, I ahm, I had learned about the blood sugar in terms of how it tops off at 120. I didn’t know that…the finger sticking is the most accurate test of sugar, or glucose and that, ahm, how people with diabetes, should eat three meals a day, approximately the same time a day. ‘Cause it’s funny ‘cause I never thought about it, but, when this came out, I thought oh that’s true,
cause my grannie used to do that. She was, you know, pretty religious about that.

(DJ)

Although not diagnosed with diabetes, Maddie informed me that her doctor instructed her
to engage in some activities usually performed by persons with diabetes so that she could
discover more medical information about herself and so that she could better regulate her
high glucose readings. She confessed that the plays helped to motivate her to comply:

…keep up with your carbs so you know how much, I’m, I’m definitely gonna
have to start doing that and I know it’s going to help. Sticking your fingers is the
most accurate way to measure your sugar, yes it is, I was afraid to do that, but I
knew that it was something that I was going to have to do, because I needed to
learn about me. I needed to find out what was going on with me and this was
going to be the only way to do that.

On the other hand, for some participants, the plays reminded them of the modifications
they had already made in their lives since learning of their diagnosis. As a person with
diabetes for the last 20 years, Neil stated that when he hears the word, ‘diabetes,’ he
immediately thinks of the life change one needs to make with regards to controlling one’s
diet. Linda could also relate to the need for changes in eating habits as it was only after
the pre-diabetes diagnoses of her two daughters that she realized how rarely she cooked
meals in her household. For her, like other caregivers and persons with diabetes, this was
a life changing disease, where routine events, like marching band camp for one of her
daughters, required more detailed planning such as ensuring she had enough sugar-free
snacks and strips while away:
I think too that you get to know your body a little bit better, ‘cause you’re listening to your body more. And, ahm, you’re able to recognize when, ahm, when it’s time to eat, even if it’s off the time. Does that make sense? You know, it, it could be an hour before you eat, you know...Your body metabolizes things definitely...You, you do, you change the way you think about everything.

Even as respondents voiced their appreciation of having the importance of eating well reinforced in the plays, some lamented the fact that reality acted as a hindrance as sometimes the availability of suitable food choices varied culturally and regionally. A Sri Lankan native, Seri, noted that her home country had different varieties of bananas, some of which were known to be beneficial for persons with diabetes. She also spoke of the availability of brown rice in her home country, which was an alternative there for her father who had diabetes, but which is an expensive option for her family here in the United States.

Along with expressing an appreciation for the encouragement to implement dietary changes, there was also a sense of gratitude for how the plays helped in clarifying misconceptions about the development and management of the disease which were being circulated within the culture. For instance, Maddie noted while she had known that diabetes was a genetic disease, she had not known that one way to counter the hereditary nature was by changing harmful eating and cooking habits, some of which were also passed down by parents. DJ was also grateful that her negative preconceptions about managing the disease were corrected:
…the other interesting thing that I found with the, with the plays was that, ahm, you know, it when they were very open about, you know, diabetes and really honestly and spoke about it, you know, with total transparency, it seemed to alleviate all of the ahm, you know, all of the taboo things that come with sugar. You know, that was the one thing that I noticed. Ahm, because even the whole notion of even calling it sugar, I think puts a negative connotation on diabetes. Because, naturally if I, with my picture clearly, you know. You know, I heard it called, you know, grew up hearing it called sugar, so naturally, it makes me think, “I can’t have sugar. I can’t have the sweet stuff, the fun stuff,” and so I think it puts a negative connotation on it.

DJ also explained that while she became more cognizant of her eating habits and how misguided she was about diabetes she could not help but pay closer attention to her loved ones. Due to the plays, she has begun to articulate concern about whether some eating habits performed by her mother, especially, are symptomatic of high glucose readings:

Ahm, and I know, and I watch her and I notice certain hours of the day, it’s like she crashes, you know, she has those like down, you know, when she just falls asleep or just, you know, and I’ve noticed her lately, where she’ll get like a taste for something sweet or things, and I asked her and say, “Mom, what is wrong with you? Why’re you been eating a lot of you know, like chips?” You know just, or just little things that I notice.

Finally, while most of the discussions focused on self-control and change in diet, some participants also verbalized other information from the plays which they believed were
also important in controlling the disease. For instance, DJ recalled that her grandmother was very committed to her daily walk, which definitely could have played an immense role in preventing multiple complications from diabetes. In addition, others excitedly mentioned being introduced to liquid glucose as an alternative for taking sweets to regulate fluctuating glucose levels. While this sub-theme presented a positive and appreciative note, understandably, there were some individuals who did not gravitate toward this message and who instead had a negative perception of the dietary changes as a means of control.

_Sugar as poison or death._

For some persons, this message of ‘Healthy Eating’ was not well-received, because it seemed too daunting and overwhelming. In fact, when the question, “What does diabetes mean to you?” or “When you hear the word diabetes, what image to mind?” was posed to respondents, the most common theme was that of ‘sugar as poison’ or as death (see Figure 5.4). This was thought to be the theme most relevant to the perception of diet changes as a means of controlling the disease:

_Figure 5.4. Ranelle’s sketch response to eating healthily to avoid diabetes._

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…you’re physically gonna die! But for me, having to eat right, and having to pay attention to, you know, the sodium intakes, and the sugar and all of that. That’s like dying. Because, I don’t like to eat right. I shouldn’t admit that [laughs]. I hate eating right, that is like the hardest thing for me to do, and to look at the back of the box and count calories and stuff. I hate that. (Ranelle)

With 14 sketches portraying sugar, sugary foods, sweets, and foods with carbohydrates as being dangerous, I found that the most common image was a sketch of a package of sugar with an “X” drawn over it (see Figure 4.1). This depiction is connected with the theme of fear and resistance which is elaborated on in the presentation of the second domain in this chapter. As some of the respondents expressed, (see Figures 5.5 and 5.6) diabetes and its complications are not welcomed, although they know that the disease can be managed:

[Figure 5.5. Lloyd’s representation of diabetes.]

…the play [Sugar Bear] really emphasized what unbalanced sugar levels can do in a person’s life. It made me think about in my culture how many things are
sugar laden and how I associate something sweet with tasting good and were I to have diabetes, this would kill me. It would, ah, eh, eh, this, eh, this stuff now becomes poison. It almost in the same sense when I found out that I had high blood pressure, salt became a demon…Now I even see how much sugar is in something, so, because sugar can be equally destructive, but you gotta have some of it. (Lloyd)

\[\text{Figure 5.6. DJ’s representation of diabetes.}\]

That’s the way I look at it, ‘cause yeah, just totally keeping me from having everything that, that could possibly taste good. I know, that’s depressing [she holds her head] (DJ)

Regardless of the apprehensive constructions of the disease, Erin noted that as a dietician her main aim was to help individuals, especially persons with diabetes, realize the benefits of making those changes and reaching their goals. As will be mentioned in the
second domain, some persons, including persons not diagnosed with diabetes, feared this message of change, because for them, it introduced a sense of deprivation and caused them to regard diabetes and carbohydrates as dangerous:

That’s usually the burning question in their mind when they get diagnosis. “How is that going to change the way I eat?” and they don’t you know, we try to help them understand that you can eat a lot of the foods that you eat right now, but you have to become a little bit more aware of the carbohydrate content, of, of your meals. Ahm, so I think that’s why they focus on that, it’s because of their meals, the confusion and the mystery behind it.

So far, we have seen that the respondents have highlighted several tips which focused on the message of healthy eating in the plays. Additionally, some of the respondents were open and honest about their dislike of the message of diet change and how this negatively affected their own perception of diabetes. However, the issue of alcoholic consumption and its impact on glucose levels also emerged during the discussions as another topic which was relevant to healthy eating.

*Alcoholism and diabetes: Drinking sugar.*

Although the association between alcoholism and diabetes was not a main theme in the plays, it was definitely one of the messages about which the audience was excited. Moreover the pedagogical power of the plays is evidenced when the respondents quickly recalled the scene even one month after the presentation of the play. In this sub-theme, the respondents reflected on the presence and effect of alcohol in their culture and family, particularly those with diabetes. The association between alcohol and diabetes was only
highlighted in *Sugar Bear* when the grandfather told his granddaughter to take a bottle of bourbon out of his coat pocket as he admitted that he still struggled with alcoholism:

PAPAW

Read it.

PEANUT

Bow er bon bowerbon. Bowerbin Bourbon. Like the bear from your story.

PAPAW

Sugar, pure sugar, and it’s doin more-- done more than rot my teeth. [Excerpt from *Sugar Bear*]

The inclusion of this minor storyline bore several implications for the audience. Significantly, some reflected on the prevalence of alcoholism within their own communities and started to draw connections between both diseases and the effects each disease could have on the other:

I knew alcohol had a lot of sugar in it, but I didn’t connect it with the diabetes, you know and alcohol and now I’m beginning to think that’s just the reason why a lot of people does drink because their sugar levels, and the sugar and the alcohol makes ‘em feel better that way, so, so they’ll just drink more and then not eat and.

(Jennifer)

Jennifer’s response provided us with some insight as to why persons with may overindulge in alcohol. One of the main reasons for alcoholic abuse or overindulgence among persons with diabetes is that the condition sometimes introduces depressing news which can range from bad reports from the doctor about one’s average glucose reading to
the development of a potentially disabling complication. Alcohol provides the means through which this news can be ignored; however, in doing so, the person with diabetes is becomes even worse. Charlie, a former Emergency Medical Technician (EMT) witnessed the effect of alcohol on diabetes while working in a region in Arizona that was occupied mostly by Native Americans:

I’ve seen several instances of ahm, unfortunately of diabetes out there and it just was no fun. Ahm, and a lot of it stemmed from drinking too much, as you presented in one of your plays, and I, just recall, ahm, people, that, it getting so bad for them that, obviously there were deaths, but other than things that I remember, are people would get, on their feet, they would almost get like, like cysts or tumors or something like that, very very bad, and ahm, and a lot of times they would toes removed or so on and so forth. And when I was just getting into that, I didn’t realize, didn’t know what diabetes meant as far as that goes, didn’t know it could be some bad stuff.

Indeed, the combination of alcohol, diabetes and its complications can be deadly as Charlie’s statement identified. Linda hoped that this message resonated with one of her daughters who had high glucose levels and who showed signs of a drinking habit:

…and I’ve had to have those conversations with our girls. It is genetic. We have it very difficult time with our middle child, right now, that we find empty bottles in her room, now, mhmm. And so, it is a craving for that, and it’s because that is genetic. And, so, ahm trying to get her to see that correlation, ah, that’s what I
really wanted her to hear. Ahm, but I don’t know if it was, because [if] she
doesn’t have a problem, then, “Why am I finding this in your room?” you know.
As I listened to Linda’s story and concerns about her daughter, I hoped that hers would
not turn into the story I heard from Jay about how his wife struggled not only with her
diabetes, but also her alcoholism up to the point of her death. Jay, an elderly gentleman
with whom I spoke at a local nursing home stated that it was only after his wife started
taking medication for diabetes that he learned about the impact alcohol could have on her
blood glucose levels. He recalled that the doctors privately advised him to get his wife to stop
drinking in an effort to improve her glucose levels. Unfortunately, the efforts were
compromised whenever his wife was joined weekly by a group of female friends who
encouraged her indulgence in alcohol and sweet foods:

Oh yes, when they all got together, they all had a lot of drinks you know and they
had a lot of tea with sugar, or something all the time and some dessert that was
real rich. They always made sure that they always served a nice rich cake or pie
after the meeting, sit down and have a piece of pie with us and a cup of coffee.
But in the coffee went 2 or 3 teaspoons of sugar. Sweetened the coffee up so you
could drink it…Well, she said, “I’ll try to cut back.” But she did sometimes for a
while, then she’d go right back again, start all over.

Through Jay’s narrative we learned how the abuse of alcohol can be connected to
instances of a lack of support by virtue of enablement as mentioned earlier under the
theme of ‘Family Dynamics.’ Although Jay encouraged his wife to manage her disease
properly this appeal was effectively countered by the influence of her peers who instead facilitated an atmosphere which was not conducive to the proper treatment of diabetes.

Indeed, enablement does not provide support for the person with diabetes who may also be an alcoholic. In fact, it is vital that family members avoid facilitating the individual’s addiction which was a concerned raised by Margaret as she watched *Sugar Bear*: “So, on one [question], ah, that went through my mind, ‘How is this family going to try to help him [the grandfather] or are they really gonna be enabling him?’” She also supported the decision to pass on the elements of temptation and struggle (the bourbon and bag of candy) to the mother: “Well, if he gave it to her, yes, that’s a different situation than if she found them and threw them out, you know, ah, totally different.” In essence, she agreed that the play illustrated that the mother was not enabling but instead responding only after both men had taken responsibility for their actions.

This sub-theme was very relevant in this region where a number of persons struggle with alcoholism or have been exposed to the effects of alcoholism. Stefann, a diabetes educator, noted that she had become more vigilant in inquiring about alcoholic intake from her clients because most were not honest in their self-reporting. Oftentimes her clients tried to paint a healthier picture of themselves during the fact-finding sessions which could actually hamper future recovery or management attempts:

*We usually say, moderation, you know and it really depends on what kind of medications you’re taking and talk to your doctor, because some of those medications don’t mix well with alcohol at all and a lot of these diabetics run multiple medications for all kinds of things. They might be on 13 to 15 different*
kind of meds. So, ahm, regarding diabetes and alcohol we say, “Don’t, if you’re on insulin, avoid alcohol between meals, because it actually drops blood sugar.” It’s metabolized like a fat, it’s not metabolized just like a sugar. But when it’s supplementing a meal, it’s more carbohydrate, so it’s ah, so we say, “you can have it with a meal, but in small amounts.” Woman, one drink a day, a male, no more than 2 drinks a day. And that’s basically the recommendations for alcohol, ahm, intake for everybody.

Finally, the sub-theme of ‘alcoholism and diabetes’ was another learned lesson from the plays. While some participants were shocked at the potentially high sugar content in alcohol, they felt more educated about its impact on attempts to eat more healthily. A number of them also made connections with personal narratives involving family members and their struggle with diabetes and alcohol.

Overall, the theme of ‘Healthy Eating’ presented a range of responses from participants. These included persons, especially those not diagnosed with diabetes, who realized how poor their eating habits had become and how important it was to control urges to self-indulge and thus control glucose levels. At the same time, several respondents openly shared their dislike of control and how this clouded their construction of diabetes. Finally, the theme ended with responses about the impact of alcohol on diabetes on healthy eating and how this dangerous combination was unfortunately prevalent within the culture. While this theme ends the focus on the main messages learned from the plays, in the next section, we will examine two elements which facilitated the reception of these messages.
Facilitating the Reception of Messages: Using Humor and Cultural Relevance

As I interacted with members of the audience and inquired about the messages they heard, I realized that their recall of these messages might be due to the presence of two main conduits of communication, humor and cultural relevance, used within the plays. The theme of humor focuses on the risk and rewards of using laughter and comedy as a means of generating discussion and reflection within the audience. Cultural relevance addresses how the audience perceived the applicability of the presentation of the plays, and their messages within the region. I believe that the cultural relevance of the plays, good scriptwriting and the use of humor created a relaxing atmosphere that allowed the participants to easily glean the aforementioned messages.

_Humor as a medium._

Humor was one of the means through which the audience was drawn into the lives of the characters and even within the tensions experienced on stage. Some respondents found this to be a useful and cleverly incorporated mechanism which aided in retaining information about the disease:

…you’re more quick to remember what you heard somebody saying what you laughed about, than you will if you had to sit through a long lecture and listen to everything that they had to say, just like, I mean, it may not have, it may not be necessarily monotone, but it’s like if you throw in a little bit of humor in there, especially on the main points that they need to focus on, it’ll be easier to recall later on, cause something could trigger it (Kelsie)
The uncontrollable laughter I witnessed during some moments of each play illustrated that the audiences found the dramas funny, but apparently not so humorous that they were distracting. One participant even remarked that the use of humor in the plays was a good way to trick persons into learning. Some participants also stated that it was better to have a narrative that was humorous, than one that was depressing and boring:

I think first of all, you need to capture your audience. And if it is, to put a little bit of humor in it to get their attention, so it be. I think the humor was in good taste because it was things that people could relate to. You could understand it. It’s nothing worse than someone before you giving some type of a presentation or having some type of a play and they’re talking over your head and it’s like, “I don’t know what they talking about. Do you understand that?” (Maddie)

I’d liked the humor, I don’t know if that has anything to do with diabetes, other than, it was, ah, it kept me very involved with it, but I think that if you didn’t incorporate the humor, it would be, be much more drawl and boring and people would be more likely to chase butterflies in their, their heads. Having humor there really, really got me and kept me interested, and, and made me want to understand more as well, so funny that was a very important emotional anchor, with that. (Charlie)

It’s kinda like when you, it’s kinda like giving a child, ahm, instead of giving them castor oil, you give them a berry flavored cough medicine. All you’re doing
is just giving a berry flavor. It’s so that, it’s so that, it’s so that it’s palpable.
Otherwise, people are like, I mean, what are you gonna do, you’re gonna scare the crap outta people? Or bore them into a catatonic state. I mean, do you want people to listen to you and take what you have to say or not? (Ilene)

In summary, it appeared that the use of humor made the message on diabetes care and prevention more palpable for the audience. As such, the information did not feel too overwhelming or technical. Instead, the audience members felt comfortable and actually appreciated the format even more.

Culture as a medium.

While humor played a vital role, many participants also stated that they could relate very well to the characters and the stories in the plays. For instance, some participants saw their grandmother or a loved one in the hard-headed character of Lucille. Others regarded the plays from a broader perspective noting that they were transplantable in various cultural settings, with just a few modifications:

…honestly if you took that play [Lucille] to like a black church in Columbus, or a black church in Cleveland and just put a black person in it, not even change the lines, nothing, or maybe change, change a couple of the things, like, like some of the more regional things, it, it would fly there too, definitely, definitely. Ahm, but I thought, I thought both of them were very culturally relevant. Now the second play [Sugar Bear], I think it would be a little harder to take that to a more urban center, because of the whole farming thing, yeah…(Ilene)
I think it’s [Sugar Bear] culturally relevant because it hits everybody. It hits relationship. It hits family, it hits self-responsibility. It hits the team mindset; it hits the knowledge and denial. I think it, I think it’s relevant; every culture has those things in it. (Lloyd)

I could see Lucille [italics added] playing in Cleveland. I couldn’t really see the Sugar Bear [italics added] playing in Cleveland and because I think that, the whole, well first, with the Sugar Bear, the, the, the placement on the farm…yeah, that, and, and, and, the grandfather’s references to hunting and, and to me, that, that, distanced me from it culturally, so it was like, I, I, as I was watched it, I could, I could appreciate it for what it was, but I couldn’t put myself into the shoes of any of those characters. Whereas with Lucille, loneliness is a universal thing, and it has nothing to do with who you, with what you do or where you are…(Sasha)

From these comments we recognize a sense of kinship or identification with the stories. It is clear that both were able to reach beyond the barriers of ethnicity by instead focusing on the commonality of emotions. As Lloyd and Sasha noted, everyone has been touched by the dynamics of relationships. Therefore, although most persons noted that Sugar Bear could have some difficulty in being transplantable, the emotions at the heart of the stories would still ensure that to some degree the narratives would be relevant and embraced.
Others were able to relate to the tension in the family dynamics portrayed in
*Sugar Bear*. One participant stated that the play reminded her of her hypoglycemic sister and the conversational exchanges they have had when they eat out together:

…because she knows that she’s not supposed to have a lot of chocolate [laughs] I love my sister to death, but, she knows, she ain’t supposed to be doing it. But she does it, and then she’ll be feeling all, loopy and stuff, oh my gosh. I tell her all the time, every time we’re out, at dinner somewhere, “I got to have me some sweets,” and then she’ll eyeball me and I’m looking at her like, “You know you ain’t supposed to be eating that big ole piece of cake. You know you not supposed to have that tall thing of strawberry shortcake.” But she does anyway. (Ranelle)

Finally, the use of cultural relevance and humor in the storylines of the plays highlighted the use of two techniques which ensured that the attention of the audience was effectively captured, thus ensuring their recall of the messages at a later date.

The implications for the use of cultural relevance and humor are pertinent within this first domain which highlighted the comfortable marriage of entertainment and education. As we recognize the articulation of lessons learned about the significance of family dynamics, dialogue and healthy eating, we also have to acknowledge that these were recalled due to engagement with compelling stories. Even the respondents have verbalized behavioral and attitudinal life changes which they had initiated due to exposure to the plays. Indeed, within a region where diabetes is prevalence, this end result is noteworthy. These articulated implications help to introduce the second domain
which focuses on the (re)construction of diabetes. Admittedly, this (re)construction was evident in the first domain especially as participants addressed necessary diet changes.

Using Narratives to (Re)Construct the Meaning of Diabetes

The role narratives play in aiding in the interpretation of the stage presentations, as well as of diabetes, can be examined along four broad themes which were further subdivided into smaller sub-themes:

(1) Narratives of Fear
   a. Fear of deprivation
   b. Fear of isolation
   c. Fear of complications

(2) Narratives of Resistance
   a. Narratives of denial
   b. Narratives of secrecy
   c. Narratives of disruption/interruption

(3) Narratives of Guilt and Shame

(4) Intersecting Narratives focused on stories not directly related to illness or diabetes which served to help the respondent explain his or her perception of the disease.

Narratives of Fear

The first theme of ‘narratives of fear’ points to several areas of dread expressed by members of the audience. More specifically, this theme describes the expression of the fear of deprivation, fear of isolation as a result of disclosure, and the fear of the
complications that could arise from the disease. Most of the expressed trepidations were from persons who are not diagnosed with diabetes who had observed the negative effects of diabetes on the lives of loved ones who were not able to manage the disease well.

_The fear of deprivation._

First, the fear of being deprived included a sense of loss of simple pleasures and even of being normal. DJ stated that in her opinion diabetes took all the fun out of living:

…when I think about diabetes I think ahm, of it as keeping me from having all the foods that I really like. Ahm, like sugars and starches, the snacky, fast food things, those are things that ahm, that I don’t have often, but when I do have them I enjoy them. You know, and for me diabetes is like, means total restriction from this good stuff, the tasty things of life, you know.

Other participants recalled the experience of loved ones and highlighted what they perceived as physiological and emotional deprivation. For example, Darla observed her maternal grandmother struggle with the disease and eventually the loss of a limb. Her face was in clear discomfort as she recalled her grandmother’s experience with diabetes, along with the pain which accompanied it. Among the complications her grandmother underwent were the gradual loss of sight and the amputation of her leg which Darla represented through her sketch in Figure 5.7:
And so, her abdomen, she was just always shooting in her abdomen. And, she wore, she wore like really strong glasses because the diabetes started affecting her eyes. And, ahm, I just remember, really thick glasses. I think she was maybe trifocals and she was, she still had trouble seeing and ahm, ahm, then she always had to have like blood tests. Ahm, in her fingers, she was always like having to prick herself and she hated that too. Because she’d worked in a shoe factory so her hands were real tough and callous so, it was real hard for the needles to get the ahm, blood out of her fingers, ‘cause her skin was so tough from all those years o’ working. And then ahm, the worst thing that happened is she had her leg amputated from the diabetes, ahm. (Darla)
For Darla, watching her grandmother endure a gradual process of losing certain motor and tactile skills, created a perception of a deficient life, one which she, personally, feared and hoped never to encounter herself. She admitted that while she knew that diabetes could be managed, this narrative about her grandmother was not positive and did not present life with diabetes as enjoyable. Despite these complications, Darla noted that her grandmother remained in good spirits and was a very funny woman until her death. Linked to the narrative of deprivation is that of isolation which could be a consequence of disclosing the disease which can be perceived by others as having a lacking life.

The fear of isolation.

Second, participants narrated a fear of isolation. I found that while a number of persons could understand the importance of disclosure within a family, at the same time they empathized with the decision not to, as this act could introduce several adverse effects, such as isolation, separation and rejection.

A person with diabetes may choose not to disclose the disease out of a fear of how others may perceive the disease and the individual. Margaret shared the story of young woman who was too afraid of sharing her diagnosis even with members of the church she attended because she feared being perceived as a non-believer in the power of God’s healing. This young woman, she noted, was also very fearful of the awkward interactions that might emerge after her diagnosis was disclosed:

You know when you speak something out that’s powerful and she didn’t want that spoken out into the air and everybody to know about it, which, you know, “Why aren’t you healed?”…I think, so that was a little part of it. And that, I think
people know, they have to treat them differently, if, if somebody has diabetes and then, maybe really don’t know what to do or how to react also, uncertainty.

Some of the participants could understand why persons with diabetes decide to remain unidentified out of a need to be perceived as similar to everyone else. Darla recalled the story of a high school friend of one of her daughters and noted that this friend wanted to be treated the same as everyone else, even though she wore an insulin pump. This young lady wanted to interact with her playmates without being treated differently:

…I didn’t know it until my daughter spent the night with her at her house and saw that she had this little machine on her side to pump the insulin in there. So I mean to her, she didn’t want to talk about it because she didn’t want nobody to feel sorry for her. She wanted to be independent and she didn’t want it to keep her from doing the other activities with other children. So she didn’t want her friends to know. She said she didn’t want nobody to feel sorry for her.

This need to be perceived as ‘normal’ or similar to everyone was an attempt to avoid isolation and the inability to share fully in collective memories due to this disease. Many persons, including persons not diagnosed with diabetes understood the desire for anonymity and the avoidance of being named as the person who needs the special diet or meal within a group of persons at a social gathering or at a restaurant for instance. This longing for normalcy was connected with the previously addressed fear of deprivation as no one wants to be denied friendship or a sense of commonality, especially in light of the fact that we are social beings by nature (Burke, 1968, 1969b). Additionally, this fear of isolation is reminiscent of a sub-theme addressed in the first domain in which isolation or
separation led to loneliness. In this sub-theme, isolation or loneliness was more a consequence of a lack of family support or indifference on the part of family members after the disease was disclosed, not out of the need to isolate the person with diabetes because he or she had a strange disease. However, the person with diabetes may eventually have to come to terms with the fact that diabetes requires a change in eating habits, which may unavoidably draw attention to him or her:

Yes, because now they’re feeling sort of isolated. They’re the only person, they’ll feel like they’re the only person who has to eat this way and then they’re gonna have to watch everyone else eating the way that they want to eat and, and it’s a struggle, because, ahm, I, I dealt with ahm, a food allergy at one point and it was, it was tough, because ahm, the thing that I was dealing with was wheat and it was wheat’s in everything. So, it’s you can’t just go to restaurant and just order whatever you want to, you see everyone else eating what they want to eat and they’re having cake and they’re having fried chicken or they’re having a sandwich and it’s like, that’s not an option for you, so, it’s, it’s extremely frustrating, to see all the people around you, ahm, doing the things that you wish that you could do (Tonie)

As previously mentioned there was a strong connection between family support which was discussed in the first domain and the fear of isolation. However, rather than focusing on how the family can create that isolation, DJ highlighted the fact that the family could act as a solution by eliminating that sense of separation. This can be done by making necessary dietary changes as the ‘Healthy Eating’ theme previously highlighted. The
person with diabetes does not have to feel alone or deprived if all family members willingly shared in the same diet or lifestyle changes:

…I think the important thing is to, ahm, to let it be known that, you know, we’re doing this to protect all of us. Because otherwise, some of the other family member, might be like, “What are they doing? I’m not the one, I’m not the one with the diabetes. Why do I need this special meal?” You know, but if they present it in a way where, “we’re being proactive, you know, we’re supporting this particular person, but we’re also ensuring that we too, you know, that we don’t get diabetes in the future,” then, I think families might be more receptive and inclusive.

