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FOCUSED ETHNOGRAPHY: STORYTELLING FOR HISPANICS
WITH LOW HEALTH LITERACY AND DIABETES

by

VIRGINIA HAMILTON CADENHEAD

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy in Nursing
School of Nursing

Beth Mastel-Smith, Ph.D., Committee Chair
College of Nursing and Health Sciences

The University of Texas at Tyler
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The University of Texas at Tyler
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Dedication

This dissertation is dedicated to the five women who took time out of their busy lives to listen to my stories and share their stories with me.

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This research could not have been done without a team of people helping me at every step. I am grateful for Dr. Beth Mastel-Smith, who encouraged me in my research long before she was officially my advisor, and my committee members for giving input and excellent advice. I am grateful to the women in my home group who helped me recruit and find participants, and then encouraged and prayed for me. I am so grateful for my husband, who has been there since I started, helping me in a thousand ways. Finally, I am grateful to God who gave me the opportunity to do research that glorified His name through helping others.

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Abstract

FOCUSED ETHNOGRAPHY: STORYTELLING FOR HISPANICS WITH LOW HEALTH LITERACY AND DIABETES

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Background: Storytelling is an intervention for health communication that has many forms, addresses varied health issues, and is suitable for low health-literate populations. Storytelling can impact knowledge, behaviors, attitudes, and health outcomes. *Population Focus:* Fictional storytelling has not been researched as an educational adaption in diabetes self-management for Hispanics with low health literacy. Forty-one percent of Hispanics in the United States have low health literacy, a contributing factor to poor health outcomes in chronic disease management. The Hispanic population has disproportional rates of diabetes complications. *Research Question:* How can short, fictional, orally presented stories be developed as culturally-adapted educational tools to improve diabetes knowledge and influence health behaviors for Hispanics with diabetes and low health literacy? *Method:* Using the qualitative research tradition of focused ethnography, five members of the Hispanic community with diabetes and low health literacy were exposed to five stories based upon recommended diabetes education, which was followed by their participation in qualitative interviews. The interview transcripts were analyzed for the concepts from the Learner Verification Interview and the Storytelling/Narrative Communication Theory. Following story revision based upon the data, the stories were shared with two participants to confirm data saturation. *Findings:* The research process produced five culturally

adapted stories. The data indicated that storytelling resulted in diabetes knowledge and theoretically influenced health behaviors. An additional concept of reciprocity was identified.

Recommendations: Research is needed to verify the impact of the stories on diabetes knowledge and health behavior, and to apply the model of story development to other topics and populations.

Chapter 1: Overview and Purpose of the Research Focus

Storytelling is a traditional communication strategy that changes attitudes and shares knowledge, but its use in health communication has been more recent. Programs such as Community Transformation Training (Olsen et al., n.d.) taught international healthcare workers to create and use storytelling for many health issues, but the value and effectiveness of storytelling has not been well researched. This research portfolio presents the definition, and review of research about the topic of storytelling as a health communications strategy. The articles in Chapter 2 and 3 give essential background to the understanding and application of storytelling as an educational tool. The original research in Chapter 4 narrows the topic of storytelling by applying it to diabetes education for Hispanics with low health literacy. Chapter 5 provides a summary and recommendation for further research.

Storytelling

The original research and the review articles are related to the application of storytelling as a health communication strategy. Oral, non-literate cultures have preferred to communicate verbally (Nordquist, 2019) and to use storytelling to learn and communicate facts (Ong, 2013). “Chapter 2: Concept Analysis - Storytelling as a Teaching Strategy in Health Communication” helped to define and clarify storytelling in health communication based upon current and past research. The state of the science review, “Chapter 3: Storytelling - An Educational Intervention for Oral Learners,” has summarized the literature about storytelling in oral, low-literacy cultures.

“Concept Analysis - Storytelling as a Teaching Strategy in Health Communication” revealed gaps in the understanding of storytelling. The literature had many different labels for storytelling: (a) narrative health messages (Frank et al., 2015), (b) culturally appropriate

storytelling (Houston et al., 2011), (c) patient narratives (Campbell et al., 2015), and (d) entertainment education (Lamb et al., 2018). Researchers used the term storytelling when discussing a variety of formats. Storytelling was described as (a) first-person storytelling (Lipsey et al., 2020), (b) fictional storytelling (Haigh & Hardy, 2011), and (c) story-sharing groups (Greenhalgh, 2006; Gucciardi et al., 2016). However, despite the different formats and applications, the defining attributes of storytelling were (a) interaction, (b) purpose, and (c) characters (Cadenhead, 2021).

The state of the science review, “Storytelling-An Educational Intervention for Oral Learners,” has been accepted for publication by the *Journal of Christian Nursing* (See Appendix A, Chapter 3). The publisher has granted permission to use the manuscript as part of a dissertation (See Appendix B, Chapter 3). Through a scholarly review of storytelling that integrates Biblical examples, this article explained the current research about storytelling for oral learners. The review summarized health issues addressed by storytelling and the formats and settings in which storytelling has been researched. The most common form of storytelling in the literature was first person storytelling (Bertera, 2014; Bokhour et al., 2016; Houston et al., 2011, 2017; Lipsey et al., 2019; Nguyen et al., 2017; Nguyen et al., 2018) and was often used in chronic disease management (Bertera, 2014; Gucciardi et al., 2017; Goddu et al., 2015; Houston et al., 2011; Houston et al., 2017; Nguyen et al., 2017; Njeru et al., 2015). Theoretical concepts that explained storytelling were included in the review (Hinyard & Krueger, 2007; Larkey & Hecht, 2010; Lee et al., 2016). Culture was an important factor in storytelling (Bertera, 2014; Bokhour et al., 2016; Larkey et al., 2015; Larkey & Gonzalez, 2007; Nguyen et al., 2017).

Diabetes Education

Diabetes is a chronic disease that has a global impact. It has been estimated that 422 million people have diabetes worldwide with 1.6 million deaths annually due to diabetic complications (World Health Organization [WHO], 2019). Diabetes self-management education is a recognized educational strategy for reducing complications and improving health outcomes (Powers et al., 2015), but many people have had no access to programs due to language and literacy barriers. In the United States, Hispanics have been particularly impacted by diabetes with higher death rates, more hospitalizations, and greater end stage renal disease than their Caucasian counterparts (Office of Minority Health, 2020). Forty-one per cent of Hispanics suffer from low health literacy (National Hispanic Council on Aging [NHCOA], 2015), a critical factor in successful glycemic control and diabetes management (Sakar et al., 2010). Storytelling as a health communication strategy in diabetes self-management has been researched in minority populations (Bertera, 2015; Greenhalgh, 2006; Utz et al., 2008) but not in the Hispanic population with low health literacy.

Original Research

The original research, “Focused Ethnography-Storytelling for Hispanics with Low Health Literacy and Diabetes,” has narrowed the focus of storytelling to a specific topic and population. The focused ethnographic qualitative research filled a knowledge gap about oral, fictional storytelling as an educational strategy for Hispanics with low health literacy and diabetes. The culturally appropriate short fictional stories designed to impact health knowledge and influence health behaviors were developed through focused ethnographic interviews. The result of the qualitative analysis of the learner verification interviews was five stories that were culturally adapted as educational tools for diabetes self-management education for Hispanics with low

health literacy. The qualitative findings suggested that storytelling interventions imparted diabetes knowledge to the low health literate participants and theoretically influenced health behaviors. This formative research provided a model for the development of culturally adapted storytelling as an intervention for low health-literate ethnic minorities.

Conclusion

Taken together, the review articles in Chapters 2 and 3 and the original research in Chapter 4 have provided a body of knowledge about storytelling in health communication and its application to a specific health issue: diabetes education in Hispanics with low health literacy.

Chapter 2: Concept Analysis - Storytelling as a Teaching Strategy in Health Communication

Abstract

Aim: To identify and clarify the concept of storytelling as a teaching strategy in health communication. *Background:* Storytelling is a recommended cultural adaption for individuals with oral traditions or low literacy, but the literature is not clear in defining or applying storytelling as a teaching strategy. *Design:* Concept analysis following the guidelines of Walker and Avant. *Data Source:* Electronic data bases searched include CINAHL, PubMed, along with reference and bibliographic searches. Search terms included storytelling, narrative storytelling, health education, patient education, and narrative communication. *Results and Conclusions:* Storytelling in health communication is a tool with the defining attributes of interaction, purpose, and characters. The use of storytelling as a teaching intervention in health communication requires the presence of a storyteller and a listener, a story, and health information. The results of storytelling in health communication vary depending upon the purpose but include changes in the storyteller or the listener such as increased knowledge, behavior change or improved health outcomes. *Clinical Relevance:* Storytelling is a teaching intervention that comes in many forms and is uniquely suited for oral communicators or individuals with low health literacy. Research is needed to further develop storytelling and apply it to current health issues.

Key words: Storytelling, health communication, patient education, narrative communication

Concept Analysis - Storytelling as a Teaching Strategy in Health Communication

Fourteen per cent of the world's population is illiterate (Roser, 2018) and an estimated 70% prefer oral learning methods (Moon, 2016). Storytelling offers an innovative strategy for sharing health information in these populations (Day, 2009). The purpose of this concept analysis is to clarify storytelling as a teaching strategy in health communication. Understanding and applying this concept will give nurses an educational tool to positively impact health disparities and potentially improve health outcomes.

Significance of Concept to Nursing

Storytelling is a recommended cultural adaption for sharing health information with people who have oral traditions or low literacy (Palacios et al., 2015; Thompson, 2015). Storytelling interventions improved chronic disease management among minority populations and changed health behaviors (Betera, 2015; Goddu et al., 2015; Houston et al., 2011; Houston et al., 2017; Shen et al., 2015). A form of experiential teaching/learning, storytelling enables the listener to understand health information and apply it to their life situation (Day, 2009; Greenhalgh, 2006). Despite these recommendations, there is a lack of clarity about storytelling as an educational strategy. A more precise understanding will help nurses apply storytelling as an educational tool to reduce health disparities in at risk populations. Following the guidelines of Walker and Avant (2005), this concept analysis includes: a) identification, b) defining attributes, c) models, d) antecedents, e) consequences, and e) empirical referents.

Concept Identification

The dictionary definition of storytelling is “the telling or writing of stories” (Dictionary.com, n.d.). Schank and Berman described storytelling as organized and structured retelling of both fictional and real experiences (2002). Stories are events that are linked with

characters and have an ending (Larkey et al., 2009). As a form of narrative communication, stories tell about striving for goals, and what is learned in the experience (Schank & Berman, 2002). Nursing theorists define storytelling as a distinct form of narrative communication that uses stories retold verbally or in other mediums (Frid et al., 2000). Storytelling is the act of communicating these stories, often with additions and embellishments (Haigh & Hardy, 2011). Telling stories is an experience that transports the listeners to another world and changes the way they view their own world (Busselle & Bilandzic, 2008). For this reason, storytelling can communicate complicated messages, ideas, and emotions (Remenyi, 2005). It links the past to the present, and anticipates the future (Frid et al., 2000).

There are many forms and labels for storytelling interventions in the literature. Narrative health messages (Frank et al., 2015), culturally appropriate storytelling (Houston et al., 2011), patient narratives (Campbell et al., 2015), and entertainment education (Lamb et al., 2018) are terms used for storytelling. Some theorists use the term narrative as a personal history, and storytelling as fictional stories shared for a particular purpose (Haigh & Hardy, 2011; Hinyard & Kreuter, 2007; Lee et al., 2016). Lipsey et al.(2019) used the term first person storytelling for the sharing of personal experiences by the narrator. Other researchers used the term storytelling to describe story sharing groups where individuals who have experience with a disease share that experience in a group setting (Greenhalgh, 2006;Gucciardi et al., 2016). In this analysis, storytelling will encompass all these forms: first person, fictional storytelling, and story sharing groups.

The purpose and formats of storytelling as a strategy in health communication are diverse. Stories can be designed to inform and change behavior (Lee et al., 2015; Shen et al., 2015) or share feelings and ideas (Hinyard & Krueter, 2007). Formats for storytelling reported

in health communication included written, digital, film, radio, drama, and oral (Bertera, 2014; Campbell et al., 2013; Goddu et al., 2015; Houston et al., 2017; Larkey et al., 2009; Njeru et al., 2015). The literature described first person storytelling in a video format where individuals shared their own disease experience to help others manage diabetes or hypertension (Bertera, 2014; Campbell et al., 2013; Houston, 2017). Fictional stories presented digitally were used for health promotion and prevention (Lamb et al., 2017; Li & Yu, 2018), and story sharing in groups supporting diabetes education (Greenhalgh, 2006).

Storytelling in health communication is a tool. As a teaching/learning tool, storytelling helps the listener remember events, and gives structure to facts and details as they reflect on the story (Schank & Berman, 2000). Storytelling in nursing research is a tool used to gain understanding and knowledge about the patient and their care (Smith & Liehr, 2005). Story sharing groups were tools that helped participants understand their disease (Greenhalgh, 2006).

Defining Attributes

Based upon the review of storytelling in health communication certain defining attributes, characteristics most often associated with the concept, emerge. These defining attributes include a) interaction b) purpose c) character.

Stories are a basic mode of human communication that involve interaction (Hinyard & Krueter, 2007). In a shared experience, the listener interacts with the storyteller, and the story. Smith and Liehr describe this interaction in nursing as a nurse-person relationship (2007). As the story unfolds, the listener is transported into the narrative by engaging with the story and identifying with the events and characters (Green & Brock, 2000). The interaction between storyteller and listener leads to reflection, part of experiential learning (Greenhalgh, 2006).

Purpose is a second defining attribute of storytelling in health communication. In the story theory by Smith and Leibr (2000) or Frid's examination of narratives in nursing research (2005), storytelling had the purpose of developing nursing knowledge. However, storytelling as an educational intervention imparted knowledge (Lamb et al., 2017; Larkey et al., 2015; Moran et al., 2016), changed health attitudes (Larkey et al., 2009), and improved health outcomes (Houston et al., 2011). In chronic disease management, storytelling helped participants reflect on their illness and create meaning and purpose (Gucciardi et al., 2016). In health promotion, storytelling interventions increased health knowledge about cancer and immunizations (Lamb et al., 2017; Larkey et al., 2015; Moran et al., 2016).

A third defining attribute of storytelling in health communication is the presence of characters or personalities within the story. The character might be the narrator themselves as in first person storytelling (Bertera, 2014; Campbell, et al., 2015), or a fictional personality dealing with an event such as colon cancer screening (Larkey, 2009). According to Green and Brock, the more the listener identifies with the characters, the more effective the story is in communicating health messages (2000). Storytelling is culturally relevant health communication when the characters reflect the target culture's ideas and beliefs, adding credibility to the story (Larkey & Hectht, 2010; Palacios et al., 2015).

Model Case/Contrary Case/Borderline Case

In a concept analysis, a model case serves as an example to clarify the concept. A model case exhibits all the defining attributes. Larkey et al. provided a model of storytelling as health communication strategy (2009). The authors described fictional storytelling used for the purpose of educating Latina women about colorectal cancer screening and prevention. The characters in the story are a father, mother, and children who confront a possible diagnosis of colon cancer

following a routine screening process. The health prevention strategy of eating more fruits and vegetables is presented along with risk factors for development of colon cancer. The story ended with the father getting a negative report and the mother deciding that based upon the risk factors she will schedule a screening for colorectal cancer. Community health workers told the story to the Latina women in the language of choice. Women exposed to the storytelling intervention had a significantly increased desire to obtain cancer screening and share the information from the story with their friends as opposed to women exposed to an educational session with a risk screening tool (Larkey et al., 2009). This research example has the defining attributes of storytelling as a health communication strategy. Interaction takes place between the community health worker and the participants. The purpose is education about colorectal cancer, and the characters in the story are the father, mother and children.

A contrary case has no defining attributes, and a borderline case contains some attributes. An example of a contrary case is when a provider fails to address a health care concern and no education, characters, or purpose are shared. Two borderline cases, where some but not all the defining attributes is included will clarify the concept. A nurse providing patient education about colorectal cancer gives a didactic handout about colorectal cancer risks. The defining attribute of purpose is present but there is little interaction and no characters. A nurse sharing a story with her patient about her personal life experience unrelated to the patient's diagnosis would include both interaction and characters but not meet the defining attribute of purpose.

Antecedents and Consequences

Antecedents of a concept are situations that must occur prior to the manifestation of a concept (Walker & Avant, 2006). In the case of storytelling as a health communication strategy,

the antecedents include a story, participants, and health information. The consequences, or outcomes, of storytelling are changes in either the storyteller or the listener.

An antecedent of storytelling is a story about an event or a person. The story could be personal testimony as in first person storytelling, where an individual shares their experience with the disease process (Bertera, 2014; Houston et al., 2017). In the story-sharing group the event is the storyteller coping with their disease (Greenhalgh, 2006). The story could be a fictional event, such as a family discussion about getting a vaccine (Frank et al., 2015). Every story has an event that confronts the character/s, real or fictional. The event presents a problem, the characters' response to the problem, and a resolution to the problem (Schank & Berman, 2002; Larkey & Hecht, 2010).

For storytelling to happen, it must have participants - listeners and storytellers. The setting can vary, as well as the distance between the participants and storyteller. Storytelling can take place within the context of a support group (Guiccardi, 2016), or a face-to-face oral presentation in an educational setting (Larkey et al., 2009; Guiccardi et al., 2016). The storyteller could be recorded on a DVD for the listeners to view in their own home (Moran et al., 2014; Bertera et al., 2014; Campbell et al., 2014).

A third antecedent of storytelling in health communication is health information. The purpose of the storytelling session determines the information in the story. The information is chosen and embedded into the narrative, such as a fictional story of a father discussing the risks of colorectal cancer with his family (Larkey et al., 2009). Health information can come from the storytellers' personal experience, as in the case of African American veterans sharing their struggles with hypertension (Houston et al., 2011). The health information can be spontaneously told with the story, such as in a story sharing group (Greenhalgh, 2006).

The consequence of storytelling in health communication is an experience that changes either the storyteller or the listener. Storytelling participants demonstrated increased knowledge about chronic diseases such as hypertension or diabetes (Bertera, 2014; Campbell et al., 2014), and improved understanding about cancer (Lamb et al., 2017, Larkey et al., 2015). As the participants understood their diseases through the storytelling process, they improved self-efficacy, the belief that they could manage their illness (Bertera, 2014; Weiland et al., 2017). Consequences of storytelling can be changes in health behavior, such as increased cancer screening or eating more fruits and vegetables (Larkey et al., 2015). Storytelling interventions improved health outcomes such as blood pressure or glycemic control (Houston et al., 2011; Wieland et al., 2017). Finally, storytelling interventions in health communication have resulted in a sense of meaning as the storyteller and listener reflected and shared their experiences in stories (Guccuardi et al., 2016).

