I, Kelly Warsinske, hereby submit this original work as part of the requirements for the degree of Master of Science in Genetic Counseling.

It is entitled:
Storytelling and Family Communication about Type 2 Diabetes in an Urban Appalachian Community

Student's name:  Kelly Warsinske

This work and its defense approved by:

Committee chair:  Lora Arduser, M.F.A.

Committee member:  Rebecca Lee, Ph.D.

Committee member:  Melanie Myers, Ph.D.
Storytelling and Family Communication about Type 2 Diabetes in an Urban Appalachian Community

A thesis submitted to the Graduate School of the University of Cincinnati in partial fulfillment of the requirements for the degree of

Master of Science

In the Department of Pediatrics of the College of Medicine 2016

By

Kelly Warsinske
B.S. Michigan State University, 2014

Committee Chair:
Lora Arduser, MA, PhD

Committee Members:
Melanie Myers, MS, PhD, CGC
Rebecca Lee, PhD, RN, PHCNS-BC, CTN-A
Abstract

Type 2 diabetes (T2DM) is an important health concern for individuals of Appalachian background, contributing significantly to morbidity and mortality. Early promotion of risk recognition and behavior adaptations can be beneficial to mitigate health consequences, yet culturally tailored resources may not be readily available for this population. In this multi-phase study, a community-driven approach was implemented to explore the use of story circles to facilitate familial communication about T2DM. In Phase I, a group of ten individuals from a low income urban Appalachian community participated in a focus group to discuss and further tailor the study plan. In phase II, 18 individuals participated in one or more of three story circles to discuss T2DM experiences and conversations. Story circles were recorded and transcribed to allow for content analysis. Major themes identified included diabetes experiences, thoughts and attitudes about diabetes, conversations about diabetes, and sharing of information about diabetes. In addition, we found that a sense of support was generated between story circle participants. Phase III consisted of seven follow-up interviews with story circle participants that were part of family pairs that attended together. Transcription and content analysis revealed that all participants reacted positively to their participation and many described ways participating led to changes in their communication or behavior patterns or supported their previous efforts toward diabetes management/prevention and communication with family members. Asking people of urban Appalachian cultural background to share stories about T2DM experiences and conversations led to dynamic discussions that allowed participants to both develop a sense of mutual support and share their experiences and knowledge about diabetes. Although support may be needed to facilitate and monitor the accuracy of information shared, incorporating group
storytelling can be an effective way to provide culturally tailored T2DM care in the Appalachian community.

Key Words: Type 2 diabetes, communication, family health history, urban Appalachian, narratives
Acknowledgements

This study was funded by the Jane Engelberg Memorial Foundation Student Research Award provided by the National Society of Genetic Counselors and by a Research Award from the Division of Human Genetics at Cincinnati Children’s Hospital Medical Center. Many thanks go out to the research team and all who were in support of the project. A special thanks to Rania Sheikh for her efforts in transcript coding and data analysis.
# Table of Contents

Abstract ............................................................................................................................................. ii

Acknowledgements.......................................................................................................................... v

Table of Contents ............................................................................................................................ vi

Introduction ........................................................................................................................................ 1

Methods ........................................................................................................................................... 5

  * Community Planning Focus Group (Phase I) ................................................................. 6
  * Story Circles (Phase II) ................................................................................................. 6
  * Interviews (Phase III) ................................................................................................. 7

Results ............................................................................................................................................. 8

  * Community Planning Focus Group (Phase I) ................................................................. 8
  * Story Circles (Phase II) ................................................................................................. 9
  * Interviews (Phase III) ................................................................................................. 15

Discussion ....................................................................................................................................... 18

  * Strengths and Limitations .......................................................................................... 22
  * Conclusions .................................................................................................................. 23

Table 1 Demographic characteristics of participants across phases ............................................ 25

Figure 1 Family distribution and relationships of participants .................................................... 26

References ....................................................................................................................................... 27

Appendix I Story Circle General Prompts ...................................................................................... 31

Appendix II Semi Structured General Interview Guide ............................................................... 32

Appendix III Demographic Questionnaire .................................................................................... 34

Appendix IV Story Circle Codebook ............................................................................................ 36

Appendix V Interview Codebook .................................................................................................. 39
Introduction

Type 2 diabetes (T2DM) is a chronic health condition that poses serious risks to many individuals in the United States. Reports from 2012 indicated that 29.1 million Americans have diabetes and 90-95% of these adults have type 2 (CDC, 2014). Associated health risks are significant and include heart and circulation problems, kidney issues, and visual impairment; in 2010, diabetes was listed as the seventh leading cause of death in the country and was likely underreported (CDC, 2014). Risk factors for T2DM include both factors that can be changed and factors that cannot (Alberti, Zimmet, & Shaw, 2007). Age, gender, genetics, race/ethnicity, and family history are all risk factors that are outside of an individual’s control and cannot be changed. Research has shown that early interventions directed at modifiable factors, including changes in diet, weight loss, and increase in physical activity, can make a difference in the course of diabetes and can even prevent the condition (Alberti et al., 2007; Lindstrom et al., 2006). Therefore, education is a common strategy currently used to enhance the health of individuals with the condition (Funnell et al. 2009).

Diabetes in Appalachian communities

People of Appalachian cultural background are one of several groups at an especially high risk for diabetes. In 2007, 81% of counties in the Appalachian region—the 422 counties across 13 states along the Appalachian Mountains from New York to Mississippi (ARC, 2014)—had some of the highest rates of diabetes in the country, with prevalence rates equal to or greater than 10.6% (CDC, 2009). Research on the health outcomes of descendants of people from this region who have migrated to more urban areas is limited, but it is thought that they face similar health disparities and heightened risks of medical conditions including T2DM (Obermiller &
Brown, 2002; The Health Foundation of Greater Cincinnati, 2012; Ludke, Obermiller, & Horner, 2012). In addition, urban Appalachians have maintained many aspects of the traditional culture including dietary habits and health beliefs (Obermiller & Brown, 2002). As such, T2DM risk is likely influenced by a combination of cultural and genetic factors passed down from their ancestors of rural Appalachia. Health disparity is evidenced specifically in the greater Cincinnati area, as urban Appalachians have reportedly higher rates of diabetes diagnoses than the Greater Cincinnati population as a whole (17% vs. 13%) (Interact for Health, 2014).

