EXPLORING DIABETES MANAGEMENT OF LOW-INCOME, TYPE 2 DIABETICS

USING A COMMUNICATION PERSPECTIVE

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In this exploratory, qualitative study, the author examined the lived experiences of low-income type 2 diabetics around managing their diabetes. Semi-structured, individual interviews were conducted with volunteer participants from a Midwest student outreach clinic (N=14; 8 men, 6 women). Interviews were first analyzed using LUUUUTT model from the Coordinated Management of Meaning (CMM) theory for gaps between stories lived and stories told. Findings suggest that the lived experience of the majority of the participants had low social support and heightened stress around managing their diabetes. Using the Communication Complex framework, the patterns of interactions around these two tensions were analyzed to make suggestions for change.

John Parrish-Sprowl, Ph.D., Chair
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Introduction

The chronic illness of type 2 diabetes has been a growing concern in the United States for decades. Since 1980, the estimated number of people in the United States diagnosed with diabetes (types 1 and 2) quadrupled to 22 million people in 2014, with type 2 diabetes accounting for about 90% to 95% of all diagnosed cases (CDC, 2014).

While these numbers are daunting, a recent study that examined the long-term trends in the prevalence and incidence of diagnosed diabetes in the United States found that incidence and prevalence of diabetes plateaued for the general population between 2008 and 2012 which indicates a slowing of the epidemic. However, the study found that incidence increased for the subgroups non-Hispanic black and Hispanic subpopulations, and prevalence increased for those with a high school education or less during that same period (Geiss, Wang, Cheng, Thompson, Barker, Li, Albright, & Gregg, 2014). These findings indicate a potential growth of racial/ethnic and socioeconomic health disparities in diabetes. Since the CDC diabetes data is not collected based on income, the designated education level of “high school education or less” is commonly considered to represent people in lower socioeconomic status (SES).

In addition to the increase in the prevalence of diabetes, research has found sharp differences in health outcomes for diabetics in lower socioeconomic status. In particular, lower SES groups have more diabetes-related complications and higher diabetes-related mortality compared to diabetic patients in higher SES groups (Robinson, Lloyd, & Stevens, 1998). Having less than a high school education was associated with a twofold higher mortality from diabetes, compared with adults with a college degree or higher education level (Saydah & Lochner, 2010). And, having a family income below poverty
level was associated with a twofold higher mortality after adjustments compared with adults with the highest family income (Saydah & Lochner, 2010).

To date there is no cure for type 2 diabetes but it can be controlled by keeping blood glucose levels as near to normal as possible by balancing food intake with medication and exercise (The Cleveland Clinic, 2015). To achieve this though, requires those living with diabetes to self-manage and self-monitor their health for years or decades. In addition to the high level of self-management, diabetes places a large, long-term financial burden on individuals affected. People diagnosed with diabetes incur about $13,700 per year, which is 2.3 times higher than people not diagnosed with diabetes (ADA, 2013). For people diagnosed with diabetes and under-resourced, this level of self-care may be difficult to attain.

A recent systematic review of studies regarding low SES and type 2 diabetes found that “patients living in deprived areas less often achieve glycemic control targets, tend to have higher blood pressure (BP), and worse lipid profile control” (Grintsova, Maier, & Mielck, 2014, p. 1).

Low SES populations do not have the same resources as the general population to make the changes current diabetes treatment asks of them (i.e. spending more money for special dietary items or safe neighborhoods in which to exercise), so for health outcomes to improve getting a better understanding of the social worlds of low-income, type 2 diabetics may help identify potential areas of change. One way to accomplish this is to take a communication perspective and examine the tensions and patterns of interaction for insights into the current situation.
This type of approach fits within the examination of nonmedical factors that contribute to health disparities or what has become known as social determinants of health. Over the last decade, there has been an increased acceptance of the idea that social determinants of health or that the social, economic, and environmental aspects of a person’s life affects their health.

In light of the increased prevalence and noted health disparities for diabetics in poverty, this communication study interviewed low-income, type 2 diabetics about managing their diabetes and examined these conversations for communication tensions and patterns of interaction. By collecting and analyzing participants’ stories, I hope to gain a better picture of their social worlds and lived experiences but also what the findings might reveal in terms of nonmedical factors that hinder successful management of their diabetes. Ultimately this study is designed to contribute to the field of research that examines the effects of nonmedical factors on health disparity. The information gathered may help inform medical interactions with a low SES population or contribute ideas for population specific diabetic treatment programs.
Literature Review

Health disparity and social determinants of health

Social determinants of health concentrate on the social and economic conditions in which people live that influence individual or group health status. While there is not one definition of SDOH used by all nations, the U.S. Centers for Disease Control & Prevention define social determinants of health as, “life-enhancing resources, such as food supply, housing, economic and social relationships, transportation, education, and health care, whose distribution across populations effectively determines length and quality of life” (Brennan Ramirez, Baker & Metzler, 2008, p. 6).

The SDOH concept gathered momentum from the efforts of the World Health Organization (WHO) when in 2005 it launched a Commission on Social Determinants of Health. In its effort to fill out the SDOH concept, the WHO investigated the pathways between social conditions and health outcomes and found that perceptions and experiences of individuals — material factors, psychosocial factors, behavioral/biological factors and the health system — influenced health (Solar, 2010). These findings were added to a conceptual framework created by Brown, Ettner, Piette, Weinberger, Gregg, Shapiro, Karter, Safford, Waitzfelder, Prata, & Beckles (2004) that connected socioeconomic factors to health outcomes of individuals with diabetes. Indeed, SDOH grew in importance and in 2010 the U.S. Department of Health & Human Services made SDOH one of the four overarching goals in its most recent 10-year national health objective plan, Healthy People 2020, which reads, “Create social and physical environments that promote good health for all” (USDHHS, 2010).
Today many studies exist examining the links between SDOH and diabetes. In fact research suggests that the social and economic conditions that influence health are the reason for the lack of change in diabetes outcomes at the population level (Whiting, 2010; Walker, Gebregziabher, Martin-Harris, & Egede, 2014). The findings of Walker et al., (2014) validated the SDOH conceptual framework and lent support for clinicians to take SDOH factors into consideration during care of patients with type 2 diabetes. While the study found direct association of employment and income on health outcomes, it also found that social support had a significant indirect effect on glycemic control (Walker et al., 2014).