Empirical Referents

Empirical referents answer the question of how a concept is seen and measured in the real world (Walker & Avant, 2007). The actual outcomes, or empirical referents measured were related to the purposes of the storytelling intervention and the type of research. Some researchers evaluated outcomes of storytelling using qualitative methods such as focus groups or interviews (Goddu et al., 2015; Njeru et al., 2015). These researchers coded the data from the interviews for engagement, identification with the characters, and motivation to change (Goddu et al., 2015; Njeru et al., 2015). Quantitative methods measured changes in the participants using standardized instruments that demonstrated increased self-efficacy, or intention to change behavior (Bertera, 2014; Campbell et al., 2013; Larkey et al., 2009). Other researchers used instruments to measure health knowledge for a specific health issue such as cervical cancer or

hypertension (Bertera, 2014; Lamb et al., 2017). Storytelling interventions that improved health outcomes had physiologic measurements such as hemoglobin A1C or blood pressure (Houston et al., 2011, 2017; Weiland et al., 2017). Some researchers alluded to changes in the storyteller as well, but no measurements were done to evaluate those changes (Gucciardi, 2016).

Conclusion

Based upon this concept analysis, storytelling in health communication is a tool for purposeful interaction between participants that includes the recounting of events with characters to communicate health information. When used as an educational strategy, storytelling can decrease health disparities by increasing health knowledge and changing health behaviors. As demonstrated by the literature, stories can be developed, taught, and shared for many health concerns, and are particularly valuable in cultures with an oral tradition. Storytelling is a teaching tool that can be easily adapted for clients with low literacy, even when teaching complex health issues such as self-management of chronic diseases. Storytelling can use technology but is not dependent upon technology, making it a valuable tool for low and high resource health systems. Storytelling has the potential to improve health outcomes for many at risk populations, but further research is needed to determine the best way to develop and apply storytelling as an educational strategy in health communication.

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Chapter 3: Storytelling - An Educational Intervention for Oral Learners

Author Note

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Abstract

This state of the science review synthesizes the current literature and theoretical background of storytelling as a health communication tool for oral learners. The term storytelling encompasses first person storytelling, group led storytelling, fictional storytelling, and traditional storytelling. Health issues addressed by storytelling interventions include chronic disease management and cancer prevention. Storytelling is applicable globally in a variety of settings and formats from simple verbal stories to film and video presentations. Cultural considerations are important when using storytelling as a health communication tool. Both theoretical and Biblical examples explain how storytelling changes knowledge, behaviors, attitudes, and outcomes. Examples from the author's experience and the faith community reinforce the value of storytelling. While further research is needed, evidence indicates storytelling is an effective tool that nurses can use to fulfill their essential role of health teaching.

Key Words: Storytelling, oral learners, health communication

Storytelling - An Educational Intervention for Oral Learners

While working transculturally as a nurse in developing countries, I learned quickly that even the simplest written instructions were not useful to the people I was serving. Whether I was trying to explain antibiotic therapy to a mother with a sick child, or blood sugar to an elderly man with a foot ulcer, written instructions were useless. Many of the people I saw had some level of literacy, but reading was not their preferred way of communicating: they were oral learners. I began to use a method of teaching I learned from the Bible and my fellow missionaries called storytelling.

Purpose

This article is a state of the science review of storytelling in health communication for oral learners. Storytelling is a form of communication used in many cultures, but the research of storytelling in the context of health communication is a more recent phenomenon. This literature synthesis will help to clarify storytelling and explain how it has been applied as an educational intervention. Examples from the Bible, and the author's personal experience with storytelling will add understanding about the use of storytelling as a health communication strategy for oral learners.

Orality Defined

Orality is the preference for oral communication found in many cultures with very low literacy (Nyquist, 2019). These cultures rely on verbal forms of communication such as stories, songs, and proverbs to share information. As many as 70% of the world's population have an oral learning preference (Moon, 2016). This preference is on a continuum (Maxwell & Macauley, 2006). Some cultural groups exist with no written language relying completely on spoken communication (Thompson, 2017) while other people groups prefer to communicate

using oral methods even when they are literate (Moon, 2016). Experts in orality recommend the use of storytelling as a communication strategy to teach oral learners from cultures with oral preferences (Thompson, 2017).

Search Strategy and Inclusion Criteria

The terms “storytelling” or “narrative communication” were combined with “patient teaching” or “patient education” and restricted by publication after 2010, in a search of CINAHL and PUBMED in May of 2020. Criteria for inclusion in the state of science review were peer reviewed studies that discussed storytelling as an intervention for a population identified as having an oral tradition, low literacy, or low health literacy. No studies were found that measured orality directly. Articles were selected based upon the criteria from the databases, with additional bibliographic searches. Review articles were also included which provided understanding about the concept of storytelling, making a total of 24 articles. Two articles by Nguyen et al. (2017, 2018) were combined as they reported on the same study. See Table 1 for a list of the articles selected and the types of research on storytelling discussed in this review.

Synthesis of Existing Science

Storytelling

Storytelling is the retelling of both fictional and real experiences (Schank & Berman, 2002). Storytelling, a form of narrative communication, recounts past events or relates a created story designed to educate and bring about change (Lee et al., 2015). Narrative health messages (Frank et al., 2015), culturally appropriate storytelling (Houston et al., 2011), patient narratives (Greenhalgh et al., 2005; Moran et al., 2016), and entertainment education (Lamb et al., 2017; Shen et al., 2015) are terms used for storytelling in the literature. Telling stories is an experience

that transports the listener to another world and changes how they view their own world (Busselle & Bliandzic, 2008).

Health Issues

Storytelling has many categories and has been applied to a variety of health issues. Researchers used the term storytelling to discuss four distinct forms or categories of narrative communication: first person storytelling, group led storytelling, fictional storytelling, and traditional storytelling. The literature was not always clear as to the type of storytelling utilized, but often it was possible to infer based upon the description of the research.

First person storytelling and group led storytelling were both used in chronic disease management. First person storytelling was represented when someone recounted their own experience, particularly with disease management (Bertera, 2014; Bokhour et al., 2016; Houston et al., 2011, 2017; Lipsey et al., 2019; Nguyen et al., 2017; Nguyen et al., 2018). Like a personal testimony, “star storytellers” were identified to share their experience of overcoming a particular health issue (Bertera, 2014; Bokhour et al., 2016; Fix et al., 2012; Houston et al., 2011, 2017; Nguyen et al., 2017, 2018). This category of storytelling was researched in the context of chronic disease management such as diabetes and hypertension (Bertera, 2014; Gucciardi et al., 2017; Goddu et al., 2015; Greenlaugh et al., 2011; Houston et al., 2011; Houston et al., 2017; Nguyen et al., 2017; Njeru et al., 2015). Greenhalgh et al. used the term storytelling to describe group led storytelling where individuals share their disease experiences within a support group context (2005; 2011). The sharing of personal stories within the group improved self-confidence to manage diabetes (Greenhalgh et al., 2011).

Both fictional and traditional storytelling have been used for health teaching. Fictional storytelling was the telling of stories developed to communicate health messages (Briant, 2016;

Kepka et al., 2012; Frank et al., 2015; Larkey & Gonzalez, 2007; Larkey et al., 2009; Moghimian et al., 2019; Moran et al., 2016; Sabaretnam et al., 2019). Fictional stories were shared to address cancer prevention, targeting specific ethnic populations (Kepka et al., 2012; Lamb et al., 2017; Larkey et al., 2015; Larkey & Gonzalez, 2007; Larkey et al., 2009). Examples include a story about a Hispanic family discussing with their father the benefits and risks of colorectal cancer screening (Larkey et al., 2008), or the story of a woman from rural India who finds she has a thyroid tumor (Sabaretnam et al., 2019). Traditional storytelling was the fourth type of storytelling found in the health sciences literature. Hearing traditional stories based upon their cultural symbols can help individuals understand and cope with an illness (DeBruyn et al., 2020). An example of this was utilizing fables and stories with recognized traditional symbols in diabetes education for native peoples in Canada (Carter et al., 1999).

Formats

Storytelling is a flexible tool that has been used in high and low technology situations, with a variety of mediums. Video or DVD was the most common delivery method noted (Bokhour et al., 2016; Houston et al., 2011, 2017; Larkey et al., 2015; Lamb et al., 2017; Nguyen et al., 2017, 2018). One study described utilizing techniques from theatre arts to train the storytellers before recording the sessions with a professional video production team (Fix et al., 2012). In Viet Nam, researchers had to give DVD players to the participants for them to watch the DVD storytelling intervention (Nguyen et al., 2017, 2018). Another low resource area used the clinic waiting room to show the recorded storytelling sessions (Lamb et al., 2017). Community health workers shared stories orally in face-to-face sessions for cancer prevention (Larkey et al., 2007; Larkey & Gonzalez, 2009), while other researchers reported using a combination of video storytelling with group led storytelling (Njeru et al., 2015; Wieland et al.,

2017). Theoretically, storytelling with songs or drama would be effective for people with an oral tradition (Moon, 2016), but there were no studies reviewed that directly addressed those formats.

Setting

The community, the clinic, the home, and the hospital were all locations for storytelling interventions. Storytelling videos shared in low cost, urban, housing developments encouraged residents to eat less salt and exercise regularly (Bertera, 2014). Interventions for outpatient clinics (Bokhour et al., 2016; Houston et al., 2011; Houston et al., 2017; Goddu et al., 2015; Lamb et al., 2017; Larkey et al., 2015) and recorded storytelling viewed in the home (Nguyen et al., 2017; Moran et al., 2016) demonstrated positive outcomes.

Culture

Integration of the target culture was an important consideration for storytelling in health teaching (Bertera, 2014; Bokhour et al., 2016; Larkey et al., 2015; Larkey & Gonzalez, 2007; Nguyen et al., 2017). Storytelling as an educational tool for oral learners should reflect the learner's culture (Larkey & Hecht, 2010), making it more effective in changing health behaviors (Shen et al., 2015). Theoretically, as the listener engages with the story, they identify with the characters, and reflect on their own life situation (Lee et al., 2015). The specific cultures targeted by storytelling included: Hispanic (Kepka, 2012; Larkey et al., 2015; Larkey & Gonzalez, 2007; Larkey et al., 2008; Moran et al., 2016; Njeru et al., 2015), African American (Bertera, 2014; Houston et al., 2011; Houston et al., 2017), Native American (DeBruyn et al., 2020), Somali (Wieland et al., 2017), rural Vietnamese (Nguyen et al., 2017, 2018), Bangladeshi (Greenhalgh et al., 2011), Hindi (Sabaretnam et al., 2019) and Colombian (Lamb et al., 2017). To ensure cultural integration, many researchers described development of the storytelling interventions using qualitative methods such as interviews and focus groups (Fix et al., 2012;

Greenhalgh et al., 2005; Kepka et al., 2012). Another form of research used to develop culture centric stories was community based participatory research, where community members were active partners with the researchers during the development and application of storytelling (De Bruyn et al., 2020; Njeru et al., 2015).

Outcomes

Storytelling has resulted in positive changes in health knowledge, health behaviors, health attitudes, and health outcomes. Table 2 is a list of the interventional and review studies with significant outcomes summarized. Most interventions compared storytelling to usual education, or factual presentation (Bertera, 2014; Bokhour et al., 2016; Houston et al., 2011; Larkey & Gonzalez, 2009; Lamb et al., 2017; Moran et al., 2016). Knowledge about hypertension, diabetes self-management, and cancer prevention were significantly improved (Bertera, 2014; Larkey & Gonzalez, 2009; Moran et al., 2016). A large, randomized control trial demonstrated that storytelling interventions significantly decreased blood pressure over usual education (Houston et al., 2011). Health behaviors such as eating healthier improved with storytelling interventions (Larkey & Gonzalez, 2009). One study in rural Vietnam found that medication adherence significantly improved with storytelling interventions (Nguyen et al., 2017; Nguyen et al., 2018). Storytelling changed health attitudes by increasing patient engagement in educational sessions (Bokhour et al., 2016; Houston et al., 2017), which translated into higher attendance in self-management classes (Greenhalgh et al., 2011). Storytelling interventions increased confidence for disease self-management (Bertera, 2014; Greenhalgh, 2011) and decreased anxiety after coronary artery interventions (Moghimian et al., 2019). Two studies did not demonstrate changes in health outcomes when comparing didactic education to storytelling interventions (Houston et al., 2015; Larkey et al., 2015). Both studies

had confounding factors in the control group that make the results unclear. In one study the control group received didactic education that included an oral presentation on DVD, an intervention that was still appropriate for very low literate learners (Houston et al., 2017). The other study had community health workers assisting both control and intervention participants to get cancer screening - the measured outcome of the storytelling intervention (Larkey et al., 2015).

Theoretical Model

The literature offers many theoretical perspectives as the basis of storytelling interventions. Larkey and Hecht's model of culture-centric narratives in health promotion explained both prevention and intervention strategies (2010). This model discussed the importance of transportation into the narrative as well as identification with the characters (Larkey & Hecht, 2010). Hinyard and Krueter agreed that storytelling is most effective when the listener identifies with the characters and experiences the story. They used the social cognitive theory to explain how storytelling increases confidence in the ability to self-manage chronic diseases (Hinyard & Krueter, 2007). Theoretically, storytelling can overcome resistance to change. Involvement in the story allows the listeners to consider new ideas or ways of coping with their disease (Hinyard & Krueter, 2007). The Storytelling/Narrative theory combined nursing theory with communication theory and explained how culturally relevant stories that appeal to the listener can bring about changes in knowledge, attitudes and behavior through transportation into the story, realism, and identification with the characters (Lee et al., 2016).

Biblical Examples

Jesus lived and worked in an oral culture. He was a master communicator who used stories to motivate and communicate with his audience. The Bible gives many examples of Jesus

and his disciples using storytelling as a teaching strategy. Categories of storytelling in the Bible include first person, group led, and fictional. Jesus' disciples frequently shared their own experiences in a form of first-person storytelling to encourage others to make life changes (Acts 2:14-36). The early believers and the disciples used a form of group led storytelling with testimonies to animate and learn from one another (Philippians 2: 27-30). Jesus tells the fictional story of the Good Samaritan to help his listeners understand about mercy and racism (Luke 10: 30-36).

Like the research literature, storytelling in the Bible reflects the culture of the listeners. Jesus understood his audience and used their culture to make his stories relevant. He shared about sowing seeds with farmers (Luke 8: 4-15), or lost sheep with shepherds (Luke 15: 1-7). Jesus told stories to help people reflect, and change their attitudes, such as the prodigal son - a story about two brothers and their relationship with their father (Luke 15: 11-32). The Bible has powerful examples of storytelling that changed attitudes or beliefs. At Pentecost, Peter shared his experience of the resurrection of Jesus and 3000 people began following Christ (Acts 2: 22-41). The Biblical examples of storytelling demonstrate the power and effectiveness of stories to change lives and impact communities. Missionaries and ministers have followed the Biblical example of storytelling as a teaching intervention for oral learners, using it to share about the life of Jesus and disciple new believers (Moon, 2015).

Discussion

The synthesis of research literature answers the question of how storytelling has been researched and applied in health communication with oral learners. This review explained that storytelling is effective in many different settings, for many purposes, and in many different cultures. The formats of storytelling varied from complex such as recorded videos to simple

verbal stories. One constant in the variety of storytelling research was the importance of culture for the application and development of stories. The theoretical models provide further understanding of how storytelling has been used as a health communication intervention for oral learners. The cultures and countries represented by the research show the global application of this health communication strategy.

Nursing Application

Nurses should be aware that many people have oral learning preferences and adapt their educational strategies appropriately. By observation and questions, the nurse who is aware of orality can identify when storytelling might be helpful. Oral learners are found in many places both in the United States and other parts of the globe. Through an educational change project about low literacy the nurses on a postpartum unit in rural Texas became aware that many of their Hispanic mothers could not read the handouts given them in Spanish (Cadenhead, 2016). Non-literate adults do not receive information in written forms, and they will not communicate with others through writing (Thompson, 2015). Therefore, one clue to identifying oral learning cultures, is to observe how they prefer to receive information. While oral learning preference is not the same as low health literacy or limited English proficiency, they are related (Sentell & Braun, 2012). A screening question for low health literacy is: Do you have difficulty filling out medical forms for yourself? The research indicates that a positive answer to this question will identify low health literacy about 80% of the time (Chew et al., 2008).

Once low health literacy is identified, the nurse can adapt teaching techniques. The nurse can take the role of cultural learner by asking patients to help in the development of stories for specific topics. These stories can be shared with patients who have similar health issues and cultural backgrounds. Storytelling can be integrated into existing forms of patient education by

adding a story to explain procedures or embedding stories within already developed education programs. In one study, adding personal stories of coping with diabetes into existing diabetes education programs resulted in improved glycemic control for African American participants (Goddu et al., 2015). In the author's personal experience working in outpatient clinics in Guatemala and Texas, a simple story about how metformin works with insulin as a lock and key helped to teach very low literate type two diabetic patients. In rural Viet Nam, storytelling DVD's helped patients understand their hypertension and the need to take medication (Nguyen, 2018). Using dolls to tell a story about family roles helped the author and her partner communicate about addiction among the street people of Guatemala City.

Storytelling is reproducible, adaptable, and useful for nurses wanting to fulfill their essential role of patient education. The setting and resources will help determine how storytelling can be applied. This review has covered many adaptations to patient education - including simple verbal stories to communicate health information, the patient's sharing of their own stories with one another, or production of storytelling videos to share in patient waiting rooms.

Faith Based Nursing

Storytelling provides the faith community nurse with a tool to share both health information and spiritual truth, enabling transformation of communities and individuals. Storytelling is recommended as oral-based communication for faith based medical providers in community development (Fielding, 2008). A training program for cross-cultural faith-based workers in Central and South America is called Community Transformation Training (CTT). CTT recommends developing a culturally appropriate story for each community health lesson (Olsen et al., n.d.). The story includes a fictional community member with an identified

problem, and how they learned to correct the problem. For example, a child who plays in the dirt and then eats without washing their hands gets abdominal pain and diarrhea. The child learns to wash their hands and they no longer get sick. Each community health lesson also has a Bible story, or moral value lesson. In the example of the fictional child who gets sick from not washing their hands, the cross-cultural worker might share the story from Luke 7: 11-15 of how Jesus had mercy on the widow and restored her son to life. The lesson is that God loves all His children and cares about their needs. As the local community health workers learn the health story, they also learn the Bible story to share with their neighbors. The core value of community transformation training is the development of both spiritual and physical health within the community. Storytelling for spiritual and physical change is an integral part of this strategy.