**Barriers and possible facilitators to communication in Appalachian health interventions**

Both people of urban and rural Appalachian background experience cultural challenges in accessing health care. These challenges include a misunderstanding of risk, poor trust of health care providers, and a lack of cultural relevance in prevention work resulting in poorer functional health literacy (Keller & Helton, 2010; Ludke, Obermiller, Jacobson, Shaw, & Wells, 2006). Effects of mistrust and misconceptions about Appalachian culture can be heightened when individuals of Appalachian background are faced with expressions of inaccurate stereotypes by others (Coyne, Demian-Popescu, & Friend, 2006). Decreased functional health literacy also has a greater impact on the ability of people of urban Appalachian background to recall information from a doctor in comparison to non-Appalachians which may be related to the lack of cultural understanding (Ludke et al. 2006). Therefore, careful consideration is needed when planning culturally tailored health interventions for people of Appalachian background.

Many of the challenges faced in planning these interventions can be mitigated by effective communication. The use of personal communication with a focus on family has already been identified as one effective way to present risks and provide education to members of the
Appalachian population (Denham, Meyer, Toborg, & Mande, 2004). Unfortunately, lack of communication between Appalachian individuals and their health care providers has also been demonstrated (Serrano, Leiferman, & Dauber, 2007). Effective communication is especially important with chronic health conditions such as diabetes for which lifestyle modifications can have important impacts on prevention and management (Alberti et al., 2007; Lindstrom et al., 2006).

If medical providers are not able to engage in conversations about diabetes in populations from Appalachian backgrounds in the ways that would be most effective, education may need to come from another source such as family members. It has been suggested that effectively engaging family members in diabetes prevention efforts could provide positive role modeling and improve the efforts’ success (Myers, Fernandes, Arduser, Hopper, & Koehly, 2015).

Specifically in the Appalachian community, there is already a strong reliance on familial support and a tendency to look to one’s family for education on health conditions and management. With strong family values in the community (Keller & Helton, 2010; Manoogian, Harter, & Denham, 2010), making diabetes communication a family discussion may also increase acceptance and facilitate the feelings of trust in the information.

**Storytelling to improve health communication**

Research on culturally relevant interventions in other communities facing cultural health disparities has suggested a narrative approach incorporating family stories could be used to facilitate collection of family history and provide health education (Petrucchio et al., 2008; O'Leary et al., 2011; Moore et al., 2012). Although not specifically in the Appalachian community, narrative methods have been used to help with overcoming misperceptions,
increasing understanding, changing behaviors and facilitating support in health management (Campbell, Dunt, Fitzgerald, & Gordon, 2013; Kreuter et al., 2007). Much of the current research on the use of narratives in health prevention focuses on media materials including films and recorded testimonies rather than face-to-face communication (Yoo, Kreuter, Lai, & Fu, 2014; Frank, Murphy, Chatterjee, Moran, & Baezconde-Garbanati, 2015; Murphy et al., 2015). Such materials take resources to develop and may not be accessible to all populations.

Given the propensity for storytelling already present in the Appalachian culture, using oral narratives in health care interventions could be an effective way to encourage the sharing of health information the community. This study explored how facilitating the sharing of oral stories in a group setting could serve as an avenue to improve communication about diabetes health.

In addition to improving communication about prevention and management, the study addressed the need to identify better ways to gather and distribute family health information within Appalachian families. Although some work has been done to develop methods to gather family history information in this community (Wallace et al. 2009), continued efforts are needed to ensure this information is being shared between relatives which could in turn foster a sense of family support. We specifically targeted families with people with a diabetes diagnosis and others that had not been diagnosed in order to both encourage support for individuals with diabetes and also reach individuals who might be at risk for diabetes in the future.

Through this study we aimed to both expand on the work of Myers et al. (2015) in characterizing the experiences and communication patterns in families with a history of type 2 diabetes as well as consider the use of storytelling as a modality to facilitate health history
conversations in urban Appalachian families. Ultimately, we planned to use knowledge gathered from this project to promote wellness, encourage the reduction of diabetes risk, and guide clinical practice when working with individuals of Appalachian background. Genetic counselors are often in a unique position of having the opportunity to learn about family health history in unaffected individuals and could use information from this project to guide their patients in talking to their family members about family disease risk. We also hoped to achieve community empowerment by involving people of the community in the process and tailoring the intervention to cultural needs.

Methods

Design and participants

A community-driven approach was used to design a culturally relevant communication intervention (Wallerstein & Duran, 2010; Ramsden, McKay, & Crowe, 2010). The project was divided into three phases. First, we met with community members to gather input on the plan for the project (Phase I). Then, we held three story circles, group discussions similar to focus groups (O’Neal, n.d.), designed to facilitate the sharing of oral stories (Phase II). During the story circles, basic prompts were given and participants were encouraged to talk about their personal experience. Once everyone was given the opportunity to share a personal story the group discussed other thoughts and implications. A facilitator was available to offer the original story prompts, ask questions and make clarifications, and help guide the discussion once everyone had shared their stories. The story circles were centered on people’s experiences with diabetes and communication patterns about diabetes. Finally, we interviewed a subset of story circle
participants to get feedback on their experiences with the story circle, changes they had made or planned to make since participating, and initially identified themes (Phase III).

Focus groups were held in Lower Price Hill, a low income neighborhood composed of predominately urban Appalachians (Brown, 2012). Participants recruited for each phase of the study were over 18 and identified as urban Appalachian, had parents that identified as urban Appalachian, and/or had parents or grandparents born in an Appalachian county. Other demographics collected during the planning focus group and each story circle included race/ethnicity, education level, employment status, diabetes status, and family members with diabetes. Recruitment was done via snowball and convenience sampling with the help of a community liaison and all gatherings took place in a local church in Lower Price Hill.

All study procedures were reviewed and approved by the University of Cincinnati Institutional Review Board.