DJ’s conclusion was especially important and boded well for her own personal approach to diabetes in the future. This remark was a telling sign of reflexivity on her part, since, by her own admission, her family was not very supportive of her grandmother while she tried to manage her diabetes.

Indeed the fear of isolation draws our attention to the intense emotional struggles which accompany this disease. I also found that several persons who were not diagnosed with diabetes but who watched loved ones with the disease also articulated another fear which combined the emotional fear with the dread of the physiological consequences of the disease.

*The fear of complications.*

This final narrative of fear conveyed anxiety over the potential development of a poor quality of life which could arise from the various complications which accompany
diabetes after a diagnosis. This fear was mostly based on the observations of the lived experiences of persons with diabetes. In fact, when asked the question, “What does diabetes mean to you?” or “When you hear the word diabetes, what image to mind?” several respondents sketched the effects of diabetes as their construction of the disease and included stories of loved ones. This section was represented by images that illustrated the physical and emotional effects of the disease. Several images reflected disability, such as wheelchairs, eyes, and eyeglasses. Other drawings showed sadness due to the perceived overwhelming nature of the disease. Linda provided a biological description (Figure 5.8) of the effect of diabetes as she understood it after one of her daughters was diagnosed with diabetes:

![Figure 5.8. Linda’s representation of diabetes.](image_url)
…it was described like a moon with a lotta little pits on it, and that, ah, and that there was a lotta places that it could get into the cell, but it still wasn’t being assimilated into the cell, to be able to be, ahm, what’s the word I want, used correctly, yes, used correctly, so that’s what that’s usually the first thing I think of, yeah. It’s the cell (laughs). Yes, it was the cell and it just wasn’t getting in correctly to be able to be used properly in the body. (Linda)

While she thought of her grandfather, Sonia, a participant in the informal focus group discussion, created a fictional person (see Figure 5.9) with a disability to represent what she thought about diabetes:

Ah, this here means where she had to have both of her legs cut off, because I had a grandpa, and and he, he died by sugar by the, and everything, yeah, that’s why,
‘cause she’s so sad and people make fun of her, so you know. Yeah I know lot of people, that, even, while, even people that were blind that ahm, they make fun of them and everything and, and I try to explain to ‘em, I say, “Hey, put yourself in their place, you know. How would you feel if they’re making fun of you?” you know. (Sonia)

Based on these constructions and especially the reactions of society to complications which could create disability, it is understandable why the newly diagnosed would fear the disease. Tarah, for instance, recalled her shock and numbness when the doctor informed her of her condition because she had witnessed her mother lose her battle with the disease:

I watched my mother die from it, so that’s part of the reason why I look at that going, ah [big sigh] “This sucks.” I mean, I literally sat in the office, the doctor’s office and cried because it was like, “Are you kidding me?” ahm, so, eh, you know, it’s just, you know, I saw the complications she had, I, I, took care of her till she died….because it’s just not, you know. I didn’t want it.

In fact, it is also reasonable for us to expect that persons who are not diagnosed with diabetes will also have a gloomy picture of the disease when they recall what they have observed, such as family members on a dialysis, getting amputations or being depressed:

…my sister’s grandma, I remember her when I was younger, she’d go and comatose all the time and then stayed at home and they’d take care of her at home and then she’d finally come out of it. She’d go, she’d used to go in a comatose for about 2 or 3 weeks straight and ahm, ‘cause her sugar was so high…she was
really bad and at the end there, she got wee little, last time I seen her, she is, looked like skin and bones compared to heavy, she’s ah, 6 foot 2, 6 foot 3 woman and we always called her, Big Mommy. (Jennifer)

Some participants who had diabetes described their own conditions which ranged from shaking and fainting to feeling extremely nervous. With these conditions being incapacitating sometimes, we find a greater call for the family to support loved ones with diabetes as they undergo these experiences. Frannie, a person with diabetes, began crying as she remembered the terrible effect the disease had on her late mother:

Yes, well, you don’t want to see your family get diabetes and it’ll kill ‘em. That’s how I lost my mom…It threwed [sic] her into seizures and heart attack. Her kidneys went out.

Frannie’s focus on the complications was also reaffirmed by Jennifer, who stated that whenever she thought of diabetes, she would always think of amputations because her uncle and sister had lost a leg and toes respectively. The fear of the disabling effects was also palpable when I spoke with persons with diabetes:

…A lot of people I know, a lot of doctors will look at them and tell them they need to lose 50 pounds or this or that or something else or they’re gonna lose their legs or their arms, most generally it’s the legs. Ahm, and they wind up either in a wheel chair or with these artificial limbs and that’s one thing I don’t ever want to happen to me is me to lose my legs, because when I was in a car wreck, in a car wreck, I was left in a hell of a predicament and I was a diabetic at that time, point in time and that’s why I don’t want to lose my legs and eh, you can see the
indentation where part of my muscle’s gone there in my leg?…I thought for sure I was gonna lose this leg. (Inga)

Inga, echoed one of the most popular fears I heard during my data gathering period – the fear of losing a limb and being placed into a life with a disability. After finding herself in a car accident several years ago and faced with the knowledge that persons with diabetes healed slowly, Inga was definitely frightened about what her prognosis would be.

Shaniqua also described how scary the situation appeared when her 23-year-old cousin informed her that she was recently diagnosed with diabetes:

I went home for my mom’s party, couple weeks ago and she kept saying, “I feel really weird. I feel kinda off. I feel kinda dizzy.” Ahm, she kept saying, “It feels like I’m high” [laughs] and, “People keep telling me I look like I’m high or something.” And she’s like, “I don’t smoke. I don’t, but I feel kinda weird.” And she kept saying, and I’m thinking, “Well, I’m not home all the time.” So I didn’t realize how long she’d been feeling that way. So, I’m just like, “well, maybe you just need to eat or you know.” And she, ahm, called and said, “I just finally called the doctor and they told me it was probably symptoms of diabetes.”

Nevertheless, beyond the effects of the complications, some people fear that diabetes, a chronic, but not a terminal illness could cause their death. Neil explained how one of his uncles went berserk after getting his diagnosis. Even though Neil’s uncle smoked cigarettes heavily and could potentially acquire a respiratory disease, he feared diabetes more and thought it meant the end of his life. Whenever I heard these concerns voiced in
the interviews I posed a question to understand why was there such a fear of the disease, as evidenced in the plays and real life, especially since diabetes was not terminal:

…perhaps they have heard of situations when the person, you know, did have a leg amputated or really was in serious condition, and that’s what they focused in on… so I don’t know if those were stories that they might have heard about, ah, no idea why it may be associated with death…Sometimes, that’s what you do though. You, you hear something and you know maybe one person that somehow’s been affected and that’s where you go (Margaret)

Toward the end of the play, the main character, Lucille commented that the diagnosis and the use of insulin meant that, “it was the beginning of the end” of her life. In essence, she had made the decision that the disease signaled that her life was drawing to a close and that her body was in effect failing her. While no person with diabetes echoed this perception to me, they understood why the feeling could arise and some openly talked about the challenges they experienced as a result of not complying with the regulations:

…this last time I went in, I wasn’t quite, I was seven point something [her A1c score]. I know, I’m not supposed to be that high but, a lot of things has happened and I was stupid and I went off all medications and I said, my stomach’s hurting me, I am not going to keep hurting my stomach. And, when I quit taking the pills, my stomach quit hurting, and I was off my medicine for over 2 months so I kinda got screwed up and last August I was in the hospital and ah, and it all started out with COPD and bronchitis and on top of that, then I had congestive heart failure. And so it was a lot of things rolled into one, but then my sugar was then so far out
of whack. We’re talking when they would test it, it would be like 400 or 375 or just, I mean, it was ungodly high and they’re bringing me my medicines…they put me on back on all of my medicines that I went off of…(Inga)

Without a doubt, this disease can take its toll when the guidelines are not followed. I admit I was flabbergasted when Inga told me the number of doctors she visited and how each fulfilled a different purpose; there was a specialist for her kidneys, one for her bladder and nerves, her regular doctor and a diabetes specialist. Also Tonie listed the complications experienced by her 67-year-old aunt for the past 20 years. Her aunt’s life, interestingly, was in sharp contrast to her aunt’s brother who was known for managing his diabetes well:

…he’s the youngest in the family and he’s very active and it doesn’t really give him a problem, whereas my mother’s ahm, sister…she’s ahm, lost the vision in one of her eyes. She’s, and her other eye she’s, she’s continuing to bleed behind that one and she’s had to have some surgeries and ahm, she’s been hospitalized several times with her blood sugar out of control and, so, I, I’m seeing like both extremes of it in the family. Most of them are very well-managed, but ahm, she’s had the most problems with her diabetes and it’s caused other problems, because she has other health problems and that’s it, it causes ahm, if, if she has a surgery, then she has to be really careful about ahm, healing, how, you know, it takes her longer to heal, she has, because of her diabetes, she has ah, she’s on dialysis now, so, ahm. There’s just a lot of things that have gone on with her…
In examining this narrative, we find that while Tonie was well-aware that the complications that arise were mostly because of improper care, she remained sympathetic to her aunt and the effects the disease has had on her life. Fortunately for her, she has been exposed to the effects of proper care through her uncle, realizing then that it was possible to live well with diabetes.

There were some positive consequences to highlighting the complications within the plays. Some participants stated that they had never known that diabetes could cause dizziness or blindness. DJ, a person not diagnosed with diabetes, for instance, stated that prior to the plays, she was unaware that diabetes could cause someone to lose their sight or that it could cause them to have a limb amputated. Fortunately, several participants maintained that this disturbing news about complications was offset by one of the lessons they learned from the play which was that diabetes does not equal death, but instead, can be well-managed:

Because, you know, initially, it seems like people think, okay, well, you know, I have this illness. I, I have sugar, you know, and that’s what we always called it, sugar. You know, so it’s like I have this, so, okay, I need to just start preparing for death, because now my life is coming to an end. But from that play, clearly ahm, I got the message that it doesn’t necessarily mean that you’re gonna die, or that death is on the way. It just means that you need to make some mod, some modifications.

This final observation on how persons expressed how they were educated about the disease’s complications reminds us of the first domain which focused on the educational
messages learned by the respondents. Essentially, we find that they identified not only
dietary messages, but also messages on complications. As Stefann stated, it is becoming
more important for persons to become more educated about the disease because then they
will recognize the changes they need to make in their lives so that they can be healthier.

In conclusion, the narratives of fear drew our attention to apprehensions
surrounding diabetes, including fearfulness about suffering deprivation, isolation and
debilitating complications if one developed the disease. Nevertheless, the theme ends
with a sense of hope as the respondents expressed appreciation for being educated about
the possible outcomes while being assured that the development of complications does
not mean the end of the road. However, in the next section we explore the resistant
response which arises from a place of fear and hopelessness.

*Narratives of Resistance: Hear no Evil, See no Evil, Do no Evil*

Extending from the theme of fear is the second theme within this domain which is
referred to as ‘narratives of resistance.’ This theme addresses narratives of denial where
persons with diabetes initially reject the presence of the disease and choose not treat it
medically or change their behavior. Denial is also acted out by persons with diabetes who
actually acknowledge the presence of the disease, but who refute the seriousness of the
disease and refuse to manage it as seriously as loved ones or practitioners would like.
Another act of resistance also occurs when noncompliant behavior is conducted in
secrecy. Finally, resistance also emerges when persons narrate their perception of the
disease as a disruption or an interruption in their lives which they try to counter as much
as possible. Essentially, this theme extends from narratives of fear, because if an individual is fearful, it could result in resistance to suggested measures of management.

*Narratives of denial.*

One of the first acts of resistance is denial which can be manifested in various forms, such as a refutation of the accuracy of the diagnosis or disbelief in the graveness of the disease even after an acceptance of the diagnosis. In the following narrative, Inga recalled her own denial even after receiving scientific evidence of high glucose readings:

…the first time that I found out was a girlfriend of mine had gotten a brand new meter. And they said she was diabetic but she was running borderline; she wasn’t really a true diabetic, diabetic, she was a borderline, which is what they call pre-diabetics now. Ahm, and she did mine and mine came back like three, 400, I, ah, “okay, I, ah, just drank a pop, that’s it. That’s what it was, I just drank a pop.”

I remember smiling as Inga recalled her first indication of the presence of the disease in her body. Even though she had a history of the disease in her family, I could see her refusing to believe that diabetes was a possibility in her life. How frightening that must have been and how useful a protective shield denial proved to be at that time.

In the play, *Lucille*, denial at the time of diagnosis was clearly illustrated, when the main character stubbornly stated “…maybe they’ll find out I don’t actually have it” as a response to the nurse’s insistence that anyone could have diabetes. Even after the nurse provided her with certain information, Lucille presented another reason for resisting or denying the disease, by adamantly insisting that there were no one with diabetes in her
family. In analyzing Lucille’s response, Leena concluded that this denial was probably because she did not feel that she met her preconceived notions of someone with diabetes:

I do notice that like a lot of people who have diabetes are, some of them are overweight. My friend in high school was rail thin. He was so skinny and like he doesn’t, he doesn’t look like he would have diabetes, like, you know, there is no face to diabetes, it’s young, it’s old, it’s, it’s all over…

Of all my participants, Inga was the one who could probably best understand what Lucille was experiencing during this interaction:

Well, it’s really hard, first diagnosed, it really is. If it’s hard to accept the fact that she is diabetic and that’s why she was in denial and, and it’s not something she wanted. It was being forced on to her. What she didn’t realize was that she was the one was forcing it on to herself, because she wasn’t controlling anything. She was letting everything control her. And you gotta be careful in the beginning. You really gotta be careful. Until you learn you own, ah, how do I put this? Ah, what she could deal with herself and learn how to change things, one thing at a time, not everything at one time. And, and, basically that’s how you have to handle, you like, like taking it one day at a time. Take one step at a time, change one thing at a time. Not everything at the same time.

Denial may also arise because an acceptance of the disease is seen as an affront to one’s religious beliefs. Linda, a devout Christian, talked about her middle daughter who had refused to take any more medication to control her glucose levels because she believed she was being healed by God:
…she’s been prayed for, you know, coming against the, the, the diabetic and the sugars and everything else, and, and the ahm, pcos [poly-cystic ovarian syndrome], and all that, so she believes God has healed her. And, and I, this is my thinking of what I think she thinks, that the medicine is not being faithful to what God is doing. Yet, God still works through doctors and what you need to take…so she still cannot see that now she’s gained the weight back. Her mood swings are horrible again, just awful, and, ahm, just has no energy to do anything again and ah, it’s, and actually she’s not functioning well mentally, because I think the sugar’s way to high, you know, she’s constantly drinking water, all the time, all the time. The thirst with it. But she doesn’t see a correlation.

As mentioned previously, denial has a strong link to narratives of fear and in fact, it is reasonable to regard this form of resistance as a necessary coping strategy used by persons with diabetes to manage the diagnosis and to reconcile their old identity with the new. After reviewing Linda’s concerns about her middle daughter and the responses from Tarah, a newly diagnosed, I began to understand how useful this method could be:

I don’t call mine diabetes because I refuse to put the curse on it because I believe that I have high sugar and I believe that it can be managed, but I also believe that by taking, just by taking it and saying, “okay, I have, I have this now, and, and, and, this is what I’m going to do.”

Interestingly, family members can also exhibit denial thus leading to an absence of support for the person with diabetes which was a sub-theme addressed in the first domain. One of the most heart-wrenching responses I received which demonstrated this
behavior was a participant’s story of how both her daughters were diagnosed as having pre-diabetes, but whose father did not acknowledge the diagnosis and offered no support:

It was very shocking, it was very shocking, because, you know, my children had been healthy all these years and to have this happen, it was, it was very hard to accept. As a matter of fact their dad still hasn’t really come on board with it at all. It’s still, he’s, he doesn’t help with it at all (laughs), so. Let’s ‘em eat whatever, drink whatever and you know, have whatever. (Linda)

Perhaps, Linda’s husband was also using denial as a coping mechanism. Unfortunately, if so, it is important for family members, especially parents, to realize that by denying the presence of the disease, any noncompliant behavior conducted by the person with diabetes will not be corrected, which could prove detrimental in the short and long term.

Apart from denying the presence of the disease, there are also persons with diabetes who will not take the illness seriously, even though they have accepted the diagnosis. This might be because the person with diabetes desired to retain a certain way of life which they view as more pleasing than the one prescribed as that approach allowed them to maintain some degree of control. Moreover, a lack of education could cause them to disregard the life-threatening potential of the disease. Neil noted that denial helped the person with diabetes ignore the change in reality and maintain a certain comfort zone: “They think if I can ignore it, and don’t, don’t, just imagine it’s not there, it’ll just go away.” As Linda’s story regarding her daughter and husband illustrated, this decision to ignore the disease proved to be a source of great frustration for loved ones, who also
function as caregivers. The frustration is also felt by medical practitioners, who feel discouraged when a person with diabetes refused to treat the disease seriously:

And it’s frustrating as the educator to know that when I walk out of there, I’ve wasted my time, you know, and I keep going back [laughs]. But, it’s true. Some people just don’t get it, or don’t want to get it about how devastating this disease can be. Yeah, yeah, we run into that a lot. We, ah, lot of denial, we, just, sometimes, people don’t get it. You know, “I feel fine, how can all these terrible things be happening to me?” (Stefann)

The lack of regard for the gravity of diabetes was also enacted in one of the plays. Darla said she was shocked when she realized that the grandfather in *Sugar Bear* was trying to deflect attention away from diabetes and his stay in the hospital by making up a funny story for his grandchildren about being attacked by a bear. She thought he should have been more serious about the issue from the start. However, she could relate to the lack of seriousness, as this was exactly her own grandmother’s reaction to her diagnosis. She stated that her grandmother was hard-headed and unwilling to change her eating habits; instead she chose to believe that the disease would cause her death, but in the meantime, she was determined to enjoy her life as it was:

…she just dealt with this on her own. And she didn’t take it very seriously. I mean, she didn’t, [laughs] I think she thought the insulin was gonna be like okay, this is medicine, it’s gonna fix me. She didn’t really change her diet. She knew, I mean she just stayed busy with her housework and things she did at the church like that. But she never got like an exercise routine, no, no [laughs].
Sometimes, even family members have difficulty getting the person with diabetes to take the disease seriously and change. Darla and Ilene provided examples of attempts of direct intervention which were simply ignored them by loved ones. In Darla’s case, the questions from family members were quickly deflected by her grandmother:

They would say [to her grandmother], they would more question like, “Are you sure you’re supposed to eat that?” “It’s gonna be all right, I took my insulin,” yeah. Because she was in the habit of eating white bread every meal. So, she kept eating her bread, her biscuits, her eggs, her bacon. Grease, everything cooked in bacon grease. Ahm, fried chicken, yeah, pork chops, mashed potatoes, potatoes, potatoes…

Ilene spoke from the perspective of a daughter-in-law who found her late father-in-law’s behavior humorous at best, even though he was well aware of the poor choices he was making during meal times, but who refused to heed the gravity of the situation:

Dad was a trip like that. Or like he would ahm, we would go to Red Lobster or something. And you know those biscuits, they have a really high sugar content and which is weird to think that biscuits have a lot of sugar, but theirs do and he would eat them and, and we’d say, “Dad, you know,” or, or Mom would do, like the basket would be here and then Mom would move it over here, and so Dad would just be like [makes a face and pretends to reach for a basket] you know, while he’s still talking like none of us notice and, and I would say, “okay, that’s three,” you know, stuff like that, [laughs] ‘cause he, he wasn’t supposed to eat them [laughs].
An additional way to understand this form of denial was by recognizing that it could be created out of a frustration of or a weariness of the required routine which can take its toll on the person with diabetes. DJ’s reflection on her grandmother’s attempts to sneak donuts, for instance, told much about the strain on her grandmother, as well as the lack of support she received from her family:

I think maybe either more shame or rebellion, intentional rebellion, because like when I think about my grandmother, she got to the point where she was like, “aw, phooey,” you know, and though she was more like, “yeah I know that, but who cares?” and I think it was more for her, maybe more rebellion, because, and frustration, because it’s like, “forget it,” you know, “yeah, yeah, I know I’m not supposed to have this, but who cares? It’s not fun having this and I want this, so I’m gonna have it.”

Inga also spoke of a similar reaction she had although she knew of the effect it would have on the glucose-insulin ratio in her body. She recalled feeling a sense of frustration and rebellion as she refused to eat the foods her doctor wanted her to eat, because she was tired of being deprived of everything she enjoyed before the diagnosis:

My sugar went sky high. We’re talking 375. Finally, I broke off and a stuck a little tiny chocolate football in my mouth. Believe it or not, that little tiny chocolate football brought my sugar down a hundred degrees. I was like 375, it brought it down 275. Now or later, I did the same thing, it brought it down more. Until I was close to being in range or 100, ah, but prior to that, I was way up there in ah, ah, I could feel my, ah, it’s kinda like the sugar shakes. And, and, but, it
was because, ah, my body, I didn’t eat anything, so my body didn’t know to shoot off the insulin. And because my body wasn’t shooting off the insulin, everything that was in my, was already there was just being sugar. And that’s why I was getting the sugar shakes, the minute I popped piece of chocolate into my mouth and I stopped at that, I, I mean one or 2 pieces and stopped. It caused my body to shoot the insulin out to counteract the sugar that was already in my body. When my body thought it was gonna get more chocolate so it dumped more insulin in and I didn’t give it any more chocolate, so that worked on the other sugar that was already up there, this little bit caused me to get a big dump of insulin and then it brought me down.

DJ and Inga’s narratives demonstrated that oftentimes persons with diabetes were aware of the effects of their decisions but chose to embark on the path of denial by ignoring the seriousness of the disease and their lifestyle decisions. Understandably, this decision could arise out of weariness from the daily strain of dealing with the disease, sometimes, by oneself without the support of family.

Finally, Lloyd presented another perspective on how this lack of seriousness could emerge. He noted that health communicators needed to be careful about how they talked about diabetes as this lack of seriousness can be fed by campaigns which advocate for diabetes management. He explained that advocates have a tedious battle to fight, because the message that there is life after diabetes could also be interpreted as “it’s not that serious [of a disease].”
Overall, as the first form of resistance, the narrative of denial ranged from the initial diagnosis to even after the acceptance of the disease. Newly diagnosed persons with diabetes struggle with first, acknowledging the presence of the disease and then, with accepting the gravity of the condition, especially when faced with frustration from bad reports or the weariness of maintaining a daily routine. Another response that hinders the effective care of the disease is the exercise of secrecy as a form of resistance.

_Narratives of secrecy._

Apart from denying the seriousness of the disease, resistance can come in the form of being secretive about habits that exacerbate the disease. Moreover, by hiding the deviant behavior, the person with diabetes is essentially keeping the condition a private affair, thus preventing loved ones from being involved adequately. This deception can be viewed as an attempt to gain some form of control in their life which was being mapped out by loved ones and medical practitioners. Seri related the story of how her mother-in-law found hidden sweets in the house when her father-in-law was away, an indication of noncompliance and poor management of the disease:

But he wasn’t, you know, he wasn’t looking after himself, ah, he also thinks that oh he knows everything and doesn’t really want to listen to doctors. Like if doctors give him some medication, he will interpret his, put his own thinking to it, and not take the accurate thing, and, you know, and he’ll like, think this is too much, and break the pill in half, do that kind of stuff, yeah. So, it was too late by the time it was 300, he had already got a, he had ah, got many strokes…
Several participants told stories of how their loved ones resisted the proper management of their blood glucose levels, sometimes, usually out of exasperation from following a strict regimen. For example, Inga recalled how exasperated she would feel whenever she would have to go to the supermarket with her mother who had diabetes and who would hide purchases. They would both take separate carts and roam the store:

Then we get home and somehow my mom has this bag of snickers. And she’s got ‘em tucked in her pocket book. They got paid for, but she hid them from me. And I don’t remember how it was, I got her pocketbook for something or another. I can’t remember what it was even for and here’s this 5, 6 candy bars. These big huge snicker candy bars. She was hooked on snicker candy bars. And I’ll tell her, “Mom, you, can’t have it.” “Well, yes I can.” She said, “at least I’ll die with my belly full.” I mean my mom was as contrary as the next person. I mean, grandma didn’t understand. Mom didn’t wanna understand!

DJ also described a clever scheme created by her grandmother to hide and eat donuts by asking one family member to buy some donuts and then ask another to buy some, and all this was done without either family member’s knowledge. This deception was maintained without anyone knowing the total amount she actually was consuming. In effect, this behavior may develop because the person with diabetes may feel that the diagnosis and treatment were unfair and that he or she deserved a little treat or reward now and then. Unfortunately, as DJ noted, this treat which may have started small, could actually turn into an unstoppable avalanche of poor eating habits.
The secrecy among men was another theme which was first brought to my attention by Charlie. He stated that while he could understand the men’s desire in *Sugar Bear* to be perceived as strong and silent on the subject, he found that they were inevitably placing the entire family in danger. In *Sugar Bear*, we see the father accusing the mother, Marlene, of being too fussy about him eating one thing that day, a Twinkie. She learned of this treat inadvertently and later, also learned by accident that he had been overindulging in a hidden bag of sweets in the chicken pen outside. Ranelle surmised that he did not want to feel like a failure in front of his family, so rather than hear the chastisement and receive punishment, he hid. Eventually, the father began to painfully comprehend the effect of his secrecy when he realized how much he was hurting the members of his family, especially his children:

…now they’ve lost all of their chickens and it’s really affected the family in a whole different manner, a little bit more widespread because he chooses to not be a key, to be responsible for what he has. And I think sometimes too, it’s almost like falling on your face and being in it to where you realize that it’s not just you that this affects, it affects every single person that you are around and until some people have it, lose all their chickens and the eggs and everything and see that wow, look what I just did to my family because I can’t control myself or because, you know, I choose not to do what I should do. (Linda)

It was for this reason, surmised Linda, that he finally changed his attitude, a decision which marked a turning point in how his family began to approach diabetes.
Continuing on the sub-theme of secrecy among male who had diabetes, Ilene used the narrative in *Lucille* to discuss the closed nature of her late father-in-law who struggled with both cancer and diabetes. She laughed nostalgically as she recalled how much Lucille reminded her of him and his refusal to engage in dialogue about his illness:

He’d try to keep it, I don’t, I don’t know if the, the right word is secretive. But he didn’t discuss it, ‘cause he was embarrassed. You know, and when he would go test, he would like get up and leave the room and go test his blood sugar. And, ahm, you know if he was, if he was feeling low, it was pretty obvious to us that he was low, because his eyes would get yellow and, you know, it was pretty obvious, but it was like, we just didn’t talk about it, because, it embarrassed him. Or the frequent trips to the, to the bathroom, you know, we just didn’t talk about it, and it, he felt less because he had it, so.

Interestingly, this sub-theme ends with a connection to the theme of ‘Dialogue’ which was addressed in the first domain. There is a reticence regarding the confession of one’s indulgences and the sharing of struggles of managing the complications which accompany the disease. There is also a sense of resistance and enactment of autonomy in being secretive about the overindulgences of certain foods, as it was the one area that disregarded the reach of diabetes. The logic behind this resistance becomes increasingly comprehensible as we explore the sub-theme of diabetes as an interruption.

*Narratives of interruption/disruption.*

Finally, part of the resistance may be due to the fact that persons feel that the disease interrupts their life, causing them to feel as if they were losing control of their
freedom and sense of independence. Therefore, diabetes is resisted when schedules are interrupted and when a limitation is placed on their lives. I found that persons who told these stories were persons who were not diagnosed with diabetes and who were reflecting on the lives of their loved ones or persons they have seen with diabetes. As we explore this sub-theme of resistance, we recognize a strong connection with the sub-theme of the fear of deprivation which was addressed earlier in this second domain. Indeed, once there is a fear of loss, one of the responses will be resistance in attempt to regain or retain what is or may be lost.