Conclusion

This review summarizes the current data on storytelling as a health communication strategy for oral learners. It provides valuable information for nurses who seek to educate patients with very low literacy. The literature describes categories of storytelling and health issues that have been successfully targeted, as well as providing models of storytelling for patient education. The results were integrated with Biblical examples demonstrating the impact of storytelling as an educational tool. Additional examples were shared from the author's experience, the literature, and the recommendations of cross-cultural faith workers. The development of storytelling as an educational strategy has the promise of improving health disparities for much of the world's population with oral learning preferences. Further nursing research will help to identify oral learners, develop storytelling interventions, and impact target populations to improve health outcomes.

Table 3.1*Review Articles Classified by Category*

	Quantitative	Qualitative	Mixed Methods	Formative	Review
Bertera, 2014			X		
Bokhour et al., 2016	X				
DeBruyn et al., 2020		X		X	
Fix et al., 2012				X	
Gucciardi et al., 2016					X
Goddu et al., 2015		X			
Greenhalgh et al., 2005			X	X	
Greenhalgh et al., 2011			X		
Houssine al., 2011	X				
Houston,et al., 2017	X				
Kepka et al., 2012		X			
Lamb et al., 2017	X				
Larkey et al., 2015	X				
Larkey & Gonzalez, 2007	X				
Larkey et al., 2009	X				
Lipsey et al., 2020					X
Moghimian et al., 2019	X				
Moran et al., 2016	X				
Nguyen et al., 2017, 2018	X				
Njeru et al., 2015		X			
Sabaretnam et al., 2019	X				
Shen et al., 2015					X
Wieland et al., 2017			X		

Table 3.2*Outcomes of Storytelling Interventions*

	Knowledge	Behavior	Attitudes	Health Outcomes
Bertera, 2014	+	+	+	+
Bokhour, et al., 2016		+	+	
Gucciardi et al, 2016 (review)			+	
Goddu et al., 2015			+	
Greenhalgh et al., 2011			+	-
Houston et al., 2011				+
Houston et al., 2017			+	-
Larkey et al., 2015		+		-
Larkey & Gonzalez, 2009	+	+		
Larkey et al., 2008		+		
Lamb et al., 2017	+		-	
Lipsey et al., 2020 (review)			+	+
Moghimian et al., 2019			+	
Moran et al., 2016	+			
Nguyen et al., 2017 Nguyen et al., 2018		+		
Sabaretnam et al., 2019				
Shen et al., 2015 (review)	+	+		+
Weiland et al., 2017	+			+

Note. + = positive change, - = no change

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Appendix A

Acceptance Letter



Journal of Christian Nursing <em@editorialmanager.com>

Mon, Feb
15, 7:40 AM

to me

Feb 11, 2021

RE: NCF-JCN-D-20-00096R2, entitled "Storytelling-An Educational Intervention for Oral Learners"

Dear Ms Cadenhead,

I am pleased to inform you that your work has been accepted for publication in Journal of Christian Nursing. Thank you for making the requested revisions. All manuscript materials will be copy and content edited / checked, then forwarded to the production staff for placement in an upcoming issue. We may publish your article ahead-of-print online before in print, or online-only in conjunction with a print issue. Note that you will receive a final copy for proofing before the article is published.

As an accepted author we would like to thank you for sharing your work in JCN and invite you to join NURSE CHRISTIAN FELLOWSHIP at 43% off the regular membership fee. Go to <http://ncf-jcn.org/membership/join-ncfusa> to learn more.

Complete the membership form and when you are directed to make payment, enter DISCOUNT CODE: JCNA43.

We would love to have you be a part of NCF!

Thank you for submitting your interesting and important work to the journal.

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With Kind Regards,

Dr. Kristen Mauk
Senior Editor
Journal of Christian Nursing

Appendix B

Permission email

Hello Virginia,

The process around authors posting their articles in their dissertation is below:

Please note that you will not need written permission to use the final peer-reviewed manuscript in your thesis as long as the below policies are followed.

- The final published article may not be used in your thesis. The final peer-reviewed manuscript is the version that is permitted to be used.

- The final peer-reviewed manuscript may be used in the print and electronic version of your thesis. It may appear in the online version of your thesis 12 months after publication as long as the content is only posted to the institution's repository and not a third-party repository. We ask that if you have the ability to password protect your thesis that you do, but this is not a requirement.

- The following notice should appear with the manuscript: "This is a non-final version of an article published in final form in [provide complete journal citation]." A link to the publication on the journal website should be included

Regards

Tom

Chapter 4: Focused Ethnography: Storytelling for Hispanics
with Low Health Literacy and Diabetes

Abstract

Problem: Thirteen per cent of Hispanics in the United States have diabetes and 41 per cent have low health literacy, leading to poorer health outcomes in chronic disease management.

Storytelling has improved self-management education in chronic diseases, but the use of short fictional stories designed to teach diabetes self-management education for Hispanics with low health literacy has not been researched. *Objective:* The goal of this formative research was to develop and verify culturally adapted, short fictional stories to improve diabetes knowledge and influence health behaviors in Hispanics with low health literacy and Type 2 diabetes.

Method: Using a focused ethnographic design, five participants of Hispanic origin with low health literacy and diabetes experienced five storytelling sessions based upon recommended self-care behaviors followed by a semi-structured, learner verification interview. The written transcriptions and the field notes were coded and analyzed providing data for story adaption .

Two second storytelling sessions verified data saturation. *Theory:* The Storytelling/Narrative Communication Theory (S/NCT) and the learner verification interview provided structure for the development of stories as an educational intervention. According to the S/NCT, storytelling impacts health behavior through transportation, identification, and realism. *Findings:*

Storytelling sessions successfully met the educational goals but were best presented in order.

Adaptions were made to the stories to increase comprehension, realism, identification, and cultural acceptability. The result was five stories culturally adapted as educational interventions for Hispanics with diabetes and low health literacy. Reciprocity, where the participants share their own stories, was an additional theme identified in the storytelling process.

Keywords: storytelling, health literacy, Hispanic, diabetes education, learner verification
interview

Focused Ethnographic Research: Storytelling for Hispanics with Low Health Literacy and Diabetes

Forty-one percent of Hispanics in the United States suffer from poor health literacy (National Hispanic Council on Aging [NHOA], 2015), meaning they have decreased ability to obtain, process and understand their health (Centers for Disease Control and Prevention [CDC], 2019). Low health literacy is linked to poorer health outcomes (Berkman et al., 2011; Al Sayah et al., 2013). For the 56.5 million Hispanics in the United States, Type 2 diabetes has been one of the leading causes of death. The 13.2% of Hispanics with Type 2 diabetes were more likely to have an amputation of an extremity than their Caucasian counterparts and 2.6 times more likely to start treatment for end stage renal disease (Office of Minority Health, 2020). Because limited health literacy is linked to poor glycemic control (Sarkar, Karter et al., 2010), low health literacy (LHL) could account for disparities in health outcomes among Hispanics with diabetes.

Personal narrative in the form of first-person storytelling has enhanced chronic disease management (Gucciardi et al., 2016; Lipsey et al., 2020), and improved health knowledge among Hispanics (Larkey et al., 2009). Telling stories has the potential to change attitudes and health behavior (Lee et al., 2016) as well help oral learners organize and store knowledge (Thompson, 2015b). Educational interventions targeted at overcoming LHL in diabetic patients increased self-care behaviors and improved health outcomes (Kim & Lee, 2016). Storytelling as an educational intervention for diabetes self-management education for Hispanics with LHL has not been researched. There is a significant gap in the literature about the development and use of fictional storytelling as a health educational tool for those with LHL. Development and application of short fictional stories as an educational tool for Hispanics with LHL and diabetes can potentially improve health disparities by increasing knowledge and self-care behaviors. The

purpose of this study was to describe the creation of culturally appropriate, educationally valid stories for Hispanics with diabetes and LHL, detailing the process and adaptations of a storytelling intervention for the target population.

Review of Literature

The literature provided background for storytelling and its application to diabetes self-management in the target population. For the review of storytelling articles, searches were made over a three-year period of the data bases CINAHL, PUBMED, Google Scholar and Cochrane Database using the search terms “storytelling”, “narrative”, “narrative communication”, combined with “patient education” or “patient teaching.” Additional searches were made combining results with “diabetes education”, “low health literacy”, and “Hispanic” or “Latino”. Limits included peer reviewed, since 2000. Bibliographic searches of the articles also provided additional literature relating to storytelling, and its development as an educational tool for low health literate populations.

Storytelling

Stories are an important medium for health communication, facilitating health behavior change among minority groups (Larkey & Hecht, 2010). Narrative health messages (Frank et al., 2015), culturally appropriate storytelling (Houston et al., 2011), patient narratives (Campbell et al., 2013), and entertainment education (Lamb et al., 2017; Shen et al., 2015) have been terms used for storytelling in the literature. Lipsey et al. used the term “first person storytelling” for the sharing of personal experiences by the narrator (2019), while some theorists have used the term “narrative as a personal history,” and “storytelling” as fictional stories shared for a particular purpose” (Haigh & Hardy, 2011; Hinyard & Kreuter, 2007; Lee et. al., 2016). Another form of storytelling has been group-led storytelling, where individuals shared about their disease

experience within a group without specific informational guidelines (Greenhalgh et al., 2011; Gucciardi et al., 2019).

Experts on orality estimate that as many as 70% of the world's population prefer to learn through oral methods such as storytelling, and that many cultures prefer oral methods, even though they are literate (Moon, 2016). Storytelling is creative and designed with a particular purpose (Frid et al., 2000; Haigh & Hardy, 2011; Hinyard & Krueter, 2007). As a teaching tool, storytelling, helps listeners store information and organize knowledge around the plot and characters (Schank & Berman, 2002).

Storytelling in the Hispanic Population. As an educational intervention, fictional storytelling has been researched in health promotion and disease prevention for Hispanics and other ethnic populations (Larkey & Gonzalez, 2007; Larkey et al., 2009; Moran et al., 2016; Wirtz & Kulpavaropas, 2014). Larkey et al. used culturally appropriate short stories told by community health workers to educate Hispanics about colorectal cancer, resulting in improved knowledge and motivation to get health screening (2009). Moran et al. (2016) used fictional video storytelling about immunization and reported that Hispanics with LHL and adequate health literacy benefited with increased knowledge about human papillomavirus.

Storytelling in Chronic Disease Management. First person storytelling, the sharing of personal experiences with disease management, and has been researched as an educational tool in hypertension and diabetes self- management (Bertera, 2014; Campbell et al., 2013; Goddu et al., 2015; Houston et al., 2011; Nguyen et al., 2018; Wieland et al., 2017). The interventions were part of educational programs for chronic disease management and indicated improved self-efficacy to manage disease (Bertera, 2014; Campbell et al., 2015) with the greatest improvement among those participants with LHL (Bertera, 2014). A first-person storytelling intervention

tested in Vietnam resulted in significantly increased medication adherence compared to didactic education (Nguyen et al., 2018). Interventions were developed using qualitative methods such as (a) focus groups, (b) community-based participatory research, and (c) interviews (Bertera, 2014; Campbell et al., 2013; Goddu et al., 2015; Houston et al., 2011; Wieland et al., 2017).

Diabetes Self-Management

Diabetes self-management programs reduced disease complications and hospital admissions (Powers et al., 2015). Diabetes self-management interventions aimed at culture and language improved health outcomes and self-care among low health-literate and minority ethnic populations (Creamer et al., 2014; Kim & Lee, 2016). In a systematic review Kim & Lee (2016) found that health literacy-sensitive interventions for diabetes self-management significantly improved HbA1C. A Cochrane Review of studies with cultural adaptations for diabetes education also noted improved glycemic control in conjunction with improved diabetes knowledge and increased patient self-efficacy (Creamer et al., 2014). Intervention adaptations based upon language and communication were successful in improving outcomes for low health-literate and/or ethnic minority participants (Creamer et al., 2014; Kim & Lee, 2016). The Association of Diabetes Care and Education Specialists (ADCES) has summarized diabetes self-management with the AADE7 seven topics that should be covered for diabetes education (ADCES, 2020).

Learner Verification Interviews

Learner verification interviews (LVI) are recommended in the development of educational interventions for clients with low literacy (Doak et al., 1996). The purpose of the semi-structured interviews is to obtain input from the target audience to improve and verify an educational tool. LVIs help create culture centric, educational materials for low literacy learners (Doak et al., 1996). A LVI consists of presentation of the educational material followed by

open-ended questions about (a) comprehension, (b) self-efficacy, (c) cultural acceptability, and (d) persuasion (Doak et al., 1996). LVIs were used to develop educational tools for cancer screening among Hispanic women as part of a focused ethnography (Hunter & Kelly, 2012). Formative research, like the LVI, documents the process of cultural adaption and justification for the modification of an educational intervention (Thompson et al., 2015a).

Health Literacy Screening

Chew et al. (2008) developed a health literacy screening tool using a single question, “How confident are you in filling out medical forms by yourself?” with five possible responses. The single question method was validated by correctly identifying inadequate health literacy 80% or more of the time when compared to the REALM (Rapid Estimate of Adult Literacy in Medicine) and S-TOHFLA (Short Test of Functional Health Literacy in Adults), the longer standardized tools used to identify health literacy (Chew, 2008). The single question screening tool has been tested in Spanish-speaking individuals with similar results (Sarkar, Schillinger et al., 2010; Singh et al., 2015). An additional benefit of this method is that it does not require the ability to read either English or Spanish, thus avoiding the difficulty produced by the other standardized tools for very low literacy populations and can be done without exchange of paper. A sample of the screening tool is provided in Appendix B.

Storytelling/Narrative Communication Theory

According to the Storytelling/Narrative Communication Theory (S/NCT; See Appendix D), quality storytelling that is logical and culturally relevant will motivate changes in health behavior and attitudes through (a) transportation, (b) realism, and (c) identification (Lee et al., 2015). This theory suggests that narrative has a persuasive effect to positively impact (a) self-efficacy, (b) attitudes, and (c) behaviors (Lee et al., 2015).

Transportation is described as the listener entering into the world of the story, and adopting attitudes and behaviors reflected in the story (Hinyard & Krueger, 2007).

Transportation is indicated by (a) attention to the story, (b) emotional reactions to the story or characters, and (c) mental imagery of the story (Green & Brock, 2000).

Identification is when listeners adopt the perspective of a character in the story, which in turn influences their health behaviors (Lee et al., 2013). Identification is evidenced by a liking for the character and applying the values and struggles of that character to their own life (Busselle & Bilandzic, 2008).

Realism is when listeners identify the story as being authentic and a true reflection of their own culture and experience (Lee et al., 2015). Internal realism answers the question, “Does this story make sense; is it coherent?” External realism answers the question, “Does this story match the world in which I live?” If listeners perceive the story is real, they are more likely to identify with the characters and be transported into the story (Busselle & Bilandzic, 2008). Theoretically, stories that are culturally relevant and logical can change health behavior through transportation, realism, and identification (Lee et al., 2015).

Short fictional vignettes that are culture-centric have the potential to reduce health disparities among Hispanics with LHL when used as an educational tool for disease self-management. The use of short, fictional stories for diabetes education has not been researched among Hispanics, but the literature has indicated that both fictional and first-person storytelling can increase health knowledge in this population and improve self-efficacy to manage chronic diseases in minority populations.

Research Question

As formative research, this study asked the question, “How can short, fictional, orally presented stories be developed as culturally-adapted educational tools to improve diabetes knowledge and influence health behaviors for Hispanics with diabetes and low health literacy?”

Design

The research design was based upon the traditions of focused ethnography applied to the learner verification interview process.

Focused Ethnography

Ethnography is a branch of qualitative research based in anthropology that focuses on understanding and describing a culture (Wall, 2015). The researcher investigates a particular culture by learning from the people who are part of that culture (Roper & Shapira, 2000). Focused ethnography is a “method for applying ethnography to focus on a distinct issue or shared experience” (Cruz & Higginbottom, 2013, p. 36). Unlike classic ethnographic research, focused ethnography may not have fieldwork or immersion into the culture (Cruz & Higginbottom, 2013; Wall, 2015). A postmodern approach, focused ethnography replaces extensive field research with intensive communication and analysis to learn about specific experiences or topics (Knoblauch, 2005). Data collection is summarized as intensive events as opposed to long-term immersion into the culture (Knoblauch, 2005) and participants have specific knowledge that the researcher is investigating (Cruz & Higginbottom, 2013). The researcher has prior knowledge about the culture, allowing focus on the specific problem or issue being investigated (Cruz & Higginbottom, 2013). The research is guided by the conceptual or theoretical orientation of the researcher (Knoblauch, 2005), and is particularly suited to investigating ways to improve care or the care process (Higginbottom et al., 2013). There are no

specific guidelines for the number of events, or interviews needed to collect the data (Cruz & Higginbottom, 2013; Knoblauch, 2005). The researcher interviews informants who are experts in the problem or care process to be addressed (Higginbottom et al., 2013).

Following the guidelines of focused ethnography, this research investigated a particular population and care issue (Higginbottom et al., 2013). Persons of Hispanic origin with LHL and diabetes shared the storytelling session and the structured interview. They were experts about their culture and chronic disease experiences. The researcher was fluent in Spanish, attended formal language education for two years, and passed numerous competency exams that confirmed fluency at an advanced level. Working in the Hispanic culture and language for more than 20 years, the researcher had previously implemented diabetes education utilizing storytelling for Hispanic adults with type 2 diabetes both in the United States and Central America.

LVI guidelines and the S/NCT directed the focused ethnographic interviews (Doak et al., 1996). Specific questions were suggested based on the recommendations by Doak, et al. to evaluate (a) comprehension (b) self-efficacy, (c) cultural appropriateness, and (d) persuasion (1996). The specific educational goals of each story evaluated comprehension. (See Appendix D for educational goals and stories followed by LVI questions). It was theorized that the LVI would verify the storytelling experience as a valid educational tool and provide participants the opportunity to give input about the stories. The S/NCT and elements of the LVI (See Table 1) were used to code interviews providing insight into the listeners' experience of storytelling and guided the revision of stories. The result of the research was (a) targeted stories that could be used as part of an educational program to improve health knowledge and change health behaviors for Hispanics with LHL and Type 2 diabetes and (b) a model of their development.

Methods

Population Sample

Informants were chosen based upon the following criteria: (a) Hispanic origin, (b) diagnosed with Type 2 diabetes, and (c) identified with LHL. The participants were recruited through the researcher's relationships with churches which had Hispanic members. Three pastors and one group leader were contacted (Appendix E) and given the flyer (Appendix F) to share with members of their congregation or group. Additional contacts were found through snowball sampling. Interested participants were instructed to contact the researcher. The purpose of the research, its benefits and risks, and initial screening for health literacy was done via a scheduled telephone contact. Health literacy levels were determined using the validated Chew method during the scheduled phone call (Chew et al., 2008). Five individuals with LHL volunteered to experience five storytelling interactions followed by five focused ethnographic interviews (See Appendix E), a total of 25 intensive interviews. Focused ethnography does not have a predetermined number of informants. Because the researcher was fluent in Spanish, the consent, stories, and interview were conducted in the language of choice. Four interviews were conducted in Spanish and one in English. All participants received a \$20.00 gift card for their participation.