Community planning focus group (Phase I)

Ten community members participated in the planning focus group along with a certified diabetes educator who was available to address any disease specific questions. During this meeting, the group was consulted on their idea of the importance of a diabetes intervention, ideas about potential questions to use to elicit stories, the extent background information about diabetes was needed as part of the story circles, and the best way to recruit participants and work within the community.

Story circles (Phase II)
Three story circles were held in which participants shared their stories and experiences with diabetes. Participants were encouraged to come with a family member with the opposite diabetes status (those with a T2DM diagnosis were to bring a family member who had not been diagnosed and vice versa). Eighteen individuals participated in three story circle discussions. Three participants attended all three story circle discussions, four people attended two, and the remaining 10 attended only one of the discussions. Twelve participants were able to attend with at least one first or second degree relative, two participants were related to others by marriage, and four did not have relatives present. A graphical representation of family relationships can be seen in Figure 1. Story circles were moderated by a local facilitator with experience in leading story circles and working with this urban Appalachian community. Each group was video and audio recorded and transcribed by one of the authors for analysis.

**Interviews (Phase III)**

Six to eight weeks after the group meetings, a subset of seven participants were interviewed to hear their perspectives about the story circles and consider changes they or others they know had made since participating. These seven individuals were chosen to represent four family pairs. Two of these pairs were from the same extended family though not all four were related by blood. One planned interviewee was unable to be reached. Interviewees represented all three focus groups and both same generation and different generation familial relationships. All interviews were conducted by phone and recorded and transcribed for analysis.

**Data analysis**

To explore the use of narratives in communication about T2DM between family members, qualitative methods were used. Data analysis was performed using thematic analysis (Braun &
Clarke, 2006). Initial codes were generated from the story in an inductive manner. These codes were then grouped into categories which gave way to the identification of major themes. Themes were considered across transcripts to recognize similarities and differences between groups and develop the coding scheme. A different set of codes was developed to describe the interviews. Each transcript was coded by two coders using ATLAS.ti and discrepancies were addressed until consensus was reached. Analysis from the story circles was also corroborated through member checking during the interviews. At the conclusion of each interview, the higher level emerging codes from the story circles were described to the participant and they were given the opportunity to comment on what they remembered as most important.

Results

Participant characteristics

Demographic information was collected from all 10 planning focus group participants and 17 of the 18 story circle participants. Across phases, participants ranged in age from 32 to 80 years old though the majority were between 50-60 years of age. None of the Phase I participants were male but three males participated in Phase II and one of those participants was interviewed during Phase III. Education levels varied from less than a high school degree to some level of additional education beyond high school. The majority of participants across phases described their employment status as unemployed. Other information about participant demographics can be seen in Table 1.

Community planning focus group (Phase 1)

Notes from the planning focus group provided feedback to guide the study in terms of how to conduct the story circles and recruit participants. Participants were receptive to the idea
of sharing stories to communicate about the serious consequences related to diabetes and felt that personal stories might help change some people’s mindsets. During the discussion, we also found that many participants expressed feelings of worry about diabetes, especially in younger generations and described a disconnect between recognizing diabetes as a problem and making changes to improve outcomes. Recognizing these concerns as an important issue to the community, we planned to follow-up on them during the story circle discussions. Overall, participants in the planning focus group were interested in the project and eager to participate and we were able to easily achieve community buy-in.

**Story circles (Phase II)**

Themes from the story circles were developed both based on what was specifically expressed during the story circles, to get a sense of what might be expressed during the discussions as an intervention, as well as the higher level implications of the discussion overall. When considering participants’ exact responses, four major themes were identified: 1) diabetes experiences, 2) thoughts and attitudes about diabetes, 3) conversations about diabetes, and 4) sharing of information about diabetes. At a higher level, an indication of provision of support between participants was deduced based on the discussions during the story circles.

**Diabetes experiences.**

When talking about experiences of diabetes, participants most commonly told stories about lifestyle challenges they have faced or have seen others face that make it difficult to manage diabetes. Personal habits and dietary restrictions in particular were frequently described as struggles for many participants. For example, one participant with T2DM described his experience managing meals for each family members saying:
I’m just not going to cook three different meals for dinner to suit everybody. You know, if they’re going to eat it I’m going to eat it because if you go to eating everything for diabetics well that costs a fortune and not everybody’s going to like it and then I wind up having to cook something else. (Group 1 participant)

When talking about experiences of diabetes, participants with and without T2DM also frequently shared stories of health problems they had observed in others they knew with diabetes. Even for participants with diabetes these stories were often about more severe consequences that others they knew have faced rather than their own related health problems. Such consequences ranged from stories of amputations and death to close calls from which the person described was able to recover. Many of these stories directly described other family members and could convey important risk information for the participant telling the story. These descriptions sometimes showed the range of effects in family members as this quote from a participant who had not been diagnosed with diabetes illustrates:

Well, me personally I haven’t had it [diabetes] and I’ve been tested for it several times but I have had aunts and uncles who have uh had it. Actually I have an uncle right now who has gone from about I don’t know 185 pounds down to about 110. And… he doesn’t uh take any medicines. He refuses to. And he’s just getting worse. My aunt actually died of it two years ago. Uh, because she refused to take the medicines. (Group 2 participant)

**Thoughts and attitudes about diabetes.**

The way people described thinking and feeling about diabetes ranged from feeling concerned about their future health or the health of others to recognizing that lifestyle changes would likely be beneficial but choosing to wait until things get worse to actually feel worried or
make the changes. For example, one participant described growing up around diabetes and feeling as though it was commonplace and manageable saying, “I was a teenager when my dad found out he had it and then I from then on I just knew people [with diabetes].” Conversely, another participant remembered being worried about the risk of diabetes when she was young but ignoring it:

There would be times like you’d get ready to eat something and you’d think, ‘Oh boy,’ you know? But I would do it anyway because that’s something I had done all my life you know and I just always knew that it [developing diabetes] would happen. (Group 3 participant)

Other participants were much less concerned about their diabetes even as their health fluctuated as illustrated by this participant: “…yesterday she [doctor] told me my number was up, I’ll go back and get it back down again. It’s not a big deal.” As the conversations evolved, participants would often note that they should probably take diabetes more seriously than they do and seemed to express a growing concern for educating younger generations.