This perceived interruption may be regarded as the beginning of a loss of control over one’s life. In essence, the person with diabetes has received the diagnosis that his or her body is not operating correctly either because of their own actions or the genetic makeup of the person. The normal way of life becomes obsolete as the individual has to learn how to accommodate diabetes and as such, part of the resistance is based on a desire to have some control over not only one’s body, but also the doctor’s orders:

…people with diabetes sorta feel like it’s like taking over their life sometimes. Ahm, and I know with the older lady and I think it was Lucille, she, like she didn’t wanna, she didn’t like having other people over her, like the nurse was trying to help her out, the nurse was saying it nicely, but she still felt like, don’t tell me what to do, like I know what I’m doing, I can do this, I can do that, da, da, da, dah. And, like, she was wanted that control, it’s like, I don’t have control over this one thing, so I need control of everything else. (Kelsie)
The perception of an interruption also emerges when the person with diabetes perceives that he or she is also losing control over the self-image he or she has constructed over the years. Diabetes has now become a new cog in the wheel which they had not anticipated. For example, at the start of the play, *Lucille*, the main character resisted the label of ‘a woman with diabetes,’ an identity that does not align with all the accomplishments she had made and created a glitch in the self-narrative she had written over the years:

…I was born in the middle of the depression, number 7 of 14 kids. I’ve lived to see a half dozen wars. I was a riveter in dubya-dubya two [WWII]. A damn good one, too. The Japs never sank one of my ships. I married my Alvin in ‘47, ran a household, raised 2 boys, taught English to children who would rather read comic books and I’ve been president of the Elks Club Lady’s Auxiliary twice. Does that sound like somebody you can run roughshod over?... Does that sound like a woman with diabetes? [Excerpt from *Lucille*]

These accomplishments provided the perception of a strong woman who was in control and able to overcome anything, such as the Great Depression and World War II. It was clear that for her, someone with diabetes was weak and not in control. In fact, she demands: “Does that sound like someone who can’t take care of herself?” This comment signaled Lucille’s belief that a person with diabetes was someone who did not know how to take care of him or herself which did not correspond with her self-image:

When she [Lucille] first found out that she was diagnosed, she kinda felt ahm, pst, left, like she was gonna be left out, like ah, she’s a sick person now, and people won’t respect her as a strong individual anymore. She felt that ahm, ahm, that
people were babying her, or you know, being condescending like the nurse, or and that she was trying to, you know, say that, “hey, I was an individual, I was a strong individual, I was very independent,” and ahm, so that the disease diagnosis kinda made her feel, like she was less independent than she was before. (Erin)

As a senior citizen, Margaret stated that she could relate to Lucille’s interpretation that the development of the disease meant a loss of independence or an identity, which she was unwilling to lose. She could also understand why Lucille was so resistant at the start of the interaction with the nurse as it was an effort to maintain some semblance of control over the life she had lived over the years.

Finally, apart from viewing diabetes as an interruption in the perception of one’s body and self-image, some persons who were not diagnosed with diabetes also perceived the diagnosis as a disruption of one’s personal freedom by virtue of the introduction of a strict level of discipline or restriction. Indeed, diabetes requires a certain degree of discipline – in eating habits, exercise regimen and the administering of medicine (such as, five shots of insulin per day).

Some participants referenced the mother’s insistence in Sugar Bear that the family had to eat at precisely 6pm as an example of unwanted restriction. Indeed, in the play, the rest of the family struggled with the schedule and found the prepared meal very depressing and of a lesser quality than other meals being eaten by friends. Dietician, Erin admitted that at first this could be very challenging for persons with diabetes and their families. For instance, learning how to measure foods and calculating the amount of carbs in each food, among other things, could be a strain:
…for one thing, just having a meter and having to check your blood sugar’s a big deal. You have to remember to take it with you, you know, when if you, if you’re gonna be somewhere and, it’s just an extra piece of equipment and it, on your to do list, extra thing to do everyday, to check your blood sugar before you eat, you know. That’s hard. Ahm, taking medications on a regular basis, remembering to take your medications. That can be hard. If they’re on insulin, you know, ahm, taking the insulin and the syringe and all that stuff and remembering, so the, there has to be more planning for a diabetic when he’s gonna do something. If he just gonna go to Parkersburg and shop for the day and eat out, you have to plan ahead, you know, I gonna eat here and how long’s it gonna be before I eat again? And then, don’t forget to take my medications with me. I have to check my blood sugar before I eat, especially if I’m giving myself a little sliding scale coverage or whatever. So it’s just, there’s a lot more to do, ahm, as far as taking care of yourself with diabetes…

The introduction of a strict regimen was regarded as a disruption of a carefree lifestyle which currently did not require much pre-planning. Indeed, a recurring narrative concerned the rigid routine that the diet would introduce:

Just because it’s so, like, ahm, you just, you have to keep track of it, and there’s so much you have to learn, like, all those counts and what is a carb and what isn’t a carb and what you can and can’t eat and how much everything has in it, you just have to keep, you have to keep, up on those things and I mean, I guess, if you get,
once you get used to it, I’m sure it’s not as overwhelming as once you first get thrown into it (Leena)

In fact, the meticulous routine portrayed in the plays helped Leena better understand the behavior of a former high school friend who wore an insulin pump and maintained a strict schedule because of his diabetes:

Ahm, but you have, eating at a, an exact time is really important, like I can see, looking at my high school friend, like I remember times when he didn’t eat when he was supposed to and his blood sugar dropped and he just, he was desperate for sugar, like he needed something right then and there.

On the other hand, Ilene was able to relate to the plays in a more personal manner, seeing herself within the storyline. For her actually, the routine was so much of an interruption, but more of a reminder of the need for her to eat properly:

…the mom [in Sugar Bear], she was on it, she’s like, “we have to eat at 6,” and I completely understand that. I do. Like if I don’t eat between 12 and 12:30. I am not a happy person. I start sweating. I start to feel, ah, ah, t, ah, ting right there. Ahm, I have, I just have to eat something. It doesn’t have to be a full meal, but something needs to be going in my m, in my body between 12 and 12:30. And so I, I completely, what I, I saw that instantly, in that play, ‘cause that’s, that’s my life.

However, for other persons who are not diagnosed with diabetes, the disease was regarded as the worst possible occurrence in their lives. In fact, in response to the question, “What does diabetes mean to you?” or “When you hear the word diabetes, what
image to mind?” some respondents sketched the use of medical paraphernalia to indicate their perception of the necessary discipline and restriction which accompanied the disease. Dennis, for instance, had a negative perception of the disease and the routines which characterized its proper care (see Figure 5.10). For him, diabetes meant not only a sense of deprivation, but also an interruption:

![Figure 5.10. Dennis’ representation of diabetes.](image)

…‘cause my wife has to check her sugar. I just always think of them pricking their finger over and over, so I kind of wanted it to be, I’m not a very good artist, but to show like a knife, you know, that had always, it, it appears to be always such a pain to do it. Even though you do it multiple times a day, I just feel, you
know, you feel kind of handcuffed by it, you know, and I wish there was an easier way.

Jenise also described what she thought was the limiting nature of the disease by recalling how one of her colleagues had to carry around snack bars in preparation for low sugar levels. She believed that this was too much of an inconvenience and thought that as a result diabetes would prevent persons from participating in simple social events, like going to the movies. Darla also agreed with this perception, admitting that while she was happy to learn the importance of carb counting as she watched *Lucille*, she lamented the strict and complicated task it seemed and indeed was. She exclaimed that she would be devastated if she received that diagnosis, because it would mean she would no longer enjoy life and could possibly face the loss of sight and mobility, as she had witnessed in her paternal grandmother’s case:

> Well, she, I, I, just remember her vision was so bad. I mean, ‘cause I loved to read. I mean to be almost blind, losing your sight, yeah, losing your pleasures. And, I don’t know, I wouldn’t, just like it, the routine, you know, of having to eat always at a certain and a certain thing, ha, I, I like my freedom too much. But, you, you know, so, but if I had that diagnosis, you know, I wouldn’t want to, definitely get it under control and I think exercise would be a, a, you know, exercise would’ve really helped my grandma.

The same sentiment was echoed by DJ who has a history of diabetes in her family. She felt that the disease would be a constraining factor:
…when I think about diabetes I think ahm, of it as keeping me from having all the foods that I really like. Ahm, like sugars and starches, the snacky, fast food things, those are things that ahm, that I don’t have often, but when I do have them I enjoy them. You know, and for me diabetes is like, means total restriction from this good stuff, the tasty things of life, you know.

Darla also observed that the new structure may be especially difficult for persons with busy schedules. It would mean a required inclusion of structure into her already hectic life, which was a concession she was unwilling to embrace. She noted that in *Sugar Bear*, the father was the person who had difficulty adjusting his schedule to his diet, especially when clients needed certain tasks completed urgently. Combined with busy schedules, the disease might be perceived as being exhausting and overwhelming and as such, could also hamper adherence to the eating regimen.

Diabetes as an ignored interruption was a recurring narrative for older persons with diabetes. In fact, in exploring this sub-theme, we recognize a connection to the sub-theme of denial where the graveness of the disease was seemingly not taken seriously. As mentioned previously, DJ noticed this behavior in her grandmother, who, while maintaining her three meals a days, increasingly started to indulge in sweet snacks as she got older. DJ believed that this was because she had viewed the disease as an interruption and was now making the decision to enjoy herself fully. Jay also recalled how difficult it was to get his elderly mother to eat better because she refused to let diabetes interrupt her life and was determined to enjoy the rest of her days by eating her heart’s desire:
She’s 95, what are you gonna do?…I said, “You use one teaspoon, you don’t have to put three or four in. Sweeten it a little bit, but don’t over-sweeten it.” But she love to over-sweeten and the same way with cereal in the morning. Spoonful of sugar is fine, but she had to have 3 or 4 spoonfuls. So, I kept telling her, “Mom, you’re gonna get sick.” [She said] “Ah, no, no, I’ve done this all my life.”

Undoubtedly, even though the strict regimen may be daunting, diabetes educator, Erin, stated that these beliefs could be countered by pointing out that while the activities may seem initially overwhelming, as with any disease, persons with diabetes get used to them quite easily and they quickly become routine. Neil, who has diabetes, would also agree with Erin noting that the key was to be more educated about the disease:

But see that’s where it’s good to, to, have the education to realize they don’t have to sit down to a full course meal. Ah, lot of times, ah, they don’t have to eat three times a day, it, make the needs to eat smaller meals, five times a day. You know, they don’t have, maybe have to sit down and eat a separate maybe, if they’re, if they’re going to the meet, the movie and ah, they have some ah, carrot sticks in their pocket or something, you know maybe there’s something, ahm, or, or, or something like that, or, or, the, the, the, no, it’s not, they, they, they don’t wanna just sit home and be a slave to the table.

Even with this sense of gloom surrounding the disease, some participants who have been exposed to or have interacted with persons with diabetes provided examples of relatives who had successfully managed their disease by adhering to the required structure:
I think one of the reasons why my mother’s youngest brother does so well is that he was always active before. He played tennis, he played basketball. In high school, he was an athlete. He played football and he has always stayed active, so continuing to stay active and keep his weight down and manage what he eats has really helped him out. Whereas some of my mother’s older brothers and sisters were not as active and it’s been a real challenge to kind of get them to get active and that’s probably one of the things that’s that hinders their efforts in managing their diabetes. (Tonie)

While a lot has been said about the strict discipline that diabetes requires especially after the diagnosis, I also spoke with a wife whose husband has lived with the disease ever since his childhood. Even as she commended his mother for placing him on this path, she also noted that for him diabetes was the norm and he had learned to make it a part of his life, even during those early years when the medication made it more difficult:

Yes, in the very beginning of course I didn’t know, ahm, but we went out with a group of friends to a pizza and he ordered a tab which was a soft drink which I thought tasted like battery acid, and [laughs], he was like 139 pounds at that time, and of course, I said, “Why are you drinking that stuff, nasty pop?” and he told me….when we started dating, he was using a glass syringe, but he was changing the needle every time, but prior to that, he had ahm, needles that were reused every day, yeah, and they were about as big around as a pencil point. And for being diagnosed before he ever went to school and then this skinny little kid, you know those had to be miserable, for him, and most of the children that were
diagnosed in the 50’s didn’t survive, so, for him to be with us is blessing and for him to be well is a miracle. (Stefann)

At the heart of what Stefann was saying was that there was a need for persons to be accountable for themselves as well. She stated that while she would do her part in providing nutritious meals at home, her spouse needed to do his part by being responsible when away from her. Lloyd addressed this need for accountability from another perspective which would require a different performance from the spouse with diabetes:

If you gotta spouse and you’re not taking care of yourself, you’re literally saying to that spouse I don’t care about you. I don’t care about my life with you, ahm, I’m insensitive to the fact that you signed on for the rest of your life with me and here I’m gonna shortcut mine, or, or lessen the quality of it, because I’m not gonna take care of what I’m supposed to do.

Lloyd’s perspective on discipline and accountability becomes especially relevant when the person with diabetes thinks of or begins to engage in resistant behavior. Often, this behavior seeks to fulfill the individual’s immediate desires without regard for the effect the actions will have on the family or significant others in the long term. Lloyd’s statement required the person with diabetes to manage the illness, if not out of a need to help him or herself, but out of a sense of responsibility to loved ones who may depend on him or her and whose lives would be adversely affected if the disease was not controlled.

In sum, the theme of ‘narratives of resistance’ covered stories or reflections on the how persons with diabetes, in particular, resist through denial, refusal to take the disease seriously, secrecy, and the perception that the disease is a disruption in their lives. At the
heart of this resistance is a fear of the disease and the new life it introduces. This knowledge bears practical implications for how we communicate with persons with diabetes at the time of diagnosis and beyond. Moreover, we learn how the stories from the lived experience with diabetes have impacted current perceptions and attitudes toward the disease. So far, we have seen a certain progression across these various narratives in this domain. The domain first began with a fear of a future with the disease and then moved to resistance which is an understandable response to the diagnosis. In the following section, we will explore the responses of guilt and shame which may arise at the time of the diagnosis, but which could persist throughout the life with the illness.

**Narratives of Guilt and Shame**

By ‘narratives of guilt and shame’ I mean the expressions of guilt and shame which can emerge at the moment of diagnosis and beyond. The theme focuses on why these emotions arise, how society addresses them and how they affect communicative interactions at various levels. It is important to interrogate these feelings because they affect how the person with diabetes engages in treatment and social interaction.

When asked why there may be feelings of guilt and shame among persons with diabetes, Dennis had a simple response which he had learned from his late father, “If you dance with the devil, you gotta pay the fiddler.” Erin’s response extended this saying by providing some of the thoughts usually possessed by persons with diabetes:

It’s because I ate sugar that I got sugar, yeah…I think, yeah, especially if someone’s already overweight and they get diabetes and they, maybe they, nobody thinks their diet’s perfect, so they’re gonna feel guilty about the diet
always, ‘bout what they’ve been eating. Ahm, if they haven’t been exercising, I think they, they know their lifestyle habits have, they feel that their lifestyle habits have, have lead to the diagnosis of the disease and there probably is some guilt associated with that.

Initiated from the diagnosis, the person with diabetes may begin to reflect on their lifestyle and choices over the past few years and believe that they are at fault for or are deserving of their current state. Oftentimes, these thoughts occur in solitude and could lead to the even more severe condition of depression:

…I think the person thinks that, “What did I do to bring this on? Is there something that I could have done to prevent it?” you know. Ahm, “Is this because I’ve been abusing my health?” And then that could wear on their minds and then when they, if, if, if it’s someone who’s dealing with a lot of complications with diabetes that their systems are such that ahm, they need a lot of monitoring, then I can see the guilt being even more so, because now they’re caught in the middle of this thing and, you know, “How could I have done this to myself? How?” you know, “Look where I am now” and that just brings on the depression and oh, and everything else because I, I, they’ll feel really responsible for the condition that they’re in and it, it’s not necessarily anything that they’ve done. (Tonie)

Unfortunately, I found that many persons with diabetes may refuse to disclose their illness due to a sense of guilt and shame, emotions which are based on how they perceive society responds to persons with diabetes. Sasha mentioned that this was understandable because within the North American culture there was a heavy value placed on controlling
weight and food and if they were not controlled the individual can be viewed as flawed or even weak. Still others also provided their own analyses:

I think they’re embarrassed. I think there is a stigma… It’s like a curse, so you don’t want to talk about it… I think it’s, you know, people like, you say, it’s almost like you get what you deserve, so you must have done something to deserve it. It might, it’s your fault. You didn’t eat right, you’re lazy, you’re fat, you know, you don’t cook right. If you’re a woman, you know, what’s wrong with you, don’t you know to better foods than that, you know. (Darla)

…I maybe the, that, character or somebody who would think like Lucille, probably has that image of what diabetes looks like to her. Maybe she sees unhealthy, older people or even black people, or people who have ahm, high cholesterol or something like that. Maybe that’s maybe, what she was thinking, like, “I don’t look like this, I eat well. Or I can afford to eat well.” Or you know if it’s lots of poor people have diabetes, so, maybe, someone who would feel like Lucille would have that same image in her mind, but, and she didn’t fit it. (Shaniqua)

In essence, guilt and shame emerged because the disease was perceived as a punishment and the person was not following the rules. This is a perception that seemed to have been harnessed all through youth and into adulthood:

Like, like they would end up telling me [as a child], “you don’t need to eat so much candy, you’re gonna have diabetes. You don’t need to eat so much this, you’re gonna have diabetes.” Like, we just knew, like, especially when I found
out the things they could and could not eat, I, they can’t eat like so much of something, then I just knew, like my Nana, her baked beans, she doesn’t eat anymore, she’ll make them, but she doesn’t eat it anymore. Her or my uncle, because she knows what she does to make them, how much stuff is in them and it’s like to me, when I, when I found that out, that’s what I thought it was. I thought it was like, “I need to be watching what I’m eating, so I don’t get diabetes.” (Kelsie)

The effects of guilt and shame can hinder the successful management of diabetes. One such effect is the presence of judgment, which has the potential to spiral into self-pity and self-loathing, especially when there are no loved ones around to help the person with diabetes. Additionally, this sense of judgment is heightened when there is a clear link between diabetes and diet, rather than with genetics:

I think that the guilt alone transforms, changes how people deal with it, ahm. Because, I think people are less likely to ask for help and they just feel like, “Oh I can control this, I have to do it.” So, I think it, it, it’s kind of an isolating disease, which is not good, [laughs] ‘cause you do need that help, you do need that support, especially if your family, especially if it is affected by food in your family, is really not being very sensitive to that. But I think, ahm, not only does the blame and guilt come from the outside, but on the inside, somebody’s thinking, “well, I have diabetes, and I just, I just need to control myself, ‘cause everyone’s eating this, and everyone’s doing that. I just need to control myself or
I should have, I should work out more, or I should do this.” But that’s hard for anybody to do everyday, ahm. (Shaniqua)

Interestingly, while some persons understood the reason for feeling guilty and ashamed, some persons who were not diagnosed with diabetes also noted that the plays reminded or re-educated them about the notion that diabetes developed due to choices one makes as well as genetics, and therefore, the person with diabetes is not always to be blamed. As Tonie pointed out: “…I think the perception is that, ‘Oh, she’s overweight, that’s, that’s what happened,’ and not necessarily, not necessarily [so].” Ilene also mentioned that she also included her Christian beliefs as a means of understanding the development of a disease. Therefore, in the end, we find that persons developed a better understanding of and a more accurate perception of the disease. This extends well from the prior theme of empathy and sensitivity toward persons with diabetes, dealt with in the first domain. Most importantly, it is clear that due to education, these persons are less likely to reinforce the feeling of guilt and shame in the presence of a person with diabetes.

In sum, the theme of ‘narratives of guilt and shame’ examined how participants perceived the development of the emotions and the effects these had on their own perception of the disease and treatment of persons with diabetes. The theme illustrated that there is a perception that diabetes is a controllable disease, therefore, if it develops then the person with diabetes conducted a poor job of controlling his or her diet or consumption. At the same time, the theme provided some good news for diabetes education efforts, as others articulated an understanding that diabetes can be a factor in one’s life due to a genetic presence. I believe we need to pay attention to these
expressions of guilt and shame as they could perpetuate a stigma about diabetes and
could facilitate the improper care of diabetes. In the next section, we continue to explore
additional reactions to illness and ways in which illness and the emotions which
accompany it are understood within a broader narrative environment.

Intersecting Narratives: Private, Staged, and Public Stories

Finally, the theme of ‘intersecting narratives’ indicates the development of a
collective understanding of illness and diabetes by addressing how several of the
participants began to draw parallels between diabetes and public dialogues or narratives
of other illnesses and circumstances. I observed that several participants started
connecting the narratives from the stage plays, with their own, as well as with public
narratives. During my conversation with Tonie, for instance, she began to talk about the
number of celebrities she knew who had the disease. Her first recollection was the impact
of the disease on singer and actress, Patti Labelle:

She lost all of her sisters from diabetes and Halle Berry, her first husband I think
they were both diabetic and they used to manage their diabetes together and he
was a professional athlete. So, you don’t, and I was just noticing since you’ve
been doing these plays, ahm, they brought up another, ahm, I think there’s a
professional football player, he just, he’s like a quarterback and he’s just found
out, not, you know, within the last year, that he’s diabetic and they’re talking
about how, ahm, he can manage, you know, what he eats and having to have so
much energy and to play the game and the type of foods you have to, what kind of
adjustments does he have to make as a professional athlete to his diet to be able to
play, and have the strength and energy that he needs, but also stay on the diet that he needs to stay on, so…

Ilene also insisted that I watch the movie, *Nothing in Common*, starring Tom Hanks, which focused on how a father and son deal with secrecy and the complications of diabetes:

…and in the movie Jackie Gleason has diabetes, and he completely ignores it, just ignores, and he ignores it so much that he develop, developed gangrene on his feet and he had to have toes removed, had to have half of his foot removed and he just, he knew he was sick, he knew it, he just ignored it, because he saw it as a sign of weakness.

Importantly, I noticed that many of my participants had also begun to reflect on the role of the family in their lives during times of illness. These connections illustrated that the narratives within the plays prompted the emergence of other narratives of illness. Essentially, this observation reveals the generative nature of narrative (Bruner, 1996) where stories that fall within the same genre remind the audience of another. Moreover, we witness the performance of the audience as the plays evoke and generate personal stories that link with other stories. Alexander (2000) described this as audiencing performance where the story acts as a magnifying glass and a reflecting mirror allowing the performer to explore a certain construct and to reflect on one’s past. For instance, as Tonie reflected on the needs of the person with diabetes, she drew parallels with her own needs as she recalled her mother’s extraordinary efforts to make her feel more comfortable during those years when she suffered from a wheat allergy as a child:
…when I was dealing with that, I was, you know, I was still in school and that’s what she did. Everything that she used to put flour in, she found substitutes for those. So, I could still have the same things, but she learned how to cook them differently. She learned how to make cookies without wheat flour, she learned how to make fried chicken with different types of things, so she did, she was very accommodating when it came to that, so…

In another instance, a couple talked about the importance of education in managing their son’s mental illness. They found that education was a two way street that involved learning about the illness from their son’s perspective, as well as how to communicate with him as he sought to manage the illness:

When Henry and I went through that 12 week course learning about what our son was going through. That made a big difference for us too. We, re-thought how we talked to him, not to, not to cuddle him at all, but to understand him at first, to, to kinda understand, perhaps, if we could at the best we could, where he was coming from. (Elizabeth)

Clearly, the lessons they learned while dealing with their son’s illness resonated well with the importance of education for the family and the person with diabetes. Another gentleman used a personal narrative as a means of understanding the reason for feeling ashamed about diabetes and perceiving it as a social stigma:

I had a diagnosis of something, ahm, that sounded awful. You won’t identify me right? So it’s a was a STD, and I just, what I, when I first found out I contracted this and this was back in the, in the military, it’s just like I thought, you could
have told me I had AIDS and I wouldn’t have felt any worse. So, I just think that anytime you’re told that you’re, that you have something, there’s a stigma with that and until you really sit down and look and say, okay, well this isn’t as bad as it seems and it took me a couple of years to get over that, so I think because I’ve gone through my own personal perspective, of, of just something that you know, sounds bad, but when you learn how to manage it, you can have a very healthy and productive life. (Dennis)

Yet another participant was able to understand the existence of denial by a person with diabetes by looking at his own struggle with congestive heart failure. Lloyd stated that he was able to understand how difficult it was for someone to receive that diagnosis and thereby, an identity, especially when they are feeling well. Just as the father in Sugar Bear did, he stated that he only admitted the seriousness of the disease when it took a drastic turn and he witnessed its effect on loved ones.

In another instance, while talking about nondisclosure and secrecy in communicative interactions with persons with diabetes, it was fascinating to hear Ilene reach for a story involving her father. The narrative was used to describe her frustration whenever information regarding diagnoses or test results was withheld from loved ones:

Like when my father had his first cancer scare, he wasn’t even gonna tell me and Ranelle. I had to get a [prophetic] word. Isn’t that ridiculous? I was so mad at my father. I was so mad, I said, you know, I said, “Daddy, I’ve been having these tripped out dreams about you,” and he said, “What?” And I said, and so I told him the dream and he’s like, “Well, I had a, I had a colonoscopy and they found some
stuff,” and I’m like, “What?! When were you gonna tell me,” “well I was just gonna wait and see what the test said.” “Daddy, that’s not acceptable.”

Henry went even further by eagerly sharing with me that the plays reminded him of a news story he heard recently on the radio. His concluded that, just like the plays, sometimes the goal has to be hidden in the way the message or the atmosphere is presented for the benefit of the audience:

A lady was actually being, when her kids were younger, was actually robbed at gunpoint in her home. The kids never knew about it, till she told them 10 years, 20 years later. Yeah, they thought, in fact, they were interviewing son, “yeah, I just thought it was a friend of dad’s.” But, because mom made it upbeat, kids never even realized what was going on, until many years later when mom says, you know, when such and such happened, when I got in, well, he wasn’t a friend of dad’s, we were actually being robbed.

In this section on intersecting narratives, we find participants drawing parallels with other types of narratives in their lives as a means of understanding diabetes and the importance of communication and health. Essentially, a ripple effect ensued, with the participants connecting public dialogues with the narratives from the plays, thus building an ever-evolving composite narrative of their own perception of diabetes, as well as the use of entertainment to educate. Most importantly, we must recognize the ability of these plays to generate different types of stories as by doing so they create a space for the dialogue of diabetes (Bruner, 1996; Frank, 1997).
Overall, the second domain which focused on the narrative reality of diabetes revealed a variety of stories which aided the respondents in constructing their perception of diabetes. The participants articulated: (1) narratives of fear of the disease and the response from society; (2) they also presented stories of resistance, which sometimes acted as coping mechanisms, especially for persons with diabetes as they struggled with the new identity and how they perceived society expected them to perform; (3) they articulated narratives of guilt and shame which once again, were based on societal perceptions of diabetes; and (4) finally, as they constructed this reality, they drew from other personal and public stories which helped them to understand diabetes. From these narratives, we learn of the generative power of staged stories and how these stories can encourage an exploration of a construct and a reflection on one’s personal past. Additionally, health communicators will recognize the influence of culture and societal constructions on the formation of the personal identity. Undoubtedly, we cannot ignore the broader societal performance when examining the personal which leads us into the third and final domain which addresses culture and how it shapes diabetes.