Setting

Due to health restrictions related to the COVID 19 pandemic, all interviews were conducted remotely, using a secure electronic medium. A variety of electronic platforms were used for the interviews, but a voice recording was obtained for all of them.

Protection of Human Subjects

The research was approved by the University of Texas at Tyler Institutional Review Board (IRB). Informed consent was in the language of choice at the time of the initial contact and again before the interview (Appendix G). An informational sheet or oral script was used to document consent ("IRB policy: Guidance for protocols involving oral consent," 2019). Oral consent is an acceptable form of consent for research that involves little or no risk to the participants and for cultures unaccustomed to signing forms (U.S. Department of Health and Human Services, 2016). The storytelling and interview involved minimal to no psychological risk to the participants and the participants had documented LHL, making an oral script in the language of choice an appropriate form of giving consent. An oral script also allowed low physical contact for a high-risk population during the COVID 19 pandemic. A copy of the consent was provided to the participants through the mail if requested. All participants had the opportunity to ask questions prior to giving oral consent (Bhutta, 2004). To ensure participants understood the research, they were be asked to verbalize their understanding. The participants' verbal consents, understanding of the research, and opportunity to ask questions were documented on the oral consent form (See Appendix G). A benefit for the participants was educational information about their diabetes. Special considerations for low literacy included (a) oral explanation of the research process and the implications of informed consent, (b) the ability to opt out of the research at any time, and (c) the use of an oral informed consent script in Spanish or English. A copy of the oral consent form documenting the consent of each participant was saved on an encrypted computer. A code number was assigned to the data of each participant for analysis. All personal information was de-identified and protected on the researcher's encrypted computer, with no personal information released or published. The audio

recordings of the interview, transcripts, and field notes of the researcher were stored on an encrypted computer.

Story Development

The ADCES has recommended seven self-care behaviors to improve diabetes outcomes: (a) being active, (b) healthy eating, (c) taking medication, (d) problem solving, (e) monitoring, (f) healthy coping, and (g) reducing risks (ADCES, 2020). Of these seven areas for education, monitoring and taking medications are skills based and would be difficult to teach in a storytelling format apart from healthcare instructions, so were not included. This research utilized the five knowledge-based recommendations as informational templates for five fictional stories aimed at teaching self-management principles through storytelling. Each fictional story communicated basic concepts of self-management principles devised by the ADCES and reflects the culture based upon the author's personal knowledge and experience. They are presented at or below the fourth-grade reading level in English. Two diabetes educators with experience teaching low health-literate Hispanic clients served as content experts and reviewed the first draft. Only one of the diabetes educators gave input about possible changes to the story content for the targeted audience. Following review, the stories were translated into Spanish by the author and verified for Spanish vocabulary and idioms by a local native Spanish speaker who was a certified medical translator. The result was five short fictional stories at or below the fourth-grade reading level in English (Readability formulas, 2020) that could be orally presented in Spanish or English by the researcher (See Appendix D).

Data Collection

Data collection occurred at two different points (a) February 2021 through April 2021 and (b) May 2021. Following the initial phone contact, health literacy screening and consent,

each participant was scheduled for an electronic interview with the researcher. Demographic information was collected at the first interview session (See Appendix H). During the encounter, the researcher told the stories in the language of choice and followed by the structured learner verification interview questions. See Appendix G for each story after review by content experts, educational objectives, and interview guide. Each story and its learner verification interview took between 10 and 20 minutes. All informants experienced the stories and learner verification interviews in two sessions with each session having between 2 or 3 stories and structured interviews. Each informant heard all five stories and responded after each. The stories were delivered in random order. The researcher evaluated the time needed after the initial interviews and adjusted data collection procedures as needed to avoid participant fatigue. The storytelling experience and interview were recorded and encrypted using a reliable electronic method.

Field notes, part of the ethnographic research tradition (Roper & Shapira, 2000), were documented. The field notes consisted of observations, thoughts, and feelings during the interview and transcription process (Roper & Shapira, 2000). In the tradition of focused ethnography, the researcher's extensive experience using storytelling when teaching oral cultures, as well as clinical experience teaching Hispanics about diabetes self-management added to the richness of the field notes as a data source (Wall, 2015). The field notes also contained the researcher's notes about Spanish language adaptations to the story and the learner verification questions.

Following analysis and story revision further data was collected in May 2021. Two of the original participants were contacted by phone and invited to listen and respond to the five revised stories. The researcher documented these calls in the field notes, detailing participant responses to include in the research findings and verify the story adaptations and data saturation.

Data Analysis

Ethnographic analysis is primarily inductive, seeking to learn from the data (Roper & Shapira, 2000). In focused ethnography, the concept orientation of the researcher and the identified problem guide inductive analysis (Cruz & Higginbottom, 2013). Audio files were (a) transcribed verbatim, (b) translated into English, and (c) verified by the researcher. The translation of Spanish was checked by another bilingual translator who taught Spanish at a local university to confirm accuracy. The participants' response to the storytelling experience, and identification of the elements of the LVI and S/NCT provided data to refine the stories to be culturally relevant, linguistically appropriate, and educationally sound.

Transcripts in English were color-coded for the elements from the LVI and S/NCT. The LVI asks questions about (a) understanding of the content, (b) persuasion, (c) cultural acceptability, and (d) self-efficacy to manage their disease (Doak, 1996). Coding the transcripts for elements of the LVI provided data for the researcher to refine the stories as educational tools. Coding for the elements of transportation, identification, and realism from the S/NCT would identify elements that lead to changes in health behaviors. Table 1 presents definitions of the concepts used for coding. A code book was developed based upon (a) the definitions and questions from the elements of the LVI and the S/NCT, (b) the actual questions used for the interview, and (c) representative quotes. The codebooks for each story were reviewed by an expert in qualitative research. Following initial coding, the codes were compared for each of the stories across respondents and collapsed into the concepts. This data was summarized and presented in the findings, along with the revised stories. An additional concept of reciprocity was identified in the data.

Field notes and demographic data were analyzed. Focused ethnography considers the etic or outsider's view as well as the emic or insider's view. (Higginbottom et al., 2013). Field notes

taken by the researcher during the interview were coded for the concepts in the LVI and S/NCT and added to the code book. Field notes included (a) reflections, (b) language notes, and (c) thoughts of the interviewer during and following the storytelling experience. Analysis and coding of the researcher's field notes provided further data for triangulation and reflexivity. Additional field notes were taken during the final verification process when the revised stories were shared orally by phone with two of the original informants a second time. Comparing the field notes with the interviews helped the researcher determine that data saturation had been reached. Respondents' demographic data was analyzed categorically and reported as means, percentages and standard deviation for scale variables.

Procedures to Enhance Rigor

In the qualitative tradition, rigor is promoted via (a) the researcher, (b) the study design, and (c) the analysis (Tong, 2007). The researcher had experience with the subject of diabetes education, the Hispanic culture, and was fluent in Latin American Spanish. As a result, interviews and data collection took place in the language of choice, adding to data integrity. Knowledge of the culture led to the researcher taking the role of learner during the interview process. The study had a defined theoretical framework, with the methodological orientation based upon both the S/NCT and the learner verification process recommended by experts in health literacy. Theoretical underpinnings from the S/NCT added rigor to data collection and analysis by identifying the elements to be coded (Tong, 2007). Interview questions provided guidance for data collection, increasing the integrity of the interview process. Accuracy and truth of the findings was verified by conducting five interviews for each story, allowing comparison and triangulation, as well as revision of the story itself (Tong, 2007). Rigor was added to the research analysis by including (a) direct quotations from the participants in both

narrative and table format and (b) a clear description of the study design based upon the focused ethnographic guidelines (Higginbottom et al., 2013). Triangulation and reflexivity were achieved by analyzing the researcher's field notes along with the interview transcripts and combining them in code book for each story and concept. Two informants listened to the adapted stories confirming data saturation, an important element in focused ethnographic research. Additional trustworthiness in data analysis came from having a second experienced qualitative researcher review the data analysis.

Results

Demographic and qualitative data were analyzed and compared in order to adapt the stories as educational tools. An additional concept of reciprocity was identified.

Demographic Data

The demographic data was collected during the initial interview and has been presented in Table 2. The participants were all female of Mexican heritage ($N = 5$). The age range was from 38 to 82 with an average time since diagnosis of 14.6 years. All participants were taking oral medications; two ($n = 2$) had managed diabetes with insulin. The participants indicated they received medical care every 2 to 4 months ($n = 5$) and were able to test their blood sugar as needed. Complications varied with high cholesterol being the most common ($n = 3$). One participant was on peritoneal dialysis for renal failure secondary to her diabetes. Depression was the second most common complication identified ($n = 2$).

The participants were not presently attending group education or exercise classes. Although diabetes self-management classes are recommended, none of these participants had attended a full range of classes. Nutrition classes were most common ($n = 2$), but the other participants ($n = 3$) had not attended formal diabetes education classes for any topic. Most of the

participants did not have a regular exercise program ($n = 3$), and none attended group exercise classes. However, in-person classes of any kind were not available during the time of the interviews due to pandemic restrictions.

Qualitative Findings

The qualitative findings are presented according to learning verification interview concepts: (a) comprehension, (b) self-efficacy, (c) cultural acceptability, and (d) persuasion, and (a) realism, (b) identification, and (c) transportation representing the S/NCT. Each concept, the qualitative data, and the changes made based upon that data are discussed in this section as well as the additional theme of reciprocity. Some concepts had overlapping meanings since they came from different sources (learner verification interview and S/NCT). For example, both realism and cultural acceptance asked if the stories reflected truth and the reality as perceived by the participants (Doak et al., 1996; Lee et al., 2015). Data was assigned to the concept for which there was the clearest and strongest application. Linguistic changes in the field notes were classified as cultural acceptability, but these changes also increased realism. Adding prayer was classified under realism; however, could have been placed in cultural acceptability. The adjustments and changes to the stories in English and Spanish based upon the data are highlighted in yellow in the revised stories (see Appendix I). These revised stories were then presented to two of the original participants to confirm data saturation and findings from the second interviews as recorded in the field notes are referenced in this section.

Learner Verification Interview Concepts. Table 3 presents educational objectives for each story with quotes and fieldnotes for the concept of comprehension. Quotes from table 3 suggest that educational goals were met for each the five stories verifying the presence of diabetes knowledge and comprehension. Data for self-efficacy, persuasion, and cultural

acceptability are discussed. All story adaptations are highlighted in yellow in the final story versions. (See Appendix I)

Comprehension. One of the stated purposes of this research was to develop stories that would improve diabetes knowledge. After listening to the stories, the participants reflected understanding of the diabetes self-management principles in their quotes. Adaptation of the stories for comprehension was based upon the order of the stories. Field notes related to comprehension, and quotes about exercise and diet when discussing the other topics indicated that diet and exercise were foundational to other story topics. If informants had not heard stories about diet and exercise first, then these topics had to be added to risk reduction, healthy coping and problem solving. Therefore, the researcher presented the stories as they have been written in the Appendix I. This change was validated by the participants who received the second interview (both of whom had heard the diet and exercise stories after the other stories). The two participants who heard the stories the second time agreed that the stories were better presented in order.

Self-Efficacy. The qualitative results classified under self-efficacy were mixed. Quotes for each story indicated both the presence and lack of self-efficacy. On the positive side, after listening to the story one participant stated, “Then, yes, I think I can do it like Leticia.” Following the story about reducing risks, two participants showed confidence to apply the information by stating they would keep their appointments for various exams. However, three participants stated that they needed classes or more information to practice the domain presented. Statements such as “One can take care of oneself and still have this problem” or “...because sometimes you just can’t do it...”, suggested that the informants were lacking in self-efficacy. It should be noted that barriers such as physical disability (two informants were unable to walk

without assistance) and the pandemic (one respondent was restricted to her home) impacted participants' responses. Since the results were unclear, no changes were made to the stories based upon the coding for self-efficacy.

Cultural Acceptability. Cultural acceptability was evaluated by the participants' responses and the field notes of the researcher. The researcher was familiar with the Hispanic culture, and the stories had been written to reflect (a) the roles of men and women, (b) cultural foods, and (c) typical occupations. Overall, the stories were culturally acceptable to the informants. Every respondent replied positively to the question, "Would you share this story with a friend or family member?" indicating cultural acceptability. (Doak et al., 1996).

Minor changes were made, however, based upon input from the participants and observer field notes. Language differences were noted, and vocabulary adaptations were made in Spanish. For example, the title in Spanish for Healthy Coping, Afrontamiento Saludable, was changed to Sobrellevando Bien con la Diabetes. Some Spanish words were changed for clarity and understanding. Other cultural adaptations were related to food and roles of men and women. Based upon participant input, bread was included with rice and tortillas as a cultural food. When discussing Story 4, one participant commented about the husband going to diabetes class, "...it's hard to believe a man would do that..." Another informant stated, "...she [the wife] needs to tell Juan to keep his checkups..." The story incorporated this input by having the wife convince him to go to classes and encourage him to go to his appointments. The Spanish vocabulary changes were confirmed by the Spanish-speaking participant in the second interview. Both participants in the final interviews stated that having the wife encourage the husband made the story better.

Persuasion. The data indicated the presence of persuasion in the stories. The stories were not changed based upon this data. One participant identified the storytelling as persuasive by saying, “Like you are motivating me now to keep on...” Another stated after hearing the story about diet, “I’ve been scheduled to go see a ...dietician. And I never went so it’s something I would consider.” Three of the participants commented that the part of the stories about sharing with someone like a friend or a support group was a motivating idea. It was sometimes difficult to separate persuasion from identification in the quotes, as liking the character added to the persuasion of the story. One comment was “Well I like a lot that he overcame this....for many times one doesn’t know how to ...talk with people, with friends....” Or another participant believed that Maria, the character in Being Active, was motivating, “It’s very good because the words that Maria said weren’t much, but they helped a lot...” and finishes with “...if I don’t have the force, but someone comes and motivates me, then like this I get up....”

Storytelling /Narrative Communication Theory Concepts. Realism, identification and transportation were the concepts derived from the S/NCT. Table 4 presents data according to internal and external realism for each story and the adaptations made. The total number of events documenting transportation with each story is summarized in Table 5. All adaptations are highlighted in yellow in the final versions of the stories (See Appendix I).

Realism. According to the S/NCT, realism increases both identification and transportation and contributes to behavior change (Lee et al., 2016). For external realism to be present, the story must reflect the world where the listener lives, while internal realism addresses the coherence or logic of the story (Busselle & Bilandzic, 2009). External realism was confirmed by all the participants: “It did seem real to me; I would not make any changes...” or

“...it seems like real conversations people would actually have....” However, there were suggestions to improve the coherence or internal reality of the stories. Two participants mentioned prayer as something that would make the story reflect their own choices to reduce risks, so the researcher added prayer to Story 3. Another participant suggested blood sugar checks before exercise should be added to Story 1. The importance of both diet and exercise was stressed and resulted in the researcher linking the ideas in Stories 1 and 2. Twelve story adaptations were made based upon the concept of realism. The second interviews confirmed suggested changes with both informants stating that the stories were “more real.” Informant 2 confirmed the addition of prayer in the final interview by sharing, “I always pray when I am tempted to make a bad choice.”

Identification. According to the guiding theory of this research, identification with characters will bring about behavior change through adoption of their viewpoints (Lee et al., 2015) and is enhanced when the characters are likeable and resemble the listener (Larkey & Hecht, 2010). The qualitative data for each story demonstrated that the participants (a) liked the characters, (b) viewed them as like themselves, and (c) adopted their viewpoints. Quotes demonstrating the liking for the characters included, “I think to help, like, Maria, this person well, she motivates. I like her...” or in Story 5 the listener liked “...the wife, how she helps, well, to give ideas like the alarm.” The story characters were perceived as being similar to the participants. One participant stated, “When they told me I had diabetes, I felt so down...” like the story character who was sad in response to a diagnosis. Another participant identified with the struggles of the main character on hearing she had diabetes by stating “...for me, this is what happens for someone who has diabetes.” Participants adopted the viewpoints of the characters. One participant used the pronoun “we” when talking about the diet choices of the main character

saying, “We think fruit doesn’t have any sugar, but, yes, it has a lot of sugar...” Another listener shared how they were helped when they went to a diabetes class “...like Juan...”, the main character in Story 4.

Changes to the stories based upon data from identification came from the researcher’s field notes. Since the population sample was female, the listeners identified most with the wives in Stories 4 and 5. The researcher noted that the wives, as favorite characters, should have names. Each wife was given a culturally appropriate name in the revised stories. This change was confirmed by the second interviews as increasing the appeal of the characters.

Transportation. The data indicated the presence of transportation in the storytelling sessions. Transportation into the narrative was demonstrated in the qualitative data by (a) fixing attention on the story, (b) having emotional reactions to the story or characters, and (c) having mental imagery. Fixing the attention of the listener on the story was demonstrated by interruptions and comments made by participants during the verbal presentation of the story. Emotional reactions were documented by the field notes and the accompanying quotes. Emotional reactions included such statements as “...she was messed up, poor woman...” or, “...I really like this story....” Mental imagery was derived from the quotes when the listener created a verbal image of the character or events in the story. Mental imagery was shown by one participant when she changed the ending of the story by imagining the wife got the car. Another participant expressed a verbal picture about participating in an exercise class by saying, “...you know because you feel uplifted by the other women.”. The stories promoted transportation in the listeners and no adaptations were done for this concept.

Additional Concept: Reciprocity. The purpose of this research was to develop fictional stories as an educational tool, but another aspect of storytelling was revealed by the data. The

researcher shared a fictional story and in return, the listeners shared their personal stories with the researcher. These stories gave insight into the culture and life experiences of each participant. Many of the first-person stories did not fit into any of the concepts covered and were gathered into a separate section in the code book labeled reciprocity. Reciprocity is defined as the "...practice of exchanging things with others for mutual benefit..." ("Reciprocity | Oxford dictionary on Lexico.com ," 2021). Some stories were related to the participant's personal diabetes experience, such as finding out about renal failure or trying to pay for insulin. Other stories were more personal. One participant shared how she had stress in her home situation because there were three women in her household.

Yes, all females. Lots of drama... I say, for example, to cope with my diabetes I want to stay more relaxed.... for as much as I try to walk or eat healthy...there is stress. Three family plates [meals] They are a lot of stress, and they don't help me.