Walker, Gebregziabher, Martin-Harris, & Egede furthered the research on SDOH and diabetes self-care in their 2015 study that examined the latent SDOH variables of psychological distress, self-efficacy, social support and social status, and their influence on diabetes self-care. The study found that psychosocial factors are more strongly associated with self-care than social status; that psychosocial factors should not be lumped into one group but separated into psychological distress, social support, and self-efficacy; and that better self-care is associated with lower psychological distress, higher social support, and higher self-efficacy (Walker et al., 2015).

Many other empirical studies help create a fuller picture of the nonmedical factors that contribute to the health disparities of socioeconomically disadvantaged type 2 diabetics. Studies have found that socioeconomic disparities in diabetes outcomes are comprised of a lack of access to health care due to lack of insurance, low income, limited education, and lack of transportation (Harris, 2001; McBean, Huang, Virnig, Lurie, & Musgrave, 2003; Brown et al., 2004; Heisler, Faul, Hayward, Langa, Blaum, & Weir,
2007). Even when socioeconomic disadvantaged people can access health care, it has been found that they still experience poorer health outcomes (Karter, Ferrara, Liu, Moffet, Ackerson, Selby, 2002; Trinacty, Adams, Soumerai, Zhang, Meigs, Piette, & Ross-Degnan, 2007). Studies suggest poorer health outcomes for low SES diabetics are likely due to not following the recommended care in a clinical setting and poor individual health behaviors in daily life (Brown et al., 2004; Tseng, Tierney, Gerzoff, Dudley, Waitzfelder, Ackermann, & Chung, 2008; Moskowitz and Bodenheimer, 2011). And while having access to health care and health insurance helps eliminate some health disparities, research shows that low income diabetics still face significant financial pressures that contribute to poorer health outcomes (Ngo-Metzger, Sorkin, Billimek, Greenfield, & Kaplan, 2012).

A study examining neighborhood safety found that type 2 diabetics living in non-safe neighborhoods delayed filling prescriptions for any reason and due to cost (Billimek & Sorkin, 2012a). Food insecurity was also found to increase delays in filling prescriptions but not affect following recommended self-care (Billimek & Sorkin, 2012b). And finally, adult diabetics who were food insufficient were more likely to report fair or poor health status and had more physician encounters than those who were not (Nelson, Cunningham, Andersen, Harrison, & Gelberg, 2001).

**Social Support**

In terms of social resources, the findings of Walker et al., (2015) support earlier studies which found social support as one of the most important and positively influential factors on diabetes management and enhanced quality of life (Pham, Fortin, & Thibuadeau, 1996; Tang, Brown, Funnell, & Anderson, 2008; van Dam, van der Horst,
Knoops, Ryckman, Crebolder, & van den Borne, 2005). Social support is also beneficial in accepting a diagnosis, adjusting emotionally, and decreasing stress (Zhang, Norris, Gregg, Beckles, 2007; Sacco & Yanover, 2006). Non-supportive behavior was associated with less-adherence to diabetes medication regimen (Mayberry & Osborn, 2012) and non-supportive behavior of family members was found to be more harmful for type 2 diabetes adults with low health literacy (Mayberry, Rothman, & Osborn, 2014). A study reviewing the empirical literature that examined social support and chronic illness found that an individual’s social network highly influenced their dietary behavior and had the potential to negatively influence their self-management (Gallant, 2003). More recently, a systematic review of 37 articles examining the impact social support has on health outcomes of adults with type 2 diabetes found that the majority of adults within the studies experienced improved clinical outcomes, decreased mortality, and increased mental stability, regardless of race or ethnicity (Strom & Egede, 2012).

**Stress**

A deeper understanding of stress, poverty, and diabetes/chronic illness has grown over the past decade. An article examining the data from four large epidemiological studies on psychological, social, and behavioral factors on disease risk, found that the greatest risk of poor mental and physical health are seen by those who experience sustained economic hardship overtime (Everson, Maty, Lynch, & Kaplan, 2002). People who experienced chronic stress (multiple and ongoing physical and psychosocial stressors brought on by poverty pressures) throughout childhood have been found to have higher rates of morbidity and mortality from chronic diseases (Cohen, Janicki-Deverts, Chen, & Matthews, 2010; Evans & Kim, 2012; Miller, Chen, & Parker, 2011). In
addition, an accumulation of stressors in adults was found to limit adherence to treatment for high-risk populations with type 2 diabetes (Osborn, Mayberry, Wagner, & Welch, 2014).

In recent years, a deeper understanding of the neurobiological pathways that link stress and health in the context of SES has been presented. Multiple stressors found in low SES environments during development and aging influence the structure and functions of the hippocampus, amygdala, and prefrontal cortex (neuroplasticity). Changes in a brain’s neuroplasticity affect coping, expression of emotions, reactions to stress, and recovery (McEwen, 2007; McEwen & Gianaros, 2010). The good news is that change in neuroplasticity is not permanent and can be adjusted by reducing the burden of chronic stress and increasing stress resiliency and health through pharmaceutical drugs, social and behavioral interventions such as physical activity and social support (McEwen, 2007).

A study examining alleviation of stress found that type 2 diabetics who received psychological interventions were more likely to show improvements in glycemic control and psychological distress (Ismail, Wikley, & Rabe-Hesketh, 2004).

Communication and Diabetes

While there is a large number of communication studies examining chronic illness, communication studies examining diabetes is a relatively small but growing subset. The studies presented here do not cover the breadth of topics that exist but are selected for their relevance to the subject of this study.

Social support in the context of health has been researched by communication scholars since the 1980s but very few communication studies examine it in the context of diabetes. Drummond (2005) using a message-centered approach to examine how social
support is verbally enacted for women living with type 2 diabetes, identified five speech acts of social support — deterrence, indifference, encouragement, compliment, and temptation — that form the basis of perceived support and nonsupport for participants who attempt to follow a self-care regimen. In a study examining the diabetic patient’s perspective, diabetics clearly reported that their families both helped and hindered their attempts to self-manage their disease and their interactions with their physician (Burke, Earley, Dixon, Wilke, & Puczynski, 2006). Examining spousal support, type 2 diabetics who held greater expectation of their spouse being involved with diabetes management (particularly females) generally reacted less negatively to spousal control (Rook, August, Stephens, & Franks, 2011). Also, findings suggest that the stress of patients' disease and distress affects both the patients and their partners on a daily basis (Iida, Stephens, Franks, Rook, 2013).