Culture and the (Re)Shaping of Diabetes

Culture plays an important role in ensuring and determining the health of an individual. In fact, Frank (1995) encouraged us to look at the culture within which health stories are embedded, as the cultural construction impacts interpersonal relations and the embodiment or the performance of the illness (Beck, 2005; Carlson, 2004). This research is guided by the definition of culture as the lens through which an individual views the world and learns appropriate and normative behaviors for survival in this world (Helman,
Undoubtedly, culture will shape how we interpret and exchange messages (Witte & Morrison, 1995). With these definitions in mind, I recognize the geographical and economical culture and diversity of Appalachia, while acknowledging and reiterating that there are several elements that remain common, such as the role of the family and traditions. It is these elements that I pay attention to within this final domain to determine their influence on how the residents perceive, treat or attempt to prevent the disease.

This final domain addresses four themes. The first section focuses on three social forces and the final theme presents solutions put forward by the respondents:

1. Poverty and Diabetes
2. Tradition and Diabetes
3. Fatalism and Diabetes
4. Combating and Working with Culture
   a. Support Groups
   b. Dialogue

**Poverty and Diabetes**

Under this first theme, I examine how poverty and the economic condition within the region impact the perception and the treatment of diabetes. Overwhelmingly, most persons lamented the expenses the disease introduced and the challenges persons within the lower income bracket faced in acquiring medication and access to medical services and practitioners, and thereby, the proper treatment of the disease. Indeed, illness diagnoses influenced decisions about how a family utilizes expendable resources.
Another element discussed was the challenges faced by a person who had a lower educational background who may not be exposed to proper treatment strategies.

As the literature illustrated in the second chapter of this dissertation, while the poverty rates of most Appalachian counties have begun to converge with the rates in the rest of the nation, there are still some counties particularly in the central area of the region, of which Ohio is a part, which still have rates that are almost twice that of the country (Lichter & Campbell, 2005). Once poverty is present, the health of residents can be negatively affected as there is a shortage in primary and mental health care or even preventative care (Denham & Rathbun, 2005). Also accompanying poverty are poor educational facilities and low literacy rates which further exacerbates the health of the region and the individual.

The responses of the participants reflected the findings of the literature. One of the main challenges discussed was the impact poverty had on accessing quality foods, medical supplies and medical care or medical services. Margaret, a local counselor within the area in which the plays were presented, worked as a consultant for a local shelter for the homeless and had some first hand experience of the effects of poverty on the access to supplies. She recalled that she recently received the information chart of one of the shelter’s patrons, which revealed that the woman was in need of diabetes supplies and medication but could not afford them. Due to her lack of exposure to persons with diabetes, Margaret was amazed at what this could mean for the lady:

…she has run out of test, tapes, or whatever you use to…yeah, I think it was called strips and she had to wait, I don’t know, I don’t know, this is the first of the
month, whether she got them or whether she knew she had the, device that you need to use for that. Ahh, I don’t know how upset she was, but I thought…is it, is it $10 she needs? You know, I’d be glad to give her $10.

Indeed, among the medical supplies which could prove costly are the lancet strips which are used to collect the blood after the finger is pricked. However, the fortunate ones, such as Maddie, have found affordable options:

Well, I specifically went to Wal-Mart because I heard it, they were more reasonable as far as your medicines were concerned. Some of it, the alcohol’s free, the alcohol pads I get. Ahm, I just had strips and I don’t think I had to pay anything, but I think because of, I don’t know whether I’m allowed per month, a certain amount. Ahm, I’m not really sure. I’ll be perfectly honest because there’s times when I may get everything together and certain times I may just one or two things. However, diabetes is very expensive, on a whole, it’s very expensive.

Poverty is far-reaching and definitely hampers the successful management of the disease. This fact is even more distressing and devastating for a person with diabetes in areas where there are jobs with little or no insurance and this is the situation of which some of the respondents have become a lot more aware:

…like say in some of the ahm, different counties in Appalachia, they don’t even have a hospital that’s really close so, do you have access to ahm, diabetes ah, education? Do you have ahm, ah, access to extended counseling to deal with, you know, the emotional aspects of being a person with, dealing with diabetes? Do you have those things? Because of the economic ah, situation that your area is
involved in, if, and the, the, just the, the basic resources that are around, do you have transportation to be able to get these things even if they are ah, maybe a, a county away? Maybe, you know, that, it can be a million miles if you don’t have transportation. So, it’s just so many different things it affects the people being able to be keep themselves well informed and ahm, stay on their medication and…(Tonie)

As Tonie explained, when a person with diabetes does not have a steady source of financing then the treatment or management of the disease is sporadic. A good source of income or financial assistance helps to address issues of transportation to distant healthcare facilities or educational resources which will inform the person with diabetes on how best to manage the disease. Without these, the individual faces a distressing picture. Additionally, poverty affects the geographical area, in that, if there is a lack of state and federal funding, healthcare facilities may not be available to residents.

As a result, sometimes persons will make desperate choices and decisions which may cause them to ignore the need to continuously manage the disease. Among these decisions is the choice to forego visiting a dietician who specializes in diabetes education or choosing to buy groceries or pay bills one month instead of purchasing a medication which has no generic brand. Moreover, even if a person with diabetes knows that health insurance is valuable, the cost may be the reason for not taking advantage of the resource. Several respondents, including persons not diagnosed with diabetes, were angered by the existence of this situation and how it had developed within the country. Many of them
articulated heartrending decisions that had to be made, but which could lead to the death of the person with diabetes:

…there’s, there’s supposed to be like a particular regimen, like a, a, a exercise regimen that they’re supposed to be on. If you’re a, if you’re a poor person with diabetes when do you have time to work out? You don’t, you have to go to work so you don’t die. You know, it’s just, I, poverty, poverty and diabetes does not mix, you know, and unfortunately, it seems to me that diabetes is a poor man’s disease. (Ilene)

…there aren’t a whole lot of jobs, that would afford you ahm, good health care, so that you would be able to ahm, maybe ah, see a better doctor or go ah, ahm, get more counseling about the things that you’re going through or so, I can see that where that would be, a, ah, a pretty good challenge in Appalachia to, simply the cost of it, it’s sad to say but ahm, so many people in this area, just, they, they don’t go to the doctor because they can’t afford to go to the doctor. They can’t afford to go to the dentist, I mean, so, they suffer or, if they go, ahm, a lot of people end up, “Well, I can’t afford to buy my medicine this month, so I’ll just take it every other day” or, “I’ll take half a pill each day, instead of the whole pill I’m supposed to take.” (Tonie)

Erin, the dietician, however asserted that resources were available for lower income persons who needed insurance and assistance with accessing medical supplies:
For someone that’s not insured, all these drug companies have these superfunds, you know, that they could tap into, like needymeds.com, and, ahm, health foundations, are these groups where pharmaceutical companies donate money to these ah, organizations and then the patient can, ah, apply to get free medications from them.

Albeit, one of the more constant complaints, was the existence of inadequate medical assistance even when it was accessible. Some participants were critical of the short nature of medical visits. They felt they did not receive adequate attention from the doctor, especially when there were a large number of clients who required assistance. Sometimes this large number was due to the high patient to practitioner ratio which was further exacerbated when the practitioner could only visit the area on certain days of the week (Denham & Rathbun, 2005). Additionally, there was a call for improvement in the communicative interaction between person with diabetes and the practitioner when attention was finally given. The exchange between Lucille and Nurse Candy reminded a young lady dealing with endometriosis of the lack of compassion and patience of the doctors she visited before she got her diagnosis. She would have liked them to take the same approach that the nurse had taken in the play.

Finally, a lower income could also prevent someone from accessing quality food products in the area. Access to fresh fruits and vegetables may be limited based on the community in which one resides. One participant touted the healthier choice of organic foods, which unfortunately may not be affordable:
It is just so expensive. I don’t understand how people who are, who are on food stamps, how are they living? Ahm, like, let’s see, I know, I know a woman, she gets $125 a month in food stamps. That’s all the money that she has to buy food. How, how do they have enough food to get through the month? I don’t even understand how that’s possible. (Ilene)

Darla also talked about the limited choices that her grandmother had from the small local corner shop in the community. She noted that in order for her to expand her choices, her grandmother would have to travel to another town or a city which were miles away. Therefore, in this instance, food choices, along with an already resistant spirit did not help create a healthy environment for the management of her grandmother’s diabetes.

Moreover, it was pointed out that since southeast Ohio was not on a major thoroughfare, suppliers have to go out of their way to come to the area, thereby making the food cost more. Some argued that, furthermore, the better quality foods never even make it to the area. Others also pointed to the fact that for persons in the lower-income bracket sometimes the only food source was the food banks that do not generally provide fresh foods. Dietician, Erin, acknowledged the challenges of cost in low-income areas, but also noted that there are ways that these costs could be circumvented:

I guess that produce can be more expensive, you know, then the canned vegetables in some, some situations, but it just depends on the produce, some of it’s very inexpensive like, green beans, and some of the, some of it’s a lot more expensive like, you know, ahm, colored bell peppers are very, you know, but you can find produce that’s not very expensive, lettuce and tomatoes, and, and green
beans and this like that, cabbage is usually a very inexpensive, so, ahm, I think that they, that they probably can, for the average person, ah fit healthy foods into their budget, if they can and that can also do things like if they’re in the rural area like this, they can grow a garden, they can grow tomatoes in the summer time, they’ll have all the free tomatoes they want.

Apart from the cost, there may also be a lack of education regarding the treatment of diabetes. This lack is probably due to inadequate access to medical practitioners, lack of health insurance to pay for diabetes education workshops or an inability to visit dieticians or doctors. As she watched Lucille, Darla said she wondered about education, and how persons who were illiterate or who did not have a high educational background, managed the task of carb counting and the reading of nutrition labels. One participant was also concerned about persons with diabetes who do not know the importance of vitamins and minerals or the pre-planning or scheduling of meals. Neil underscored the importance of education as he recalled that when he first got his diagnosis, one of the best things the medical practitioner did for him was to send him to a diabetes education class that helped him figure out how to eat properly. This class also helped him identify some of the misconceptions about treating diabetes. An example he provided was of his mother telling him to stop taking pills and start taking insulin shots so that he could eat whatever and how much he wanted. In the same vein, if the family was not educated about the disease, they would neither monitor the loved one well, nor be helpful in identifying important symptoms. Inga also recalled the benefit of these classes as she prepared to take her mother home from the hospital after she received her diagnosis:
I’ve been to a lot of classes on diabetes. I’ve been there, I’ve done that. And when my mom first came home with diabetes, they wouldn’t let her come home until I’d finished some classes at OSU. Yup, she was in the, she was in the hospital, and, and, she was diabetic and they said, “You know, we can’t send her home unless we know that you can take care of her.” And they put her in a wheelchair and they pushed her down to this room and they took me with her and they said, “Here you go.” And we both sit through those classes.

Although Inga’s experience was conducted forcibly then, her narrative demonstrated the importance of including a family member in the educational process which she explained helped her to directly speak to her mother about her eating habits. Unfortunately, due to their economic status, some persons may not be able to afford this information.

Overall, this first theme looked at the effect of poverty on access to medical information and services, and medical supplies relevant to the person with diabetes. The responses of the participants also drew our attention to what life for the person with diabetes would entail if there was an inadequate source of income. Personal poverty impacts food choices including the quality of the foods selected. Additionally, personal poverty is intensified when this is lived within geographic poverty, which itself lacks medical and educational facilities to cater to the health needs of its residents. These insights from the participants explain that there are actually tangible reasons for the high prevalence of the disease and the complications that develop within the life of the person with diabetes, besides a sense of guilt and shame or even resistance to the diagnosis, as were discussed in the second domain. An inadequate income could cause a person with
diabetes to rely on other factors to justify decisions. One such factor is tradition which some participants thought could be either an Achilles heel or a source of strength for the person with diabetes.

*Tradition and Diabetes*

In this second theme, I examine the effect of tradition on the management and prevention of diabetes. Specifically, I explore responses to the effect of traditional eating rituals on diabetes, as well as the effect of education in challenging these traditions. Essentially, I look at how tradition can prevent exposure and compromise attempts to stem the prevalence of diabetes.

My definition of tradition is guided by the work of Gadamer (1989) and Bakhtin (1981) who informed us that we are in constant existence with the old or the multiple voices and stories from the past. These elements constitute our multi-dimensional reality through which we are interpreted and through which we consequently interpret. Gadamer believed that we enter and revisit current decisions in light of the past especially to gain an understanding of how best to act in our world. Finally, we also cannot ignore the fact that stories from the past act to give meaning to our present and future (Ricoeur, 1990; Williams, 1997).

With this construct of tradition in mind, we first recognize that undoubtedly, contributing to the construction of diabetes is the impact of unhealthy eating habits which have been reinforced over the years. Some of these habits include the manner in which the family customarily treats the disease and the practice of other rituals which demonstrate how the past determines how we treat food. To illustrate the power of our
past and how we sometimes unquestioningly follow our ancestors, Linda recalled a humorous narrative she recently heard and retold to a friend:

…and I said, “Well, it’s because it’s always been done that way.” You know, the, the granddaughter’s cutting the ends off the ham for Easter and, “Mom, why’d we do that?” “Well, I don’t know, ‘cause grandma always did,” “Well grandma, why did we do that?” She said, “Well, I don’t know.” So she calls her feeble mother and says, you know “Why, why, do we?” “Well, ‘cause my pan was too small.” You know, so here we are four generations later, you’re still cutting the ends off the ham, you don’t know why and it was just because her pan was too small. You know, but I think sometimes we just keep on with these generational things.

In other words, Linda was stating that by not questioning, we find ourselves falling into the same traps as our parents. Former EMT, Charlie, recalled that it was sad to see how members of the families on the Native American reservations on which he served sometimes treated diabetes. It was a seemingly never-ending cycle which continued on across generations:

…a lot of times it was the Dad with the diabetes and you could, you could very well tell though, he was leader, he was the alpha male and ah, he was in charge, there wasn’t anybody telling him what to do which is paradoxical in nature as well, because usually the family is very close. Ah, but ah, as far as that goes, like I said, ahm, I did see the family around… we’ll call those ah, individuals frequent fliers, yep, and you could, and now that you mention it, it brings it back to me, there was, you knew when you walked into a place, like that, what you were
doing, dealing with primarily. There was a very distinct smell of an individual with bad diabetes. Yes, and, and it’s almost as if, you are gone, “jeez, how bad is this person’s liver by now?” Yeah, and there are, because there are a lot of things that are associated with alcoholism, including diabetes, but, you know, you can only do what you can do.

In essence, Charlie was describing a culture which struggled with alcohol and diabetes because the treatment of the disease was hindered by certain traditional mindsets, which ultimately determined the quality of life of the person with diabetes in the reservation.

Therefore, tradition can sometimes be restrictive. As previously mentioned by DJ, sometimes participating in a buffet meal or overindulging can be a detrimental choice. But she pointed out that we are sometimes locked in our poor eating behaviors as a result of some of the eating habits we have learned from our parents:

You know, that’s another thing in our culture, at least for me, growing up, I remembered, you know, my grandfather, you know I think, because our family is coming from ah, backgrounds where they were maybe like impoverished, you know and really didn’t have a lot. So, it’s one of those things but when you have food, or somebody offers you food, you eat it. You know, because, ahm, you know, you don’t, because otherwise that would be wasting. You know that’s funny ‘cause I, I think about my family and I’m like, I mean, yeah, I mean, if you had something on your plate, you were expected to eat it.

Providing a different scenario, Jennifer, a regular patron of free dinners in her community, observed that better help and education needed to be given at these
functions, especially to patrons who had diabetes. These functions, which were family-friendly, while seeking to help, may inadvertently facilitate unhealthy eating habits:

I think people tends [sic] to overeat too because I notice, I, I go to the dinners and they have lots of food there, right, which they don’t need that much food, you know, like three items, that’s it, you know and that, I guess they’re trying to reach to people with different tastes and the different lives, but I’ve seen people just pile up their plate [laughs], so and I don’t think diabetics should be eating, overeating, should they?

While attempts could be made to challenge habits established from our past, we also need to be prepared for resistance. Native of Kentucky, Darla, expressed that deviating from the norm and refusing to indulge in traditional activities and meals that were loved by predecessors was regarded as a disrespectful gesture to their memory, even if this decision would introduce healthier choices. Neil provided the example that even on national television, outside of Appalachia, there was a clear opposition to any deviation from traditional ways of cooking:

I was watching this cooking show, and, and, and, ah, they was cooking on there and the woman got ah comments back from the people. She was cooking, she was cooking, ah, greens, and she put olive oil in it and stuff and cooking it. And ah, and, and everything. So people wrote in and says, your mama should, give a talk to her or spank her, ‘cause when you cook your greens you put your hamhocks in it, you know, you know, I mean, and that’s how she, she, she, admitted that’s how her mom did it, but she was trying to show them a way of cooking healthier, you
know. And, and, and they got, they got offended, they got mad, you don’t cook your greens like that.

For Neil, this incident calls for a reexamination of the society’s relationship with food and the tendency to overindulge. While his previous example was in support of an attempt by popular culture to confront tradition, at the same time, he called for increased vigilance not only in the media, but also within the community:

> In this country, well, ah, you go watch our commercials, we’re obsessed with food. I mean, how many commercials, ah, they have on food and then here’re you are in this country and all the different ethnic people and all the different foods. I mean, ah, I don’t know how many would be in Athens, within maybe a, a, half-hour’s drive, the different types of foods you can eat. I mean, there’s Chinese and there’s probably Indian over there, you know.

Some participants also mentioned that over the years, aspects of the North American culture have changed and these have subsequently affected how we traditionally eat. At the same time, these changes have introduced new traditions which are also unhealthy by nature. Elizabeth stated that the culture of the North American youth has evolved into one that is very sedentary, with a lack of exercise and with some of the worst foods being the cheapest and the most accessible. However, an even more striking review came from Linda, who remembered that during her childhood her family never ate in restaurants, but instead spent time around the table at meal times, partly because they could not afford to eat out and partly because not many restaurants were available. However, this narrative
changed over the years, with her current family moving quickly each day and eating whenever it was convenient for them, because they were so busy doing multiple tasks:

You know, and when I started pre-school at the Christian academy, I did before and after school care. And we would get something for breakfast on the way out the door, ahm, or we would cook the oatmeal at school and there were times that I would just buy the family lasagnas and I would make it for lunch in the microwave there because my kids went to school there, so they all would come and get the convenience again and then we’d have to order a pizza at night because I was there extended care, but then we had flag or dance practice after that and so by the time we got home, we just went straight to bed. You know, so, it, it becomes, we’ve become a convenience society.

Seri agreed with Linda’s observation, but at the same time, contributed a cross-cultural point of view:

Whereas you would, see in our cultures, I don’t know, where I come from [Sri Lanka], you still prepare the food at home, where making food is not a big chore, whereas here people, because they are, well, they’re not, they’re learned to prepare food, so, like when it comes to changing your diet, people are like, at a loss, kind of, they don’t know what to do. That’s why it’s so difficult here, I think, because they still have to eat out.

But even within the United States, there can be cross-cultural differences, where shock is expressed at the eating styles and differences between regional groups and the effects those habits have on the health of each group:
Well I grew up in northern Ohio, so we didn’t really have this, but, every family function that I have been to with my husband’s family, ‘cause they’re from Appalachia, mashed potatoes with a slop and pile of noodles right on top of that. And I’m going, “That’s a carb nightmare!” I, I don’t care for noodles anyways, so that’s good for me, yes. Fried, fried chicken, fried everything, I’m like…that’s why papaw was in the nursing home [laughs] ‘cause he didn’t do what he was supposed to do. (Tarah)

Family traditions can also prevent exposure to alternative choices as well. This notion was introduced briefly in the theme of ‘Family Dynamics’ in the first domain. As Denham et al. (2004) pointed out the family is an important discursive unit that teaches us how to eat. One way through which this is done is by storytelling whereby the family performs its identity and its rituals through narratives (Langellier & Peterson, 2004). If this narrative is challenged by virtue of entering into a new culture a conflict emerges, and while one family member could accept the narrative, others may resist because it is not part of the performance with which they are comfortable. For instance, Darla reminisced about her initial experiences as a college student, and her re-education about food from her experience in the dining halls. Upon her arrival at college, she stated she was introduced to new foods of which she had never heard and soon began to recognize how limiting the culture in which she was raised had been:

I’d never had broccoli. I’d never had cauliflower. Ahm, I had never, I don’t think I’d never seen a bagel! Hm-mm. We were used to eating these big whole home made biscuits with butter running out of ‘em. And, ahm, yeah, so it’s like all
these, so you’re not even exposed to these foods, because your parents didn’t eat them, your grandparents didn’t eat them. So, when I came to college, I was like, “What is all this?” you know, it was so different. So I think it’s just, you know, a lot of us, it’s just tradition, what you eat in your family and not even exposed to healthy foods…and I remember calling my mom, like when I was coming home, I said, “Maam we had these bagels and we put cream cheese, they were so good and I said, can you buy some bagels.” She said, “Oh we don’t eat those, those are for Jewish people.” I mean, that’s in her mind that’s what those were for and like other people didn’t eat that. I was like, “that’s crazy.” [laughs]

Darla concluded that it was sad that illiteracy or a lack of education could mean that you will not be exposed to or educated about alternative healthier food choices. Interestingly, her narrative could have taken a different path based on her mother’s response, but due to education and exposure, she created a new one for herself and her future family. Indeed, some participants began to recognize that before the state of health in some areas can be changed, some cultural mindsets will first have to be challenged:

West Virginia, I mean, you would talk about smoking, obesity, diabetes, whatever it may be. I mean, I can’t say it was a joke, but people used to call it, ‘Heaven’s Waiting Room.’ You know, because I mean, the mortality rate, everything, the, the, ah, eh, the typical age of death of an adult’s much lower than the rest of the country. So, there’s just a lot of issues. Ahm, in that state, and certainly, you know, we’re not too far away from where we used to live in West Virginia. So, even in this area, yeah, ahm, ah, there’s just a lot of factors that contribute to it,
it’s not just one thing but, but certainly the, not being able to get adequate healthcare and then being part of a support group or being educated, ‘cause I do think some people’ll probably make a better effort, ahm, if they knew. (Dennis).

However, we can conclude, like Elizabeth, that the current state of diabetes in the region could really be as a result of the interconnectedness of several factors:

It’s a lack of education and tradition, and then the stubbornness and then the finances. They’re really interlinked. You know, my mom ate this way, I can’t afford to eat that way, so I’m gonna eat my way and you just pretty much have it all in one little lump.

In conclusion, this theme addressed the responses to the effect of tradition on the construction of eating rituals and diabetes in Appalachia. At the beginning, we acknowledged that tradition was inescapable because we live in an interpretive and plural reality which is impacted by our past. Unfortunately, we engage with these voices from the past unquestioningly and due to a lack of education, consequently, we harm our own health. Several of the respondents noted that resistance to change was inevitable, especially when these practices were constantly narrated to us within our families, through the media and within the broader community. Of interest, under this theme as well is the fact that while traditional eating rituals were being discarded, new and unhealthy ones were replacing them. Finally, this second theme informed us that we have to examine the state of diabetes in a holistic manner, recognizing the effect of the economy, education as well as tradition on the developing perception of diabetes.
However, these stories of the past affect not only our eating rituals, but how we perceived ourselves which is the focus of the third theme of ‘fatalism and diabetes.’

*Fatalism and Diabetes*

The impact of culture on diabetes was also narrated through the lens of fatalism, the third theme under this domain. Fatalism addresses the powerful sense of inevitability, a belief that the fate of family members is sealed and unpreventable when diabetes is biologically present within the genes. Fatalism, which also originates from those voices of the past which order our present and our future (Bakhtin, 1981; Gadamer, 1989), provides us with an additional insight into how a family performs health and passes on that narrative to the next generation, effectively superseding the impact of education. The respondents addressed the impact of fatalism on management and preventative efforts. On one hand, there are persons who refuse to abandon what they believe is their fate, while others have changed their lives to prevent the disease from being passed on to younger generations. This theme was unfamiliar to some participants, particularly those who were unaware, before the plays, that diabetes was hereditary. The respondents who spoke freely about fatalism were either persons with diabetes or had family members with diabetes.

Fatalism affects the extent to which a person with diabetes will treat the disease or the degree to which a family will attempt to prevent the disease from developing in other relatives. The theme of fatalism was more prevalent in *Sugar Bear* within a conversation between the two children of the family, where the boy startled his sister by informing her of the inevitable fate of the family. Fortunately, the conversation was ended by the father
who used the opportunity to correct both children’s misconceptions that their own state of health was already predetermined:

PEANUT

I’m dying?

ANDY

Yes. Yes you are.

PEANUT

How? Why? When?

ANDY

Well, Papaw has a thing called the sugar. And dad has it too, so you and I have it ‘cause as far as I can tell it’s passed through blood and we all have the same blood.

PEANUT

Dad is dying?

ANDY

No… see you have to be strong or you die and Papaw is strong and dad is strong and I am strong so we can handle it.

PEANUT

I’m strong.

ANDY

No, you’re a girl and girl’s aren’t strong.

PEANUT

I don’t want to die.
ANDREW

Enough of this, enough. No one’s dying, not now and not for a long time. Give me that bag of stuff. [Excerpt from Sugar Bear]

Participants with diabetes in their family are becoming more aware of the genetic nature of the disease and have begun to recognize the presence of fatalism and how resigned some family members are to developing the disease after they have started seeing signs or symptoms. As Jennifer explained, encouraging family members to conduct regular check-ups because of the prevalence of the disease in their family can be exasperating:

...I don’t think they try to prevent it around in this area. They don’t do anything about it until they’re diagnosed with it and I don’t think they take the down with the, you know, the hereditary there on it. I mean, they might hear it and it’s hereditary, but I don’t, I think it’s just “I don’t care” situation and they don’t try to prevent it. I think it would be good if they would try to prevent it before…

DJ also noted, sadly, that her mother appears to be taking the same path rather than finding ways to reduce her levels:

You know, ahm, I, I think my mother, I think she’s kind of ah, embracing it, in the sense that, she knows that my grandmother had it, so she’s thinking, “Oh, maybe I have this too.” Ahm, and I don’t know that she has con, has consciously trying to exhaust all possibilities. But, just because, you know, my grandmother had it, she’s like, “Oh well yeah, you know, this might be what I have, this probably is.”
When I probed DJ to determine whether she fears that this disease could be part of her genetic makeup, it was clear that while she was aware of the possibility, she struggled with owning that possibility:

I never thought ah, that I would get it. But now that my mother is you know like, uhhh [laughs], you know, now that she’s like, embracing this whole, I may have diabetes thing, and ahm, and that she’s, you know, seeing, I’m seeing her test her sugar, it makes me ahm. It makes me a little more concerned that I might get it. Ahm, the difference though, is that see I don’t really like, a lot of, you know, sweet sweets, like, I’m not a big dessert person. But you know, I drink soda, you know, I like starches, and so those two things, I’m like, mhm, they may not work in my favor, you know. Ahm, so I never, until recently, I never thought it, I never thought it, thought of it as something that could possibly affect me, you know, yeah.

However, when I pushed further to determine how she would feel if she received the diagnosis, she responded in mortification:

But I don’t want it! So I’m hoping and praying I don’t get it. Ahm, but yeah, ‘cause I think if, you know, ahm, if my mother was to get it, if it turned out that she does have it, it probably would make things a little more devastating for me...

In another interview, Inga recounted her days as a child when she helped her grandmother who suffered from diabetes. It appeared that Inga had long accepted the fact that she too would walk the same narrative paths outlined by her grandmother:
…we had to keep things up off the floor, ‘cause grandma couldn’t see, because she was getting the sugar cataract. And then she had put medicine in her eyes and they would burn the cataracts off her eyes, her eyes would just tear and I, I would feel so bad ‘cause out here I’m a little kid and my grandma’s crying and I didn’t want my grandma crying but it burnt so bad, she couldn’t help but cry and if she didn’t use it, she couldn’t see…And they’re telling me that I’ve got the beginning stages of cataracts and I, I believe it, because I have a hard time sometimes seeing things….ahm, some days my eyes are better, sometimes my eyes are worse, but when my eyes are worse I know my sugar’s out of whack.