Another listener stated, "I'm going to tell you the story of my COVID..." and finished by sharing with the researcher her near death experience with the disease. If the stories demonstrated a defined concept, they were coded under that concept, but the additional first-person stories are coded under reciprocity.

Discussion

This focused ethnographic study answered the research question by describing the process of story development and demonstrating with qualitative data that the stories imparted diabetes knowledge and had the potential to influence health behavior. The research indicated that the stories were persuasive, but no data was collected to confirm their actual impact on health behaviors, and the data about self-efficacy was inconclusive.

The Research Question

The research question was, “How can short, fictional, orally presented stories be developed as culturally adapted educational tools to improve diabetes knowledge and influence health behaviors for Hispanics with diabetes and low health literacy?” The focused ethnographic design allowed the participants to give input about the stories and provided details of the story development and adaption answering the first part of the research question.

Previous research has shown that fictional storytelling could be effective for sharing health information in the Hispanic population (Larkey & Gonzalez, 2007; Larkey et al., 2009; Moran et al., 2016), but this was the first study looking at its application to diabetes self-management education for Hispanics with LHL. Current findings agree with previous research that storytelling was effective for imparting diabetes knowledge (Bertera, 2014; Goddu et al., 2015; Weiland et al., 2017). The short, orally presented fictional stories helped the Hispanic participants with LHL reach the educational goals set by the researcher in five domains of diabetes self-management education. The demographic data showed that none of the participants had attended a full range of diabetes self-management classes before the interviews (see Table 3). However, the participants came to the interviews with a baseline knowledge about diabetes, making it difficult to evaluate if the stories were the only factor in meeting the educational objectives.

The research goal was to develop orally presented short fictional stories to influence health behavior change. Previous storytelling research for diabetes education documented improved outcomes or changes in health behaviors (Campbell et al., 2015; Weiland et al., 2017). Research has indicated that narrative interventions such as storytelling add persuasion to health communication (Shen et al., 2015). Analysis of the stories indicated a persuasive impact on

participants. The S/NCT indicates that the stories should have an influence on health behaviors. Identification with the characters in the story, transportation into the story, and realism were documented in the data from the interviews, all concepts that promote behavior change. Therefore, theoretically, the stories might impact health behaviors such as diet and exercise and improve health outcomes in the target population, but the actual influence was not measured.

Another key element in behavior change for diabetes self-management is self-efficacy (Beckerle & Lavin, 2013). First person storytelling has increased self-efficacy (Bertera, 2014; Campbell et al., 2015), but this study did not indicate a clear impact on self-efficacy in diabetes self-management. This could be because of the interpretation of the data. The participants' quotes stating that they needed classes and wanted to learn more about their diabetes in order to apply the principles taught could have resulted from exposure to the stories. In the code book these quotes were classified as a lack of self-efficacy. Another factor could be that, unlike previous studies (Campbell et al. 2015; Weiland et al., 2017), the storytelling sessions were not part of a larger diabetes self-management education program.

Additional Information

The presence of reciprocity in the findings adds to the understanding about storytelling. The participants interacted with the researcher by sharing their stories in response to the researcher's stories and questions. The story theory by Smith & Liehr describes storytelling as connection and dialogue (2005), but the reciprocal aspect of storytelling is not addressed in the S/NCT (Lee et al., 2015). Story sharing might be part of the mutual benefit derived from the storytelling process recommended for culturally competent research (Meleis, 1996). The participants benefited from the educational stories, and the researcher learned more about the diabetes experience of the participants. Further research is needed to investigate reciprocity in

storytelling and its importance in the use of storytelling as an educational intervention. Listening to the participants stories might clarify the storytelling process as an educational tool and add to further interaction with the content.

Strengths and Limitations

One strength of this research was the combination of two theories. The study combined the LVI as recommended by health literacy experts (Doak et al., 1996), and the theoretical explanation of the S/NCT for storytelling in minority populations with the qualitative research tradition of focused ethnography. The interview questions from the LVI guided the focused ethnographic interviews. The S/NCT explained why the storytelling experience was an effective communication tool for the target population. The presence of identification, realism, and transportation in storytelling sessions verified the process of storytelling to influence health behavior (Le et al., 2015). Analyzing the transcripts with the concepts from the LVI and S/NCT resulted in qualitative data to adapt the five stories as culturally adapted educational tools.

Another strength of this research was that it filled knowledge gaps about storytelling in relation to (a) fictional storytelling, (b) diabetes education, (c) health literacy, and (d) oral format. As stated earlier, fictional storytelling for diabetes education has not been researched. This research has added to the knowledge about storytelling as an adaption for LHL. Storytelling in its many formats has been researched as a cultural adaption for educational purposes (Houston et al., 2011; Campbell et al., 2013; Weiland et al., 2017), but few researchers have considered LHL as a factor (Moran et al., 2016). Additionally, most of the previous research about storytelling was in a video or film format (Bertera, 2014; Campbell et al., 2015; Houston et al., 2011; Lamb et al., 2018 Larkey et al., 2015; Moran et al., 2016; Nguyen et al.,

2018). Orally presented short fictionally stories have been under-reported in the literature (Larkey et al., 2009).

The research added to storytelling knowledge by demonstrating a model for fictional storytelling development. This study design has provided a template that can be followed by health professionals wanting to develop educational tools for low health-literate audiences. As formative research, this study explained how fictional stories were developed for a target population. The model presented is flexible, economical, and reproducible, making it applicable to many topics and settings.

Adding to the strength of the study was the researcher's knowledge and experience. The researcher was fluent in Spanish, adding rigor to data collection and analysis. The ability to speak Spanish gave the researcher access to an at-risk population. Previous work experience as a diabetes educator and international worker in Guatemala added to the development of the stories. Based upon cultural knowledge, the researcher took the role of learner during the interviews, which added to the richness of the data.

While the research filled knowledge gaps about storytelling as an educational tool, it must be considered in light of limitations. The study did not include all diabetes self-management topics, nor confirm that storytelling produced behavioral change, a key component for diabetes self-management. The findings indicated diabetes knowledge was present, but without a pre- posttest design, it was not possible to confirm that the knowledge came from the storytelling sessions. The findings are not transferable to other populations. The participants were all females who lived in a specific geographic area of the United States and of Mexican heritage. The small, geographically limited, female sample makes it difficult to generalize even within the population of Hispanics with LHL.

While the use of two different theories provided a framework for creating culturally adapted stories for a low health literate population, data analysis was complicated by similarities between conceptual definitions. Although the concepts were refined based upon the original sources, the meanings derived from two theoretical frameworks sometimes overlapped. However, the ambiguity did not detract from the purpose of the research. The story adaptations were based upon the data, not how it was classified.

Recommendations

Storytelling has the potential to improve diabetic health outcomes in the target population. This qualitative research developed five stories for diabetes education for Hispanics with LHL. Further research is needed to determine the stories impact on diabetes knowledge, self-efficacy, and health behavior. Quantitative research could determine if storytelling interventions improved health outcomes such as HbA1C. The stories could be tested individually or as cultural adaptations within an existing diabetes education program. Once established as an effective educational intervention, storytelling could be used in a variety of setting for diabetes education to improve the health outcomes of the 13.2% of Hispanics with diabetes (Office of Minority Health, 2020).

Further research is needed to determine if the model presented in this study is applicable to other health topics and/or other populations with LHL. The model is flexible and adaptable to other health issues and populations. Further research could establish storytelling as an important tool for impacting global health disparities.

Summary

This research was an initial step in establishing oral storytelling as an educational tool in diabetes education for Hispanics with LHL, documenting the (a) process, (b) information gathering, and (c) adaptations for fictional storytelling interventions (Thompson et al., 2015a). The research filled knowledge gaps about storytelling for low health-literate audiences and the use of fictional storytelling for diabetes education. The result was culture-centric stories based upon the educational domains of the ADCES self-care behaviors. The final version of the stories is provided in both English and Spanish. Further research is needed to establish fictional storytelling as a communication strategy that can impact the existing health disparities among Hispanics with diabetes and LHL and provide a model that can impact global health disparities among other LHL populations.

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Appendix A. Chapter 4 Tables

Table 4.1

Definitions and Questions - Concepts for Analysis

Learner Verification Interview (Doak, et al., 1999, p 168-169)

Comprehension (Understanding of content): Can the listener restate the main ideas of the story in their own words? Do their comments reflect the educational goals of the story? Can they change the message from one format to another demonstrated by application to their own life experience or sharing a story about the information?

Self-Efficacy: Does this story communicate something the listener can actually do in their own life? Do they feel confident that they know enough to apply the information to their own life situation?

Persuasion: Does the story convince the listener to take action? What could be added to make this story more persuasive?

Cultural Acceptability: Does the story reflect the target culture? Does the story seem true to the listener and reflect reality in their culture? This includes ideas such as vocabulary, names, roles of men and women, stressors or conflicts they might face or other cultural norms.

Storytelling/Narrative Communication Theory (Lee, et al, 2015)

Transportation: The listener enters into the world of the story as demonstrated by attention to the story, emotional reactions, or mental imagery. Does the listener demonstrate that they are paying attention to the story when it is being told? Does the listener express a mental image of the story when discussing it? Does the listener have an emotional reaction to the story or characters? (Green & Brock, 2000)

Identification: The listener sees the events through the eyes of the characters. The listener likes the characters and adopts the perspective of the characters. Do they like the characters? Do they see things from the perspective of the characters? Do they identify the characters perspective as their perspective? (Busselle & Bilandzic, 2008)

Realism: Realism can be both internal and external. External realism asks the question-does this story reflect the world where I live? Internal realism asks the question- does this story make sense and is it coherent? The more the listener perceives the story as real, the more likely they are to identify and be transported into the story. (Busselle & Bilandzic, 2008)

Table 4.2*Demographic Data*

Characteristic		<i>Range</i>	<i>M (SD)</i>
Age,		38-82	58.8 (19.3)
Years with Diabetes		1-30	14.6 (13.13)
	<i>Category</i>	<i>n</i>	<i>%</i>
Sex	Female	5	100
Language of choice	Spanish	4	80
	English	1	20
Complications (a participant may have more than one complication)	Cholesterol	3	60
	Heart disease	1	20
	Depression	2	40
	Renal Failure	1	20
	Deafness	1	20
	Skin	1	20
	High Blood pressure	1	20
Medication	On insulin	2	40
	Oral medication only	3	60
Exercise	No regular routine	3	60
	Daily in the hallway	1	20
	2 to 3 times a week for 45 minutes	1	20
Medical care	Every 2 months	1	20
	Every 3 months	2	40
	Every 4 months	2	40
Diabetes Education Class	None	3	60
	Nutrition classes	2	40
Blood Glucose Monitoring	4-5 times/day	1	20
	1-2 times/day	3	60
	Less than 1/week	1	20

Table 4.3

Comprehension - Educational Goals and Supporting Qualitative Data

Story	Qualitative Data
<i>One - Being Active</i>	
1. The listener will recognize that physical activity helps to maintain blood sugar and reduce risks.	Participant 1: "...the numbers don't go down but the body understands..." Participant 1: "...it is about taking care of oneself. No? She has a disease and has to take care of herself to manage her disease." Participant 2: "Exercise is very good..." Participant 3: "...to help a person...how to improve their blood sugar level..." Participant 3: "Well I would say, and do say, do exercise so you can be healthier. To lose weight. So that you don't have to take pills..." Participant 4: "If you do exercise and eat well you can live longer." Participant 5: "...how we need physical activity..."
2. The listener will identify that physical activity can include visits to the gym, organized classes or simply adding exercise to a daily routine.	Participant 2: "...that they could walk, swim...if they don't run, they do that kind of thing. There's also exercises for people that are older..." Participant 3: "Walking, doing exercise is to be active..."
3. The listener will state actions that they have taken or could take to incorporate physical activity into their daily routine.	Participant 1: "...I will go walking up to 45 minutes, this is all. I come back with more energy and more relaxed, happier..." Participant 3: "...like the story to walk. Start with 10 or 15 minutes. After that little by little increase it..." Participant 4: "...walking and going to the country and all you can see..." (shared as a way to be active)

Table 4.3 (continued)

Story	Qualitative Data
<i>Two - Eating Healthy</i>	
1. The listener will recognize that fruit and other high carbohydrate foods such as tortilla and rice will impact blood sugar.	Participant 1: "Like they told Leticia, there's fruit that has sugar." Participant 1: "... I will tell them what they can't eat, for example, tortilla, arroz and frijoles all this together..." Participant 3: "Yes, what she ate is what helped her lower her blood sugar and lose weight because she ate better." Participant 5: "Cut out the rice...or a very small amount..." Participant 2: "...like with a banana you are only supposed to eat half a banana..."
2. The listener will state actions they have taken or could take to maintain a healthy blood sugar thru healthy eating. Examples in the story are keeping a food diary, decreasing carbohydrate intake, reading food labels, and asking for help.	Participant 1: "Stop Carbohydrates!" Participant 2: Example of asking for help-"It's about getting more information...getting education...educating people on diabetes and how to care for it." Participant 2: "It was good to see that she wrote them down, she was able to see what she was actually eating and how that wasn't helping her." Participant2: "Eating healthy is trying to change your diet...You have to make lots of changes." Participant 3: "You have to read those food labels..." Participant 4: "The amount of food you eat is important and the total carbohydrates..." Participant 5: "You have to learn to read labels because there are some things that aren't called sugar, but they are..."

Table 4.3 (continued)

Story	Qualitative Data
<i>Three - Reducing Risks</i>	
<p>1. The listener will state actions that reduce the risks of diabetes complications. Examples of these actions include monitoring blood sugar, checking blood pressure, going for scheduled appointments, getting an eye exam, checking A1C, and other recommendations by the provider.</p>	<p>Participant 1: “it’s how to prevent diabetes...how to maintain your diabetes... and how to overcome the diabetes....”</p> <p>Participant 2: “...get a check very year ...to walk, do exercise. Be careful what you eat....” (This comment was made by informant who had not heard story 1 and 2 first)</p> <p>Participant 2: “to test every day to make sure” -referring to blood sugar.</p> <p>Participant 3: “And after a time if you take care of yourself, the disease doesn’t have to advance.”</p> <p>Participant 3: “Number one go to the doctor...Number two, keep to a diet-control your sugar, control you cholesterol. That’s why you go to the doctor to control everything.”</p> <p>Participant 3: “Get your blood sugar checked. Go to the doctor. You need to know how to control your glucose. You check it once every other day. You have to know how to control your diet.” (informant’s comment made before hearing Story 2 on healthy eating)</p> <p>Participant 4: “That we take care of ourselves to prevent all the risks that there is for a diabetic.”</p> <p>Participant 5: “ Well, do those checkups.”</p>
<p>2. The listener will state actions they have taken or could take to reduce the risk of diabetes in their own life situation.</p>	<p>Participant 1 shared her A1C results from the past two visits.</p> <p>Participant 3: “ I can give my example. With the passage of time diabetes ruined my kidneys. And now I am doing dialysis.”</p> <p>Participant 4: Informant shares story of how she went to the dentist and how it helped her.</p> <p><i>Field note: This story should come after healthy eating and being active because eating and activity were mentioned many times by informant #2 and #3 when this story was presented before healthy eating and being active.</i></p>

Table 4.3 (continued)

Story	Qualitative Data
<i>Four - Healthy Coping</i>	
1. The listener will recognize positive behaviors that lead to healthy coping with diabetes that include getting support, talking with others, and making positive choices.	<p>Participant 1: “to face this and talk with people, with friends it’s when these helps come. For example, he faced this and went to look for help for his own good.”</p> <p>Participant 1: “This same motivated him to change and with the help of his wife...”</p> <p>Participant 2: ”Like he says...he can go walking with his wife, with his children...go to the park.”</p> <p>Participant 2: “you know, kind of planning...”</p> <p>Participant 2: “She helps him to get the classes.”</p> <p>Participant 3: “Well he did well. He made a change...It should help him a lot ...for his good changes...He didn’t drink like before...”</p> <p>Participant 3: ”Stop drinking beer.”</p> <p>Participant 4: “ Healthy coping is making, like, making a priority list.”</p> <p>Participant 4: “There are a lot of things you can eat and eat healthy.”</p> <p>Participant 5: “This story is about how we need to look for support groups....so we can feel better...and talk about what we feel, what is happening...”</p> <p>Participant 5: “Well to make some lists like the Senior. What you could do and what you could change...”</p>

Table 4.3 (continued)

Story	Qualitative Data
<p>2. The listener will state actions they have taken or could take that represent healthy coping with their diabetes.</p>	<p>Participant 1: Informant applies the story to her own life by discussing her life situation with her daughters and how she tries to cope.</p> <p>Participant 1: "...just making it a plan every day for your family on how you are going to be better, to deal with it."</p> <p>Participant 1: "One has to think in how to cope and think better..."</p> <p>Participant 2: "we all turn to certain things that would not be good for us. Such as some people may smoke, some people may drink. Or like I did, eat sweet foods. You know other ways to cope..."</p> <p>Participant 2: "You know one way is to get the whole family involved."</p> <p>Participant 2: "Just start learning to eat better or drink better , or exercise with the kids if they can."</p> <p>Participant 3: "you make sure that you're eating well, drinking enough water."</p> <p>Participant 3: Shares story of her cousin that died of covid who had diabetes but refused to manage her disease or get help- "She didn't go to dialysis like she should have. She ate what she shouldn't eat".</p> <p>Participant 4: shared about a friend who died young from diabetes who did not stop drinking: "so that is always in my head to know...this could happen to me if I don't control my blood sugar."</p> <p>Participant 5: "...everything that makes me feel bad is prohibited...like right now if I eat tortillas, my sugar will go up."</p>

Five - Problem Solving

<p>1. The listener will recognize the steps of problem solving- 1) identify the problem, 2) come up with solutions, and 3) take action.</p>	<p>Participant 2: Identifies need to take action. "It's about keeping control of your diabetes and staying healthy. Um, finding ways to manage your diabetes better."</p> <p>Participant 4: "I would offer to help them make a chart or help them, maybe do things together with them."</p>
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Table 4.3 (continued)

Story	Qualitative Data
2. The listener will state how they have or will practice problem solving in their own diabetes self-care.	<p data-bbox="621 338 1360 401">Participant 1: Stated that her daughter who is diabetic uses her phone as well...just like in the story.</p> <p data-bbox="621 436 1414 569">Participant 1: “Because in the moment I forget my pills too. And I forget all of the sudden...now I put them in the bedroom. At night I have some here.”- informant sharing how she problem solved forgetting to take her pills.</p> <p data-bbox="621 604 1373 737">Participant 1: “By myself I am motivated and when I do I come back with more energy. I feel good when I do the things I don’t want to do because that is when more energy comes and motivation.”</p> <p data-bbox="621 772 1385 869">Participant 2: “...help them [a friend] find ways to cope with um you know when they are stressed. Because stress can cause your sugar to go high.”</p> <p data-bbox="621 905 1373 968">Participant 4: “...when I feel like funny or dizzy, I will check it [blood sugar]. And if it is low, I will eat something.”</p> <p data-bbox="621 1003 1390 1066">Participant 5: “ Or if I go to a party and eat too much... I want to say I will do exercise to lower it.”</p> <p data-bbox="621 1102 1414 1165">Participant 5: Gives example of problem solving in preparing lunch ahead of time or making good choices when she eats out.</p> <p data-bbox="621 1201 1401 1302">Participant 5: Discusses problem solving with how to get her exercise “...because when you aren’t walking you have to work to make yourself walk a little more.”</p>