Communication studies examining sociocultural influences of health outcomes of diabetics, contributed to the larger picture of diabetes self-care. For rural Hispanic Americans with type 2 diabetes, researchers found three sociocultural concerns that influence their self-care — the importance of parents and family; a culturally-based diet and a mainstream fast food culture that challenge healthy eating; and a lack of support from the larger sociocultural networks such as teachers, community leaders, and the media (Heuman, Scholl, & Wilkinson, 2013). Another study about families living in rural Appalachian areas with intergenerational diabetes, used an interpretive study of meaning-making and found that family members inherit and re-story their family’s health legacy and this affects the health outcome not only of the current generation but also future generations (Manoogian, Harter, & Denham, 2010). And a study examining the
conversations between African American mothers with type 2 diabetes and their adult daughters revealed three conversational themes — talking about diabetes among their families, personal experiences of living with diabetes, and prevention (Cooke-Jackson, 2011).

Uncertainty management for diabetics has also been examined through communication studies. Using a grounded theory approach, one study examined the narratives of diabetics facing long-term complications and found the main themes of ‘coming to terms’, ‘keeping going’ and ‘making sense’ (Ternulf Nyhlin, 1990). A meta-synthesis examination of previous qualitative studies of diabetic patients’ experience, suggest that the existing models of uncertainty management may need to be extended to include guilt and maintenance of health and identity (Vevea & Miller, 2010). While a more recent study examining the source of the uncertainties for type 2 diabetics, found medical, personal, and social sources of uncertainty that included perceived personal stigma and financial concerns (Middleton, LaVoie, & Brown, 2012).

As far as communication research that focused on low-income, type 2 diabetics, I found only one study and this looked at the association between health literacy and health outcomes. The study conducted by Al Sayah, Majumdar, Egede, & Johnson (2015) found no association between health literacy and health outcomes in a predominantly low-income, African American population with type 2 diabetes. So while communication research on diabetes is growing, to my knowledge no study uses a communication perspective to examine the lived experiences of low-income type 2 diabetics around managing their diabetes.
Theoretical Orientation

This study uses coordinated management of meaning theory (CMM) and the communication complex (ComComplex) framework to understand participants’ lived experiences around managing their diabetes.

Both CMM and ComComplex take a social constructionist view in which we create the lives we live — our social reality and our relationships — through the conversations we have. That is, it is through conversations that we story our world to manage meaning and coordinate our actions with others (Pearce, 2007). CMM calls this the communication perspective, which means relationships, events, and objects are made in the process of communication. That is not to say that events and objects are only created by patterns of communication, but that we see them as textures of communication. In this context, CMM views organizations, persons, families, and nations as clusters of people in conversation (Pearce, 2001). The implication being that the quality of our social worlds reflects the quality of our conversations and that every moment is a creative act in which we make something that never existed before (Pearce, 2001). To apply the communication perspective, CMM focuses on three aspects of our social interactions — coordination, coherence, and mystery.

Coordination focuses on how our actions mesh or are coordinated with others to get through the day to create patterns of communication. These patterns make up the events and objects in our social world (Pearce, 2001).

The coherence of the stories we tell helps us make meaning of our lives. CMM suggests that the stories we live and the stories we tell are not always consistent and this creates the tension that creates the richness of our lives. But when the gap between the
stories we live and the stories we tell is significant, we are forced either to re-story our lives or change our actions to lessen the tension (Pearce, 2001).

And finally, how we acknowledge the *mystery* of our world informs our outlook. Mystery acknowledges that our world changes by our actions, the stories we tell, and how we act into it. Mystery acknowledges that any number of possibilities could have happened in any situation. So why did people make this particular situation? (Pearce, 2001).

Ultimately CMM seeks to answer the question, “What are we making together?” (Pearce, 2001, p. 8).

Both CMM and ComComplex recognize the need to move from a simplistic, message-based view of communication to one that is more complex. However, ComComplex extends CMM and incorporates the complexity of recent research of interpersonal neurobiology (IPNB) and provides an applied communication approach that supports intentional social transformation (Parrish-Sprowl, 2014a).

Communication complex, drawing on CMM and IPNB, is framed by *process*, *patterns*, and *perturbations*. In ComComplex, communication is a non-stop process that is always in motion and can change at any moment. Communication, like our thoughts, can twist and turn and be influenced by current or past conversations that both shape and are shaped by our actions and actions of others (Parrish-Sprowl, 2014b). That is, ComComplex focuses on the notion that we live “in” communication with others and takes a more social view of the individual experience (Parrish-Sprowl & Parrish-Sprowl, 2014). This draws on the research in neuroscience that suggests that cognitive processes
emerge from the coordinated action of people (Hassan, Ghazanfar, Galantucci, Garrod, & Keysers, 2012).

The second framework of ComComplex is our patterns of interaction. Our brains develop patterns of neural firings based on the patterns of interactions we experience with others or in other words, there is a reciprocal relationship between the mind, brain, and relationships (Porges, 2011; Siegel, 2012). This means that our patterns of interactions shape who we are as individuals – how we react to stress, how we express ourselves, or how we engage with the world. This implies that the quality of our relationships is constructed from our patterns of interaction (Parrish-Sprowl, 2014b).

And finally, altering one’s communication, changes one’s patterns of interactions. By changing a pattern of interaction or perturbing it, people can change the quality of their relationships overtime. Changing the trajectory of a conversation, changes the pattern of interaction which changes the neural firings in the brain which changes the behavior of the person. Communication Complex calls this perturbation or perturbing the communication pattern (Parrish-Sprowl, 2014b). By engaging in new patterns of communication, change can occur.