At the end of the interview, she also informed me that her daughter was diagnosed with hypoglycemia, which could lead to diabetes eventually. So, it appeared that there is further acceptance that disease was about to start moving into the fourth generation of this family. Another participant, Shaniqua, was alarmed at her family’s response to the presence of diabetes. She noted that no direct counteraction is being taken; instead there is an existing atmosphere of oblivion:

“Oh grandma can handle this, probably not a big deal sneaking a Snickers is not gonna hurt me if I get it.” I think if, if we realize there’s so much things, so many different things to manage it, then the attitudes would change, instead of thinking, “Oh well, I’ll probably just get diabetes, go ahead and hand me that extra sweet peach cobbler or I just,” and “I love carbs, that’s all I eat is carbs.” Ahm, just “I’ll be fine, I won’t get it until I’m 60 and I’ll be cool,” instead of thinking, “Oh man,
I could get diabetes when I’m 60,” or we could all change our habits and change, you know, I guess the cycle. I don’t think people think like that, ahm.

Dennis provided a contrasting scenario, admitting that he would not be surprised if his young daughter developed diabetes because she shared many similarities with her mother. While he presented this confession, he stated that he and his wife were constantly monitoring her and have been open about his wife’s diabetes with his children. While we see an effort to combat fatalism in Dennis’ response, he and his wife have partially embraced the possibility so that they will not be overwhelmingly fearful or surprised if diabetes develops in the future.

Lloyd, a local pastor, stated that while he accepted the fact that diabetes could have a strong genetic link within families, he insisted that persons who knew there was a strong possibility of passing on the gene should also pass on strategies for dealing with the disease. He believed that if they did not disseminate this information they would be responsible for lessening the quality of life of the individual who was at risk. He also provided words of advice for persons of the Christian faith who may perform the disease differently because they believed that they had been overlooked by God:

…and for a Christian, you did not slip by God. You did not slip by God when you, when you, God knew that there was another diabetic being born, and he still let it be born so whatever he has for you to do, diabetes is a part of it and you dealing with diabetes is it. That’s no different than dealing with being black, that’s no different than dealing with being a woman or a man, or, or, or being whatever you are.
Still, some persons with diabetes in their family vowed, like the father in Sugar Bear, to prevent it from being passed on to their children. Seri explained that while diabetes was present in both hers and her husband’s families, they were taking precautions to prevent either one of them from developing the disease or passing it on to their children. Her husband, for instance, became a vegetarian, and began checking his sugar levels:

…and the important thing about families is that you’re teaching then the younger generation to also eat healthier. That’s the, because, just because they’re kids, doesn’t mean they can be eating all this junk food, anyway, so it’s I think better for everybody to gradually change and for everybody’s good to eat on time.

Seri’s comment put into perspective Langellier and Peterson’s (2004) focus on storytelling in daily life. Seri and her husband have decided to write and perform another script for their children in contrast to the script and stories of their past. Inga had adopted the same position with regards to her grandchildren. It was clear that she was trying to end the cycle of diabetes that she, her children and her predecessors have experienced:

I, we have my grandkids out to Friday night supper this last Friday night and they set up a big bowl for them next to them, and a big bowl of vegetables out there. My grandkids grabbed the bowl of vegetables and went for the cauliflower and the broccoli. And that woman said, “Boy, I was so tickled to see them go for the vegetables and the fruits.” And I said, “Yeah.” I said, “Our kids love their vegetables and they love their fruit”….somebody’s gotta teach ‘em because if they don’t that’s exactly what they do, is that they become a piece of sugar. They become a what they call, a diabetic. And all that amounts to is that you’re a big
blob of sugar. And you don’t make good decisions on anything. Ah, but actually, the decisions that you make in life, is, is the same ones that you need to make in your foods and what is going to control me or what am I going to control?

However, there were others who had not yet seen evidence of diabetes in their life even though family members had already been diagnosed with it. Jay, already in his mid-70s, stated that even though his mother had it, all his tests had returned negative. Tonie also examined her own family and noted that out of nine children, her mother and two other aunts were the only ones who were not diagnosed with diabetes and she hopes that this bodes well for her and her children.

Finally, this theme on fatalism addressed the beliefs of participants on the hereditary nature of the disease and the potential impact this sense of inevitability could have in determining the development of the disease. There was an indication that persons were becoming more aware of the hereditary nature of the disease and this was a positive sign for the effectiveness of public education efforts. Hopefully, this information will lead to greater sensitivity toward persons with diabetes as was expressed in the second domain. Still, there is much work to be done as there are persons who are indifferent to or who have already embraced the disease even if they have not yet been diagnosed. Nevertheless, there are persons who are committed to ending the cycle and changing the performed narrative of fatalism within their family. The combative approach evident in the comments of some of the respondents introduces the last theme which presents a call for finding ways to confront and to create an ally of culture.
Combating and Working with Culture

As I neared the completion of my interviews and interactions with participants, I began to realize that my participants were not only critically examining their own actions, but also suggesting ways in which we could collectively challenge the cultural norms that currently compound the difficulty of properly managing the disease. I examine here the call for additional support groups and more dialogue about the disease within families.

This theme began to emerge from the very outset, although I did not recognize it at first. In reflection, I recalled that all of the respondents expressed a desire to deal with diabetes in their community, especially after they examined their own actions and those of family members with diabetes. There was an acknowledgement of a lack and they articulated ways in which this could be addressed.

Support groups.

One of the first suggestions was a call for the presence of more support groups for persons with diabetes within communities. While the participants acknowledged the need for the family as the core source of support, the role of the community was also required. According to some participants, these groups could cater solely to persons with diabetes, and to families with relatives who had diabetes. These groups would allow persons to recognize that they were not alone in the process and thus it would make it easier to talk about the disease and engage in activities, such as a daily walk, that would help them manage the disease better. These groups could also assist in maintaining a degree of accountability, while helping to break the silence that surrounds the disease as persons share their narratives in a safe environment. Essentially, the call for support groups
reiterates that need for support which was articulated in the first domain. Moreover, the
groups will also act as a means of countering nondisclosure and secrecy which were
articulated in the first and second domains respectively. Some participants also pointed to
the fact that in the play, Lucille mentioned that her neighbor had diabetes and that she
had seen her testing her blood glucose level before. This individual could be an additional
and valuable source of support for Lucille and could be someone she could rely on
whenever adhering to the regimen seemed especially challenging.

Another support group could be the local churches, Erin mentioned. In fact,
Kelsie stated that in her church in north Ohio they had begun to talk openly about
diabetes. While everyone knew that the pastor had diabetes, no one was aware of the
number of members with diabetes until the church held three sessions on diabetes and
since then, the care of these members had been overseen by a nurse practitioner:

She’s like, when she sees them in church not doing good, or she see that we’re
about to be there for a minute, she’d be like she is now, she brings in continental
breakfast in the mornings, every Sunday morning and just make sure for the
people, even for the people who come in late, she keeps something downstairs
and just says, if it starts getting too low, there’s something downstairs for you.
Like she, she’s on our nurses guild, ’cause she takes care of our pastor. So she
makes sure like everybody stays on top of it. So it’s not like it’s a secret, like,
when we see somebody coming up with like a apple juice or a little bit of orange
juice or something, she’ll bring ‘em up in a little cup or something and it’s like,
with a couple of crackers. It’s like, oh it’s not like, “Oh why did he get that special treatment? da, da, da, da, dah,” no we all know…

One participant also suggested that support could also come in the form of groups that would help people initiate backyard farming that would provide some fresh produce for the family. This was a suggestion that Erin had mentioned earlier as a strategy for addressing costly foods:

See that’s a really good thing, ‘cause like I went to the farmer’s market and they got this thing started now where, it’s like a big old organization where they teach people to plan their own stuff and teach ‘em how to farm. That’s a really good thing, ‘cause when they live out in the country, your seeds don’t cost that much. Water’s free, ah, usually out in the country ‘cause it comes from a well. (Jenise)

Other participants also thought of the importance of using family reunions and family gatherings as spaces of change and support. Kelsie recalled her first visit to a family reunion for her father’s relatives. As she recalled a conversation she overheard, she was reminded of how surprised she was at their deep concern and openness about the disease:

I remember the first time I ever went like the one guy just, he ended up asking one of the girls like, ah, “Did you check your blood pressure [blood sugar] today?” ahm, ‘cause she, what was she drinking? I don’t even remember what she had to drink, but he just was like, “You know that got a lotta sugar in it?”

Kelsie’s comments also remind us of the performative nature of the family and of the importance of this unit in offering support to the person with diabetes.
Clearly, a number of ideas as to how persons with diabetes could be supported were developing within these participants. I believe that this was an extension of their increased awareness and greater sense of sensitivity. Furthermore, the ideas spoke to the ability of the plays to move an audience into a space of action which can only be facilitated through dialogue.

Dialogue.

As was mentioned previously both in the first domain and earlier in this domain, participants also noted that it was important that persons with diabetes solicited help from their family by communicating with them and not engaging in or reinforcing a culture of silence regarding the disease. Leena noted for instance, that the family in Sugar Bear will probably be more open with each other after this incident:

I think it’d be more of a discussion, like, more of a “Hey, how’s this going?” Like, more open and, instead of people hiding things and like keeping it all private to themselves. I think now, after that, it’s more, ahm, it’s more of a public issue and so it’s gonna be more, you know, like, “How’s this doing?” and you know, you, you just, when things are discussed, you feel more welcomed to ask about them later instead of like, the mom saying, “Hey, don’t eat that, don’t eat that,” it’s like, “hey, how’s this, how’s this doing?”

Another perspective on the importance of dialogue had some of the participants talking with the characters of the play to demonstrate the importance of dialogue or the enactment of dialogue as a means of breaking the silence about the disease. Margaret applied her counseling skills and suggested that Lucille try to improve her relationship
with her daughter-in-law who was proving to be a vital source of support in her life, whether she liked it or not. One way to do so, she suggested was by being open about the disease, the requirements, and the needed support from the daughter-in-law:

…by saying, you know, I [Lucille] learned a lot about it, ahm, and in the end I’m not sure I can comply with everything that she [Nurse Candy] had told me, ahm, I’m looking for help maybe from you [Judy, the daughter-in-law] or maybe from somebody else and maybe you could give some recommendations where I could go for support. Rather than, “You’ve gotta help me.” [laughs]

The participants spoke so effortlessly into the lives of the characters as if they were seated right beside them. This highlighted the fact that the audience clearly interacted with the characters, so much so that they felt comfortable with the characters in the plays. This characteristic also addressed the fact that the stories and their characters were compelling and fit well into the lives of the audience. We can infer that by speaking to the characters, the audience members were modeling or practicing how to speak about the disease to loved ones. The plays have created a space for articulating needs:

…so one of my recommendations [to Lucille] was, “you know, come, you know, I’ll come over, every couple days, we can go for a walk, it’s exercise,” like if, “I can, you know, help you monitor the things when your family isn’t around,” ahm, just suggest that, ahm, strengthening those support systems, getting out, and, and being around more people, and, ahm, being more active and being ahm, ahm, not ashamed of having diabetes. And that ah, ahm, not to fight, she seems like she
was really opposed to (laughs) you know, anything that had to do with that, but just, just kind of encourage her to, to deal with the reality of her situation. (Tonie)

I would probably just say [to Lucille], “hey, you know like, I do this. Like trying doing this, it helps, it helps to regulate things and like, it helps to kind of take the weight off of it and here I have this cook book, so I can cook these foods and it’s, it’s diabetic-friendly and that kind of thing and how ‘bout you give this to your daughter-in-law because that will help her know like what you can eat and what you can’t,” and or like “this restaurant has diabetes-friendly,” that kinda thing, so (Leena)

Finally, the need for support groups and dialogue was highlighted in an observation Tonie made while visiting local pharmacies to obtain medical items for one of her children who had been ill. Tonie’s surveillance provided a visual support for the statistics on the prevalence of diabetes in Appalachia provided in Chapter one:

I see ahm, just, like over at Rite Aid [Pharmacy], they keep a little diabetes, ahm, newsletter type thing, right when you come in and it’ll have, sometimes it’ll have celebrity faces on it… just seeing, ahm, just going to the ah, pharmacist and getting the ahm, different needles and things, how many needles that they had, that how many diabetic needles that they had on hand, I was like, “wow, they must deal with a lot of people with diabetes in this area for them to have so big of a stock,” and just seeing how many different types of monitors and medicines,
that just seeing that behind the desk at the pharmacy, just made me think that, it
probably is a big problem in this area even without anyone talking about it, so...

There is a need for additional talk and support and the plays have the ability to create or
facilitate the development of an audience who would be willing to accommodate this.

Overall, the final domain on culture and diabetes provided us with several lenses
for considering how culture (re)shapes diabetes. The first section of the domain addressed
intertwining social forces. The respondents drew our attention to the impact of poverty,
tradition and fatalism on diabetes. With regards to poverty, several respondents outlined
the effects of inadequate finances on the health of a person with diabetes. This was
exacerbated by tradition or historical stories which prevent the effective treatment of the
disease. Also, while a lack of education can perpetuate a sense of fatalism, there are
persons who are either focused on preventing the continuation of the disease in their
family or are working on educating the next generation on how to treat it properly.

However, this domain ended with a sense of hope as there was a call for action at
the individual level and within the family and the community as a means to counter these
forces. The reshaping of culture can be done by providing support to persons with
diabetes through safe settings. An interesting development was the enactment of dialogue
by audience members. A number of them chose to demonstrate how dialogue should be
conducted by talking directly to the characters. All in all, the domain demonstrated that
the audience was not passive, but was actively involved in the storylines and could
independently come up with its own ideas about how to address the problem. Their
suggestions remind health communicators that it is important to involve community
members and approach them for solutions before a health communicative initiative is taken. Finally, the suggestions demonstrated the ability of the plays to create the space for decision-making and problem-solving in health-related matters.

**Summary**

As an entertainment-education medium, it is clear that theater can be quite effective, especially when its purpose includes educating its audience about a health issue of importance. The goal of the plays was to educate audiences about the implications of developing, preventing and managing diabetes. The responses of the participants indicated that they engaged with the stories and their responses were placed under three domains.

Within the first domain, the educational value of the plays was underscored as the participants articulated four messages gleaned from the presentations. These messages indicated that there was some degree of transformative and reinforced learning, even as they were entertained. The participants learned that while families can be a point of weakness in the life of the person with diabetes, they can also be a source of vital strength. With the help of the families, persons with diabetes can learn how to manage their illness well. First this can be achieved by eating better, which can be an easy or challenging change for some. Effective management can also be achieved by engaging in dialogue and disclosure regarding the disease as this allows both parties to become more sensitive and empathetic about each other’s lived experience. Finally, the plays also helped to hone the critical skills of the audience as they reflected on the pedagogical effectiveness of the plays through the use of cultural relevance and humor.
Under the second domain, the emphasis was on the narrative presentation of the audience’s reflections on diabetes and other illness. The personal perception of an illness is definitely affected by the social construction of that disease. As such, the participants told narratives in which diabetes was approached in fear, resisted and accompanied by guilt and shame because of the social perception. Finally, the space that the plays created allowed participants to examine their personal narratives in light of the public ones in which they had participated and the staged ones with which they were just presented.

In the final domain, participants addressed the manner in which culture can be confronted and incorporated as an ally in efforts to curb the prevalence of diabetes in the region. Among the issues presented was the effect of poverty or an inadequate source of financing on access to medical care and supplies. Additional attention was paid to the impact of geographical poverty on personal poverty as well. This domain also reminded us that we operate within multiple voices which are manifested in the maintenance of traditional eating rituals and habits which undermine the efforts of diabetes management. These stories also appear in the theme of fatalism which limits the individual’s sense of power against the disease. In the end, the respondents presented solutions for confronting the culture, highlighting specifically the use of support groups and dialogue.

Ultimately, the domains indicated an engaged audience who had rich responses and who cared about the topic. These three areas also provide several theoretical and practical implications for the field of diabetes research and health communication. In the following chapter, I present an overview of my findings and discuss their theoretical and practical implications.
Chapter Six: Discussing Where We Go from Here

This research started off with a desire to get involved in the field of entertainment-education and to explore how and why this method might be an effective tool for disseminating messages on diabetes care and prevention. Entertainment-education as a health intervention initiative in the United States is still lagging behind the work conducted in developing countries (Beck, 2004). One of the aims of this study was to determine whether the initiative could be as effective in the United States, especially when targeting persons who lived on the margins of access to health services, who had a history of oral tradition and who were at risk of falling prey to the growing epidemic of diabetes. Additionally, I yearned to explore the applicability of theory, curious to discover what happens at the intersection of narrative, performance and social construction. This aim, in particular, allowed me to situate communication research and the centrality of language deeper within the field of health care and prevention, particularly with regards to the performance of diabetes.

In the end, I am enriched by the results, encouraged about my current place in this field and hopeful that more initiatives will be taken to incorporate E-E as a means of addressing issues within marginalized populations. Furthermore, the findings have provided strong evidence for considering theater as an alternative medium for targeting mainstream populations especially those that have high levels of pre-diabetes. Theater would operate as a complementary lens for mainstream groups who readily embrace the commonly used television or textual documents. If nothing else, this research has pointed to the ability of narratives to generate reflexivity and additional narratives within an
audience. This fact cannot be ignored, especially after the research revealed how much of the lived reality of the audience is performed and impacted by narratives.

This study focused on the role of the narrative in constructing and challenging the meaning of diabetes. In essence, I looked at the role of language in shaping the lived experience with diabetes in southeast Ohio, especially in rural Appalachian Ohio. The interrogation of those stories was done by way of presenting audiences from within the region with narratives from two plays on diabetes – *Lucille* and *Sugar Bear*. After the viewing, I hoped additional narratives would emerge from the audience and would provide further insight on the perceived performance of diabetes, as well as narratives on how culture influenced this perception.

To accomplish this, I explored: (1) the messages that the audience recalled after watching the plays and how these acted as entries in the discourse on diabetes; (2) the construction of diabetes by examining the narratives that emerged within the audience and the degree of identification with the stories in the plays; and (3) how the audience perceived the lived experience of diabetes within the culture of the region.

The findings from this study revealed the centrality of language and the role of human communication in determining our experiences with diabetes or the manner in which we approach diabetes. This research also refocuses attention on the narrative construction of this reality. The story is used to explain, justify and call into action means of addressing cultural forces. Additionally, we recognize the use of language (narrative) as a sense-making tool which helps us sort through our emotions and reasons for having a certain perception of an illness. In essence, this study has extended the application of the
theoretical orientation of the social and narrative construction of reality. Also, by placing attention on how persons within the region regard diabetes, the lifestyle and the complications it could bring, this research provides health communicators and health promoters with a better understanding of how their target audience regards the disease. Furthermore, the use of theater provides practitioners with an alternative tool which can host culturally relevant values.

In this chapter, I return to the research questions posed at the end of Chapter Three and focus on the theoretical and practical implications of the findings presented in the previous chapter. Within this section, I ask, what do the findings teach us about theory and how theory illuminates the findings. I also address the limitations, future research directions and end with conclusions.

Theoretical and Practical Implications

Within this section I examine the theoretical and practical implications arising from the responses categorized under the three domains presented in the previous chapter. I revisit theoretical orientations addressed in Chapter Three and connect them with the findings.

The Centrality of Language in Entertainment Pedagogy

The first domain sought to interrogate, at the outset, the pedagogical efficacy of entertainment-education. Was entertainment-education capable of teaching persons in southeast Ohio about diabetes? Could they recall the messages and how did they receive or apply these messages within their own lives? Second, this question considered the audience’s perception of the performance of diabetes within the plays and what they
believed were the main themes or elements evident within this performance. Four themes were unearthed: ‘Family Dynamics,’ ‘Dialogue,’ ‘Healthy Eating,’ and the use of ‘Humor and Cultural Relevance.’ The emergence of these four messages reveals much for theory and praxis.

Theoretical Implications

The five themes which emerged in the first domain revealed the centrality of language in symbolic interaction (Burke, 1968). As Burke noted, we order our lives according to categories and labels so that we are able to participate well in the world and identify with others. As the audience observed the interaction of the characters in the plays and then further reflected on their own interactions, we are drawn to how they interpreted the language and how this meaning related to their world. First, we find that the themes that emerged indicate that the audience had multiple interpretations for diabetes performance. In their responses, we realize that they began to apply these interpretations to the ones previously held before the presentations. Some of these previous interpretations were challenged, while others were reinforced during and after the plays. This act of revisiting is part of the process of identification (Burke, 1969b) where the individual finds areas of similarity with ‘the other.’ This similarity emerges by identifying categories and interpreting these areas as similar to the world in which we reside or in the same manner as the individual with whom we feel similar.

Second, the centrality of language is emphasized as the audience addresses the importance of dialogue and disclosure for someone with diabetes. Theory helps us recognize how we use language to relate to ‘the other’ and engage in social relations.
(Burke, 1969). As Gadamer (1989) argued, language is “the medium in which substantive understanding and agreement take place between two people” (p. 384). This is reminiscent of Burke’s (1969) notion of consubstantiality, where we are constantly trying to connect our interests with those of others. Whereas complete understanding and agreement may not occur all the time, especially when interacting with a resistant person with diabetes or an unsupportive family member, it should be an aim which is strived for during times of illness as we try to be open to the different experiences of ‘the other.’

Using the lens of the theory of language also makes us more sensitive to the manner in which language is used to help us identify the dialectical tensions that arise in our reality. As Bakhtin (1981) would remind us, we live in a world that is characterized by heteroglossia and as such, differences will collide. Conflicting interpretations of diabetes, for instance, may arise and cause tension in the treatment and management of diabetes. We would also recognize that there are multiple historical, social, cultural, personal and intergenerational stories that impact the individual. This theoretical understanding would prepare health communication scholars for multiple and contradictory interpretations of diabetes. At the end of it all, this dissertation further incorporates the work of Bakhtin (1981) and Gadamer (1989) into the field of health communication. The findings presented in the previous chapter indicate a multiple and interpretive social reality with regards to an illness. The findings resist the notion that Appalachia is a homogenous region. Also, the responses remind us of the multiple interpretations of diabetes which could take place within the patient-practitioner and patient-family interactions and how these interpretations could both collide and collude.
The emergence of the sub-theme of gendered caregiving in a family with diabetes draws our attention to past research in this area (Denham et al. 2004, 2007) and the fact that language can be used to reify roles and determine how these are performed in society (Berger & Luckmann, 1989). We find that a number of the respondents challenged the reification of the role of the woman as the main supporter within a family, while others acknowledged that unfortunately this sole responsibility had been legitimized across the generations and would be difficult to change even through discourse because of the power of the greater social discourse on the role of the woman. Some of the responses have painted the picture that the role of the woman is socially constructed and is sometimes filled with tension and conflict brought on by the introduction of an illness. It then becomes difficult to gain that mutual understanding for which Gadamer (1989) advocated because the woman is both living within and struggling with multiple interpretations of what her role is supposed to be.

Furthermore, the participants helped us understand how we use language to evaluate the meanings associated with our symbolic language (Gadamer, 1989). We saw the audience enacting this as they sketched their meaning of diabetes and critically evaluated their interpretation as well as how they arrived at these meanings. The privileging of the visual (Flaherty, 2008; Greiner et al., 2007) and the performative (Conquergood, 1988) allow us to examine how we ask questions and receive responses. Clearly the sketching and an examination of the plays allowed persons to take a different view of themselves, their preconceived notions and their world. The narrative of the plays
also caused several to revisit, re-enter and re-evaluate (Gadamer, 1989) their insensitivity toward persons with diabetes. Theory also serves to illuminate the practical implications.

**Practical Implications**

With regards to praxis, the responses to this question remind us of the need for entertainment-education products to achieve a balance between entertainment and education (Singhal & Rogers, 1999). While the audience’s attention was captured by the entertaining stories in the plays, at the same time, they were able to pinpoint several teachable moments or learning points within the presentations, thus indicating that the plays were not educationally overwhelming. For instance, some respondents articulated that they learned about the normal range for blood glucose levels and the important role of the family. As such, health communication campaigns utilizing E-E need to ensure that the stories they present are compelling in nature and attract and hold the attention of the audience with gripping interaction between the characters as they journey through conflict and resolution. In essence, E-E needs to ensure that the audience members are drawn into the stories by the characters, mostly because they recognize similar personalities and stories within their own lives (Slater, 2002).

Audience involvement and identification is vital and must occur at the cognitive and affective levels before any form of self-efficacy or interpersonal communication takes place within the audience (Sood, 2002). Following the descriptions presented by Sood (2002), although not addressed in detail in the previous chapter, it is clear that the audience engaged in affective involvement by identifying with the characters, such as when Inga stated that she was just like Lucille. Referential involvement was evident as all
of the respondents drew on stories from their personal lives to explain their construction of diabetes. The extensive recollection of the different messages indicated that they paid close attention to the plays and thought through the messages, which was indicative of cognitive involvement.

The audience’s reflection on the educational themes not only highlighted cognitive involvement, but also cognitively-oriented parasocial interaction (Papa et al., 2000). In essence, by paying close attention to the characters, the audience recognized behavioral alternatives in their own lives. Admittedly, there were mixed responses in the expression of self-efficacy, which is one’s belief that he or she has the ability to effect change and manage future situations (Bandura, 1995); self-efficacy should be a product of cognitive parasocial interaction. However, Ranelle stated, for instance, that a change in eating habits would mean death for her and Dennis noted that not being able to eat what he wanted would be akin to living with handcuffs. However, others, such as Maddie and Lloyd, have started adjusting their lives and paying attention to the foods they purchased, due to watching the plays.

Second, the health promotion and education field will recognize the pedagogical worth of E-E, specifically theater. This study demonstrated the potential of this medium to teach and to aid in the recall of important messages about health care and prevention. This ability becomes even more valuable within a culture that honors oral tradition, as well as before a group of audience members who may not have a high educational background. Undoubtedly, this pedagogical worth cannot be stated without acknowledgement of the previous point, that is, about the importance of providing
compelling stories. Naturally, this point is grounded on and further supports the work of Freire (1993) and Boal (2000) who concentrated on not only teaching audiences, but also on activating them by causing them to reflect on their problems and engage in problem-solving strategies.

Furthermore, theater is also recognized as a cultural narrative which reinforces and challenges beliefs (Conquergood, 1988). That is, apart from receiving the transmitted messages (Singhal & Rogers, 1999), the audience also interacted with the characters and this speaks to an additional effect of the plays. Several persons mentioned seeing their lives or their family members within the plays. This indicates that theater can be a suitable catalyst for generating personal reflection as mentioned before, as well as interpersonal communication about diabetes. The theme of ‘Humor and Cultural Relevance’ highlighted this connection between education and entertainment, in that, most of the respondents pointed to this connection as contributing first, to the maintenance of their attention and then, to their retention of the messages. In fact, a number of participants indicated that without the humor, they probably would not have paid close attention to the plays or the messages, which would have hurt the pedagogical effect of the plays. Furthermore, the audience’s recollection of the messages indicated that they did not trivialize the health issue because of the entertaining nature of the stories and neither did the humor lead them to believe that diabetes was not a serious disease.