Table 4.4*Qualitative Data for Realism*

Story	External Realism	Internal Realism	Adaptions
One - Healthy Eating	<p>Participant 1: “It did seem real to me; I would not make any changes.”</p> <p>Participant 3: “It seems real...”</p> <p>Participant 4: “Yes it [the story]is good.”</p> <p>Participant 5: “Will you read this story to my daughter so she will listen to all of it?”</p>	<p>Participant 3: “Before walking you need to check your blood sugar. Because if you have low blood sugar and you go walking, it will make your sugar go down....If you have low blood sugar, better takes some apple juice or something.”</p> <p>Participant 4: “It is because they are like, to tell you the truth, what happens to us. They are real...like the things that happen to us.”</p> <p>Participant 3: “I would say exercise is good, but you need to eat healthy, the two things go together. That would make it better.” <i>(Field note: Link story 1 and 2.)</i></p>	<p>Added about checking blood sugar and taking snack when exercising.</p> <p>Added-Anna said, “I think I understand about my diet, but what else can I do...” linking diet and exercise in the story.</p>

Table 4.4 (continued)

Story	External Realism	Internal Realism	Adaptions
Two - Eating Healthy	<p>Participant 1: Yes [it would be OK for you and your friends], it would be worth it. Yes.”</p> <p>Participant 2: “Yes” it is good for you and your family.</p> <p>Participant 3: “Well, I think it is well done, I like it.”</p> <p>Participant 5: “I think so...yes...very well...” it is good for you and your family.</p>	<p>Participant 3: Suggestions to put in more about amounts of food.</p> <p>Participant 1: “For me this is what happens when someone has diabetes.”</p> <p>Participant 1: “But how can they live with so much sugar? This is real, this is true...”</p> <p>“Well, you are almost telling my story. That is how I feel.”</p> <p>“Every time I go to the doctor it was the same for me.”</p> <p>Participant 2: “Give examples of starchy foods. A lot of people don’t know what starchy foods are. So, it would be like telling people you gotta look at carbohydrates.”</p>	<p>Added, “Be careful about how much you eat. Portions are important.”</p> <p>Used carbohydrates instead of starchy foods</p>

Table 4.4 (continued)

Story	External Realism	Internal Realism	Adaptions
Three - Reducing Risks	<p>Participant 2: “It seems real to me. It seemed like real conversations that people actually have.”</p> <p>Participant 3: “No, I think it is perfect. No, I think it is good.”</p> <p>Participant 4: “ No because everything is good.”</p> <p>Participant 5: The story is good “...to explain to them [family member] how to take care, yes....”</p>	<p>Participant 3: Suggestions for improving the story “...Anna, that someone would watch her children so she would go to the hospital to get checked.”</p> <p>Participant 2: “...that Maria would talk to her and give her tips on how to do it for herself... You know, offer to help babysit if she needed it.”</p> <p>Participant 4: “It’s perfect the way she [Maria] does it.</p> <p>Participant 4: “Yes because she [Maria] is doing the right thing. She is checking her sugar...she is good getting her check-ups when they call her.”</p> <p>Participant 1: “I just can’t because the sugar is very high, and I am stressed too much....Then what I do is begin to pray...”</p> <p>Participant 1: “...for me the story more real is like...OK I can’t do it, God...I am stressed, my sugar is high...I leave it in Your hands...that looks like it lowers my stress. I come with a lot of stress, and this is what I do.”</p> <p>Participant 2: “It’s like medicine that I sometimes take, my spiritual prayers...”</p>	<p>Added to story- Anna gets help from Maria to go to her check up and get a blood pressure monitor. Anna decides to go to her next check up with the help of her friend.</p> <p>Spiritual element added “I ask God to help me with all of this.”</p>

Table 4.4 (continued)

Story	External Realism	Internal Realism	Adaptions
Four - Healthy Coping	<p>Participant 1: About the story...change as it is, nothing.”</p> <p>Participant 3: About the story - “Yes, it is good.”</p> <p>Participant 3: Comments about if they would change the story “well, I wouldn’t change it.”</p> <p>Participant 4: About the story “it is good, it is very pretty.”</p> <p>Participant 5: “No really, I think it is all good [the story]”.</p>	<p>Participant 1: “Overall suggestion to include more tips or clues for healthy coping.”</p> <p>Participant 2: “The story for me in my words is that she helps him go to classes. They are very good because one is motivated there in those classes.”</p> <p>Participant 1: “ It is a very real story. It is like one is living it.”</p> <p>Participant 3: “No...its good the way he did it. He saw things he could do- the good things and the bad things, those that might have consequences. And he was able to make good decisions for his family.”</p> <p>Participant 3: “...say to Juan he should go for his routine check-ups.”</p>	<p>Tips are included in the next story about problem solving, so no change was made to this story.</p> <p>Routine check-ups were addressed in story three. This suggestion is addressed by presenting the stories in order.</p>

Table 4.4 (continued)

Story	External Realism	Internal Realism	Adaptions
Five - Problem Solving	<p>Participant 1: “No I really think it [the story] is good.”</p> <p>Participant 3: “Yes” the story is good for informant and family.</p> <p>Participant 4: “Uh-Huh” when asked if the story was good for her family.</p> <p>Participant 5: “Yes” the story is good for family members.</p>	<p>Participant 1: “It’s good what they did. The snacks, the alarm for the medicine....those sandwiches that she did so that his sugar would be kept at a lower level...”</p> <p>Participant2: Story seems real “...because there are a lot of people that you see like this that don’t have the strong will but a person that motivates them”</p> <p>Participant 3: “Well I would say that he could do exercise, too, because when you aren’t walking, you have to work to make yourself walk a little more.”</p> <p><i>(Field note: This comment came when the story was presented before being active...the stories have an order, Being Active and Healthy Eating are foundational for the other stories.)</i></p> <p>Participant 5: “ Well, I say it is good [the story]. They did what they could.”</p> <p>Participant 4: “Well, it is good that she helped. But for people who live in the country who do all with their machete it is not good [the story]”</p> <p><i>(Field note: Participant #4 is referring to rural Mexico where she spends some of her time.)</i></p>	<p>This suggestion was addressed by keeping the stories in order.</p> <p>Stories were intended for residents of USA, so this suggestion was not applied.</p>

Table 4.4 (continued)

Story	External Realism	Internal Realism	Adaptions
		Participant 2: “Probably if it were , there were portions of the story that showed he went to work and he was to make time to take, you know, check his sugar.”	Added- “When Jose tried these things, he was able to do his extra job. He kept his diabetes under control.”
		Participant 3: “ I would say, you know, show a part where he can explain how he started his new job, and he did what he...[needed to do]”	
		Participant 4: “They could have gotten the car. She could have gotten her car.”	Added that the family was able to buy the car.
		Participant 5: “well, yes” to suggestion about changing by adding they bought the car. <i>(Field note: Informants like the idea that they buy the car.)</i>	

Table 4.5*Summary of Transportation Data*

Story	Interruptions	Emotional Reactions	Mental Imagery
Story One - Being Active	9	0	2
Story Two - Eating Healthy	9	1	0
Story Three - Reducing Risks	19	1	0
Story Four - Healthy Coping	13	1	0
Story Five - Problem Solving	10	0	2

Table 4.6*Timeline for Research*

Date	Dissertation/Research Activity
October, 2020	Proposal to Dissertation Committee
October, 2020	Stories written and sent to diabetic educators
November 19, 2020	Defend Proposal
December 2, 2020	IRB applications
January- February, 2021	Enroll study participants following IRB approval
February – April, 2021	Data collection and transcription
April-May, 2021	Data analysis and story revision
May, 2021	Data collection to verify revised stories
June 2021	Results written and sent to Academic Advisor
June 18 , 2021	To committee
July 5-9, 2021	Defend Research Portfolio
August 2021	Graduate

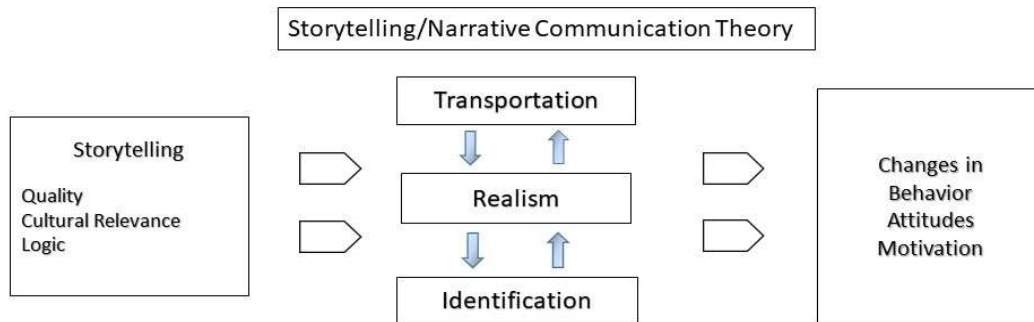
Appendix B. Chew Screening Question

English	Spanish
How confident are you filling out forms by yourself?	¿Qué tan seguro(a) se siente al llenar formas médicas usted sola?
Extremely	Completamente seguro (a)
Quite a bit	Bastante seguro (a)
Somewhat	Algo seguro (a)
A little bit	Un poco seguro (a)
Not at all	Para nada

Answers of “Somewhat”, “A little bit”, and “Not at all” indicate inadequate health literacy.

Appendix C. Storytelling/Narrative Communication Theory

Storytelling/Narrative Communication Theory



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Appendix C (continued)

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1/10

Appendix C (continued)

Dear Virginia,

Yes, I am happy to give you permission to use my theory and diagram in your research proposal.

In case, please check it with publisher!!

Please share your findings with me when you complete your study.

best regards,

haeok

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Appendix D. Original Stories/Interview Questions

Script for storyteller: Please listen to each story carefully. After the story I will ask you questions. Please answer the questions based upon the information from the story. This is not a test. You are here to help me make the story better. Feel free to share your thoughts and ideas.

Being Active

Educational Goals (not shared with the participant)

1. The listener will recognize that physical activity helps to maintain blood sugar and reduce risks.
2. The listener will identify that physical activity can include visits to the gym, organized classes or simply adding exercise to a daily routine.
3. The listener will state actions that they have taken or could take to incorporate physical activity into their daily routine.

Anna just found out she has diabetes. She felt scared with all the things her doctor told her. She was very upset and imagined all kinds of problems. What if I have to give myself shots? What if I lose a foot like my grandma? Anna decided that she wanted to stay well. She asked her friend Maria how to stay well. Maria had diabetes too. Maria told her about daily exercise.

Anna said, "I don't have time to go to a gym. How can I do that?"

Maria said, "No you just have to find 10-minute times during the day." So, Anna tried walking to work for 10 minutes. She walked 10 minutes during her lunch break.

She told Maria, "I am not sure if this is working. I don't get sweaty and out of breath." Her friend told her that was ok. It was still using energy and helping her heart.

Anna was exercising 30 minutes. She managed to fit it into her schedule. She felt better and decided to add a Zumba class two days a week. Her blood sugars were better when she checked them. She noticed she was less anxious. Mostly she felt more confident, like she could do something about her diabetes to stay well.

Appendix D (continued)

Grade Level 4: Easy to Read (Readability Formulas, 2020)

Learning verification interview questions:

- Who was your favorite character in this story? Tell me about that.
- What would make this story seem more real to you?
- How would you change this story? Tell me more about that.
- Is this story ok for you and your family? How would you make it better?
- How and when would you exercise? Would you need to know more to exercise?
- How would you explain exercise to a friend of yours with diabetes?
- Tell me in your own words about exercise.

Eating Healthy

Educational Goals (not shared with the participants)

1. The listener will recognize that fruit and other high carbohydrate foods such as tortilla and rice will impact blood sugar.
2. The listener will state actions they have taken or will take to maintain a healthy blood sugar thru healthy eating. Examples in the story are keeping a food diary, decreasing carbohydrate intake, reading food labels, and asking for help.

Leticia was waiting for her clinic visit. She was worried. She always seemed to have high blood sugar. She took her medicine every day. She tried not to eat sweet foods. She tried to avoid drinking sweet drinks and eating candy. But her blood sugars were still up. Sometimes she just wanted to quit. She wanted to eat sweet things. But she knew too much sugar in her blood could raise her blood pressure. She knew that high blood sugar could make her feet and hands hurt. She was worried. She might get sicker and sicker. The nurse told Leticia to write down what she ate for a few days. Leticia did. Now she was visiting her care provider. She

Appendix D (continued)

talked to the nurse. They both looked at the food diary. She found out that she was eating starchy things that made her blood sugar go up. Leticia ate tortillas and rice with every meal. The nurse explained that starchy foods like tortillas and rice turn to sugar in her blood. Leticia asked if she could eat fruit.

“Well, yes,” said the nurse. “Fruit is healthy but also has sugar. Be careful how much you eat.”

She helped Leticia understand that some foods had hidden sugar. Leticia should read the food labels. After this clinic visit, Leticia made small changes. She only ate half an apple instead of a whole. She limited her tortillas to one with each meal. She ate more fish and chicken. Every week she tried to make one small change.

After a month, her blood sugars were better. Leticia was losing weight. She felt much better. By making small changes to reduce her starchy foods, Leticia was able to eat better food. She was able to lower the amount of sugar in her blood. She was glad she asked questions and got help. She told all her friends about how much better she felt.

Grade Level 4: Easy to Read (Readability Formulas, 2020).

Learner verification interview questions:

- Tell me what you thought about Leticia and her problems.
- What would make the story seem more real to you?
- How would you change this story? Tell me about that.
- Is this story ok for you and your family? How would you make it better?
- How would you make changes to eat healthy? What would you need to know more about to start eating healthier?

Appendix D (continued)

- How would you explain healthy eating to a friend of yours with diabetes?
- Tell me in your own words what is all this about? Anything else?

Reducing Risks

Educational Goals (not shared with the participants)

1. The listener will state actions that reduce the risks of diabetes complications. Examples of these actions include monitoring blood sugar, checking blood pressure, going for a scheduled appointment, getting an eye exam, checking A1C, and other recommendations by the provider.
2. The listener will state actions they have taken or could take to reduce the risk of diabetes in their own life situation.

Maria and Anna were both busy mothers and wives. They both had type 2 diabetes. They were talking about problems they faced having diabetes.

Anna told Maria, “I am afraid that I will lose my vision. I am afraid my kidneys will stop working. When the doctor talks, I get really scared.”

Maria said, “I have a checklist to help me. First is my blood sugar. I check my blood sugar every day. Every 3 months I get a Hemoglobin A1C. That tells me how my blood sugar has been over the last three months. I have a blood pressure monitor at home. I check that too. When you have lots of sugar in your blood, it can make your blood pressure go up. I go for a check-up once a year. They look at my feet for any problems. I get more blood drawn to check my cholesterol. When cholesterol or fat builds up in your arteries, you can have heart problems. They also check how my kidneys with a blood test. I get an eye scan every year. The scan is done by a machine that looks into my eye. I go to the dentist. Bad teeth can cause problems too.

“Isn’t it a lot of time and money to go to do all that?”, asked Anna. She was thinking about how hard it was to find a ride. She had to take her children with her to the clinic. It was more than just the money. It was all the time and effort.

Appendix D (continued)

Maria answered, “I always tell myself I am doing these things so I will have a better future. I get the flu shot. It is better to stay healthy now so I can enjoy my children when they are grown. I want to keep my feet, my teeth, and my kidneys. It is a lot of visits to the clinic. But all this will help me enjoy my grandchildren when they come.”

Anna thought her friend was smart. She decided she wanted to start doing things to have a better future. Maybe if she were careful about getting her checkups, she could stay healthy. Maybe she would get to enjoy her adult children and their families one day.

Grade level 3: Easy to Read (Readability Formulas, 2020).

Learner verification interview questions:

- Who was your favorite character? Tell me about that.
- What would make the story seem more real to you?
- How would you change this story? Tell me about that.
- Is this story ok for you and your family? How would you make it better?
- How would you make changes to reduce risks? What would you need to know more about to reduce your risks?
- How would you explain about reducing risks to a friend of yours with diabetes?
- Tell me in your own words what is all this about? Anything else?

Healthy Coping

Educational Goals (not shared with the participants)

1. The listener will recognize positive behaviors that lead to healthy coping with diabetes that include getting support, talking with others, and making positive choices.
2. The listener will state actions they have taken or could take that represent healthy coping with their diabetes.

Juan and his wife were talking about his recent diagnosis with type two diabetes. Juan told his wife that some days he felt great. Some days he felt able to manage well. But other days he was worried about getting sick. He would have thoughts like: What would happen to my family if I lost a limb with diabetes. He would want to go drink beer with his friends. He wanted to forget it all. The next day he would feel bad. His blood sugar would be high. His wife suggested that he go to the diabetes support group at the community center.

Juan went to the group. He met some other men who had diabetes. He realized he wasn't alone. They talked about how hard it was to take care of their families and stay well. One of the men said he made a list of things that would help. Then he made a list of actions that made him sicker. When he wanted to give up, he would choose from the helpful list. He might work in the yard instead of watching TV. Or he might talk with a friend instead of drinking too many beers.

Juan realized there were things he could do to feel better. He realized he could cope with diabetes. He made a list of the things that were hard for him. He wrote about eating regularly after taking his medicine when he was on the job. He wrote about how hard it was to not drink or eat too much at family fiesta. He thought he could choose better ways to cope. He wrote good things like helping his son play soccer. He wrote how he could go to church with his wife. He shared at the group about the hard days. They gave him more ideas about how to cope with his diabetes. He still had bad days but now he knew he wasn't alone. He knew he could make choices to cope better.

Grade Level 4: Easy to Read (Readability Formulas, 2020).

Learner verification interview questions:

- Tell me in your own words about healthy coping.

Appendix D (continued)

- Who was your favorite character? Tell me about that.
- What would make the story seem more real to you?
- How would you change this story? Tell me about that.
- Is this story ok for you and your family? How would you make it better?
- How would you make changes to cope in a healthier way? What would you need to know more about healthy coping?
- How would you explain about healthy coping to a friend of yours with diabetes?
- Tell me in your own words what is all this about? Anything else?