To apply these ideas, CMM provides several analytical tools to identify the social worlds people create in conversation. One tool, named by its substantial acronym, is the LUUUUUTT model (stories Lived, Unknown stories, Untold stories, Unheard stories, Untellable stories, story Telling and stories Told). The LUUUUUTT model provides a deeper understanding of the social worlds people create through their conversation by exploring the multiple stories that coexist at the same time. These multiple stories “influence how one responds to others and how others understand those responses”
(Creede, Fisher-Yoshida, & Gallegos, 2012, p. 33). LUUUUTT brings particular focus to the tensions that exists between the stories Lived and the stories Told. That is, the tension found between what we do in coordination with others (stories lived/coordination) and how we make meaning of the lives lived (stories told/coherence). According to CMM, it is this tension that drives the development of our relationships and if the gap between stories Lived and stories Told gets too great, a person will re-author or change their actions to lessen the tension (Pearce, 2007). LUUUUTT also sheds light on less obvious stories – Untold stories, Unknown stories, Unheard stories, Untellable stories, and story-Telling – which enlarges our understanding of the social world created by a person’s conversations. (Griffin, 2014).

Using this approach to analyze the data will reveal the tensions individually and if in common with others, help explain how low-income, type 2 diabetics manage the meaning of their chronic illness with their social network and how they coordinate their actions with others around their diabetes. Identifying the patterns of interaction with ComComplex will also suggests ways to perturb the situation in hopes of changing health outcomes. Through this process-oriented framework, I hope to better understand the lived experiences of low-income, type 2 diabetics and discover what, if any ways there are to change health outcomes.

**Research Questions**

Given recent research validates the importance of SDOH on diabetes self-care, and that low-income, type 2 diabetics experience greater prevalence and have worse health outcomes than diabetics in higher SES groups, this study seeks to answer through one-on-one interviews the following research questions:
RQ1: What tensions and patterns of interaction exist in low-income, type 2 diabetes’ conversations about managing their diabetes?

RQ2: Given the patterns of interactions found, how can we perturb the patterns to create new health outcomes?
Methodology

The study was conducted in a Midwest urban city in the United States at a student outreach, free health clinic. It consisted of one-on-one interviews with the clinic’s patients who were diagnosed with type 2 diabetes and who agreed to participate. The student-run health clinic serves a neighborhood where 50% of the residents live at or below the poverty level (IU-SOC, 2013). Because the clinic only sees patients that do not have health insurance, it ensured all participants were in a low SES population. In 2013 the majority of the clinic’s patients (over 65%) had been diagnosed with a chronic illness that was managed by the clinic. Diabetes Mellitus was the second highest chronic disease that the clinic treats and in 2013 made up 19.4% of the chronic illnesses treated. (IU-SOC, 2013). Looking more closely into the prevalence of diabetes in the area, Table A1 shows that the statistics of the clinic’s zip code is consistently higher than compared to that of the county, state, and national statistics (see Appendix A).

The clinic is open only on Saturdays and clients are seen on a first-come, first-serve basis. Because of this, patients experience long waits — up to two hours to see a doctor, as well as additional time waiting for prescriptions to be filled — and in these windows of downtime the interviews were conducted.

Participants for the study were recruited with the help of the clinic’s check-in staff. The clinic staff identified the type 2 diabetic patients in the waiting area to me. I then asked the patients if they would consider being interviewed while they waited to see their doctor. The staff held the patient's spot in line during the interview and agreed to notify the patient if we were still in the interview when the patient was called to see the doctor. No interviews were interrupted throughout the data collection period.
The interviews were held in private rooms throughout the clinic. Before starting the interview, I explained the study verbally in more detail as well as provided the participant the IRB study information sheet. If the participant had no more questions and verbally agreed to continue, the interview proceeded and was digitally recorded. The study was approved by the university’s institutional review board and granted exempt status.

The data was collected over four consecutive Saturdays with 16 interviews conducted. Two interviews were not included because one person was pre-diabetic and the other was a family member of a type 2 diabetic but not diabetic herself. The final data sample consisted of 14 adults (over the age of 18) who had been diagnosed with type 2 diabetes. Participation in the study was limited to those who spoke English. Participants were not paid for participating. Of the 14 interviews, 8 were male and 6 were females — 9 Caucasian (64.3%), 3 African-American (21.4%) and 2 immigrants (14.3%) — one Hispanic and one Eastern European. The clinic’s patient demographics broke down as follows: 48.7% Caucasian, 37.3% African Americans, and 6.5% Hispanic.

The study used an exploratory, qualitative approach and conducted semi-structured individual interviews lasting around 30 minutes each. The following questions framed the interview:

- Can you recall any conversations you had with family, friends, or coworkers about your diabetes?
- What do family or friends say to you about your diabetes?
- Do you avoid talking about your diabetes with family or friends?
- What do you like to tell people about your diabetes?
• What do you not like to tell people about your diabetes?
• Can you recall when someone said something that was not helpful to you when you were trying to manage your diabetes?
• Has diabetes changed your relationships with family and friends? How?
• What is the hardest part of managing your diabetes?
• How do you feel you are doing with managing your diabetes?
• Does anyone help you manage your diabetes?
• Where or from whom did you learn the most about managing your diabetes?
• Since being diagnosed with diabetes, what is the biggest change in your relationships that you have experienced?
• Is there anything about your diabetes that you need help with? (i.e., taking your medicines regularly, understanding medical instructions, questions about type 2 diabetes?)

Other follow up questions were asked depending on the answers to the questions and how the conversation developed.

Interviews were recorded and transcribed verbatim by the interviewer.

Throughout the entire process identities of the participants were never collected. If identities were revealed through the course of the interview, the participant’s identity was removed from the transcript.

Methods of Analysis

Participants’ stories were analyzed using CMM’s LUUUUTT model. After reading and rereading each transcript, five themes that the conversations broke into were identified. These themes were diabetes, family, diet, stress, and other relations. For each
interview, a spreadsheet was created with the column headings being the thematic categories and the row headings being the seven types of stories identified in the LUUUUTT model – stories Lived, Unknown stories, Untold stories, Unheard stories, Untellable stories, story Telling and stories Told. (See Appendix B.) As mentioned earlier, using the LUUUUTT model helps explore the multiple stories that coexist at the same time and examines the tensions that exists between the stories lived (what we do in coordination with others) and the stories told (how we make meaning of the lives lived) (Pearce, 2007). If there exists a significant gap between stories lived and stories told, this identifies areas of high tension in the participant’s social world and a potential area for change. After completing a spreadsheet for each interview tensions with the greatest gap were identified. The tensions centered on social support, stress, and societal systems. Next, using ComComplex’s second framework, the patterns of interaction were examined for what they revealed about the quality of relations exhibited and if they suggested potential ways to change or perturb the patterns of interaction.
Results

Social support

While the majority of the people I interviewed spoke of managing their diabetes by themselves and receiving no support other than the medical staff, the participants revealed a tension around social support. This tension was revealed when talking about managing their diabetes. What they said was they manage by themselves or they didn’t need any help (stories told) and yet later reveal they don’t have anyone they can rely on or they live in a non-supportive environment often with other diabetics (stories lived).