In discussions related to attitudes about diabetes, participants also would often consider their risk or the risks of other family members for T2DM more closely. Participants expressed a general sense that having family members with T2DM put them and/or their family members at risk, but discussions within the story circles allowed some participants to understand the risk in a newly personal way. For example, one individual described the T2DM in her family in relation to risk for another participant saying:

But she’s younger. She’s older. She’s younger. You see what I’m saying? So if it’s not- I mean it can hit you at any time. From what I understand. It can hit you at any given age at
any time. You can be- if it’s in your family and in the genes than you’re susceptible, is
that not correct? (Group 2 participant)

Openly communicating this risk based on family history also led to growth in people’s interest in
finding ways to educate the younger generations in their families as well as others in the
community.

Conversations about diabetes.

After discussing overall experiences with diabetes, participants were asked about
communication patterns, “I let them know you know, this is in the family, this is in the family
and you need to you know always be checked for this and do this,” often not everyone in the
family shared this openness. In such cases it was frequently older generations that were less
willing to share information, especially if health history questions were not specifically asked.
Participants described additional barriers to conversations about diabetes including people not
wanting to hear and/or not caring, fear of being nagged or judged when confronting others, and
people having too many other things to worry about. Participants reported that others may also
not recognize the conversation as important for a person who does not yet have a diagnosis as
illustrated by this quote:

Til I had it… even though my father had it they never discussed it with us. Never would-
ever said or anything. So it’s the truth it was never talked to us about it. (Group 1
participant)

Discussing conversations that were currently happening outside of the story circle and
barriers to additional conversations also led to brainstorming about ways to make communication
more effective and to reach additional people. These ideas included using group conversations, bringing up the information gradually among other topics of conversation, and emphasizing that if a person is diagnosed with diabetes there is an opportunity to control and even reverse it.

**Sharing information about diabetes.**

As they discussed experiences with diabetes, story circle participants would frequently offer advice to one another and educate each other based on what they had heard and/or read. People would often bring up various medical recommendations and determine if they were consistent with what others had heard and experienced. This included specific bits of advice they had heard from their medical providers as well as ideas people with diabetes had come to learn through their own management. For example, one participant with diabetes addressed complaints from another participant of feeling sick after taking diabetes medication saying:

Can I tell you something? I mean I- I found this for myself because I usually feel sick if I take my medicine without eating and it tells you on your metformin to eat with it. What about like even- I don’t know what you guys think- but maybe even like a slice of bread and a drink of milk with it is better than not having anything at all. (Group 3 Participant)

Discussion of medical information about diabetes also offered participants an opportunity to get feedback on information they were unsure if they understood correctly and ask questions of one another. Although people who already had diabetes were frequently more active in these discussions, it did offer people who were at risk for diabetes to ask questions as well. One participant who had not been diagnosed asked about the need for individualized management saying:
So do you guys-I mean I’m listening to everybody saying that they kinda figured out their own thing that kind of works for them. Do you have to do kinda the same thing? Like did you figure out what to eat? (Group 2 Participant)

Although there was not a direct way to monitor the accuracy of information shared, discussion provided an opportunity for participants to hear about how ideas of management were integrated in the lives of others they knew coming from a similar background. It also offered some introduction to diabetes to the many unaffected participants who expressed a lack of understanding of the disease.

**Support to others.**

As participants shared personal or family stories and medical information they developed a sense of mutual support. As one participant put it, “It’s nice to be able to talk about this stuff like this. You know and…You may not know everything that somebody else knows and yous are feeding each other.”

Feeling a sense of support seemed to be an important aspect of diabetes health maintenance in the community. One participant described the support she provided for her friend in the story circle saying:

Well she- at first when she was first diagnosed with diabetes I’ll never forget she said, “Well I’m not taking that medicine it makes me sick.” I said just keep giving it a little more time. A little more time. A little more time. (Group 2 participant)
Many people described challenges to managing their diabetes, but having people available to encourage them seemed to make a big difference in being able to keep their disease under control and follow recommendations from health care providers.

**Interviews (Phase III)**

During the individual interviews we explored the participant’s experience in the circle as well as perceived conversation and lifestyle or behavior outcomes since participating. As part of the feedback, we discussed further barriers participants identified to communicating about diabetes or making lifestyle changes in themselves/encouraging lifestyle changes in others and ways they thought similar programs could be used in the future.

**Overall feedback about story circles.**

All interviewees reported feeling comfortable in the story circles and most listed advantages in comparison to talking to people one on one. Such advantages included feeling less intimidated, appreciating hearing more opinions/ideas, and being able to interact with people they already knew. Multiple interviewees expressed interest in continuing to participate in similar groups and encouraging others to participate. As one interviewee put it:

Well, it’s a lot better when you’re with a group because you can you know you can learn stuff off them and they can learn off of you also. They may not know stuff that you know and vice versa.

Such statements illustrated high perceived benefits for the use of story circles to promote diabetes awareness and share ideas that could help improve management.
Additional barriers to family communication even when sharing stories that interviewees discussed included a lack of opportunity to talk with their family members, difficulty encouraging family members to translate their knowledge into action, and experiencing others dismiss the information without fully listening. One interviewee also brought up concern that other disadvantages in the neighborhood including limited community resources contribute to a lack of interest in listening to health information.

Despite these barriers, a few interviewees expressed an interest for sharing through story circles to continue. One interviewee also felt that the information gathered should be distributed to health care providers to help them better understand the specific impact of diabetes in the community saying:

I think that doctors should hear about this story circle and think about questions and think about how to get you know their patients to talk to ‘em and to get people to start talkin’ to family members and stuff.

**Conversation and management outcomes after participation.**

The impact on diabetes conversations reported by participants following participation in the story circles varied. Some individuals felt that although they had not made significant changes in conversations, ideas shared in the story circles further supported efforts they were already making to discuss diabetes and related health concerns with their families. For example one participant described the way she continued to talk about diabetes in her family saying:

Uh well my family members they’ve known about you know um my diabetes from day one. So um… they knew you know what to expect and I mean they had a lot of questions
but you know I just explained to ‘em you know the ups and downs of diabetes and uh you know they was pretty much well understanding.