Problem Solving

Educational Goals (not shared with the participants)

1. The listener will recognize the steps of problem solving- a) identify the problem, b) come up with solutions, and c) take action.
2. The listener will state have or will practice problem solving in their own diabetes self-care.

Jose was sitting at his table after dinner. He was worried. His wife asked him if everything was ok. He told her he was getting an extra job. Then they would have money to pay for a new car. Jose found out he had diabetes last year. He had a schedule for his medicine. He had a schedule for checking his blood sugar. He knew if he was working the extra hours, it might be hard to remember to take his pills. It might be hard to check his blood sugar. He wasn't sure if the job was worth it. He was feeling better since he started eating better. He was taking his medicine just like the doctor said. Maybe the extra work would make him sick again. His wife said he could set his phone. He could set it to go off when his needed medicine. She could pack him healthy snacks. Eating healthy snacks would help his blood sugar. Jose and his wife

Appendix D (continued)

thought up ways he could keep doing physical activity. He could take steps during breaks. He could walk around the field during his son's soccer practice. Maybe he could do this extra job. Maybe he could take care of his diabetes. He felt better about his choices. He felt able to care for his family.

Jose and his wife practiced problem solving. They saw the problem of not remembering to take his meds. They came up with a solution. They saw the problem of eating healthy food. They came up with a solution. They saw the problem of needing to stay active to keep his blood sugar down. They came up with some solutions. When Jose tried these things, he was able to do his extra job. He kept his diabetes under control. He practiced problem solving and felt more confident.

Grade Level 4: Easy to Read (Readability Formulas, 2020).

Learner verification interview questions:

- Who was your favorite character? Tell me about that.
- What would make the story seem more real to you?
- How would you change this story? Tell me about that.
- Is this story ok for you and your family? How would you make it better?
- How would you solve problems in your life that come up because of your diabetes?
- What more would you need to know to practice problem solving?
- How would you explain about problem solving to a friend of yours with diabetes?
- Tell me in your own words what is all this about? Anything else?

Appendix D (continued)

Original Spanish Versions of the Stories

Historias/Preguntas de entrevista

Por favor, escuche cada historia cuidadosamente. Después de la historia le haré preguntas. Por favor, responda las preguntas basadas en la información de la historia. Esto no es una prueba. Está aquí para ayudarme a mejorar la historia. Siéntase libre de compartir sus pensamientos e ideas.

Ser Activo

Anna acaba de descubrir que tiene diabetes. Estaba bien asustada porque su médico le dijo muchas cosas. Imaginaba todo tipo de problemas. Pensaba cosas como: ¿Y si tengo que hacerme una inyección? ¿Y si pierdo un pie como mi abuela? Anna decidió que quería mantenerse bien. Le preguntó a su amiga María cómo mantenerse bien. María también tenía diabetes. María le habló del ejercicio diario.

Anna dijo: "No tengo tiempo para ir a un gimnasio. ¿Cómo puedo hacer eso?"

María dijo: "No, sólo tienes que encontrar 10 minutos durante el día". Así que Anna camino hacia su trabajo. Esto duro 10 minutos. Caminó 10 minutos durante su descanso para almorzar. Ella le dijo a María: "No estoy seguro de si esto está funcionando. No sudo y me quedo sin aliento". Su amiga le dijo que estaba bien. Todavía estaba usando energía y ayudando a su corazón.

Anna empezó a hacer ejercicio 30 minutos tres veces a la semana. Se las arregló para encajarlo en su horario. Se sentía mejor y decidió añadir una clase de Zumba dos días a la semana. Sus azúcares en la sangre eran mejores cuando los revisó. Se dio cuenta de que estaba menos

Appendix D (continued)

ansiosa. En total se sentía más segura, como si pudiera hacer algo con su diabetes para mantenerse bien.

Preguntas sobre la entrevista de verificación de aprendizaje:

¿Dime con sus propias palabras, de que se trata todo esto?

- ¿Quién era tu personaje favorito en esta historia? Háblame de eso.
- ¿Qué haría que esta historia le pareciera más real?
- ¿Cómo cambiaría esta historia? Cuéntame más sobre eso.
- ¿Esta historia está bien para usted y su familia? ¿Cómo lo haría mejor?
- ¿Cómo y cuándo haría ejercicio? ¿Necesitaría saber más para hacer ejercicio?
- ¿Cómo le explicaría el ejercicio a un amigo suyo con diabetes?
- Dígame con sus propias palabras sobre el ejercicio.

Comer saludable

Leticia estaba esperando su visita en la clínica. Estaba preocupada. Siempre tenía un nivel alto de azúcar en la sangre. Tomaba su medicina todos los días. Trató de no comer alimentos dulces.

Trató de no tomar bebidas dulces ni comer cosas dulces. Pero su azúcar siempre estaba alto. A veces sólo quería dejar de preocuparse. Quería comer cosas dulces. Pero sabía que el exceso de azúcar en su sangre podía aumentar su presión arterial. Sabía que el alto nivel de azúcar en sangre podía hacer que le dolieran los pies y las manos. Estaba preocupada. Puede que ponga más enferma. La enfermera le dijo a Leticia que escribiera lo que comió durante unos días.

Leticia lo hizo. Ahora estaba visitando a su médico. Habló con la enfermera. Ambos miraron el diario de la comida. Se enteró de que estaba comiendo cosas con carbohidratos como pan, tortillas y arroz que hacían subir su azúcar. Leticia comió tortillas y arroz con cada comida. La

Appendix D (continued)

enfermera explicó que los alimentos con carbohidratos como las tortillas y el arroz se convierten en azúcar en su sangre. Leticia le preguntó si podía comer fruta.

"Bueno, sí", dijo la enfermera. "La fruta es saludable, pero también tiene azúcar. Ten cuidado con la cantidad de comida. La cantidad también se importa. Solo comer media manzana en vez de una entera"

Ella ayudó a Leticia a entender que algunos alimentos tenían azúcar oculta. Leticia debe leer las etiquetas de los alimentos. Después de esta visita a la clínica, Leticia hizo pequeños cambios. Sólo comió media manzana en lugar de un todo. Limitó sus tortillas a una con cada comida. Comió más pescado y pollo. Cada semana intentaba hacer un pequeño cambio.

Después de un mes, sus azúcares en la sangre eran mejores. Leticia estaba perdiendo peso. Se sentía mucho mejor. Al hacer pequeños cambios para reducir sus alimentos con almidón, Leticia pudo comer mejor. Ella fue capaz de reducir la cantidad de azúcar en su sangre. Se alegró de hacer preguntas y recibió ayuda. Les contó a todos sus amigos como se sentía mejor.

Preguntas de la entrevista de verificación del alumno:

- Dime con tus propias palabras, ¿de qué se trata todo esto?
- Dime lo que pensé sobre Leticia y sus problemas.
- ¿Qué cambios lo haga en la historia para parecer más real?
- ¿Cómo cambiarías esta historia? Háblame de eso.
- ¿Esta historia está bien para usted y su familia? ¿Cómo lo harías mejor?
- ¿Cómo haría usted cambios para comer sano? ¿Qué necesitarías saber más para empezar a comer más saludable?
- ¿Cómo le explicaría la alimentación saludable a un amigo suyo con diabetes?

Appendix D (continued)

Reducción de Riesgos

María y Anna eran madres y esposas ocupadas. Ambos tenían diabetes tipo 2. Hablaban de problemas que enfrentaban con diabetes.

Anna le dijo a María: "Tengo miedo de perder mi visión. Me temo que mis riñones dejarán de funcionar. Cuando el médico habla, me asusto mucho".

María dijo: "Tengo una lista para ayudarme. Primero es mi azúcar en la sangre. Le hago un chequeo cada día. Cada 3 meses me reciben una hemoglobina A1C. Eso me dice cómo ha sido mi azúcar en la sangre en los últimos tres meses. Tengo un monitor de presión arterial en casa. Yo también lo compruebo. Cuando tiene mucha azúcar en la sangre, puede hacer que la presión arterial sube. Voy a hacer un chequeo una vez al año. Me miran a los pies en busca de problemas. Me sacaran sangre para controlar mi colesterol. Cuando el colesterol o la grasa se acumulan en las arterias, puedes tener problemas cardíacos. También comprueban cómo están mis riñones con un análisis de sangre. Me tocan los ojos todos los años. La exploración es hecha por una máquina que mira dentro de los ojos. Voy al dentista. Los dientes malos también pueden causar problemas.

"¿No es mucho tiempo y dinero para ir a hacer todo eso?", preguntó Anna. Estaba pensando en lo difícil que era sin caro. Tuvo que llevar a sus hijos con ella a la clínica. Era más que sólo el dinero. Fue todo el tiempo y el esfuerzo.

María respondió: "Siempre me digo a mí mismo que estoy haciendo estas cosas, así que tendré un futuro mejor. Me vacunan contra la gripe. Es mejor mantenerme saludable ahora para poder disfrutar de mis hijos cuando crezcan. Quiero mantener mis pies, mis dientes y mis riñones. Es

Appendix D (continued)

un montón de visitas a la clínica. Pero todo esto me ayudará a disfrutar de mis nietos cuando vengan".

Anna pensó que su amiga era inteligente. Decidió que quería empezar a hacer cosas para tener un futuro mejor. Tal vez si ella tenía cuidado de hacerse chequeos, podría mantenerse saludable. Tal vez algún día podría disfrutar de sus hijos adultos y sus familias.

Preguntas de la entrevista de verificación del alumno:

- ¿Quién era tu personaje favorito? Háblame de eso.
- ¿Qué haría que la historia te pareciera más real?
- ¿Cómo cambiarías esta historia? Háblame de eso.
- ¿Esta historia está bien para usted y su familia? ¿Cómo lo harías mejor?
- ¿Cómo haría cambios para reducir los riesgos? ¿Qué necesitaría saber más para reducir sus riesgos?
- ¿Cómo explicarías acerca de la reducción de riesgos para un amigo suyo con diabetes?
- Dime con tus propias palabras, ¿de qué se trata todo esto? ¿Algo más?

Afrontamiento Saludable

Juan y su esposa estaban hablando de su reciente diagnóstico con diabetes tipo dos. Juan le dijo a su esposa que algunos días se sentía muy bien. Algunos días se sintió capaz de manejar bien. Pero otros días estaba preocupado por enfermarse. Tendría pensamientos como: ¿Qué le pasaría a mi familia si perdiera una extremidad con diabetes?

Querría ir a beber cerveza con sus amigos. Quería olvidarlo todo. Pero, al día siguiente se sentiría mal. Su nivel de azúcar en sangre sería alto. Su esposa le sugirió que fuera al grupo de apoyo para la diabetes en el centro comunitario.

Appendix D (continued)

Juan fue al grupo. Conoció a otros hombres que tenían diabetes. Se dio cuenta de que no estaba solo. Hablaron de lo difícil que fue cuidar de sus familias y mantenerse bien. Uno de los hombres dijo que hizo una lista de cosas que ayudarían. Luego hizo una lista de acciones que lo enferman. Cuando quería rendirse, elegía entre la lista útil. Podría trabajar en el patio en vez de ver la televisión. O podría hablar con un amigo en lugar de beber demasiadas cervezas.

Juan se dio cuenta de que había cosas que podía hacer para sentirse mejor. Se dio cuenta de que podía hacer frente a la diabetes. Hizo una lista de las cosas que eran difíciles para él. Escribió sobre comer con disciplina después de tomar su medicina cuando estaba en el trabajo. Escribió sobre lo difícil que era no beber o comer demasiado en la fiesta familiar. Pensó que podía elegir mejores maneras de sobrellevarlo. Escribió cosas buenas como ayudar a su hijo a jugar al fútbol. Escribió cómo podía ir a la iglesia con su esposa. Compartió en el grupo sobre los días difíciles. Le dieron más ideas sobre cómo lidiar con su diabetes. Todavía tenía días malos, pero ahora sabía que no estaba solo. Sabía que podía tomar decisiones para sobrellevarlo mejor.

Nivel de grado 4: Fácil de leer (Fórmulas de legibilidad, 2020).

Preguntas de la entrevista de verificación del alumno:

- Dígame con sus propias palabras sobre afrontamiento saludable.
- ¿Quién era tu personaje favorito? Háblame de eso.
- ¿Qué haría que la historia te pareciera más real?
- ¿Cómo cambiarías esta historia? Háblame de eso.
- ¿Esta historia está bien para usted y su familia? ¿Cómo lo harías mejor?
- ¿Cómo haría cambios para hacer frente de una manera más saludable?
- ¿Qué necesitarías saber más sobre cómo hacer frente saludable?

Appendix D (continued)

- ¿Cómo explicaría acerca de la salud de hacer frente a un amigo suyo con diabetes?
- Dime con tus propias palabras, ¿de qué se trata todo esto? ¿Algo más?

Solución de Problemas

José estaba sentado en su mesa después de cenar. Estaba preocupado. Su esposa le preguntó si todo estaba bien. Le dijo que iba a conseguir un trabajo extra. Entonces tendrían dinero para pagar un auto nuevo. José descubrió que tenía diabetes el año pasado. Tenía un horario para su medicina. Tenía un horario para revisar su azúcar en la sangre. Sabía que si estaba trabajando las horas extras podría ser difícil recordar tomar sus píldoras. Podría ser difícil controlar su nivel de azúcar en sangre. No estaba seguro de si el trabajo valía la pena. Se sentía mejor desde que empezó a comer mejor. Estaba tomando su medicina tal como dijo el doctor. Tal vez el trabajo extra lo enfermaría de nuevo. Su esposa dijo que podía usar su teléfono. Podría poner una alarma cuando su medicina necesitara. Podría empacarle bocadillos saludables. Comer bocadillos saludables ayudaría a su azúcar en la sangre. José y su esposa pensaron en maneras en que podía seguir haciendo actividad física. Podría tomar medidas durante los descansos. Podía caminar por el campo durante la práctica de fútbol de su hijo. Tal vez podría hacer este trabajo extra. Tal vez podría cuidar de su diabetes. Se sentía mejor acerca de sus decisiones. Se sentía capaz de cuidar de su familia.

José y su esposa practicaron la resolución de problemas. Vieron el problema de no recordar tomar sus medicamentos. Se les ocurrió una solución. Vieron el problema de comer alimentos saludables. Se les ocurrió una solución. Vieron el problema de tener que mantenerse activo para mantener su azúcar en la sangre baja. Se les ocurrieron algunas soluciones. Cuando José

Appendix D (continued)

intentó estas cosas, fue capaz de hacer su trabajo extra. Mantuvo su diabetes bajo control.

Practicó la resolución de problemas y se sintió más seguro.

Nivel de grado 4: Fácil de leer (Fórmulas de legibilidad, 2020).

Preguntas de la entrevista de verificación del alumno:

- ¿Quién era tu personaje favorito? Háblame de eso.
- ¿Qué haría que la historia te pareciera más real?
- ¿Cómo cambiarías esta historia? Háblame de eso.
- ¿Esta historia está bien para usted y su familia? ¿Cómo lo harías mejor?
- ¿Cómo resolvería los problemas de su vida que surgen debido a su diabetes?
- ¿Qué más necesitaría saber para practicar la resolución de problemas?
- ¿Cómo le explicaría acerca de la resolución de problemas a un amigo suyo con diabetes?
- Dime con tus propias palabras, ¿de qué se trata todo esto? ¿Algo más?

Appendix E: Letter to Pastor

Dear Pastor,

I am Assistant Professor of Nursing at California Baptist University and a PhD Candidate at University of Texas in Tyler doing formative research for development of storytelling as an educational intervention. As part of this research, I would like to interview people of Hispanic origin who have diabetes and low health literacy. The benefit to participants will be receiving a free education about self-management of their disease based upon the recommended guidelines of Association of Diabetes Care and Education Specialists in a story format. If you have any members of your congregation who would be interested in helping me by participating in the interview, please share my contact information with them.

The result of this research will be stories that can be used in diabetes self-management as an educational intervention designed particularly for this population in Spanish and English.

Thank you very much for helping me complete this valuable research project.

This study has approval from the Institutional Review Board at the University of Texas in Tyler and California Baptist University.

Sincerely,

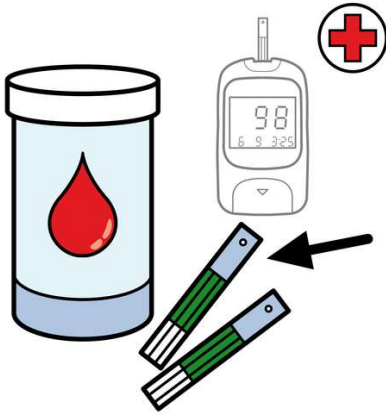
Virginia Cadenhead MSN, RN, CNM

Assistant Professor of Nursing/ California Baptist University

903-804-6445/ email: vcadenhead@calbaptist.edu

PhD candidate/University of Texas at Tyler

Appendix F: Recruitment Flyer



Research for Diabetes Teaching

Do you want to know more about your diabetes?

Do you identify as Hispanic? Do you identify as Latino?
Do you have trouble reading forms?

Take part in a study to help teach about diabetes using stories.

Enjoy story telling sessions.

Share your ideas about the story.

All names will be private. Taking part is by choice.

Those who can help should be:

Hispanic or Latino.

Have type 2 diabetes.

Have trouble reading medical forms.

- All helpers will receive a 10\$ Walmart gift card.

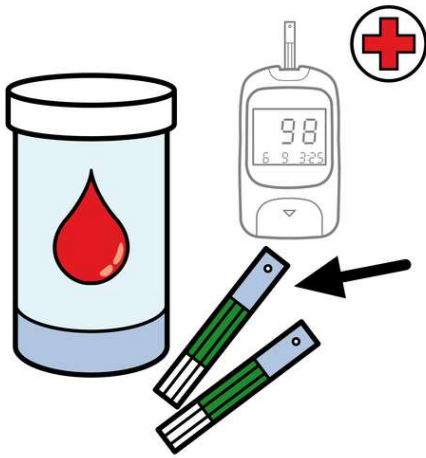
To learn more call: 903-804-6445. Ask for Virginia.

This study has IRB approval from University of Texas at Tyler. There is no possibility of harm to participants. All participants will benefit by receiving additional education about their diabetes in Spanish or English.

Grade Level 4: Easy to Read (Readability Formulas, 2020).

Investigación para la enseñanza de la diabetes

¿Quieres saber más de la diabetes?



¿Tiene problemas para entender las formas medicas?

¿Te identifiques como Hispano o Latino?

Participar en un estudio para la enseñanza de la diabetes utilizando historias.

Disfrute de sesiones de enseñanza.

Comparte tus pensamientos con el investigador.

Todas las sesiones serán en español o inglés.

Toda la información es privada. Participar es voluntario.