One woman when asked if anyone helped her manage her disease said, “No (laughter). No one holds my hand because I’m supposed to be the strong one. Every Sunday I put all our little diabetes medicine in our little pill things for all three of us.” But later in the interview reveals in answering if she could recall a time when someone said something that helped her with her diabetes…

As far as family, most of them have diabetes as well, so they understand and at the same time share the same root cause of the improper choices for food. So that’s no good. Same thing in my adult household too. So, not really, no.

Further into the interview it is revealed that she lives with an alcoholic husband and a verbally abusive housemate who both have diabetes.

And so what happens is when I have… and I live with an alcoholic, I live with a verbal… a different person that is verbally abusive, um, not always, but you just never know (mumble; can’t decipher) so there’s a lot of eggs, walking on eggs you know, kind of thing. So there is a lot of, um, when that pressure gets high then I go for the comfort foods you know. So from the comfort food, my blood sugar goes up, which makes me depressed, which makes the bipolar worst, which makes me eat… I mean it just keeps going around in a vicious circle.
Replied to the same question (to recall when someone said something that helped them manage their diabetes), another woman who had been living with diabetes for 15 years said, “Um other than when I first got diagnosed they showed me how to do it, other than that I’ve been on my own pretty much.” She reveals near the end of the interview that she’s concerned for her granddaughter developing diabetes since she and others in her family have diabetes.

See my nieces and nephews they got it so bad that a couple of them went into diabetic comas and not eaten. They get up and run, run, run, and they don’t eat a breakfast and a little lunch, and … (mumbles/can’t decipher) … they really don’t take care of themselves.

Another person when asked if he had anyone helping him manage his diabetes said, “Well I stay with a couple and take care of their house and property and I cook for them and they help out.” He then reveals that they too have diabetes so I asked how he felt he compared with them in managing his diabetes. His reply revealed a very unsupportive environment.

Well the woman, she was doing better than me but she’s slacked off on doing better and does a fair amount of sweets and it makes it harder for me (laughter). You know. Her husband he’s always been really bad. He does drinking behind her back and stuff like that. She lost her sense of smell as a young teenager so she can’t smell it.

Another example is from an interview with an older man when asked if anyone helps him manage his diabetes replies… “No, no. I stay with my ex and she got the diabetes. She manages it in her way and I manage it in my way and that’s how it works.” Then when asked if he ever talks with his family about his diabetes he responds, “Yeah, they know but we don’t get along. My family we kill themselves — we don’t want to see each other.”
One woman, when asked if anyone helped her manage her diabetes, replied, “I don’t really need nobody to remind me to do stuff. I’m pretty good if my mind is not too busy.” When asked if she ever talk about her diabetes with family and friends said, “I don’t talk to [my children] because they have their own stuff they’re working on. They know that I have diabetes but I don’t bug them [about it].” Then later when asked if she ever avoided talking about her diabetes with family or friends replied,

I don’t have very many friends. I’ve been away from friends for a long time. I didn’t have time for friends for over 18 years. I was either working or driving the kids somewhere. I didn’t have nobody at all. It’s been real hard for me to get back the social life. I’m still struggling because I don’t trust very many people.

In each of these, the stories told were of independence and control, while the stories lived revealed an unsupportive or a complete lack of communication with others about their diabetes.

On the flip side, one interview revealed an example of how a supportive environment produced positive diabetes management. This interviewee was diagnosed with type 2 diabetes in 2013 and lives with his girlfriend who has had diabetes for about 20 years. When asked if anyone helps him manage his diabetes he replied that his girlfriend does.

She tells me the risks. What to eat and what not to, the sugar, and different things like that. What can trigger it or what makes your sugar get too low and the affects of it all. She’s told me a whole lot, a whole lot.

As the interview continues he reveals they work together on their diabetes and that since being diagnosed he has already quit smoking and drinking and summarizes his experience with diabetes saying, “Diabetes helped me.” This is a stark contrast from people who are not in supportive conversational environments.
Stress

Indeed non-supportive environments increase stress for individuals; however, the stress I highlight here is produced from a lack of funds to support proper diabetes management. Conversationally, the tension arises from knowing what they need to do in order to manage their diabetes (stories told) and being unable to afford items such as food, medicine, blood sugar test strips, or insulin as well as the health outcomes that result from not having these resources (stories lived).

In asking an interviewee what he was doing to manage his diabetes he replied, “Well it’s pretty hard the less money you have to keep it at a reasonable level. Cause everything that is good for diabetes is expensive.” He continued, “The more vegetables you eat and all that kind of stuff you eat, the better off you are.” When asked how he felt he was doing managing his diabetes he said, “Well for the type of foods I have to eat, fairly good. … I’m on the strongest pills you can take.” Through other comments he made it was clear he knows what he should be doing but could not take the actions that proper management requires due to lack of funds.

“Well the hardest part about [managing diabetes] is having test strips to be able to test my sugar level. Very rarely do they have strips here… [and] the meter I’ve had for quite a while you know, to buy them, the cheapest place I know of is $98 for 50 strips.”

Another person related conversation with a friend who had emphasized that he had to “get his diabetes under control.” In response the interviewee said, “It’s kind of hard to when you have to eat certain things and you’re getting 90-95% of all your food from a food pantry. You don’t have that option. That’s kind of where I’m sitting.” This particular person acknowledged taking his medicine regularly spoke about blood sugar
levels. “I never know my blood sugars. Can’t afford the test strips. I can pretty much tell how I’m feeling because I’ve been a diabetic for so long.”

Another woman expressed the desire to eat the healthy foods she prefers but can’t afford to do so.