These findings have been noted by health care facilities in the past and this is a lesson that should be considered by health care practitioners in Appalachia. Indeed, healthcare facilities are incorporating the use of humor as a means of facilitating
communication in patient care (Draheim, 1995) and in creating a sense of a safe environment for patients. Sonder et al. (2006) noted that humor acts a buffer when information about chronic and difficult illnesses is presented. In *Lucille*, the character utilized humor as a coping mechanism and the audience appreciated this as the dialogue addressed difficult complications and a change in life. This need to balance seriousness with laughter is explained by Priest (2007) who described the warm reception of the humorous Canadian theatrical character, “Mrs. Pudding,” who was presented in a 15 minute comical vignette. Priest argued that using humor to talk about type 2 diabetes was easier as it relaxed the audience, suspended judgment and enhanced learning.

Third, the themes of ‘Family Dynamics’ and ‘Dialogue’ indicated that the audience recognized that illness never occurred alone, but participates in and impacts the lives of others (Adelman & Frey, 1997; Beck, 2005). The plays demonstrated the positive dynamics, but also the tension that could arise when dialogue was initiated and resisted, thus modeling the reality of life with illness. Health care providers, including diabetes educators and community volunteers who struggle to inspire involvement from the family or significant others, can utilize E-E to help these loved ones venture vicariously into the nuances of dialogue. However, the benefits of this strategy extend beyond helping practitioners meet their own needs. The plays provide persons with family members with diabetes with a model for dialogue and they will have the opportunity to look into the world of diabetes which may not have been clearly described by the practitioner or the diabetic loved one. Additionally, the person with diabetes can also use theater as a means of initiating dialogue with family members who are lacking in their support. Even the
short role-playing activity conducted by Candy, the transitional nurse, and Lucille to help Lucille talk with her daughter-in-law, could be a creative alternative for health care workers as they broach the topic with their patients.

Moreover, the plays were effective in instigating a need for greater sensitivity toward persons with diabetes and the emotional and physical problems they were experiencing. The audience articulated their recognition of the importance of support, which comes in various forms, such as the monitoring of medication and meal plans. This positive outcome can be anticipated by diabetes educators who know that support from family members can lead to improved health (Denham, 1996; Denham et al., 2007).

However, this support cannot be possible without the presence of dialogue. This reflection on the importance of dialogue also highlighted the role that culture plays in perpetuating silence about an illness within the community, as well as within the family. The themes of ‘Family Dynamics’ and ‘Dialogue’ emphasized the key role of the family in the formation of self-identity or self-construction within Appalachia. Indeed, we cannot regard the person with diabetes as being separate from the social context, whether the context is the region or the family (Markus & Kitayama, 1991). As researchers (Denham, 1996; Denham et al., 2007) have pointed out that the family is part and parcel of the person with diabetes so much so that as Markus and Kitayama stated, persons with diabetes would be “motivated to find a way to fit in with relevant others, to fulfill and create obligation, and in general to become part of various interpersonal relationships” (p. 227). This interdependency becomes a foil when tradition from within the family and culture enters as a mediating factor. For instance, the family dynamics in Appalachia
often dictate that the women in Appalachia are the main caregiver. Sometimes, this results in women adhering to familial obligations and deciding against changing meals out of an obligation to the members of the family who do not have diabetes.

Finally, while not specifically addressed within the main research question, diabetes educators, in particular, will be excited about the articulation of some of the seven self-care behaviors advocated by the American Association of Diabetes Educators (AADE7) (American Association, n.d.) in the responses of the participants. Again, this highlighted the pedagogical worth of the plays and augurs well for their use in the field. The main self-care behavior which identified was the importance of ‘Healthy Eating.’ A number of the respondents stated that they were excited about learning about the effects of foods on the blood glucose level and how important it was to be mindful of the nutrition facts, including the number of carbohydrates being consumed. While information on the effects of alcohol on the glucose level was received with shock by some participants, this was mostly appreciated and indicated that the audience may make more informed choices regarding their alcoholic intake. However, this message of making smart food choices was interpreted as being restrictive by some persons. In fact, some of the respondents classified sugar as ‘poison.’ Helman (2007) further defined this category, which generally occurs in affluent countries, as comprising food that was “a substance dangerous to health, or causing disease, and should be avoided” (p. 57).

Helman described this as a symbolic reaction within the public which identified our relationship with food and ultimately our relationship with each other.
Other self-care behaviors addressed were monitoring, taking medication and healthy coping. The audience retained information on the importance of regularly monitoring one’s blood glucose level and taking medication as a means of avoiding complications and determining how one is doing on a given day. The self-care behavior of healthy coping focuses on how persons with diabetes recognized and managed physical and emotional problems that arise due to diabetes. I believe this theme was addressed under the message of ‘Family Dynamics,’ because this behavior cannot be performed successfully without the help of the family and significant others. Some participants remarked that while this routine felt rigid, it was important. Surprisingly, not much mention was given to being active. Nevertheless, the articulation of these behaviors should signal the potential use of E-E for diabetes educators who are struggling to find alternative methods of reaching target audiences. These messages are important for audiences which include persons with diabetes and persons with pre-diabetes who could implement these behaviors to prevent or delay the development of diabetes. In essence, the responses in this domain draw our attention to practical implications of the use of E-E, as well as the use of the lens of the theory of language to help understand the effectiveness of this tool. Another theoretical lens which helps us understand the construction of diabetes is narrative theory.

Connecting the Narratives Presented with the Narratives Emerging

The second domain interrogated the applicability of the social construction of reality theory (Berger & Luckmann, 1989) and by extension the narrative construction of reality theory (Bochner, 1994; Bruner, 1996, 2002; Frank, 1995). Through this section we
were able to tease out narrative as ontology and determine what emerges at the
intersection of narrative and performance.

Four broad themes emerged from an investigation of the second research question
which grounded the second domain: (1) narratives of fear, which centered on stories of
the fear of deprivation, isolation and rejection; (2) narratives of resistance, which
included stories of denial, not treating the disease seriously, and perceiving the disease as
a disruption; (3) narratives of shame and guilt; (4) and intersecting narratives, which
focused on how the audience drew parallels between the plays and public and personal
narratives of other diseases. The responses revealed much about theory and praxis.

*Theoretical Implications*

Theory was enacted and extended as these narratives gave us a better
understanding of what was actually occurring within the audience members. First, we
saw multiplicity in action (Bakhtin, 1981; Bruner, 1996). All the participants had varying
ways of interpreting the performance of diabetes. There was a heteroglossia of stories of
diabetes that have combined with those presented in the plays to further create a
perception of the disease. Therefore, we recognize the formation of a hermeneutic reality
that, in essence, involves an interpretive understanding of diabetes. For instance, an
individual could articulate a personal story of resistance, but at the same time, confront a
public story of hope. This combined construction was further reconciled with the staged
construction of fatalism in one of the plays, thus creating a composite and interpretive
understanding of diabetes.
Also, the responses from the persons who did not have diabetes, in particular, helped us to recognize how language is used to aid our attempts to relate to others, while remaining distinct (Bakhtin, 1981). Through the responses, we recognize that while the persons not diagnosed with diabetes had gotten closer to an understanding of living with diabetes, they still remained distant, looking at the world of diabetes from the outside, a world, which some of them have stated, they did not want to be part of. However, the narratives from some of the respondents not diagnosed with diabetes indicated an attempt to bridge the gap between knowing and being (Bochner, 1994; Frank, 1995; (Harter et al., 2005). While the differences between persons with diabetes and persons not diagnosed with diabetes were not interrogated in detail, we could infer that they would each have a different level of identification with the plays and characters. I believe that their stories could indicate a greater sense of empathy as was articulated under the first domain.

Second, we see the narrative construction of the reality of diabetes emerging (Bruner, 1996). Most of this interpretation of the performance of diabetes has emerged from personal experience with diabetes or from discursive interaction with persons with diabetes. Most of the respondents had in some way, watched a loved one or an acquaintance manage the disease, either effectively or ineffectively. This signaled the fact that the perceptions and meanings about a particular illness arise from social interactions about the disease (Kleinman, 1988; Sontag, 1978, 1988).

We find too, that the narratives were used as organizing tools, helping to make sense of this reality (Arntson & Droge, 1987; Bochner, 1994; Bruner, 2002; Frank, 1995). A number of the respondents drew on their own personal narratives to make sense of the
narratives they viewed in the plays. Interestingly, sometimes the narratives that emerged
took different trajectories than the ones in the plays. For instance, I found some of the
respondents still had a negative construction of diabetes, even though the respondents
recalled that a loved one had managed the disease effectively and that the stories in the
plays ended on a positive note. Hence, we observe the articulation of narratives of
resistance and disruption amid positive personal stories and staged presentations. The
same was true even if they recalled the message of the benefits of healthy eating; there
was still an abiding sense among some of the respondents that persons with this disease
would perform it in a restrictive manner, especially if disabling complications emerged.
For instance, Darla was very enthusiastic about learning how dietary changes positively
impacted one’s health. Yet, she still regarded the disease as restrictive and noted that if
she were diagnosed, she would perceive diabetes as an unwanted interruption and she
used the story of her late grandmother to justify this, even though she had witnessed a
coworker who managed his diabetes very well. In essence, Darla was organizing her
perception of diabetes (Frank, 1995) and she did so through reflection on several stories
that were generated (Frank, 1997).

Furthermore, the responses indicated that there was an overwhelming negative
social construction of diabetes. In reflecting now on the narratives that emerged from the
audience, I realize that they were mostly pessimistic as they often addressed issues of
derivation, guilt and shame by attributing the development of the disease to a lack of
control over one’s food (overindulgence) and the body. This social construct is embodied
by the person with diabetes whose actions will only be mitigated by effective family
support and proper monitoring. Additionally, S. L. Fisher’s (2001) remarks about the shame of being labeled an Appalachian remind us that indeed this cultural label can affect one’s self-identity and also one’s approach toward treating a disease.

So far, social construction theory has caused us to be aware of the negative construction of diabetes. This theory also informs us of the fact that persons with diabetes were aware of the power of language and how the construction of a disease can determine the outcome of social interactions. For this reason, many resist disclosure or dialogue because they understand how the disease or the sick person has been constructed in society (Frank, 1991; Japp et al., 2005; Kleinman, 1988; Sharf & Kahler, 1996; Sontag, 1978, 1988). Persons with diabetes who did not disclose did not want to be perceived as abnormal, special, or pitied. Other participants, such as Darla, invoked the role of culture and intergenerational behaviors, by noting that where there was silence regarding diabetes, sometimes this is out of fear that by speaking about the disease, the person may contract the disease. This behavior underscored research conducted on the powerful impact of the family in Appalachia (Denham, 1996; Denham et al., 2007), particularly the fact that the family provided the frame of reference for describing and understanding illness (Denham et al., 2004). Hutson et al. (2007) and Caldwell (2007) also talked about the effects of intergenerational stories in making sense of illness. In essence, there is an awareness that language can be used to legitimize knowledge passed on to future generations (Berger & Luckmann, 1989). Nevertheless, we can appropriate this knowledge, passing on instead, ways in which diabetes can be prevented or more efficiently managed.
Finally, these responses remind us of the generative nature of stories (Bruner, 1996; Frank, 1997; Ricoeur, 1990). The respondents presented stories that sounded like the ones they perceived were presented in the plays. That is, a narrative of resistance in the play begat a narrative of resistance from within one’s personal life. For instance, Inga presented the story of her reaction to her first glucose reading which indicated high levels as a story of denial as she reflected on Lucille’s response to the nurse’s diagnosis at the beginning of the play. There is an attempt to connect with the narratives in the plays, whether they are narratives on diabetes or narratives of other illnesses. These intersecting narratives, in particular, indicate a method of telling (Polkinghorne, 1988), a way in which they tried to make sense of the plays observed and connect them to life observations and experiences, as well as the public and social lives of others. As the audience engaged in this sense-making, I did not perceive too much difference in the interpretation of the actions of the characters (Sharf & Vanderford, 2003) with the exception of when the father was perceived to be more effective than the mother in Sugar Bear. The respondents seemingly entered into this interaction from various angles and perspectives and perhaps this was due to personal backgrounds and concepts of the role of the woman. This interrogation of heteroglossia, narratives and language leads us to think also of the practical implications of these theoretical extensions.

Practical Implications

With regards to praxis, first, the social construction of reality encourages us to be reflexive about the meanings that we assign when we use language and how those meanings are perpetuated through social interactions (Gadamer, 1989). It is our language
that informs us of our biases, concerns and our subjectivities. Participatory sketching can play an important role in tackling some of these perceptions as health educators seek to stem the spread of diabetes. This method can be used to interrogate how patients define and describe the lived experience with diabetes. This method can be used to tackle the language used within a family with diabetes, and address the fears of the family of and the person with pre-diabetes.

Additionally, we need to recall that language can aid in the construction of a new narrative reality, causing us to create worlds that are not currently present. Therefore, we can control the discourses on diabetes and the meanings embedded within these discourses (Bruner, 1996). If we consider that narratives beget other narratives, this provides us with an optimistic expectation and rationale for the use of the plays in public education initiatives within communities and even small family gatherings. Through the plays, diabetes educators and medical practitioners can recreate and challenge the stories of their audience. Moreover, persons with diabetes and pre-diabetes can be encouraged to envision a new world which has hope and not necessarily fear.

Indeed, these stories serve as a reminder to health practitioners and educators that narratives are transformative, not historically or culturally bound. As practitioners, patients and researchers, we can help to change the plot with the help of health intervention mechanisms like entertainment-education. One of the best examples that illustrated this was the transformation which was evident within DJ. She had initially noted that her family provided no support to her grandmother who had diabetes, but in one of her final comments she talked about the need for vocalizing support as a first step.
in protecting all family members. For someone who did not have this as a model while growing up, this was a good indication of behavior transformation as a result of the plays.

Also, the findings within this domain inform practitioners and educators that we are in constant negotiation with culture because of the hermeneutic nature of society which includes varied interpretations. The reality about diabetes, for instance, can be read in so many different ways as these narratives indicated. Therefore, we cannot ignore the social system from which the individual emerges as this will impact their recovery (Bakhtin, 1981). Therefore, before any communicative initiative is undertaken, we must interrogate the stories of the social system, including those of the family, as well as the historical stories. I use the term ‘communicative initiative’ loosely as this includes interactions between the patient and the practitioner as well as community events. Furthermore, by adopting this perception, health practitioners will recognize, anticipate and be more comfortable with the fact that each individual will have a different story, and therefore, must be treated differently.

These stories also remind us of the narrative construal of our reality and how persons organize a sequence of events over a period of time in order to elicit meaning (Ricoeur, 1990). Sometimes, while the perception of diabetes is being explained and justified, chronological time does not help in determining the meaning of experiences. Instead, a relationship between events is created as the past is reconstructed it gives meaning to the present and purpose for the future. We see this in the stories of respondents like Linda and Inga who often referred to their past to give meaning to the present. As mentioned previously, it is important that we are sensitive to the temporal
nature of narratives, since this is often the manner in which individuals and even family members not diagnosed with diabetes will approach the disease. One way to apply this finding is to encourage health professionals to take time and evoke stories from patients during visits, because this information would provide them with insight on how the patient will manage future treatment of the disease. A brief question such as, “How did this all start?” may be enough to introduce relevant and powerful stories. Lucille would be the more suitable of the two plays to demonstrate this adaptation. By encouraging health professionals to view the story, they may be encouraged to critically reflect on their own interactions with patients (see Appendix A for the script of Lucille).

Finally, stories can help explain non-chronological events and be used to create new story plots, thus narratives act as maps or guides for others. For instance, the narratives, both positive and negative can be used to help steer the audience in different directions. Therefore, this theoretical framework helps health practitioners apply and justify the use of entertainment-education in diabetes prevention and management campaigns as a practical means of guiding at-risk audiences as is observed in the third and final domain.

The Impact of the Social and Cultural on the Personal

The third domain sought to interrogate the intersections of performance and narrative and determine the performance of diabetes within a larger social framework. Through the plays, the audience was able to receive an opportunity to enter into the world of the person with diabetes and in some way experience a common encounter and emotion with the characters. The plays have helped participants to make sense of the
perceived lived experience of diabetes and a number of them went on to address social and cultural factors which impede this experience and performance. Four themes emerged: ‘Poverty and Diabetes,’ ‘Tradition and Diabetes,’ ‘Fatalism and Diabetes,’ and ‘Combating and Working with Culture.’

Theoretical Implications

First, the intersection of narrative and performance provides us with an understanding of how culture, poverty and traditional events impact the lived experience with diabetes in Appalachia. Peterson and Langellier (2006) stated that by viewing narrative through a performative lens we will recognize four consequences, one of which is that “narrative is constrained by situational and material conditions” (p. 176). This lens informs us that the narrative performance of the person with diabetes will always be impacted by social and material conditions (Bruner, 1996). Therefore, we cannot look at the performance without paying close attention to the social conditions as was just discussed in the previous section. Moreover, as this research indicated, within Appalachia we have to recognize that economic conditions, such as poverty and differing family dynamics, including the degree of emphasis on traditional events, intergenerational stories and even the presence of fatalism are affected by the strong sense of interdependence. These factors will cause ideas about diabetes in southeast Ohio to be viewed in certain ways, but also differently. Essentially, no one person will have the same performance because understandings about diabetes likely differ.

The narrative performance theory informs us that diabetes is embedded within and ordered by fields of discourse (Peterson & Langellier, 2006). These discourses can
take place at the micro-level, such as within the family, determine who speaks and what is regarded as salient. On the larger scale, we recognize as was said before, that culture can determine who tells the story and this introduces an issue of control. In essence, we recognize that there can be larger narratives that constrain how we legitimately express and enact our lived realities (Beck, Harter, & Japp, 2005). If the dominant narrative, in the culture, or in the family is one of shame, then it will be difficult for individuals to enact personal narratives that are different from the dominant one presented.

However, as Peterson and Langellier (2006) indicated, these discourses of control can be challenged through narrative performance, where the narrative produces knowledge (the knowing), as well as the performance (the doing). This connects with the previous assertion that stories can generate new stories (Bruner, 1996; Frank, 1997), thus placing the power of change within the hands of the individual storytellers. For instance, this informs us that the narrative of fatalism and tradition can be changed if the context is changed (Burke, 1969) and it is within this change that we locate entertainment-education as a facilitator to transform ways to look at social and material discourses of control. The final section within the third domain addresses this change in how we perceive material and social forces of control. Some respondents expressed outrage at the treatment of diabetes in the society and argued for the circumventing of the social tradition of silence. For instance, Lloyd posited a need for a change in mindset among persons who indulge in fatalism, noting that if persons changed how they looked at relationships and the impact of their actions on the younger generation they would take a more active stance and would talk more about preventing the disease.
With this said, it becomes understandable why one of the responses from the audience regarding the research question on culture included a call for more dialogue about the topic. It is in this call that we can situate the effective use of the narrative as a means through which we enter into dialogue with the other (Bochner, 1994). There was a desire to end the silence as a means of preventing the disease from developing in the lives of others and allowing individuals to support the person with diabetes’ efforts to manage the disease. The findings underscore the fact that language teaches and allows us to relate to each other, thereby bringing us closer to a more proactive and dialogic engagement (Bakhtin, 1981), one which enacts the application of theory.

Practical Implications

Narrative is inherently co-constructive (Harter et al., 2005) and can be used to induce other stories (Burke, 1968) and alternative readings of a disease (Bruner, 2002; Garro & Mattingly, 2000). Stories provide us with better understandings of one’s world and suggest that there are practical implications for using narrative to address social and material forces. This knowledge helps to explain the audience’s call for more dialogue on the disease within the family and through support groups in Appalachia. Diabetes educators and advocates for persons with diabetes can consider that both the family and support groups will allow persons not diagnosed with diabetes an opportunity to talk with persons with diabetes and vice versa so that a common meaning can be shared, thus facilitating that ‘fusion of horizons’ that Gadamer (1989) described. Co-construction becomes important as both parties try to negotiate through emotional issues brought on by the disease (Adelman & Frey, 1997; Ellis, 1995). As such, it serves consideration that
a play that addresses the dialectics of illness relationships can spark conversation and understandings at the interpersonal level. This notion ties well with the theoretical literature on entertainment-education (Bandura, 1977; Singhal & Rogers, 1999; Singhal, Cody et al., 2004) where tools, such as theater are used to focus on initiating psychological change within the audience so that social performance of personal narratives can also be altered. Understandably, this audience in Appalachia recognized that dialogue can initiate a change in performance and could generate mobilization on community issues as has been exemplified by e-e strategies in the past.

In fact, finally, within this domain, we also see the mention of ‘healthy coping’ which is one of the seven self-care behaviors from the AADE. This self-care behavior is evoked by the call for support groups within the area to help persons with diabetes and their families talk about the physical and emotional problems experienced. First, we recognize this as an outcome of the plays which again provides additional support for their use in public education initiatives. Not only do the plays call for support, but audience also mirrors this call. Second, we recognize that the audience is stating that these groups would allow persons with diabetes to engage in dialogue with others, receive support from others who are experiencing the same problems, as well as from those who had overcome the problems. In essence, the narrative can aid in bridging the gap between knowing and being, where loved ones who do not have a diabetes diagnosis can utilize the time for dialogue to draw closer to a better understanding of what it means to be the person with diabetes. Essentially, we recognize once again, the power of language to change and produce a new cultural reality, while at the same time
understanding the ability of language to perpetuate perceptions and hinder the healing and illness management process. While these implications are celebrated, I will now address the qualities of the project in more detail, future directions, and conclusions.

**Strengths and Limitations**

This narrative exploration has been characterized by several ups and downs. However, the presence of both elements was necessary and allowed me to create a rich narrative of diabetes in southeast Ohio.

**Strengths**

In reflection, several strengths characterized this research. The first strength was the intersubjective nature of the research. I have coupled the responses of the participants with my own understandings and have presented several emerging themes. While the emergence of these themes was personal, they are not to be considered as totally limiting or biased, but instead as revealing. Additionally, my readings of the stories call to attention personal stories and join them in conversation with the stories of the field of health communication and narrative performance.

Linked to this intersubjective nature is the fact that I approached the research as a person not diagnosed with diabetes and one with limited prior exposure to diabetes. My understanding of the responses introduces the perspective of the outsider, who, as Gadamer (1989) suggests is trying to create a ‘fusion of understanding’ by entering into the world of the person with diabetes. Rather than focusing on embodied differences which could appear to have hampered my interaction with the audience, I celebrate them as I believe they created a safe space for interacting with participants. The fact that I am
from a different nationality, ethnicity, and sometimes a different educational background from those of the respondents provided a different lens through which diabetes was understood. I entered with fascination, a desire to honor and learn, while engaging in the participant’s story to the degree that they allowed me.

Additionally, an advantage of being an outsider who was seemingly ignorant about diabetes and its performance was that it aided my reception by the audience. As mentioned in Chapter Four, I often felt that the audience was trying to help me out. As they willingly shared their stories, many expressed a desire to see me graduate and some openly brought diabetes medical paraphernalia if they were a person with diabetes to educate me. Also, in some venues, I received easy access to participants. This was purely because of the amicable relationship I had with the leaders of the organizations. Without this rapport, I am uncertain as to how the research would have unfolded in an area with which I am largely unfamiliar.

An additional strength was the fact that I conducted my academic tenure within the field of study. One of the first advantages of this was that it gave me easy access to the participants. Also, I was able to gain a little exposure and insight to the lived experience of the participants by being able to recognize and incorporate physical locations and historical experiences, which I would not necessarily have been able to do if I were not in the area. Moreover, my presence in Appalachia for the past six years had provided me with a degree of empathy and an eagerness to give space to the narratives of the residents a place that had helped me academically.
Moreover, the fact that the project went through a number of stages before the actual exploration requires mention. The plays went through meticulous redrafting and re-reading before the final scripts were completed. I believe that my involvement from the stage of conception to the stage of investigation helped to underscore the credibility of and the rigor involved in the project.

Finally, this research was multi-method in nature and incorporated a variety of qualitative research strategies. These included the use of in-depth interviewing, open-ended questionnaires, participatory sketching and focus group discussions. The use of each method created a rich composite of the narrative reality of diabetes in southeast Ohio. The inclusion of participatory sketching, in particular, gave value to the visual explanation and interpretation of the lived experience of diabetes. The use of this textually-based strategy complemented the orally-based in-depth interview or focus group discussion. The combination also ensured that there was an added element of verification of individual interpretations.

In essence, the strengths of the research project were varied. However, these cannot be heralded alone, but must be balanced with the limitations of the study.

Limitations

In reflection, there were three areas that could have enhanced the research findings. First, there was the lack of additional financial resources to conduct the extensive research I initially planned. I spent approximately two months focused on presenting the plays and collecting audience responses. In total, there were eight presentations of the plays, with both plays being presented in three venues. With
additional funding, I would have been able to secure the talents of the actors and director for a longer period of time and also visit additional counties which form part of Appalachian Ohio. Furthermore, by not being able to present in additional venues, I found that my respondents were not as mixed or representative of the population as I would have liked. While I believe that I have received rich responses, I may be lacking in stories for instance that address the impact of culture and economics on diabetes.

Second and still connected to the matter of intersubjectivity which was addressed initially as a strength, I must also acknowledge that since I have never experienced the life of diabetes directly nor lived outside of the academic environment within southeast Ohio, my readings of the responses might be different from someone who is from this culture and who lived in the area. Additionally, although I am not overtly aware of this, my nationality and ethnicity may have hampered access to potential participants. There is a distinct divide between the researcher and the ‘researched,’ and it would have been clear that I was not part of the local community, especially in venues at the Good Works Shelter for the Homeless and in Chesterhill. I hoped that my personality, as I introduced the plays, would have decreased the divide and I also made a special effort, as suggested by the director at Good Works, to interact with patrons before the presentation of the plays. So far, I have received no negative feedback about my involvement.

Finally, the extent to which I was able to employ research methods was impacted by several setbacks. These included a lack of access to potential research participants, and the limitation of time, for instance in conducting a focus group discussion. Additional access to participants in some venues would have provided a more accurate presentation
of results. Also, the restriction of time sometimes prevented the project from accomplishing its academic purpose, that of conducting research on diabetes; instead, there was a focus on entertainment. After considering the limitations and strengths, it is imperative that I also address future directions for my continued research on narratives, entertainment-education and health communication.

**Directions for Future Research**

I believe that this research has provided another example of the manner in which entertainment-education can be utilized to generate narratives of reflection, evaluation and transformation. This purpose can be effectively applied to health communication initiatives involving diabetes care and prevention. Still, several questions remain that need to be interrogated to more fully determine the efficacy of applying this method particularly within Appalachia.

A question that emerged is how would audiences from other Appalachian regions respond to the narratives within the plays? While the audience in southeast Ohio believed that the plays were culturally relevant and transplantable in other areas, would this actually be possible? This question addresses the nature of stories of illness. Will one story be accepted and generate similar stories within multiple audiences? What qualities or forces would prevent the stories from being accepted? This question teases out the idea of applicability within narrative theory and also causes us to appreciate institutional forces, not just individual ones that could impact the presentation of a story. Recent findings from the Centers for Disease Control and Prevention (2008a) indicate an increase in prevalence in diabetes in some counties in Ohio that are not part of
Appalachia. Additional funding would allow me to extend the presentations beyond current counties within this research to other Appalachian and non-Appalachian counties to receive a richer perspective on the lived experience of diabetes.

Another question that arises is the need to explore the unspoken undercurrents about diabetes (Beck et al., 2005). For instance, there were some stories that were not heard, such as the positive stories about diabetes. It was not until my analysis that I realized how overwhelmingly negative the representations of diabetes were, despite the positive endings they observed in the plays. Therefore, another study of this nature could focus on highlighting the positive or enduring stories of diabetes as a counterbalance to those presented here. This need is concurrent with our knowledge of a multiple reality (Bakhtin, 1981; Gadamer, 1989) and it behooves us as narrative scholars to further explore the plurality of this representation (Beck et al., 2005). Additionally, this is relevant to the education of health professionals, that is, how can they be trained to elicit, interpret and re-story ideas about diabetes and its outcomes within clinical practice? Also, we need to examine how dominant socio-political narratives can constrain the personal narratives, as well as how personal choices can hinder narrative telling. That is, how do social and material discourses impact the presentation of stories? This understanding impacts how we work with families who experience these storied life events.