Other participants did describe taking advantage of new opportunities to discuss diabetes and ask questions to their family members and others they knew. More than one participant also described learning about new diagnoses in their family members or a change in the required treatment since participating and opening a dialogue about diabetes. This increase in sharing of diabetes experiences was expressed by one participant saying:

Um because of us talkin’ there… we found out more stuff so I think we’re more conscious of each other when we call and talk to each other we’re saying what’s going on how you feeling, you know are you doin’ what you need to do.

Behavioral and cognitive outcomes also differed between participants. Multiple participants both with and without diabetes expressed a change in their understanding of diabetes since participating as illustrated by this participant:

I think when we did the story circle the one thing is that we all took it more serious.

Including myself. I mean we think it’s all serious when we hear about somebody losing a limb but I think it’s kind of we’ve looked at it as if it could be one of us losing that limb.

In terms of behavior and management, participants also frequently described changes they had made to improve their health prior to the story circles and continued afterwards. Some also described changes they had adopted since the story circles. With increased conversation, some of these behaviors were extending beyond one participant as indicated by this participant’s statement about her family, “We’re all trying to get a right diet here. And stick with it.”
on support of others was not uncommon in expressions of change and management of behaviors further reinforcing the important role of a sense of support in the community.

**Discussion**

Using storytelling to explore how health information is communicated and understood takes advantage of the human propensity to organize thoughts in terms of stories and experiences (Petraglia, 2007). This is particularly relevant in a population from an Appalachian background with a rich storytelling culture. Previous work on perceptions of cancer has found that storytelling can influence the way Appalachian people think about health (Hutson, Dorgan, Phillips & Behringer, 2007). When given the opportunity to share stories related to diabetes, story circle participants were quick to recall their own experiences and those of their family and friends.

Accounts of diabetes experiences sparked conversations about lifestyle factors influencing diabetes management and portraying their attitudes about the disease. Initiation of such conversations allowed for a deeper exploration of the frustrations some participants felt and recognition of a need to take health care more seriously in other participants. These findings were not unlike those noted by Myers et al. (2015) when talking with at-risk family members of individuals with T2DM who described a need to increase risk awareness and the sharing of health information between family members. Although many people are aware of diabetes risk factors, it can be difficult for people to fully comprehend their personal risk and long-term consequences may not be completely appreciated specifically in Appalachia and elsewhere (Della, 2011; Gordon, Walker, & Carrick-Sen, 2013). By recognizing the challenges faced together, participants were able to feel connected to people facing similar challenges, such as
poor dietary habits and managing meal preparation for all family members, recognize the seriousness of the disease, and experience mutual support for one another.

Family health narratives can be complicated and the story of each family can vary based on their complete health picture (Lindenmeyer, Griffiths, & Hodson, 2010). The variety of experiences disclosed during the story circles also presented opportunities for participants to learn from one another. Disclosed experiences varied from specific management strategies, such as how to incorporate exercise or adjust eating habits, to ways to approach communication with health care providers or family members. The story circles provided a safe space for participants to explore advice they had heard or read and ask questions about things they had not understood. Most participants who did not have diabetes described a lack of understanding of the disease and were eager to learn more about its impact. Of course the information shared within peer story circles is limited to that of the knowledge of the participants and there exists a risk that inaccurate information could be shared. Evidence for the efficacy of group appointments for T2DM care is already growing (Burke and O’Grady, 2012) and may offer an opportunity to combine storytelling between patients with the guidance and expertise of a trained health professional.

Talking in the story circles also identified a diverse set of communication experiences in relation to T2DM. Some people described their families as very open about medical conditions in the family history while others felt their family kept things to themselves or shared only on an as needed basis. This is similar to the ideas presented by Manoogian, Harter, & Denham (2010) who described family members in Appalachian communities as “intergenerational lynchpins,” who pass on health information, and “intergenerational buffers” who keep family health information to themselves. When they explored these communication patterns in more depth,
many of the participants in our groups described older generations as being less open about family history and expressed a desire to change this with their children and grandchildren.

For participants who described currently having limited conversations with their family, the group was able to discuss why conversations were difficult and barriers that exist when trying to engage at-risk relatives. Again, responses were similar to those previously reported in other populations including family members being unwilling to listen, expressing apathy, or not understanding the relevance of the risks to them (Myers et al., 2014, Whitford, McGee, & O’Sullivan, 2009). The group then developed ideas about how to share health information and encouraged one another to continue to strive to overcome communication barriers with the input of at-risk relatives. Conversations stressed actively reaching out to relatives and appreciated the idea of talking in groups to help spread the message. Having a designated meeting to discuss diabetes experiences also seemed to mitigate some of the barriers participants identified when talking about diabetes. In the story circle, people were aware that diabetes was the topic of conversation and were willing to listen to one another, perhaps more so than they would have been in their previous one-on-one conversations.

During the second and third story circles, some repeat participants discussed how meeting together and sharing stories had already led to more open communication and increased disclosure and reliance on one another. For example, participants frequently referenced encouraging each other to take part in a new walking group. Another participant reported that her relative opened up about her own T2DM management changes since participating in the story circle. Multiple participants during interviews discussed an appreciation of both the support generated inside the story circle and ongoing support that had persisted after the group meeting. This support extended both to encouragement of proactive changes being made by individuals.
without a diabetes diagnosis as well as encouragement for those actively managing diabetes. Although this study did not directly assess impact on diabetes control, previous studies have suggested that family involvement in diabetes education program can improve the level of diabetes control (Baig, Benitez, Quinn, & Burnet, 2015; Shi et al. 2015). Additionally, in Appalachian communities specifically, managing familial support has been identified as highly important to diabetes care as family plays such an integral role in the Appalachian culture (Lohri-Posey, 2006).

After gathering together, participants seemed driven to improve health in relation to diabetes in the community and their families. Participating in group discussions like the story circles may help promote ideas of self-efficacy for Appalachian individuals as called for by Serrano, Leiferman, and Dauber (2007). In addition to impacting the participant’s own health, for individuals with diabetes in particular, there was a strong interest in sharing experiences of diabetes with those who had not been diagnosed so as to inform them of possible consequences of the disease. Though not all interviewees described having altered their conversation patterns most felt that participating in the story circle had some effect on their approach to diabetes conversations or further supported ideas they previously held.