You know once in a while I need a little iron but other than that I don’t eat meat. My favorite things to eat when I’m home is (inaudible) or fresh fruit, orange juice and like that. But it’s hard to afford them. When I have the luxury to buy them I notice my grocery bill a little too high. …

Moments later in the interview when asked if there’s anything about her diabetes she needs help with, she explains why she is at the clinic that day…

My thing broke (she shows me her meter)… that’s why I came here today. It’s not working no more. It’s been about three weeks since I did my reading. Everything broke. I struggle a lot to get my strips and general lancets. I struggle a lot. Sometimes I buy one thing and it takes me a couple more weeks to get the lancets.

In this next example the interviewee works long hours to make ends meet which affects her having time to take care of herself. She knows what she should do (what she says) but can’t find the time to take the actions (what she does).

And it’s hard for me to take lunch, especially now that we are moving, ... I don’t take lunch. I work too much. I work too much. … I try to make lunch to take with me but I’m almost too sleepy to make any kind of lunch. I wake up so early to go to work, so I don’t make lunch to take with me. …

In response to my comment on how much she works she said, “It’s not that we want to, we have to, the way we live. The bills pile up and you stop working — you’re in trouble.”

The affects of not being able to eat properly will affect most people’s performance but for people with diabetes, skipping meals puts them at risk for developing low blood sugar, or hypoglycemia, which can impair cognitive abilities and job
performance. This next example shows how managing diabetes without enough resources snowballs into greater situations of stress.

My husband who’s also a diabetic, he said, “have you been eating right?” I said, “well no.” And of course I started crying, which is part of the blood sugar thing and the stress. The sobbing. So I said no, because we’ve been trying to save money because we’re so broke so I haven’t been eating very much for breakfast and lunch.

Due to her blood sugar imbalance she produced more mistakes at work and inconsistent work output. Because of this she realizes that she needed to talk with her boss about her diabetes.

And having to reveal that to her and to remind myself that, oh my gosh, I could easily lose my job if I don’t watch that. So there’s pressure, about the pressure, about the pressure, you know? I mean, its just layers. But that’s how important it is for me to be balanced.

When we spoke she was scared of losing her job if she couldn’t get her diabetes under control (what she says), yet she was still struggling to find balance (what she does) with her blood sugar levels. Often resolving health problems take more time when a person has fewer resources than it does for people with resources.

So the last two days I didn’t feel well, I didn’t have insulin for one of them because I couldn’t get the doctor to call in to the right pharmacy. It was just a cluster mess. And I knew… I just didn’t go to work. I took two sick days. Because I knew if I went, number one, I would urinate all the time. I’d have to be away from my desk all the time or I might not make it. And that’s maybe too much information but that’s the truth.

These interviews reveal that trying to managing diabetes without enough resources and then dealing with the health repercussions that result adds stress to already highly stressed individuals.
When asked how they deal with the stress, several participants flat out said they eat sweets. One woman said, “I do like to eat chocolate when I’m stressed. Then regret it afterwards.”

Another woman explained her strategy of eating sweets for stress:

[I have] things in my house I should not have. I have hostess cupcakes and I have a big bag of Halloween candy that was 50% off and who can pass that up? You know? And I have that sitting right there knowing full well that when I bought both of them that I don’t have the willpower always to not eat that. But I have enough maybe to not eat any of that until after work. And then I think it’s okay, you know, to be a nut head after work. Oh well who cares if I’m going to cry and my blood sugars going to ping pong around. I’ll have it finished by the time I have to get up and go to work tomorrow. Maybe it will be settled down.

Another person when asked what she does to manage stress answered, “Nothing.” She then described her heavy workload and experiencing high stress at work. She continued, “I really do nothing to manage my stress. And I don’t know what to do. I don’t really know what to do to manage my stress.” I offered a couple of ideas like walking or reading which prompted her to respond. “I got home [from work] at 10:30 last night. It’s a little dangerous to take a walk by myself at that time… And I was exhausted. I was very, very tired when I got home.”

**Cultural or societal systems**

Up to this point the focus has been at the interpersonal level yet a number of participants made comments about the societal systems that they regularly came into contact that affected them. Overall I think the participants’ comments reflect the tension between a society that views diabetes care as solely the responsibility of the individual, low-income or not (stories told) and the reality that society’s actions affect this population (stories lived) in ways that makes following a diabetes regimen more difficult.
or leaves the diabetic feeling left out, isolated, and at times overwhelmed. These are the stories of the participants and reflect how they are making meaning and coordinating their action around their diabetes.

In one example an interviewee who comes regularly to the clinic for medication and to get his blood sugar tested makes this observation:

It’s like here [the clinic]. There is a huge number of the people who come here who have diabetes. I would say 70% or better. What do they serve out there every time? Donuts and that kind of stuff. And the coffee. They have sugar but they don’t have any Sweet ‘n Low. And even Sweet ‘n Low isn’t sugar free. People come here for help and what do you do? You gas them up with more sugar. Most of the world’s like that. You’ve got diabetes; deal with it. You get left out of a lot of stuff.

This person feels a dichotomy of support. That same interviewee when asked if people know about diabetes said the following in regards to the general public:

I think they do [understand]. I just don’t think they care. There was a lady at the library who was talking about diabetes and dah, dah, dah, and asks who has diabetes? I raised my hand and the guy next to me said, “Too bad, so sad” and walked off.

Other societal-based support tensions come up around food systems. One person who was very knowledgeable about his diet, who exercised regularly, and very confident of his ability to manage his diabetes shared this when asked if there was anything he needed help with managing his diabetes:

Well if I had the power of God, and I don’t have, I would come down on grocery stores and corporations. If you walk into a grocery store and try to find something to drink without sugar in it, it’s almost impossible. If you don’t drink water you’re forced to drink diet sodas and all kinds of other stuff and most of its junk anyway. In fact I made a complaint to Kroger. They sell a gallon of orange flavored orange juice and it’s not really even orange juice. It contains no orange in it whatsoever. It’s flavored like orange juice and its 35% sugar and, let’s see, sugar and water with orange flavoring in it. And people buy this stuff and drink it. It’s garbage; absolute garbage.
Another example of a person who came regularly to the clinic to get his blood sugar checked and was very mindful of limiting his sweets felt he was battling the greed of the larger food corporations.

I do believe that our companies, food companies don’t give a damn about our health. They put everything sugar on it because it tastes better. The better it tastes, the more you going to eat. The more you eat the more you’re going to buy. They want it for their pocketbook. Now I just control it, I stay away from the sweets as much as I can. You need a little bit but…

Another example is unsupportive work environments as expressed in this comment made by a woman who previously mentioned she didn’t have time to make lunch before work due to the long hours that she works. “But it’s still too hard to manage my eating; still too hard. I try to avoid them but at work there’s not very many things that I can choose to eat.”