Another question which was not entirely addressed in this study was the disabling impact of diabetes. While, several respondents shared their fears and opinions about this possible development, additional research needs to explore these fears and the possible connections with identity construction and the social construction of disability. It is clear
that with the rising epidemic of diabetes, the future labor force of the country will be impacted; therefore, these stories of fear, chaos, diagnosis, acceptance, rejection, and change in identity need to be interrogated. Furthermore, this interrogation may allow us to alter these stories so that they can include the more positive messages of prevention and self-management that can lead to healthy experiences.

The value of stories has also caused me to be curious about how this approach can be incorporated within institutions that give care to persons with diabetes. Clearly, they will be able to appreciate the value of the pedagogical tool of theater and its ability to generate stories from within groups of persons who experience diabetes. An additional area of inquiry is work with the diabetes educators and community volunteers who may use these plays and determine how my findings and the plays could cause them to alter clinical practice and by so doing create hopeful stories of change and healthier lives.

Finally, as Singhal and Rogers (1999) noted there are some additional questions about entertainment-education that need to be investigated. First, we need to explore the long term effects of this study. Clearly, in the short term, about one month after the presentations, the respondents still recalled details from the plays. It would be interesting to measure whether they still possessed the same amount of recall six months or even a year later. Also, it would be important to determine whether they had applied any of the lessons learned, either personally or in their interactions with persons with diabetes. Furthermore, we also need to consider how this method compares to the traditional methods used in diabetes education.
Conclusions

In conclusion, theater provides an additional avenue through which health narratives can be presented and explored. Through this medium, we were able to interrogate the discourses and construction of diabetes performance within southeast Ohio which comprises a small part of Appalachia. This investigation led us to understand the dual role the plays undertook, acting both as narratives, while at the same time presenting narratives. We were able to better understand the nuances of language and the role it placed in helping us determine how the audience perceived diabetes was performed in the plays. Then, we also investigated the narratives which were generated within the audience and how these were combined with personal narratives to provide a larger understanding of the construction of diabetes. Finally, we explored the cultural, material and social conditions that can constrain and enable the performance of diabetes.

In all, we learned that diabetes is also socially constructed and that there are multiple interpretations and performances of this disease. There appears to be a fear and a negative opinion of the disease due to the experiences persons have had with the disease and have observed in the lives of others. Additionally, we found that diabetes is narratively constructed, as with most other health issues, and that the narratives of the disease include those of family and significant others. Finally, we determined that these narratives are enabled and constrained by material and cultural forces such as tradition, fatalism and poverty.

On a personal note, this research study, while exhausting, was extremely fulfilling. I have found a great love for the story and was grateful when persons expressed
how much they actually enjoyed the interview, the setting and the format. I am at heart a narrative scholar and I have found myself listening more closely to stories of illness, change and organization, among others. I have also learned the importance of valuing organization and I am still attempting to embrace and be comfortable with the uncertainty of the field. The uncertain is nothing to fear, but should be anticipated like an unexpected gift! Finally, I have found the joys and pains of writing, suffering through writer’s block to witnessing the completion of a dissertation. At the end of it all, I am a much more organized writer who is eager to represent, translate, receive guidance and share the stories of others who may not have received the voice to do so.
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Appendix A: \textit{Lucille} Script

\textbf{LUCILLE}

By G. William Zorn
(Lights up on a hospital room. LUCILLE is in bed. CANDY, a nurse, enters.)

CANDY

Hello. Mrs. Myers.

LUCILLE

If you’ve come for more blood, I’m all out. Empty. Caput. The tank is on E and I’m runnin’ on fumes.

CANDY

Mrs. Myers?

LUCILLE

Who’s askin’?

CANDY

I’m Candy, your transition nurse—

LUCILLE

Transition to what?

CANDY

Well, I hear you’re going home tomorrow.

LUCILLE

News to me.

CANDY

Oh. Well, you’re going home tomorrow. Ta-da!
LUCILLE

Dandy.

CANDY

(Louder.)

No, Candy.

(Looking through chart.)
Are you having trouble hearing?

LUCILLE

No, little girl, I was saying Dandy. As in, I’m looking forward to going home. ‘Bout as much as I would look forward to each and ev’ry one of my fingernails being removed with a rusty pocketknife. See, hon, that’s called sarcasm.

CANDY

Oh. I…uh…

LUCILLE

Isn’t it amazing? All that in one little word? Dandy.

CANDY

That’s right. You used to be an English teacher.

LUCILLE

Retired now, yes. How do you know—?

CANDY

Let’s see.
A wise man should consider that health is the greatest of human blessings, and learn how by his own thought to derive benefit from his illnesses.

LUCILLE

Well now. That was one o’ them Greeks. If I was the bettin’ sort, I’d say Hippocrates.

CANDY

Very good.

LUCILLE

(Reciting.)

The only way to keep your health is to eat what you don't want, drink what you don't like, and do what you'd druther not.

CANDY

Mark Twain.

(Reciting.)

Medicine to produce health must examine disease; as music, to create harmony must investigate discord.

LUCILLE

Plutarch. Gimme a hard one at least.

(Reciting.)

Attention to health is life’s greatest hindrance.
CANDY/LUCILLE

Plato.

(They laugh.)

CANDY

Say, am I going to have trouble with you, Lucille?

LUCILLE

Prob’ly. You want trouble?

CANDY

Honestly? Yes.

LUCILLE

Brave girl.

CANDY

If you’ve got something to fight about, you’ve got something to fight for.

LUCILLE

I don’t know that one.

CANDY

Well, I haven’t published it yet. Give me a couple years.

LUCILLE

(Smiling.)

This is gonna be fun.
CANDY

Now. Your doctor told me how important it is for you to get home in time for Thanksgiving.

LUCILLE

I never said that.

CANDY

Oh. It isn’t true?

LUCILLE

Yes. I would like to be home for Thanksgiving, but I never told him that and he didn’t ask me either.

CANDY

Well, I think your daughter-in-law talked with your doctor, actually.

LUCILLE

What was your name again?

CANDY

It’s Candace, but everyone calls me Candy.

LUCILLE

Candy, I love my family.

CANDY

I am very happy to hear that. It is so import—
LUCILLE

Let me finish. I love my family, but I am not a child. I was born in the middle of the depression, number seven of fourteen kids. I’ve lived to see a half dozen wars. I was a riveter in dubya-dubya two. A damn good one, too. The Japs never sank one of my ships. I married my Alvin in forty-seven, ran a household, raised two boys, taught English to children who would rather read comic books and I’ve been president of the Elks Club Lady’s Auxiliary twice. Does that sound like somebody you can run roughshod over?

CANDY

No—

LUCILLE

Does that sound like someone who doesn’t deserve to be addressed directly?

CANDY

No—

LUCILLE

Does that sound like someone who can’t take care of herself?

CANDY

No, ma’am.

LUCILLE

Does that sound like a woman with diabetes?
CANDY
Well, yes. To be honest. Anyone can—

LUCILLE
Oh, bull pucky. There is no diabetes in my family history.

CANDY
Well, Mrs. Myers, we’re finding out more and more about this disease everyday—

LUCILLE
Then maybe they’ll find out I don’t actually have it.

CANDY
Mrs. Myers, normal blood sugar tops out at about 120. Do you know what your blood sugar was when you were admitted to the emergency room?

LUCILLE
They told me it was high.

CANDY
It was 982. You were essentially in pancreatic failure.

LUCILLE
But, I didn’t feel that bad.

CANDY
Mrs. Myers, you couldn’t see.

LUCILLE
Will you knock it off with that Mrs. Myers stuff!

CANDY
I didn’t want to be presumptuous. May I call you Lucille?

LUCILLE

Well…your mama raised you right, didn’t she? Yes. Please call me Lucille.

CANDY

Thank you. *Lucille* it is then. So, what has your doctor told you so far?

LUCILLE

Not a lick. He’d rather talk to someone nearer his own age, I guess. I’ve seen him for all of five minutes since I been here. Hell, my nosy daughter-in-law knows more than I do.

CANDY

I’m sure she only has your best interests in mind.

LUCILLE

Not much. That bony-butt, holier-than-thou wallet-chaser has one and only one purpose in life and that is to spend Alvey Junior’s money. Not look after my care and feeding. I don’t know what I did wrong by those boys o’ mine, but all my sons married the snootiest women they could find. Think they’re better than everybody else. Neither one of ‘em got a lick o’ common sense either. You can knock all day long but nobody ever answers the door, if ya know what I mean. Do you have children?

CANDY

Yes ma’am, I have a daughter.

LUCILLE

She the kinda girl that’d make fun of her poor, elderly mother-in-law?
CANDY

She’s eight.

LUCILLE

Oh. Well, you make sure you raise her right, like your mama did by you, okay? If she don’t particularly care for someone’s cooking, there are ways to say it without hurtin’ anybody’s feelings. Not tasting the tiniest morsel of a person’s green bean casserole only to suggest that Thanksgiving be catered next year and moved to her house.

CANDY

I take it you and your daughter-in-law don’t get along?

LUCILLE

Did they teach you to state the obvious that way in nursing school? Didja figure that one out when I called her bony-butt or when I called her a bad housekeeper?

CANDY

I didn’t hear you say she was a bad housekeeper.

LUCILLE

Well, I meant to.

CANDY

We can’t choose who our children fall in love with, Lucille.

LUCILLE

Amen to that.

CANDY

Doesn’t mean you have to love them, too.
LUCILLE
Well now, hold it right there, sister. I never said I didn’t love her. She’s family now.
That’s automatic love. She makes Alvey Junior happy, such as it is. Happiness and good
taste, however, are two very different things. But I never said I didn’t love the girl. Like
her? Well, that’s a horse of a different flavor. Why were we talkin’ about this?

CANDY
Thanksgiving.

LUCILLE
Right. So, she told my doctor that it was important to me that I get out of here in time for
Thanksgiving. Do I have that right?

CANDY
Seems that way, yes.

LUCILLE
Hmm…

CANDY
Ma’am?

LUCILLE
Well, I have to wonder. Judy’s not the come-right-out-and-say-it type.

(Picks up her purse and takes out a photograph.)

That’s her. Judy. Bony-butt. So, I have to wonder if she wants me to be there at
Thanksgiving to show me how much better her Thanksgiving is or to shove all the food I
can’t eat anymore under my nose.
CANDY
She’s that much of a fire-starter, huh?

LUCILLE
Trust that I am not exaggerating when I say that Gandhi woulda smacked that girl right upside the head. *Well, isn’t that just the loveliest sheet, Mr. Gandhi. I had some bed sheets just like that...years ago. But, I’m sure you don’t get many nice things in the desert.*

CANDY
Wow.

LUCILLE
Mm-hmm.

CANDY
Well, Lucille. I certainly can’t tell you how to make your daughter-in-law a nicer person. What I can tell you is that you can eat whatever you want for Thanksgiving.

LUCILLE
I can?

CANDY
Yes, ma’am. You just can’t eat as much as, I’m willing to bet, you normally would.

LUCILLE
Oh.
CANDY

That’s actually a good place for us to start. I’ve brought along some literature for us to go over.

LUCILLE

Not much for reading these days, Candy. I like my papers. *The Star. The Enquirer.* And the daily paper, of course.

CANDY

Well, this will be something you’ll need to read before every meal.

(Opening a small booklet.)

This is your carbohydrate counter. It lists the amount of carbohydrates in almost every food you can imagine. After a week or two, you’ll practically have it memorized. Now, what would a typical breakfast for you be?

LUCILLE

Oh, I don’t know.

CANDY

Well, let’s start from the beginning. You get up in the morning…

LUCILLE

I get up. Get the paper off the porch. Oh. I usually have to pee first thing. You need to know that?

CANDY

Not necessarily, but go on.
LUCILLE
Well, then I get a cup of coffee. Alvey and I bought one of those Mr. Coffee’s with a
timer a few years ago, so it’s ready when ya get up. And I sit and read the paper at the
kitchen table.

CANDY
Good. Now, what do you usually have for breakfast?

LUCILLE
Well, I can’t say that I’m always hungry first thing in the morning.

CANDY
It’s going to be very important from now on that you eat three meals a day. If you can
eat around the same time every day, that’s even better. Do you think you can do that?

LUCILLE
Doll, I’m a widow living on a pension. I play bingo twice a week. I’m pretty sure I can
fit it into my busy schedule.

CANDY
Excellent. Now, what do you like to eat for breakfast when you’re hungry?

LUCILLE
Bacon and eggs.

CANDY
Toast?

LUCILLE
Sometimes.
CANDY

Very good. That’s very good, Lucille. Alright, so let’s say you have an egg, a strip of bacon and two slices of toast.

LUCILLE

And coffee.

CANDY

Yes, and coffee. Do you have sugar in your coffee?

LUCILLE

Lord, no. It dulls my orneriness.

CANDY

We wouldn’t want to do that. So, black coffee.

LUCILLE

Yes.

CANDY

Alright, so now turn to the back of your carb counter and look up eggs.

LUCILLE

(Flipping through the booklet.)

Eggs. Page twelve.

(Flipping through the booklet.)

It says there aren’t any carbs in eggs.

CANDY

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That’s right! You’re doing very, very well, Lucille.

LUCILLE

What did I say about treating me like a child?

CANDY

Sorry. Now, there are other things in eggs like cholesterol and fat that you’ll want to keep to a minimum.

LUCILLE

Well, I get my eggs from my brother Betty.

CANDY

You have a brother named Betty?

LUCILLE

I surely do. And a sister named Bob. Those are just nick-names, of course. My name’s Batch to my brothers and sisters. They’re all long stories that I have told folks before, but believe me, it’s much more interesting if ya don’t know the reasons behind them.

CANDY

Alright, I’ll trust you on that.

LUCILLE

Brother Betty used to run a chicken farm. Retired now, too. So, he just has about ten layin’ hens. Brings me over a dozen eggs a week I’d say.

CANDY

Good. So, we have an egg. No carbs there. How about the bacon?
LUCILLE

(Flipping through the booklet.)

Well, let me see here. Bacon. Page ten.

(Flipping through the booklet.)

Says bacon doesn’t have any carbs either.

CANDY

That’s right. Yay! Again, you have to watch out for cholesterol and fat with bacon.

LUCILLE

I usually get turkey bacon, if that helps.

CANDY

Well, you’re just on your way to being my star student, aren’t you?

LUCILLE

See, now you’re doin’ that on purpose.

CANDY

Little bit. But that cuts the amount of fat and cholesterol a lot. Now what else did we say? Toast.

LUCILLE

That’d be under bread, I’ll assume.

(Flipping through booklet.)

One slice of bread has fifteen grams of carbs. So, if I have two slices that’d be thirty grams altogether.
CANDY

Yes. Excellent. You sure you weren’t a math teacher?

LUCILLE

I’m about ready to smack you.

CANDY

(Laughing.)

Well, if it helps. I’ll even turn the other cheek. Seriously, you’re catching on very quickly. It takes some folks a lot longer, believe me. Okay, so—

LUCILLE

Let’s just cut to the chase here. Forty-five grams for breakfast.

CANDY

Exactly.

LUCILLE

(Flipping.)

And if I have a BLT for lunch, that’s thirty for the bread and nothing for the bacon. Right? Lettuce and tomato, five grams each. That’s forty for lunch. Why do I have to keep track of these?

(CANDY takes out an insulin syringe.)

CANDY

Well, you need to know how much carb ratio insulin to give yourself.

LUCILLE

Uh-oh. The “I” word…
CANDY

*(Setting down the syringe.)*

We’ll cross that bridge when we come to it, alright. You’re doing great. Now, do you eat out a lot?

LUCILLE

Oh, every once in a while I get a hankerin’ for a cheeseburger down to the Dairy Queen. No more than once a month or so.

CANDY

Alright. Now you’ll find a listing for those in the back of your carb counter too, under *Combination Foods.*

LUCILLE

Let’s see here.

*(Flipping through booklet.)*

Thirty grams of carbs and twelve grams of fat. Lord. That’s a lot.

CANDY

Yes, but if you keep it to once a month, you’ll do just fine. Now that’s how you determine the amount of carb ratio insulin. Let’s talk about how to measure your blood glucose level.

LUCILLE

Now my next door neighbor’s a diabetic. I’ve seen her do that. She’s got one of them little stabbers. Pokes a hole in your finger, right?
CANDY

Yes, ma’am.

LUCILLE

I believe I’m not gonna care much for this part.

CANDY

It is the most accurate way to determine your glucose level, or blood sugar. After a while, most patients don’t even feel it anymore.

(Takes our lancet device.)

Now this is the lancet device.

LUCILLE

Stabber.

CANDY

Lancet device—

LUCILLE

Stabber.

CANDY

Now Lucille—

LUCILLE

Stabber. It’s a stabber. Call it what it is. It stabs.

CANDY

Alright, then. If you want to get technical about it, this is just the stabber-holder. You have to insert the stabber into the end like this.
(Demonstrating.)
You’ll get a prescription for all of these things from your doctor before you leave. But, we’ll make sure to send you home with a little starter kit, too.

(Takes out lancet.)
Now, you insert the lancet—

LUCILLE
Needle.

CANDY
Into the lancet device—

LUCILLE
Stabber.

CANDY
You know what? We can’t even do this now anyway. They just took your blood sugar before lunch, right?

LUCILLE
Yep. Stabbed my pinkie that time.

CANDY
Believe me, Lucille. After a while you won’t even feel it.

LUCILLE
Oh, I didn’t feel it. Sweetie, I sew. Needlepoint. Musta stuck my own finger a thousand times over the years. Occupational hazard. It’s not the stabbin’ I take issue with. I don’t like the sight of my own blood.

CANDY

Oh. Well, there’s really no way around that. What do you do when you stab your finger sewing?

LUCILLE

Well, I usually do my sewing on the couch in the front room. Alvey sittin’ in the recliner. He’d see me turn a shade whiter than normal and he’d know right off. Kleenex at the ready, he’d grab hold of my finger and tell me a story. Usually about something we’d both been through. When we took the boys up to Wren’s Lake or that trip to see the Grand Canyon. His eyes never leavin’ mine till I completely forgot about—

*(She begins to cry. Embarrassed.)*

Oh, look at me.

CANDY

It’s okay, Lucille.

LUCILLE

Blubberin’ all over myself.

CANDY

You lost him recently?

LUCILLE

Yes, honey, I did. December.
CANDY

I’m so sorry.

LUCILLE

Oh, don’t be. We had our time together. I have no regrets. Ain’t nothin’ to be sorry for. He was a good man and I miss him. And here I am, crying in front of someone I barely know. That’s prob’ly how I got this. You cook for two for so many years, when you forget to hate to see it go to waste. It’d be admittin’ somethin’.

CANDY

I bet he kept Judy in line, huh?

LUCILLE

Oh, good Lord, no. She scared the crap out of him. And after livin’ with me that long, that’s sayin’ somethin’.

CANDY

You know, Lucille. I can’t help but think that the biggest obstacle to your recovery might be your family.

LUCILLE

Continue.

CANDY

Well, we see a lot of patients become lax in their efforts to keep up with their blood sugar readings or they might start to forget their insulin. But, those that have support from their families always do much better. Someone to ask if you’ve taken your insulin today or to encourage you to eat better.

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LUCILLE

Well, I rarely see the boys. Alvey Junior drives truck cross-country and Davey’s manager down at the Super 8.

CANDY

And your brothers and sisters?

LUCILLE

Well, I see Betty once a week when he drops off the eggs. Sister Bob lives over ta Greenville. I see her every couple months. The rest of us are all scattered. I have a brother in Denver and one in Springfield. We have a reunion about once every couple years, but that don’t help you none, now does it.

CANDY

So, who do you see most often? Family-wise.

LUCILLE

(A beat.)

Bony-butt.

CANDY

Oh.

LUCILLE

Every Tuesday, like clockwork she stops by and we go do the grocery shopping.

CANDY

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Hmm…

LUCILLE

What?

CANDY

Do you enjoy that time with her?

LUCILLE

Well, I gotta shop. She’s gotta shop. All God’s chil’en gotta shop. It’s more convenient to go together, that’s all.

CANDY

I see.

LUCILLE

She spends too much time in the hair color aisle, though, if you want my honest opinion.

CANDY

I wonder if you’ll let me try something, Lucille.

LUCILLE

I tell her, honey, they don’t have a gallon-size.

CANDY

I would like to try a little role-playing.

LUCILLE

(Suspicious.)

Okay.
CANDY

I would pretend to be you and you can pretend to be Bony—

I mean, Judy.

LUCILLE

And what would the point of that be?

CANDY

I think it might help me to see how difficult your transition will be.

LUCILLE

Okay…

CANDY

And it might help you test the waters a bit. See if she’ll be more help or hinderance.

LUCILLE

Oh, she’ll be alright, I think. She’s just stuck-up ’sall.

CANDY

Well, let’s find out. Now, it’s Tuesday morning and your doorbell rings.

LUCILLE

Don’t have a doorbell.

CANDY

Then there’s a knock at the door.

LUCILLE

She’s never knocked on a door a day in her life. Usually she just—
CANDY

(As LUCILLE.)

Come in!

LUCILLE

(As JUDY.)

Morning, mother Myers. Sorry I’m late.

(As LUCILLE.)

She’s always late.

CANDY

I thought you said like clockwork.

LUCILLE

Yeah. If she says she’s comin’ over at ten, she’ll be there at ten fifteen. If she says ten thirty, she’ll be there at ten til eleven. Like clockwork.

CANDY

Oh.

(As LUCILLE.)

Well, hello there, Judy.

LUCILLE

What the hell was that?

CANDY

What?

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LUCILLE

Ya make me sound like a car salesman.

CANDY

(Doing a crankier LUCILLE.)

Hello, Judy.

LUCILLE

(As JUDY.)

Oh good. You’ve got coffee on. I just didn’t have the time before I left. Rush rush rush. That’s all I do these days. My nails. My hair. I simply must spend your son’s money before he gets smart and divorces me. Are you outta sugar? Oh that’s right. I’m sorry. Well, Equal will just have to do, I guess. How are you feeling?

CANDY

I’m feeling fine, Judy. Just fine.

LUCILLE

I’m glad. You know you gave us quite a scare the other night. How you could have let yourself get that sick I’ll never know, bless yer heart. At death’s door—

CANDY

I wasn’t at—

LUCILLE

And you arguing with that poor nurse in the emergency room.
CANDY

I told her my veins roll—

LUCILLE

She was only trying to help you.

CANDY

Well, she wasn’t—

LUCILLE

Honestly, you just have to be a little nicer to people and they’ll do whatever you want them to. I should know. But, you scared us half to death, bless yer heart. I came this close to singin’ it.

CANDY

(As CANDY.)

Singing what?

LUCILLE

Your song, of course. You know. Kenny Rogers. Yer favorite. I told you I’d be singing it at your funeral.

(Singing.)

Ya picked a fine time to leave me, Lucille.

CANDY

(As CANDY.)

Oh, Lucille, that’s awful.
LUCILLE

*Four hungry children and a crop in the field.*

CANDY

She wouldn’t really do that, would she?

LUCILLE

*I’ve had some bad times. Lived through some sad times. But this time your hurtin’ won’t heal.*

CANDY/LUCILLE

*Ya picked a fine time to leave me, Lucille.*

*(They are laughing.)*

CANDY

Oh, that’s horrible.

LUCILLE

This is fun. I used to do this with my students. I must’ve heard *Romeo and Juliet* a thousand times. I still know all the speeches. Comes out at the oddest times, even now.

*(LUCILLE picks up the insulin syringe.)*

LUCILLE

*(Reciting.)*

*I sell thee poison; thou hast sold me none. Farewell. Buy food and get thyself in flesh.*
CANDY

(Reciting.)

Come, Cordial and not poison, go with me to Juliet’s grave; for there I must use thee. I know what you’re doing, Lucille. That is not poison and this is not the end of your life.

LUCILLE

Maybe not. But it’s the beginning of the end, isn’t it? I was about five, I think, when my grandmother called me into the kitchen to teach me how to make her stuffing. This was important. This was the equivalent to a state secret. The entire county clamored to get their hands on that recipe. Including my mother. And here I was, my precocious, little five-year-old self, learning about soaking the celery in bacon grease overnight and using biscuits instead of croutons and never letting a utensil get anywhere near that stuffing. Your hands, she said. Your lovin’ hands are what make people envious. People think there’s some mysterious ingredient, and there is, but not what they think. No herb or spice or temperature can replace your own hands, baby girl. That’s where the love comes from. But Candy, I ain’t makin’ Thanksgiving this year. It’s bein’ brought in by people I don’t even know. In big foil pans kept warm with Sterno. Touched by plastic and metal. And strangers’ hands. Where’s the love in that? It’s the beginning of the end.

CANDY

Maybe it’s time to pass it along.

LUCILLE
What?

CANDY

Your grandmother’s stuffing. Maybe Miss Bony-Butt never had that kind of relationship.

She doesn’t know that a caterer can never live up to her mother-in-law.

LUCILLE

And maybe Sean Connery will ask me to marry him.

CANDY

I can’t imagine that someone who has as much fight, as much pure, unfiltered, unfettered orneriness would — could — ever go gently into that good night. You’ve taken everything I’ve thrown at you today and sent to back to me twice as fast. I’ll bet you match ol’ Bony-Butt toe to toe, too. You don’t love that girl because you have to. You love her because she’s a good sparring partner. But, she can’t read your mind. Sparring is good. Keeps your mind sharp, but talk to her. Have a real conversation and see where that takes you.

LUCILLE

Well, not to toot my own horn, but I can give as good as I get.

CANDY

I’ll bet you do. And something tells me as long as you can hold your own against somebody like that, you’re gonna be just fine, Lucille.

LUCILLE

I tried to tell you that when you first got here. Now, don’t you have some sick people you need to see? I can’t be the only one in this place…with diabetes.
CANDY

Yep. You’re gonna be just fine, alright. I’ll be back before your dinner arrives to show you how to check your own glucose and we’ll take care of your insulin then.

LUCILLE

Stab away.

CANDY

You tell the day nurse to come get me if ya need anything, alright?

LUCILLE

I got a bed, my needlepoint and a TV Guide crossword just beggin’ to be put outta its misery. What else do I need?

CANDY

Alright then. You remember my name, right?

LUCILLE

Honey, I am a diabetic and your name is Candy. What do you think?

CANDY

Irony.

LUCILLE

There’s hope for you yet.

(CANDY exits. LUCILLE puts on her reading glasses and picks up the needlepoint.

After a moment, she stops and picks up the insulin syringe.)
LUCILLE

There are worse things, I suppose.

(From down the hall we hear a voice.)

JUDY

(Off.)

Yoo-hoo, mother Myers! Where they hidin’ you, honey? Ya picked a fine time to leave me, Lucille.

LUCILLE

Lord, gimme strength.

END OF PLAY.
Appendix B: *Sugar Bear* Script

*Sugar Bear*

A One-Act Play

By Dana Lynn Formby
Sugar Bear

People appearing

Andrew...............................................................Dad
Marlene.............................................................Momma
Andy.................................................................Son
Peanut...............................................................Daughter
Papaw..............................................................Grandpa


Time: 5:26 PM
(MARLENE is standing on a chair and has one end of a long banner in her hand and is trying to get it to stick to the wall.)