Although narrative health intervention outcome research is limited, using narrative messages provides some unique ways to influence behavior including modeling, alteration of perception, and change in normative beliefs (Hinyard & Kreuter, 2007). It is difficult to determine the specific impact of the story circles with a limited number of open ended interviews. The results suggest people may be more inclined to continue to have conversations about diabetes, make changes in their lifestyles, and encourage others to make lifestyle changes after sharing stories
with friends and family. In addition, multiple interviewees described a desire for similar interventions to continue and themes from discussion to be shared with health care providers.

**Strengths and Limitations**

The lack of an organized structure from which to identify and work with participants was both a strength and limitation of this study. Relying on community members to recruit participants limited the reach of the study but also mimicked its application in communities that may not have an established structure for such an intervention. Gatherings of individuals to share stories about diabetes may not have to be formal and could be something communities or families develop without the need for extensive outside support. It was also not our original intention to have participants attend multiple focus groups but some participants seemed to find value in continuing to meet with slightly different groups and were eager to continue to participate.

We did not have as many family pairs as was originally desired so there may be bias towards participation by at-risk family members who are interested and willing to listen to stories from their family members or more emotionally close to their family members with diabetes. For those who did not have a family member present, there may have been an impact on their level of participation but they also may have found support from other participants that they did not have in their own families. Perhaps if storytelling about diabetes was incorporated into a larger program or alternate event an audience with even greater diversity could be reached.

We also had some participants attend without a significant family history of diabetes. Although the participants without a close family history of diabetes presumably do not have the same risk factors as those with a significant family history, they still expressed an interest in
learning about the disease and felt the experience was valuable. When working in a community that has an overall increased rate of diabetes such as the Appalachian culture there may still be value to offering participation to individuals even with less of a familial risk.

Follow-up in this study was relatively short term and only could reach a limited number of participants. Future studies could track reported changes by participants over greater amounts of time, including tracking the impact of story circles on diabetes control, changes in interactions with health care providers, and diabetes prevention efforts among those at increased risk of diabetes.

**Conclusions**

When asked to share stories about diabetes, resulting conversations encompassed both personal experiences and experiences of friends and relatives, as well as attitudes about diabetes and related risks. These stories opened up discussions on strategies for diabetes care maintenance and gave an opportunity for people to ask questions to one another in a comfortable environment. Gathering people together to discuss such stories may address barriers in some communities to talking about diabetes including a perceived lack of interest from the listener and ideas that discussions are unnecessary until problems arise. Fostering a sense of togetherness in efforts toward addressing care relating to diabetes may also improve perceived support and increase motivation to follow through with medical recommendations. Ensuring such support is available may be something to consider when working toward improved disease management and prevention. Discussion of using story-telling to share family history information could be used both in talking with patients one on one about family history such as in a personal genetic counseling session or in larger public health initiatives. Consideration of group story-telling may
also help shape the development of diabetes care and prevention resources that address cultural considerations for the Appalachian population although further research will be needed to better understand the full potential impact.
Table 1 Demographic characteristics of participants across phases

<table>
<thead>
<tr>
<th>Phase of study</th>
<th>Gender</th>
<th>Age</th>
<th>T2DM Diagnosis</th>
<th>Education</th>
<th>Family Hx 1-2° relative with T2DM Reported</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
<td>Female</td>
<td>31-40</td>
<td>41-50</td>
<td>51-60</td>
</tr>
<tr>
<td>Focus group</td>
<td>0</td>
<td>10</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Story Circles*</td>
<td>3</td>
<td>14</td>
<td>5</td>
<td>0</td>
<td>11</td>
</tr>
<tr>
<td>Interviews</td>
<td>1</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>5</td>
</tr>
</tbody>
</table>

*Demographic information was unavailable for one story circle participant
Figure 1. Family distribution and relationships of participants
References


Appendix 1 - Story Circle General Prompts

Original Prompt:

I. Tell a story about your own experience with diabetes, whether your own or that of a person close to you.
   
   How has diabetes impacted your life/choices and/or the lives of people you care about?
   
   What worries you about diabetes?
   
   What do you feel are the major risks associated with diabetes?
   
   For non-affected (if not responding): What concerns do you have regarding your family members and diabetes?

Original Prompt:

II. Tell a story about a conversation you had about diabetes. It can be a story about when the discussion went really well, or maybe not so well. Or even a story about when you wanted to talk about it but felt like you couldn’t.

   What do you feel is important to discuss with family members about type 2 diabetes?
   
   Who do you talk to about diabetes (risks and/or experiences)?
   
   What do you discuss about diabetes?
   
   What barriers do you face in talking about diabetes (if any)?
   
   For non-affected (if not responding): How do you discuss diabetes with your family members who are managing the disease (if you do talk about it)?

Original Prompt:

III. How could the stories we discussed be used to communicate about diabetes to family members?

   Does story telling make it easier to bring up (why or why not)?
   
   Does story telling make risks seem more personal/relatable (why or why not)?
   
   How can story telling encourage support of family members in their diabetes management?
   
   For non-affected (if not responding): How would you feel hearing stories from your family members?
Appendix II- Semi Structured General Interview Guide

Hi, is this [name]? This is Kelly Warsinske from the University of Cincinnati. I helped facilitate the story circles you took part in last month. Do you remember that?

I am just calling because you indicated you would be willing to be contacted for a follow-up interview. Is this still something you are interested in?

If no- Not a problem thanks for your time and participation.

If yes- Is this a good time for the interview?

If no- Arrange for a possible time in the future.

If yes- Are you in a private place where you feel comfortable talking?

I have a few questions for you about how things have been since the story circles. Is that alright? If you do not want to answer any of these questions please let me know and we will skip the question and move on to the next.

Follow-up assessment

What do you remember most from the story circles?

Did you feel comfortable sharing in the circle? (How was your experience in comparison to one on one discussions?)

What impact has participating in the story circles had for you?/have you thought about the information we talked about in the story circles since then?