Another employment example speaks to co-workers’ lack of awareness of the diabetics around them. After sharing her diabetes with co-workers so that they will be aware if she begins to “act funky” she also shared this.

But at the same time, when the office brings in all that cake, it’s not like they bring in a big vegetable tray. It’s like cakes, and cookies, and bagels, and all those carbohydrates and all those carbohydrate with sugar as well, the sweets.

Other comments shared were about the general public. One woman said, “They usually try to make you feel like you have a disability. And it’s not really a disability. It’s something that happens to people.” Another women said, “A lot of people don’t like to talk about [diabetes]. I think it makes them too sad. I think it’s too threatening.” And another woman related when asked if she talked about her diabetes with others, “I’m embarrassed that I have it. You know, so that’s the first hurdle to get over. You know, is the personal feeling of I caused this; I’m weak.”
In addition to being economically cut off from many aspects of society, these statements reflect that a low-income diabetic’s health status may add to their isolation.
Discussion

Using CMM’s LUUUUUTT model to uncover the tensions between stories told and stories lived, participants in this study indicated lived experiences that have low social support and heightened stress around managing their diabetes at the interpersonal level. The interviews also revealed the possibility of unsupportive interactions with larger systems in society. Using a communication perspective, this study adds dimension to previous research regarding low-income, type 2 diabetics and suggests areas for change in diabetic treatment for low-income diabetics.

The first tension was found in the gap between participants saying they managed their diabetes by themselves or they didn’t need any help (stories told) and yet the interviews revealed that they either didn’t have anyone they can rely on or they lived in a non-supportive environment often with other diabetics (stories lived). Mores specifically using CMM terms, the coordination with others (stories lived) or the ways in which their actions mesh together to produce patterns — created a pattern of managing on their own. That is their actions of having to deal with their diabetes meshed with either the non-supportive actions of people they lived with or meshed with their personal isolation due to distrust or a break down of family and produced managing their diabetes on their own. The coherence or the stories told to make meaning of their situation revealed that participants played down their lack of support saying they didn’t need help or what help they did need, they received from the clinic. Using the other elements of the LUUUUUTT model to fill out the picture, the untellable stories (too painful to tell) might be how their unsupportive or isolated environments create stress and hinder managing their diabetes. And the unknown story (information that’s missing) could be how positive support would
help them. This bolsters research that found non-supportive behavior was associated with less-adherence to diabetes medication regimen (Mayberry & Osborn, 2012).

Viewing this finding through ComComplex, the patterns of interaction between the diabetic and their family and friends are low or nonexistent. These patterns reflect a very low quality of relationship — a general distrust at the most intimate level. These patterns of interaction develop patterns of neural firings, which shape how individuals engage with their world. According to ComComplex a change in these patterns of interactions, will change the neural pathways, and ultimately change behaviors. Since our focus is on the person with diabetes and not the family or existing support unit, one way to change these patterns is to incorporate a social support element into the treatment of low-income diabetics. Given research has found that social support is one of the most important and positively influential factors on diabetes management and enhanced quality of life (Pham et al., 1996; Tang et al., 2008; van Dam et al., 2005), that it is beneficial to the diabetic in accepting a diagnosis, adjusting emotionally, and decreasing stress (Zhang et al., 2007; Sacco & Yanover, 2006), and that this element may be missing in low-income diabetics lived experience, adding a social support element to a diabetes management program for low-income diabetic populations may be worth considering.

The second tension found was the gap between participants knowing what they need to do in order to manage their diabetes (stories told) and being unable to afford items needed to manage their diabetes well (stories lived). This tension between stories told and stories lived produce spotty or inconsistent diabetes management and poor health outcomes, which increases their stress levels. That is their actions of trying to manage their diabetes appropriately through diet, exercise, and medication conflict with
inadequate resources to do it and produce an inability to follow their diabetes treatment. Repeatedly, participants shared stories of frustration and struggle to secure the treatment items they knew they needed. With this tension the *unheard story* (what isn’t acknowledged) is that this inability to manage their diabetes on a regular basis is causing greater stress through medical complications, missed work, and spreading their resources (time and money) even thinner.

These stressors contribute to the already known chronic stress level that exists for people in low SES populations which research has found causes higher rates of morbidity and mortality from chronic diseases (Cohen et al., 2010; Evans & Kim, 2012; Miller et al., 2011) and that recent neurobiological research found that the ongoing, multiple stressors in low SES environments influence the brain’s neuroplasticity, which affects coping, expression of emotions, reactions to stress, and recovery (McEwen, 2007; McEwen & Gianaros, 2010). This also bolsters the finding that an accumulation of stressors in adults was found to limit adherence to treatment for high-risk populations with type 2 diabetes (Osborn, Mayberry, Wagner, & Welch, 2014).

In addition, many interviewees’ stories lived indicated an inability to manage stress in a healthy way which increased medical issues around their diabetes. Using the other elements of the LUUUUTT model to fill out the picture, the *untellable story* could be how study participants managed stress by eating sweets or not knowing how to manage stress; and the *unknown story* for participants could be how to manage stress in a healthy way.

Viewing this finding through ComComplex, the patterns of interaction between the diabetic and the medical field, which provides the diabetes treatment guidelines,
indicates a relationship that appears inflexible or unresponsive to the lived experiences of its clients. Providing a one size fits all diabetes treatment may not serve every population group equally well. Given the U.S. health system, looking for a perturbation of these patterns of interaction may again lie in the diabetes treatment plan. The current diabetes management approach given to low SES diabetics doesn’t address the higher level of stress that diabetes management appears to add to low SES population’s already high stress levels. This suggests again that a different or broader approach to treating diabetes in low-income populations—one that includes a healthy stress management program—may prove beneficial. Adding a healthy stress management dimension to diabetes treatment for low-income populations would also support the neurobiological findings of McEwen (2007) which found that change in neuroplasticity from chronic stress is not permanent but can be adjusted by reducing the burden of stress and increasing stress resiliency.