MARLENE

Come on now. Stick. Stick. (It falls. She looks at it.) Well, aren’t you just a holiday off with no pay. Alright we’re gonna try this again. And your gonna listen this time. See I know you’re gonna like that wall. It’s your friend, it wants to hold you and love you and the tape is going to feel so good, smooth-- (It falls) You darn thing, you. (Calling out) Peanut! Peanut!

(Enter PEANUT with her pet rock.)

MARLENE (Cont’d)

I need some tacks.

PEANUT

Flipper wants to know what’s for supper, Momma.

MARLENE

Flipper? Who’s Flipper?

PEANUT

He’s my pet rock and I made him in school and I named him Flipper because I found the rock in the stream out by the hen house and I glued his eyes on and painted stripes, four stripes, and Mrs. Sonday’s says he’s granite. Strong.

MARLENE

I wish life was as easy as Kindergarten pet rocks.
PEANUT

What’s wrong momma?

MARLENE

Nothin’. Well, Flipper, we’re havin’ Country French Chicken.

PEANUT

Yay, Fried Chicken!

MARLENE

I said French-- Country French chicken.

PEANUT

What’s that?

MARLENE

A new recipe I cut out of Self magazine.

PEANUT

Yuck.

MARLENE

Don’t squench your face up like that.

PEANUT

Rabbit food. Debbie doesn’t have to eat rabbit food, they get real food.

MARLENE

Debbie doesn’t live here and doesn’t have a Papaw coming in tonight.
PEANUT
We eat like that even when Papaw’s not here. Flipper says, “Rabbit food is yucky!”

MARLENE
Flipper better learn some manners or Flipper’s gonna have a sore behind.

PEANUT
When does Papaw get in?

MARLENE
Soon.

PEANUT
What’s soon?

MARLENE
Auntie Laura’s picking him up. So who knows?

PEANUT
Auntie Laura knows.

MARLENE
Go find your momma some tacks.

PEANUT
Okay.

(Exit PEANUT. Enter PEANUT.)

PEANUT
Here.

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MARLENE

Thank you, honey.

PEANUT

Yup.

(Exit PEANUT)

MARLENE

Peanut!

(Enter PEANUT)

PEANUT

Yeah?

MARLENE

I need a hammer.

(Exit PEANUT)

MARLENE

Kristy Marie Myers!

(Enter PEANUT)

PEANUT

Yes, Ma’am?
MARLENE

Pick up these toys before someone slips, and

BOTH

Breaks their neck.

PEANUT

And dies.

MARLENE

Girl.?!?

PEANUT

I’m not being smart, Momma. Just cautious. See? Toys picked up.

MARLENE

Just get me a hammer.

(Enter ANDREW.)

ANDREW

I’m about to pull some heads off that’s what I’m about.

PEANUT

Hi Daddy!

ANDREW

Clean off from the shoulders, head: gone!

PEANUT

Bye Daddy.
(Exit PEANUT)

ANDREW

It’s gonna be hard to breathe with out a head.

MARLENE

Good day at work?

ANDREW

I’m tellin’ you that boy-- that boy left the--

MARLENE

Where’s your hammer?

ANDREW

Hammer? Who’s concerned about a hammer? He left the cage unlocked. Unlocked.

MARLENE

You don’t know that now, now Andy--

ANDREW

There’s locked, and unlocked and unlocked is what I’m gonna do to that boy’s head.

MARLENE

What does that even mean?

ANDREW

Like we got chickens growing on weeds
MARLENE

Get up on that chair and hang this up.

ANDREW

Where is he?

MARLENE

Not even back from school yet.

ANDREW

I’ll show him back from school yet.

MARLENE

Andy, you are home and if I’m not mistaken that means you can at least take your coat off.

ANDREW

Marlene, he doesn’t know discipline. Discipline I tell you.

MARLENE

And his father does?

ANDREW

What was that?

MARLENE

You know what I said.

ANDREW

It’s a miracle that there’s any chicks left.
MARLENE

This banner listens better than you.

ANDREW

I pull up: gate wide open. Where’re you going?

MARLENE

I don’t have-- have the time to just stand here and listen to you pontificate.

ANDREW

Pontificate.

MARLENE

This thing’s not cooperating and dinner’s not gonna cook itself. Daddy’s coming home tonight. Your sister and the kids.

ANDREW

You’re not gonna cook that rabbit food are you?

MARLENE

Depends, how was your day?

ANDREW

I like real food, Marlene.

MARLENE

Yeah? That good, huh?

ANDREW

Oh don’t start in on me.
MARLENE

Andrew Martin Myers Junior!

ANDREW

I got busy, there were four calls about sinks, 2 toilets. I was crawlin’ on my back all afternoon. Those pipes aren’t gonna fix themselves. I didn’t have time to sit down for a second and...

MARLENE

You mean you ate a Twinkie.

ANDREW

Way early this morning but it was no big thing. I was alright the rest of the day. Marlene.

MARLENE

And the shotgun pointed at your head on our wedding day was for souvenir photos only.

ANDREW

Oh come on, you know I love you, baby.

MARLENE

Love? Who’s talkin’ about love?

ANDREW

Marlene--

MARLENE

What time did you eat last?
ANDREW

I had lunch.

MARLENE

Lunch at what time.

ANDREW

Like said I was busy.

MARLENE

Did you even read this banner, baby? Huh? Peanut made it. A six-year-old, six.

ANDREW

That girl’s smart, six and already reading and writing.

MARLENE

I just hope you’re around to see her hit twelve.

ANDREW

You’re overreacting. It was a Twinkie!

MARLENE

If I can’t get through to you, maybe she will.

ANDREW

Marlene…

MARLENE

Don’t Marlene me, and you best grab a hold of this thing and get it to make friends with that wall or the only real food you’ll be eating is something you cook yourself. And I’m not too sure how well burnt macaroni is on your figure.
(ANDY takes his coat off and lays it on the couch.)

MARLENE (Cont’d)

You know, god made hangers for more than airplanes. So I suggest you find a place to Park that coat. (He does.) Thank you.

ANDREW

Marlene, Jenna is dead.

MARLENE

Jenna?

ANDREW

Dead.

MARLENE

Dead. I loved Jenna.

ANDREW

No more twin yolks.

MARLENE

That wolf get in the gate?

ANDREW

Like the boy handed him an invitation.

MARLENE

She was our last hen.
ANDREW
Store bought eggs.

MARLENE
Who else did he get? Did he get anyone else?

ANDREW
Sally and Raymond.

MARLENE
That only leaves us 3 chicks.

ANDREW
And Ben.

MARLENE
I’m gonna kill that boy.

ANDREW
After I subtract 7 of his 10 years, you can take the other 3.

(Enter ANDY)

ANDY
(Saying hello)

Mom, Dad.

ANDREW
Where you going, boy?
ANDY

Room.

ANDREW

What, school only teach you to talk in one word syllables?

ANDY

No.

MARLENE

Sit down Andrew Martin Myers the third.

ANDY

Did I do something?

ANDREW

I don’t know, did you?

ANDY

If given the option, no.

MARLENE

The gate was left open.

ANDY

Wasn’t me.

ANDREW

I guess the chicken fairy has a set ‘keys.

ANDY

I guess.
MARLENE

Don’t get smart with your father.

ANDY

Sorry, Ma’am.

MARLENE

That’s more like it.

ANDY

I didn’t touch the gate, Sir, honest. Honest.

ANDREW

Oh I see, I see, so you didn’t do your chores this morning then.

ANDY

I did my chores.

ANDREW

You teleport in the pen?

ANDY

Teleport

ANDREW

That how you scrapped the chickens?

ANDY

I was running late and I just threw the scraps over the gate. I don’t need to go in the pen to give ‘em scraps. If I was seedin’ them, sure, but you’re the one who does that.
MARLENE

Jenna’s dead.

ANDY

Dead.

ANDREW

Dead.

ANDY

No more twin yolks.

ANDREW

Yolks? Twin yolks, yolks, a family member is dead, Andy, dead.

ANDY

She was a chicken.

ANDREW

You look at the world like that and that’s how the world’s gonna look at you.

ANDY

Like I’m a chicken?

MARLENE

Andrew!

ANDY

I didn’t do it, mom.

ANDREW

And prisoners volunteer to go to jail.
MARLENE

Andrew!

ANDREW

Well, that’s where liars go and I’m not about to raise a liar in this house.

MARLENE

Andy, go put your stuff in your room and then come help this one hang the banner.

ANDREW

Marlene, Discipline I tell you, discipline.

MARLENE

I don’t have time for this. Look at the time? We eat at precisely 6 PM and it is already 5:33. And don’t even get me started on you, Mr. Myers, why I’m in a hurry. So you get up on that chair. You: room. I’ll be in the kitchen and I don’t want bothered unless the roof caves in and even then if it doesn’t affect the kitchen it doesn’t concern me. What are you two lookin at, move.

(They move.)

ANDREW

This isn’t over, boy.

MARLENE

Yes, It most certainly is, Mr. Myers.
(MARLENE and ANDY exit.)

ANDREW

(Reading the banner.) Welcome home Papaw. (Calling out to MARLENE) Babe? Babe? You seen my hammer?

MARLENE (Off Stage)

Is the roof caving in?

(ANDREW reaches up with the banner and a tack. Enter PEANUT.)

PEANUT

Daddy, where’s your tool box?

ANDREW

I don’t know, Peanut. Just hand me that thing there.

PEANUT

Daddy that’s Flipper.

ANDREW

He wants to help me out.

PEANUT

Do you want to help Daddy, Flipper? He says no.

ANDREW

No?

PEANUT

No.

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ANDREW

He’s not very helpful.

PEANUT

Flipper, do you want to be helpful?  Nope?  Sorry dad.

ANDREW

Find me something… that… I can… hit this tack…

PEANUT

Are you okay, Dad?

ANDREW

Yeah, fine.  Just a little… come here… help this old man off this chair.

PEANUT

Okay.

ANDREW

Just a little light headed.  Don’t want the shakes to come on.  Little lady, go get my coat.

(Enter ANDY.)

ANDY

Dad, do you need help?

ANDREW

No… no I got this.  I got this.

PEANUT

I can’t reach the coat it’s too high.
ANDREW

Son, get in my coat pocket, grab that thing. That little reader thing… computer.

ANDY

Here dad, here’s your tester thingy.

ANDREW

Thank you, son.

(ANDREW tests his blood sugar.)

PEANUT

Ow. Eiewe blood. Doesn’t that hurt?

ANDREW

No. Nope. Not if your big and strong like me.

(ANDREW reaches in his pocket and gets out a little vial of vial of something. He eats it all.)

PEANUT

Flipper would like some of that.

ANDREW

Baby, Flipper is a rock.

PEANUT

I want some of that.

ANDREW

Oh no this stuff, this stuff tastes awful.
PEANUT

(Reading the vial.)

Lih koo id… glue kos. Liquid glue kos. What’s glue Kos?

ANDREW

It’s a glue that kosses.

PEANUT

Kosses?

ANDREW

Causes me to feel better. Liquid glue feel better. And since you feel fine you don’t need any.

PEANUT

Here dad, Flipper said he wants to help you. He’s okay with blood and he can make you feel better.

ANDREW

Thank you, Darlin’.

(Exit PEANUT)

ANDY

Is it okay dad?

ANDREW

A little prick never hurt nobody, right?
ANDY
Right.

ANDREW
Now get up on that there chair and let’s hang this thing.

(ANDY does.)

ANDY
Papaw goes away a lot.

ANDREW
Okay Flipper, time to go to work.

(ANDREW pounds the tack in with Flipper.)

ANDREW (Cont’d)
Catch this, son. Ready?

ANDY
Ready.

(ANDREW tosses Flipper to ANDY. ANDY drops it.)

ANDREW
I didn’t know I was throwing it to a girl.

ANDY
I didn’t know you was gonna throw it like a girl.
(There is a knock on the door.)

ANDY (Cont’d)

Got it.

(ANDY opens the door. It is PAPAW!)

PAPAW

Hey, boy. Good to see you.

ANDY

Papaw’s here!

(MARLENE and PEANUT come running in.)

MARLENE

Oh Papaw, you look good, real good. Your color looks good.

PAPAW

Color?

PEANUT

I missed you!

PAPAW

Hey, PP.

PEANUT

It’s Peanut, silly!

MARLENE

That banner was supposed to be hung up before he got here.
ANDREW

Sorry, hun.

MARLENE

Pop, you’re gonna have to go back outside. Go on now. Go. Peanut worked all morning’ on this.

PAPAW

We’ll it was nice seeing you all, enjoy dinner.

(Exit PAPAW. ANDY jumps up on the chair to hang up the other side.

He pounds the tack with Flipper.)

PEANUT


MARLENE

All right drama queen, he’s fine now. Everyone hide. We’re gonna surprise him. (They hide) Pop! You can come in!

(Enter PAPAW)

PAPAW

Hello? Anybody home? Hello! Where is everybody?

PEANUT

(Giggles)

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PAPAW

I guess there’s no one here.

ALL MINUS PAPAW

Surprise!

PAPAW

Aghhhh! Almost give me a heart attack.

PEANUT

Welcome back from the hospital, Papaw!

PAPAW

Good to be home, good to be home PP.

PEANUT

It’s Peaaaanut, sillllly.

MARLENE

Where’s Laura?

PAPAW

She had to pick up a late shift at the Grocer, so I took a taxi.

MARLENE

A taxi? They don’t drive out here.

PAPAW

I’m here aren’t I?
MARLENE
You should have called.

PAPAW
It wasn’t any big thing. I didn’t want to bother any of you about that.

MARLENE
How much did it cost?

PAPAW
No you never mind. I wasn’t gonna stay one more day in that sterile place. Nurses, the only medicine keeping me alive.

ANDY
Nurses?

MARLENE
Hush now, you dirty old man.

PAPAW

ANDY
Truth.

PEANUT
Why were you in the hospital Papaw?
PAPAW

Well, I have to tell you, I’ve never been so scared in all my life, Peanut. It was late at night, the stars were shining, everything was calm, calm like an unopened bottle of Kentucky straight bourbon--

MARLENE

Andrew Martin Myers Senior!

PAPAW

Hang on now. I said unopened! Opened may not be so calm.

PEANUT

Whiskey?

PAPAW

What I meant was if you don’t open a bottle everything is calm. So we were calm. I was calm that night.

PEANUT

Calm.

PAPAW

Then the bottle opened and I hear this roar, a roar that sends my blood a pumpin’, I look around: nothing. I call out, “I have a gun!”

ANDY

A gun?
“A gun.” Then: silence. (Pause) Wham! Like that I’m on the ground. I close my eyes because I’m not too sure I want to see what’s pawed me to the ground. I’m screaming, screaming like a baby.

ANDY

A baby.

PAPAW

Yup, a baby. I’m scared but I open my eyes…

PEANUT

You open your eyes…

ANDY

And…

PEANUT

Papaw?

PAPAW

I’m staring straight in the face of an Appalachian Black bear!

MARLENE

Bear? I’d better get back to the kitchen.

(Exit MARLENE.)

MARLENE

Andy Jr., let those kids yack at their papaw.
What did you do?

Help me with the table.

I laid on my back and prayed to god.

Get it set.

Prayed.

Lord, lord, lord.

(Exit ANDREW.)

Yes prayed. Then I found the strength to roll over. I got on top of him. And I’m beating him in the face with my fists see?

Did he bite?

Near took out my heart.
PEANUT

What happened next?

PAPAW

So my fist keeps coming down hard on his jaw and get this, Andy, I gave that bear a right hook he’ll never forget.

ANDY

Really?

PAPAW

Really. I near took off his jaw.

ANDY

His jaw?

PAPAW

Hit him so stinkin’ hard I saw one of his incisors

PEANUT

Incisor?

ANDY

A tooth.

PAPAW

A razor sharp pointy tooth. I saw one fly out of his mouth at the ‘lightning speed’ and imbed itself into a maple tree.

PEANUT

Into the tree?
Yeah it must’ve went in two or three inches, and sprung a leak. Syrup was spraying everywhere.

Bullshit.

That’s a mighty big word for a boy to use.

I call it as I see it. Trees don’t spray syrup. You think I’m stupid?

Sweetheart can you go find Papaw, go find him… find me something?

What do you need?

Nothing, he just wants to talk to me alone. Without you here.

Go find a place other than here for the moment.

See?

Okay, but Flipper’s gonna stay to make sure you don’t fight.
(PEANUT gives Flipper to PAPAW. She exits.)

PAPAW

You shouldn’t talk to me that way.

ANDY

Dad says liars go prison.

PAPAW

First things first, then when we get to the last I better here an apology pourin’ out of that mouth of yours. First, I’m not a liar. Peanut’s not ready to hear why I was in the hospital. Her little brain can’t handle that right now. Second that word you used doesn’t belong under the roof of this house. Third, it seems to me that you don’t understand the word respect and for recompense you best be singing a tune full of Sirs and Ma’ams when you address anyone over three feet tall in this household. Do you understand, boy?

ANDY

Yes sir.

PAPAW

That’s more like it.

ANDY

Sir? Why were you really in the hospital?

PAPAW

I just got bit by a little of the sugar, that’s all. Nothing I can’t handle.
ANDY

Yes sir.

PAPAW

Now I want you to sit here and compose an apology for that language you feel is appropriate. I want it written down on paper, and you will be reading it aloud in front of the whole family.

ANDY

Yes sir.

PAPAW

I’m gonna go check on supper and when I get back I expect words fit for Shakespeare.

ANDY

I’m on it.

PAPAW

Excuse me?

ANDY

I’m on it sir.

PAPAW

Thin ice I tell you, boy, thin ice.

(PAPAW sets down Flipper and exits. ANDY pushes Flipper onto the floor.)

ANDY

I’ll show you recompense. Sorry Flipper. What should I say in this note?
(ANDY starts writing a letter. Enter PEANUT with a bag and a Hammer.)

PEANUT
You’ll never guess what I found.

ANDY
I don’t care.

PEANUT
It’s really super dooper neat!

ANDY
Go away.

PEANUT
No look, there’s Doritos and Ding-dongs, I found some Hershey kisses!

ANDY
Woah! Where did you find all this stuff?

PEANUT
I went to the chicken coup to see the babies and Ben, because I thought Ben would be missin’ Jenna, So I thought it would be nice

ANDY
Hey PP get to the point.

PEANUT
My names not PP, dummy!
ANDY

You’re the dummy.

PEANUT

I’m gonna tell mom!

ANDY

Don’t be a baby. Just tell me where you got all this stuff.

PEANUT

No, I don’t think so. Not till you’re nice to me. I think I’ll keep this gold mine all to myself.

(ANDY grabs Flipper.)

ANDY

Hey, Flipper, Flipper? You ever wonder how it’d feel to be thrown in a washing machine?

PEANUT

Give him back.

ANDY

Swimming around in there, I bet your eyeballs would wash clean off. And your little stripes: gone down the drain--

PEANUT

You wouldn’t!

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ANDY

(In the voice of Darth Vader)

You’d have no mouth with which to scream!

PEANUT

You’re scaring him.

ANDY

(Mocking Flipper’s voice) No no no! (Mocking Flipper’s voice with no mouth screaming. Then evil villain laughter. ) Ha Ha Ha

PEANUT

No!

ANDY

Tell me.

PEANUT

I found it in the chicken coup in a barrel next to the seed. Daddy’s hammer was on top of it.

ANDY

Really?

PEANUT

Yes. Now give him back.
ANDY

Here.

PEANUT

It’s okay Flipper, he didn’t mean it. No washing machine for you.

ANDY

Look at all this stuff, Peanut!

PEANUT

I know it’s like Christmas! It’s like we got a whole junk food buffet in our back yard.

ANDY

Mom’d kill us if she knew we had this.

PEANUT

Do you want to share it with me?

ANDY

Heck yeah!

PEANUT

Where should we hide it?

(Enter ANDREW. He sees the sack of goodies and stands and watches in silence.)

ANDY

Well you know it’s Dad’s right?

PEANUT

What do you mean it’s Dad’s?
ANDY

Well he’s not suppose to eat this stuff.

PEANUT

He’s not?

ANDY

Kristy, Papaw wasn’t attacked by a bear.

PEANUT

Yes he was.

ANDY

No he wasn’t, he’s sick.

PEANUT

Sick.

ANDY

Really sick.

PEANUT

Is he gonna die?

ANDY

No, but someone is.

PEANUT

Someone? You mean like the wolf eating Jena?
ANDY

Yes.

PEANUT

Who? Who’s gonna die?

ANDY

You’re gonna die.

PEANUT

I’m dying?

ANDY

Yes. Yes you are.

PEANUT

How? Why? When?

ANDY

Well, Papaw has a thing called the sugar. And dad has it too, so you and I have it ‘cause as far as I can tell it’s passed through blood and we all have the same blood.

PEANUT

Dad is dying?

ANDY

No… see you have to be strong or you die and Papaw is strong and dad is strong and I am strong so we can handle it.

PEANUT

I’m strong.
ANDY

No, you’re a girl and girl’s aren’t strong.

PEANUT

I don’t want to die.

ANDREW

Enough of this, enough. No one’s dying, not now and not for a long time. Give me that bag of stuff.

PEANUT

Here daddy.

ANDY

Mom’s gonna kill you.

(Enter MARLENE and PAPAW.)

PAPAW

Andrew Martin Myers the third, do you have something to share with the family, something you want to read, boy?

ANDY

Yes sir.

PAPAW

Come on, Shakespeare.
ANDREW

*(ANDREW picks up Flipper.)*

I’ve been a bad parent, Flipper.

PAPAW

Son?

ANDREW

But I’m gonna get better.

MARLENE

Andrew Martin?

ANDREW

I have an apology to make.

ANDY

Run, Peanut.

PEANUT

Take cover.

MARLENE

Cover?

PEANUT

There’s gonna be blood. Don’t kill ‘em, momma.

MARLENE

No one’s killin’ anyone. Sit down, you two. What’s this about *(To Andrew)* Andy?
ANDREW

I killed Jenna, and the chicks because I let the wolf in the pen.

PEANUT

What?

ANDREW

Son, I’m sorry I accused you. I forgot, I went out to fix the pen and by fixing pen that means going out to my stash and eating things that I shouldn’t be eating.

MARLENE

Andrew Martin Myers Junior, what are you talking about?

ANDY

Run! Save yourself!

MARLENE

Quiet, now.

ANDREW

We don’t run from things in this house, son. We own up.

PAPAW

 Discipline.

MARLENE

Start talking.

ANDREW

I’ve been sneaking a sugar fix out in the pen… and I went a bit overboard, been goin’ overboard for a while. So I thought that if I skipped out a little on other things, bein’
lunch-- I know, I know…I thought the weight gain would be so noticeable. I want to apologize to this whole household and I’m handing this over to you, Marlene.

(Gives the bag to MARLENE.)

MARLENE

So you’ve been eating foods that are high in sugar-- the bad carbs-- so you wouldn’t gain weight-- so you wouldn’t get caught? Then you would starve yourself the rest the day? Baby, your sugar level must be bouncin’ all over the place. Is it low now?

ANDREW

No… I just-- just a little bit go got it set right.

MARLENE

I try so hard to regulate this family. Keep us eating at precisely the same time. So that your blood levels have the best chance at stayin’ normal. Then you go and do this? I should tack you to the wall.

ANDREW

Tack me. If that helps me get through this. Do it. Here’s my hands. I can’t handle this sugar thing by myself. I need all of you to be strong, so I can be strong. I screwed up big time. I’ll go to hell before I’m gonna pass this disease onto my kids.

PAPAW

What are you sayin’, boy?

ANDREW

Nothin’ sir.
PAPAW

You sayin’ you’re sick, ‘cause of me? That what you’ sayin’?

ANDREW

No sir. I make my own choices.

PAPAW

Gosh darnit. Andy… go to my coat.

ANDY

Papaw?

PAPAW

My coat. Go. Go get it.

(ANDY gets PAPAW’S coat. And Hands it to him.)

PAPAW

Give it to Peanut.

ANDY

Here, sis.

MARLENE

What is this about?

PAPAW

Life.
PEANUT

Papaw?

PAPAW

Left coat pocket, inside.

PEANUT

What’s in here?

(PEANUT pulls out a bottle of Bourbon.)

MARLENE

Took a taxi huh? Made sure he made a pit stop. That’s an expensive drink.

PAPAW

Marlene…

MARLENE

Peanut, honey, go to your room.

PEANUT

Momma, I don’t wanna--

ANDREW

This is adult stuff. Go on now.

(PEANUT goes to leave.)

PAPAW

Hold on Andrew, she needs to see this. Come here, Kristy.
(PAPAW holds PEANUT as he talks.)

PAPAW (Cont’d)

Look at that, take a close look.

PEANUT

What is it?

PAPAW

Read it.

PEANUT

Bow er bon bowerbon. Bowerbin Bourbon. Like the bear from your story.

PAPAW

Sugar, pure sugar, and it’s doin more-- done more than rot my teeth. Much more.

Marlene can you dump that out?

MARLENE

Sure, I can do that. Dump it out.

PAPAW

Thank you.

MARLENE

We’ll get through this.

ANDREW

Any rabbits here want to join their dad in a meal?
PEANUT

Flipper’s ready to eat!

ANDY

Hold on, I still have to address the family.

PAPAW

Well, Shakespeare?

(ANDY pulls out his apology out of his pocket and clears his throat.)

ANDY

Achhem. Ladies and Gentleman of the Myers’ Court… Achhem.

MARLENE

Go on now

ANDY

… I am very disappointed in my behavior towards my elders and I’m sorry to say, I allowed pollutant sounds to fall out of my mouth.

PAPAW

You bein’ smart?

ANDY

No sir, just sorry. So sirs and Ma’ams and Peanut-- Kristies please forgive me.

PAPAW

That’s more like it.

ANDREW

Let me see your rabbit faces!
(Everyone scrunches their nose like a rabbit.)

ANDREW (Cont’d)

To the kitchen!

(They exit like rabbits to the kitchen.)
Appendix C: Open-ended Questionnaire

Explanation of Study

The purpose of this study is to determine your interpretation of the messages within the play(s), “Sugar Bear,” and/or “Lucille”. Please fill in the answers to these questions and place them in the box made available. If you cannot participate in the discussion, please return this form before you leave.

Age: _____________ Sex: Male: _______ Female: ____________________

Marital Status (Check one that best describes you):

Single: _________
Not married and with a partner for under 6 months _______________
Not married and with a partner between 6 months and 1 year _______________
Not married and with a partner between 1 year and 2 years _______________
Not married and with a partner for more than 2 years _______________

Married: __________

Divorced: __________

Ethnicity (Check one that best describes you):

African __________
Caucasian __________
Asian __________
Hispanic __________
Native American __________
Other __________

County of Residence: ____________________
1. What were some of the messages that you heard in the play?

2. How can family members help someone with diabetes?
3. When you hear the word ‘diabetes’ what comes to your mind?

4. What are some of the challenges of having diabetes in Appalachia?
Appendix D: In-depth Interview Protocol

1. What does diabetes mean to you?
2. What were some of the messages you recall now, since it has been some time since you saw the plays?
3. What characters most likely represented your life experiences with diabetes?
4. What role does your family play as you manage your diabetes?
5. What did you think about the role of women in the plays? How true was this depictive of the roles women play in families with illness?
6. What stories in your own personal life do these plays remind you of?
7. How do you deal with diabetes in your life?
8. What do you think persons need to know about diabetes in Appalachia?
9. How do people talk about diabetes in Appalachia?
10. Why was there a message of doom and gloom associated with the plays?
11. What are some of the challenges to being a person with diabetes in Appalachia?
12. What did you think about the use of humor in the plays? Was it effective, risky, or did it trivialize the topic of diabetes?
13. Do you think the plays were culturally relevant? What qualities caused it to be culturally relevant or not culturally relevant?
14. Do you think the plays could be performed in other areas and what would cause this to occur effectively or ineffectively?