Have you talked to anyone new? Have you talked about anything new?

Probe based on response.

What additional conversations you are planning to have?

If yes to either above question- How have your conversations been different?

Have you told your story(s) to anyone in your family? What have you shared with your family?

If participant says they have told their story: Who have you told? Does this person have diabetes? How are they related to you? Why did you decide to talk to this person?

How did your family react to the discussion?
Would you encourage other people to share their story with their family members? Why/why not?

If participant says they have not told their story:

Do you plan on sharing your story? Why/why not?

Questions to use for further clarification depending on their earlier responses

What concerns do you have about telling your story to your family (if any)?

What differences are there in conversations with your family members about diabetes?

Is talking with your family easier, more difficult, or about the same?

What continues to prevent you from talking about diabetes with your family (if anything)?

How have your behaviors and/or the behaviors of family members changed since the story circles?

Questions for further clarification as needed:

Has anyone talked to their doctor about diabetes?

What lifestyle changes have you or your family made or planned to make?

What other feedback do you have in relation to your experience in the story circle?

Now that it’s been some time since we came together as a group I also want to see what you think about some of the ideas that we felt were important that came out of our discussion…

Member checking

Describe some quotes from the dialogue and our interpretation/coding framework for the quotes to assess agreement or disagreement

Great, thanks for your input. It is really helpful to us as researchers.

Do you have any other questions or concerns?

Thanks so much for your participation! Feel free to contact me at 513-803-9038 if you have any future concerns.
Appendix III Demographic Questionnaire

Please answer these questions so that we can learn a little bit more about you. These questions will be used to help us make sense of the data we collect. If you are uncomfortable answering any question, feel free to skip it and move on to the next question.

What is your age? __________

What is your gender? ________________

Race/Ethnicity: How do you describe yourself?

☐ American Indian or Alaska Native
☐ Hawaiian or Other Pacific Islander
☐ Asian or Asian American
☐ Black or African American
☐ Hispanic or Latino
☐ Non-Hispanic White
☐ Other_____________________

Education: What is the highest year of school you completed?

☐ Less than a high school diploma
☐ High school diploma/GED
☐ Some College, no degree
☐ Trade/technical training
☐ Bachelor’s degree
☐ Graduate school/advanced degree
☐ Other_____________________

Employment: Are you currently:

☐ Employed for wages
☐ Self-employed
☐ Unemployed
☐ A student
☐ Retired
☐ Unable to work
☐ Other_____________________
Do you identify as Appalachian/urban Appalachian?

- Yes
- No

Do your parents and/or grandparents identify as Appalachian/urban Appalachian?

- Yes
- No

In what city/state were you born? ___________________

In what city/state were your parents born? ___________________

In what city/state were your paternal grandparents (your father’s parents) born? _________________

In what city/state were your maternal grandparents (your mother’s parents) born? _________________

Have you been diagnosed with type 2 diabetes?

- Yes
- No

Who in your family (if anyone) has been diagnosed with type 2 diabetes? Mark all that apply.

- Mom and/or dad
- Brother(s) or sister(s)
- Child/children
- Grandparent(s)
- Grandchild/grandchildren
- Aunt(s)/Uncle(s)
- Other relatives

How many people do you know of in your family have been diagnosed with type 2 diabetes? ______
Appendix IV Story Circle Codebook*

Diabetes Experiences
1. Diagnosis- description of what it was like to be diagnosed
   a. Perceived causes- comments about what they feel led them (or someone they know) to get diabetes
   b. Reactions to diagnosis- initial thoughts related to a their diabetes diagnosis
   c. Taking action after a diagnosis- Initial behaviors or planned behaviors in connection with initial diagnosis
2. T2DM management- Description of how a participant is taking care of their diabetes or has seen others take care of their diabetes
   a. T2DM healthcare - description of diabetes management overseen by HCP (health care visits, medication, insulin/shots, sugar monitoring for doctor)
   b. Lifestyle changes after diagnosis - description of diabetes management in everyday life (diet, exercise, changes in habits)
3. Health consequences in others- Examples of consequences to other people the participant knows
   a. HC - Family* - use this code if person described is a family member
   b. HC - Others* – use this code if the person described is not related to the participant
4. Personal health consequences- examples of health problems due to diabetes complications in the participant his/herself
5. Other medical concerns/monitoring - discussion of monitoring by those who don’t have diabetes and/or other health related experiences participants use as examples that are not due to diabetes
6. No experiences with diabetes - unaffected - participant describes a lack of experience because they have not been diagnosed with T2DM
7. Lifestyle challenges- Participant discusses something in their daily life that makes it difficult to follow diabetes management recommendations
   a. Dietary- specific concerns that make following dietary recommendations difficult
   b. Difficult habits - Participant describes specific habits that are against recommended management or make management more difficult
8. Learning about individualized management- participant describes having to figure out what works for them in taking care of their diabetes
9. Success story/good example- participant offers a positive example of taking control of diabetes or preventing diabetes (could be their own or story of someone else)

Thoughts and attitudes about diabetes
1. Attitudes about diabetes - general ideas about diabetes
   a. Knowing changes are needed - participant expresses knowing that they need to do things differently (whether or not they currently are)
   b. T2DM is commonplace - participant expresses feeling like T2DM is the norm- may increase or decrease their concern about it
   c. Waiting to make changes- participant expresses a desire to wait to make changes until something gets worse (could be they get a diagnosis or could be they are told they must change treatment)
d. Motivations to change - participant discusses something specific that has driven them to make changes in their life or would motivate them in the future

e. Lack of worry about diabetes - participant expresses that they are/were really not that worried about having diabetes or feel others aren’t as concerned as they should be

f. Reactions to management- participant describes how they feel about their treatment or possible future treatment and/or describes the experience of someone they know dealing with their prescribed treatment

g. Dislike/Changing is difficult- participant describes an overall dislike for dealing with T2DM and/or talks about how difficult it is (without describing specific barriers or challenges)

h. Worry about T2DM- participant expresses concern about being diagnosed with diabetes or their diabetes getting worse

2. Lack of T2DM knowledge- participant expresses that they really don’t know a lot about diabetes/diabetes risk and/or others they know who do not have good knowledge of T2DM

3. Risk consideration - participant considers their own or another person’s risk for diabetes (includes descriptions of considerations before diagnosis for those now currently diagnosed)
   a. Generational differences- participant describes the way people of different generations or ages perceive their risk differently
   b. Lack of known family history- participant expresses a lack of family history in an individual
   c. Family history - participant references family history of disease in relation to their risk or the risk to other family members
   d. Lifestyle changes before diagnosis- participant describes making changes in their life that may reduce the risk of diabetes before actually being diagnosed.