A third tension reflected the gap between a society that views diabetes care as solely the responsibility of the individual, low-income or not (stories told) and the reality that society’s actions affect this population (stories lived) in ways that makes following a diabetes regimen more difficult or leaves the diabetic feeling left out, isolated, and at times overwhelmed. This suggests participants are experiencing unsupportive interactions with larger systems in society however the patterns of interactions were not consistent enough to draw conclusions. While this finding does not present actionable information to affect change in the health outcomes of low-income diabetics, I felt it was important to share for there seemed to be a pattern developing and it may imply an area for further research. Is it a reflection of the isolation that the participants already feel from society in
general or do diabetics in all population groups feel this stigma or isolation? Again, further research may clarify.

While this study’s findings suggest that social support and healthy stress management might be beneficial additions to low-income diabetes treatment, change is beginning to occur at the policy level. Just a few months ago, the American Diabetes Association (ADA) released their new 2016 clinical practice recommendations for diabetes treatment and for the first time the ADA added a specific section for vulnerable populations (ADA, 2016). Updated annually to reflect the most recent research, ADA’s position statement for vulnerable populations provides “recommendations for those with food insecurity, cognitive dysfunction and/or mental illness, and HIV, and a discussion on disparities related to ethnicity, culture, sex, socioeconomic differences, and disparities” (ADA, 2016, p. S4). In their discussion of disparities, the ADA acknowledges the importance of social support and recommends that lay leaders, peers, and community health workers assist in self-management support services (ADA, 2016, p. S8).

In looking at the studies referenced by the ADA to add social support for vulnerable populations, the list includes both literature reviews and randomized trials that explore program possibilities that go beyond medical staff. A few examples include: A program comparing peer mentoring and financial incentives to improve glucose control of African American veterans, found peer mentoring improved glucose levels better than financial incentive or the control group (Long, Jahnle, Richardson, Loewenstein, & Volpp, 2012); in a comparison of reciprocal peer support (RPS) versus nurse care management (NCM), RPS was found to increase the quantity and quality of diabetes self-care support more than NCM (Heisler, Vijan, Makki, & Piette, 2010); and a literature
review of community health workers (CHW) in diabetes care indicates that CHWs shows
great potential in providing culturally appropriate services to underserved areas (Shah,
Kaselitz, & Heisler, 2013).

Additional stress management programs however, were not part of the ADA’s
annual clinical recommendations of diabetes treatment for low SES populations, although
one could argue that adding a social support component to diabetes treatment may also
help lower stress.

As mentioned before, the findings of this study is not necessarily new but adds
dimension to the growing numbers of studies looking at type 2 diabetes management, low
SES population, and social determinants of health. At the very least, it will inform the
participating health clinic about the patients in their care. By using a communication
perspective, one that focuses on the notion that we live “in” communication with others
and takes a more social view of the individual experience, the research provides a
different perspective into a problem society has yet to solve.

Limitations

This study has several limitations. First, the study had a limited ethnic mix.
Additional studies in other neighborhoods would expand the findings. Second I used an
interpretive theoretical framework, so other interpretations may be possible. And third,
findings may be limited to the geographical area or the clinic in which the study took
place.

Conclusions

The tensions and patterns of interaction suggest that a broader approach to
treating low-income diabetic populations might include social support and healthy stress
management options. Findings also revealed the possibility of unsupportive societal interactions around diabetes management and while not providing clear actionable information it may suggest an area for further research. This information along with further investigation into diabetes management of low SES populations can inform efforts to develop programs that address the needs of a population group frequently overlooked.
Appendix A

Table A1

*Prevalence of diabetes, as a percentage of population, 2010*

<table>
<thead>
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<th>Age</th>
<th>Marion Co.</th>
<th>Indiana</th>
<th>U.S.</th>
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<tr>
<td>Overall</td>
<td>13.38%</td>
<td>11.15%</td>
<td>10.04%</td>
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<td>18-49 years</td>
<td>5.40%</td>
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<td>50-64 years</td>
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<td>64+ years</td>
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## Interview#XX

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<th>STRESS</th>
<th>Other RELATIONS</th>
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References


Indiana University-Student Outreach Clinic. 2013. Indiana University-Student Outreach Clinic 2013 annual report. Indianapolis, IN: IU School of Medicine.


CURRICULUM VITAE

Mary Angela Breidenbach

Education
Master of Arts, Applied Communication, Indiana University, Indiana University-Purdue University at Indianapolis, 2016

Bachelor of Science, Economics, University of Illinois, Champaign-Urbana, 1986

Research and Training Experience
Research Assistant, Communication Study, IUPUI, Indianapolis, IN, 2014 – 2015
Assisted implementation of a study commissioned by the Indiana State Legislature examining the underreporting of adolescent sexual assault under the guidance of principal researcher, John Parrish-Sprowl, Ph.D. Primary responsibility was to recruit, record, and facilitate focus groups, distribute of two, state-wide surveys, enter data, and contribute to analysis. Research resulted in the report: An investigation into adolescent sexual assault underreporting in the state of Indiana. (http://www.in.gov/children/files/An-Investigation-into-Adolescent-Sexual-Assault-Underreporting-in-the-State-of-Indiana.pdf)

Professional Experience
Independent Contractor, Cumulus Design, Indianapolis, IN, 2001–present
Provide clients with a variety of communication services — writing, editing, design, and project management along with excellent customer service.

Marketing Manager, DisciplesWorld, Indianapolis, IN, 2002–2006
Developed and implemented marketing plans for a denominational magazine.

Production Manager, Cranfill & Co., Indianapolis, IN, 1999–2000
Managed projects from production to delivery of finished product, purchased all print, and worked closely with art directors and vendors.

Marketing Manager/Designer, JIST Works, Inc., Indianapolis, IN, 1995–1999
Designed and coordinated business-to-business and direct mail marketing pieces.

Layout Technician, IDG Books Worldwide, Indianapolis, IN, 1993–1995
Designed and laid out instructional trade books and supervised other production artists.

Project Assistant, Indiana University, Healthy Cities Indiana Program, 1988–1992
Assisted in the research and development of volunteer organizations for the six participating cities in the project.
Conferences


Service
Indy Circles of Support, Indianapolis, 2012–present

Indy Circles Guiding Coalition, Chair, Resource Committee, 2013–2015

Reading Tutor, Read-Up Program, United Way of Central Indiana, 2009–2011

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National Communication Association, 2014–present