Conversations about diabetes

1. Current conversations about T2DM - participant gives examples of when they talk about diabetes
   a. Conv- People with T2DM- specifically descriptions of talking to people who have a diagnosis
   b. Conv- people w/o T2DM- specific descriptions of talking to people who do not have T2DM but may be at risk

2. Conversations with HCPs - participant describes conversations with their health care providers about diabetes and/or risk
   a. Not talking with doctor- participant describes a lack of regular communication with their HCP about diabetes
   b. HCP conversation strategies - participant describes ways to effectively communicate with suggestions (may be things they do or ideas they have)

3. Barriers to talking with others - participant describes factors that prevent them from talking to others about diabetes
   a. Too many other things to worry about- participant expresses there are too many other things to worry about so concerns about diabetes are not a high priority
   b. Not wanting to be nagged- participant hesitates to bring up diabetes to others because they don’t want to be told how to take care of themselves
c. Desire to avoid negative conversation - participant feels that others won’t want to hear about something negative
d. Not wanting to hear about it - participant finds others to not care or they are uninterested
e. Feeling that an undiagnosed family member doesn’t need a conversation - participant or others they might talk to think it is unnecessary to discuss diabetes with someone who doesn’t have diabetes
f. Facing judgement when confronting others about T2DM - participant feels like others get defensive when they bring up diabetes

4. Facilitating Positive conversations about T2DM - participant offers ideas of or describes experiences of how to talk about diabetes with others (and have more success)
   a. Talking in groups - participant describes the use of group conversations

5. Communicating about family history - participant discusses how family health history information is shared between their relatives
   a. Not sharing family history/medical information*
   b. Open conversations about family history*

Sharing information about diabetes

1. Medical advice/education - participant describes some form of advice they have received or read about diabetes
   a. Reversal - participant describes or emphasizes the ability to reverse T2DM
   b. Questions - participant asks questions to other participants about things they don’t know or aren’t sure about
   c. Other information sharing - participant describes other aspects of diabetes diagnosis, management, care, prevention, etc.

Support to others

1. Mutual support - participants describes ways that they support one another and/or support or feel supported by friends or family members
2. Expressing concern for family members and others - participant describes worrying about other people in their family in relation to T2DM
   a. Concern - with diagnosis - use this if participant specifically describes worrying about someone in their family who has diabetes
   b. Concern - At risk - use this if participant specifically describes worrying about someone in their family who does not have a current diabetes diagnosis (but may be at risk)
3. Wanting to educate others - participant expresses a strong desire to reach out to others and teach them about diabetes and/or possible risk

*Consensus was reached in the first order in addition to those codes with an asterisk
Appendix V Interview Codebook

1. Memories of the story circle
   a. General story- participant describes a nonspecific theme they remember hearing about
   b. Specific story- participant describes a specific story they remember
   c. Being able to talk to others in a group- participant describes something related to the participating in a group
   d. Learning something new- participant focuses more on a specific idea/concept they learned from participating rather than a story or theme

2. Comfort in the circle
   a. Comfortable- Participant describes feeling comfortable
   b. Uncomfortable- Participant describes feeling uncomfortable

3. Group Discussion
   a. Knew everyone- participant describes liking that they knew everyone in the group
   b. Feel less isolated/intimidated- participant describes feeling less alone with their diagnosis and more willing to talk about it in the presence of others in the group
   c. Learn from one another- participant emphasized the opportunity to learn from other people’s experience/knowledge base

4. Discussions/conversations after the story circle
   a. New people/setting- person describes speaking to new people since participating
   b. New discussions- participant describes change in conversation topics or outcomes in discussions with people they have previously discussed DM with
   c. New intentions- participant intends to talk to new individuals or use new tactics to discuss DM but has not yet had the opportunity to do so
   d. Support to current conversations- participant describes a continuation of previous conversations supported by their participation in the story circle
   e. No change- participant has not experienced any change in discussions nor has any specific plans to change their conversations

5. Changes in participant
   a. Lifestyle/behavior changes- participant describes one or more specific things that they have changed in the way they live after participating
   b. Intent to change- participant describes changes they plan to make after participating
   c. Attitude change- participant describes a change in attitude since participating
   d. Knowledge change- participant describes something they learned after participating
   e. Support to current lifestyle- patient describes behaviors/attitudes/knowledge they previously had that was supported by participating
   f. Unsure of change- participant is unsure if anything has changed or ideas of things they could change

6. Changes in others
   a. Others lifestyle/behavior changes- participant describes the way participating has led to changes in behaviors in other people
   b. Other communication changes- participant describes ways family members or others have changed in their communication since participating
   c. Others- support- participant describes how others have continued behavioral or communication habits after participating
d. Other-lack of change- participant describes a lack of change in others

7. Barriers
   a. Remaining barriers- participant describes additional factors that prevent changes in behavior/communication
   b. No additional barriers- participant feels that no additional factors are preventing desired communication/behaviors

8. General comments/feedback about story circles
   a. Easier to speak in a group- participant described it being easier to speak in a group/aspects of the group that allowed him/her to be open or comfortable
   b. Enjoyed support- participant describes the value of support within the group(s)
   c. Continued support- participant describes way(s) that support has continued between participants since the story circles
   d. Change in opinion- participant was unsure about opening up during story circle but had a better experience than expected
   e. Wider application- participant feels that group story circles should be applied more widely
   f. Desire to promote knowledge- participant describes wanting to continue to educate others about DM/things they learned

9. New Ideas
   a. Ideas to promote future conversations- participant offers new ideas about how to communicate with others
   b. Other DM experiences- Participant brings up other experiences they had or someone they know had with DM