Los voluntarios deben

- identificarse como Latinos o Hispanos
- tener diabetes
- tener problemas de entender las formas médicas.

Todos los que participen en la investigación recibirán una tarjeta de regalo Walmart de 10\$.

Para obtener más información, llame al 903-804-6445 y pregunte por Virginia

Este estudio cuenta con la aprobación del IRB de la Universidad de Texas en Tyler. No hay posibilidad de daño a los participantes. Todos los participantes se beneficiarán al recibir educación adicional sobre su diabetes en español o inglés.

**THE
UNIVERSITY OF TEXAS AT TYLER**

**Informed Consent to Participate in Research (Oral Consent Script)
Institutional Review Board # IRB-FY2021-76
Approval Date:**

Things that are bold will not be read but their simplified version will be read with the script. The readability without proper titles and the parts in bold is 5th grade level.

Name of the study (*Title of Research Study*): Focused Ethnography: Storytelling for Hispanics with Low Health Literacy and Diabetes

What is being studied (*Project Description*) : Hello my name is Virginia Cadenhead. I am a nurse who does research. I am studying at University of Texas at Tyler. I teach nursing at California Baptist University. I am studying about stories for diabetes teaching. I need help with the stories. The stories will be for Hispanic people. They are for people who have diabetes. They are for people who have trouble reading medical forms.

What you will be asked to do (*If you agree to participate in this study, we will ask you to do the following things*):

- Share your name, age, and sex.
- Share about your diabetes.
- You will hear 5 stories.
- You will be asked about the stories.
- You will share your ideas about the stories.
- You can stop when you want to
- You can choose not to answer any questions.
- The interviews will be recorded.

Possible dangers (*Potential Risks*):

- Helping me with the stories is not dangerous.
- Learning about your diabetes with stories is not dangerous.
- There is only the danger of everyday life.
- In research there is a risk of sharing your name publicly but

Appendix G (continued)

- Your name and all other things you share will be kept locked.
- All recordings will be kept under lock and key.
- I will not share your name with anyone.

Good things for helping (**Potential Benefits**):

- Learn about your diabetes.
- Make the stories better.
- Be a part of helping others who can learn from the stories.
- 10\$ gift card from Walmart for each time you help.

I agree that: (**Understanding of Participants**):

1. I can ask questions about the study. I understand the dangers if I help. I know the good things if I help.
2. If I help, I agree that:
 - a. I can choose to help in the study.
 - b. I can stop any time during the study.
 - c. The researcher may keep what I share for 10 years.
 - d. My name will not be shared unless I agree.
 - e. Other things that tell who I am will not be shared.
 - f. The words and ideas I share may be published.
 - g. The words and ideas I share may be shared with others.
3. A group of people called the UT Tyler Institutional Review Board will help. They keep studies safe. They make sure that those who help are safe. They may look at what you share. They will make sure the study is safe. They will make it safe by watching over the study.
4. The main study person is Virginia Cadenhead. Her number is 903-804-6445. Call if you have any questions. If you would like to talk with someone else contact the faculty advisor Dr Beth Mastel-Smith. She works at University of Texas at Tyler. Her phone number is 713-416-5690. Her email is bmastelsmith@uttyler.edu
5. If you have any questions about helping in the study, call the Office of Research & Scholarship at (903) 565-5858. Their email is research@uttyler.edu
6. This study may be shared with other researchers. No names or things that tell who you are will be shared. No names or things that tell who you are will be published.

ORAL CONSENT FOR PARTICIPATION IN THIS RESEARCH STUDY

- I agree to help in the study (*Researcher will write, yes agrees to help*)
- I understand the reason for the study (*Researcher will write yes if participant can*)

Appendix G (continued)

- All my questions have been answered (*Researcher will write yes agrees*)

.Name of participant:

Researchers Name:

- 7. I have discussed this project with the participant, using language that is understandable and appropriate. I believe I have fully informed this participant of the nature of this study and its possible benefits and risks. I believe the participant understood the explanation. I have read the consent to them and answered all of their questions.**

Researcher/Principle Investigator

Date:

Researcher/Principle Investigator

THE UNIVERSITY OF TEXAS AT TYLER

Informed Consent to Participate in Research (Oral Consent Script)

Institutional Review Board # IRB-FY2021-76

Nombre del estudio :

Focused Ethnography: Storytelling for Hispanics with Low Health Literacy and Diabetes

Hola mi nombre es Virginia Cadenhead. Soy una enfermera que investiga. Estoy estudiando en la Universidad de Texas en Tyler. Enseño enfermería en la Universidad Bautista de California. Estoy estudiando historias para la enseñanza de la diabetes. Necesito ayuda con las historias. Las historias serán para los hispanos. Son para personas que tienen diabetes. Son para personas que tienen problemas para leer formularios médicos.

Voy a pedirles:

- Comparta su nombre, edad y sexo.
- Comparta sobre su diabetes
- Escucha 5 historias
- Se le preguntará sobre las historias
- Compartirá sus ideas sobre las historias
- Puede detenerse cuando desea
- Puede optar por no responder
- Las entrevistas se grabarán

Posibles peligros

- Ayudarme con las historias no es peligroso
- Aprender sobre su diabetes con historias no es peligroso
- Sólo existe el peligro de la vida cotidiana.
- En la investigación existe el riesgo de compartir su nombre públicamente
- o Su nombre y todas las demás cosas que comparta se mantendrán en secreto.
- o Todas las grabaciones se mantendrán bajo llave
- o No voy a compartir su nombre con nadie

Cosas buenas de ayudar

- Conozca su diabetes
- Mejorar las historias
- Ser parte de ayudar a otras personas que pueden aprender de las historias
- Tarjeta de regalo de 10\$ de Walmart por cada vez que me ayude

Estoy de acuerdo en que

1. Puedo hacer preguntas sobre el estudio. Entiendo los peligros si ayudo. Sé las cosas buenas si ayudo.
2. Si ayudo, acepto que:

Appendix G (continued)

- a) Puedo elegir ayudar en el estudio
- b) Puedo detenerme en cualquier momento durante el estudio
- c) El investigador puede conservar lo que comparto durante 10 años.
- d) Mi nombre no será compartido a menos que esté de acuerdo
- e) Otras cosas que dicen quién soy no serán compartidas
- f) Las palabras e ideas que comparto pueden publicarse
- g) Las palabras e ideas que comparto pueden ser compartidas con otros

3. Un grupo de personas llamado la Junta de Revisión Institucional de UT Tyler ayudará. Mantienen los estudios seguros. Se aseguran el estudio es bueno. Pueden ver lo que compartes. Se asegurarán de que el estudio sea seguro.

4. La persona principal del estudio es Virginia Cadenhead. Su número es 903-804-6445. Llame si tiene alguna pregunta. Si desea hablar con otra persona, póngase en contacto con la asesora de la facultad, la Dra. Beth Mastel-Smith. Trabaja en la Universidad de Texas en Tyler. Su número de teléfono es 713-416-5690. Su correo electrónico está bmastelsmith@uttyler.edu

5. Si tiene alguna pregunta sobre cómo ayudar en el estudio, llame a la Oficina de Investigación y Becas al (903) 565-5858. Su correo electrónico es research@uttyler.edu

6. Este estudio puede ser compartido con otros investigadores. No se compartirán nombres ni cosas que digan quién eres. No se publicarán nombres ni cosas que digan quién eres.

CONSENTIMIENTO ORAL PARA LA PARTICIPACIÓN EN ESTE ESTUDIO DE INVESTIGACIÓN

Estoy de acuerdo en ayudar en el estudio (El investigador escribirá, sí está de acuerdo en ayudar)

Entiendo la razón del estudio (El investigador escribirá sí si el participante puede)

Todas mis preguntas han sido respondidas (el investigador escribirá sí está de acuerdo)

Nombre del participante:

Fecha:

Appendix H: Demographic Information Form

Age

Gender

At what age were you when diagnosed with diabetes?

Have you ever attended diabetes education classes? When was that?

Do you test your blood sugar? If yes, how frequently?

How often do you see the doctor or nurse about your diabetes?

What medications do you take for diabetes? Do you take them according to the doctor's order?

Do you smoke?

Diabetes complications:

High blood pressure

High cholesterol

Kidney failure or problems

Limb amputation

Heart problems

Vision changes

Pain or numbness in feet

Wounds or sores that won't heal.

Feeling sad

Do you exercise? If yes,

a. How many times / weeks?

b. For how long each time?

Preferred language for interview and consent:

Appendix I: Revised Stories in English and Spanish

Story 1

Being Active

Anna just found out she has diabetes. She felt scared with all the things her doctor told her. She was very upset and imagined all kinds of problems. What if I have to give myself shots? What if I lose a foot like my grandma? Anna decided that she wanted to stay well. She asked her friend Maria how to stay well. Maria had diabetes too.

Anna said, "I think I understand about my diet, but what else can I do?"

Maria told her about daily exercise. Exercise could make her blood sugar go down. Maria also told Anna to be sure and check her blood sugar before starting exercise. She told her to take some fruit or juice with her. She could drink the juice if she felt bad while she was exercising. Sometimes blood sugar could go too low with exercise.

Anna said, "I don't have time to go to a gym. How can I do that?"

Maria said, "No you just have to find 10-minute times during the day." So, Anna tried walking to work for 10 minutes. She walked 10 minutes during her lunch break.

She told Maria, "I am not sure if this is working. I don't get sweaty and out of breath." Her friend told her that was ok. It was still using energy and helping her heart. It was still helping her blood sugar stay low.

Anna started exercising 30 minutes. She managed to fit it into her schedule. She felt better and decided to add a Zumba class two days a week. Her blood sugars were better when she checked them. She noticed she was less anxious. Mostly she felt more confident, like she could do something about her diabetes to stay well.

Grade Level 4: Easy to Read (Readability Formulas, 2020)

Appendix I (continued)

Ser Activo

Anna acaba de descubrir que tiene diabetes. Ella se asustó con todas las cosas que le dijo su doctor. Imaginaba todo tipo de problemas. Ella estaba triste y se imaginaba toda clase de problemas.

Pensaba: ¿Y si tengo que ponerme una inyección? ¿Y si pierdo un pie como le paso a mi abuela? Anna decidió que ella quería mantenerse bien. Le preguntó a su amiga María cómo mantenerse bien. María también tiene diabetes.

Anna dijo: "Creo que entiendo sobre mi dieta, pero ¿qué más puedo hacer?"

María le habló del ejercicio diario. El ejercicio podría hacer que su azúcar en la sangre baje.

María también le dijo a Anna que revisara su azúcar en la sangre antes de comenzar el ejercicio.

Ella le dijo que llevara un poco de fruta o jugo con ella. Podía beber el jugo si se sentía mal mientras hacía ejercicio. A veces, el azúcar en la sangre podría bajar demasiado con el ejercicio.

Anna dijo: "No tengo tiempo para ir a un gimnasio. ¿Cómo puedo hacer ejercicio?"

María dijo: "No, sólo tienes que separar 10 minutos durante el día". Así que Anna camino hacia su

Trabajo, eso duro 10 minutos y caminó 10 minutos durante su descanso para almorzar.

Ella le dijo a María: "No estoy segura de si esto está funcionando. No sudo y me quedo sin aliento". Su amiga le dijo que estaba bien. Todavía estaba usando energía y ayudando a su corazón y todavía su azúcar estaba bajando.

Anna empezó a hacer ejercicio 30 minutos tres veces a la semana. Se las arregló para incluirlo en su horario. Se sentía mejor y decidió añadir una clase de Zumba dos días a la semana. Su nivel de azúcar en la sangre era mejor cuando lo revisó, ella se dio cuenta de que estaba menos

Appendix I (continued)

ansiosa. Por lo general, ella se sentía más segura, como si pudiera hacer algo con su diabetes para mantenerse bien.

Story 2

Eating Healthy

Leticia was waiting for her clinic visit. She was worried. She always seemed to have high blood sugar. She took her medicine every day. She tried not to eat sweet foods. She tried to avoid drinking sweet drinks and eating candy. But her blood sugars were still up. Sometimes she just wanted to quit. She wanted to eat sweet things. But she knew too much sugar in her blood could raise her blood pressure. She knew that high blood sugar could make her feet and hands hurt. She was worried. She might get sicker and sicker. The nurse told Leticia to write down what she ate for a few days. Leticia did. Now she was visiting her care provider. She talked to the nurse. They both looked at the food diary. She found out that she was eating things high in carbohydrates like bread, rice and tortillas that made her blood sugar go up. Leticia ate tortillas and rice with every meal. The nurse explained that carbohydrates turn to sugar in her blood. Leticia asked if she could eat fruit.

“Well, yes,” said the nurse. “Fruit is healthy but also has sugar. Be careful how much you eat. Portions are important. Eat half an apple and not a whole one. Only have a small serving of rice, not a whole plateful.”

She helped Leticia understand that some foods had hidden sugar. Leticia should read the food labels. After this clinic visit, Leticia made small changes. She only ate half an apple instead of a whole. She limited her tortillas to one with each meal. She ate more fish and chicken. Every week she tried to make one small change.

Appendix I (continued)

After a month, her blood sugars were better. Leticia was losing weight. She felt much better. By making small changes to reduce her carbohydrates, Leticia was able to eat better food. She was able to lower the amount of sugar in her blood. She was glad she asked questions and got help. She told all her friends about how much better she felt.

Grade Level 4: Easy to Read (Readability Formulas, 2020).

Comer saludable

Leticia estaba esperando su visita en la clínica. Estaba preocupada. Siempre tenía un nivel alto de azúcar en la sangre. Tomaba su medicina todos los días. Trató de no comer alimentos dulces y trató de no tomar bebidas dulces ni comer cosas dulces. Pero su azúcar siempre estaba alto. A veces sólo quería dejar de preocuparse. Ella quería comer cosas dulces. Pero sabía que el exceso de azúcar en su sangre podía aumentar su presión arterial. Sabía que el alto nivel de azúcar en la sangre podía hacer que le dolieran los pies y las manos. Estaba preocupada. Podría ponerse más enferma. La enfermera le dijo a Leticia que escribiera lo que comió durante unos días. Leticia lo hizo. Ahora estaba visitando a su médico. Habló con la enfermera. Ambos analizaron el diario de la comida. Se enteró de que estaba comiendo cosas con carbohidratos, como pan, tortillas y arroz que hacían que su azúcar subiera. Leticia comió tortillas y arroz con cada comida. La enfermera explicó que los alimentos con carbohidratos como las tortillas y arroz se convierten en azúcar en su sangre. Leticia le preguntó si podía comer fruta. "Bueno, sí", dijo la enfermera. "La fruta es saludable, pero también tiene azúcar. Ten cuidado con la cantidad de comida. La cantidad también importa. Solo tienes que comer media manzana en vez de una entera"

Appendix I (continued)

Ella ayudó a Leticia a entender que algunos alimentos tenían azúcar oculta. Leticia debe leer las etiquetas de los alimentos. Después de esta visita a la clínica, Leticia hizo pequeños cambios. Sólo comió media manzana en lugar de una entera. Limitó sus tortillas a solo una con cada comida. Comió más pescado y pollo. Cada semana intentaba hacer un pequeño cambio. Después de un mes, sus azúcares en la sangre mejoraron. Leticia estaba perdiendo peso. Se sentía mucho mejor. Al hacer pequeños cambios para reducir sus alimentos con almidón, Leticia pudo comer mejor. Ella fue capaz de reducir la cantidad de azúcar en su sangre. Se alegró de hacer preguntas y recibió ayuda. Les contó a todos sus amigos que se sentía mejor.

Story 3

Reducing Risks

Maria and Anna were both busy mothers and wives. They both had type 2 diabetes. They were talking about problems they faced having diabetes.

Anna told Maria, “I am afraid that I will lose my vision. I am afraid my kidneys will stop working. When the doctor talks, I get really scared.”

Maria said, “I have a checklist to help me. First is my blood sugar. I check my blood sugar every day. Every 3 months I get a Hemoglobin A1C. That tells me how my blood sugar has been over the last three months. I have a blood pressure monitor at home. I check that too. When you have lots of sugar in your blood, it can make your blood pressure go up. I go for a check-up once a year. They look at my feet for any problems. I get more blood drawn to check my cholesterol. When cholesterol or fat builds up in your arteries, you can have heart problems. They also check my kidneys with a blood test. I get an eye scan every year. The scan is done by.

Appendix I (continued)

a machine that looks into my eye. I go to the dentist. Bad teeth can cause problems too. I ask God to help me with all of this, to help me find a way to stay healthy.”

“Isn’t it a lot of time and money to go to do all that?”, asked Anna. She was thinking about how hard it was to find a ride. She had to take her children with her to the clinic. It was more than just the money. It was all the time and effort.

Maria answered, “I always tell myself I am doing these things so I will have a better future. I get the flu shot. It is better to stay healthy now so I can enjoy my children when they are grown. I want to keep my feet, my teeth, and my kidneys. It is a lot of visits to the clinic. But all this will help me enjoy my grandchildren when they come.”

Anna thought her friend was smart. She decided she wanted to start doing things to have a better future. Maybe if she were careful about keeping her checkups, she could stay healthy.

Anna said, “I have an appointment next week to check my A1C. I think I should go. It will help me stay healthy. And maybe I can get a blood pressure monitor to check at home.”

Maria responded, “Let me help. I can get my daughter to watch your children. Then we can both go to the clinic in my car. I think they are giving away blood pressure monitors at the clinic if you ask for one. Then you can get your A1C checked as well.”

Anna smiled at her friend. She was glad to have help. Having blood sugar problems was hard.

Maybe one day they both would enjoy their adult children and grandchildren together.

Grade level 3: Easy to Read (Readability Formulas, 2020).

Appendix I (continued)

Reducción de Riesgos

María y Anna eran madres y esposas ocupadas. Ambas tenían diabetes tipo 2. Hablaban de problemas que podían enfrentar por tener diabetes.

Anna le dijo a María: "Me temo que perderé la visión. Me temo que mis riñones dejarán de funcionar. Cuando el doctor habla, me asusto mucho."

María dijo: "Tengo una lista de verificación para ayudarme. Primero es mi azúcar en la sangre. Reviso mi azúcar en la sangre todos los días. Cada tres meses consigo una Hemoglobina A1C. Eso me dice cómo ha estado mi azúcar en la sangre en los últimos tres meses. Tengo un monitor de presión arterial en casa. Yo también lo compruebo. Cuando tienes niveles alto de azúcar en la sangre, puede hacer que tu presión arterial suba. Voy a hacerme un chequeo una vez al año. Me revizan los pies en busca de cualquier problema. Me atrae más sangre para controlar mi colesterol. Cuando el colesterol o la grasa se acumulan en las arterias, puedes tener problemas cardíacos. También revisan mis riñones con un análisis de sangre. Me hacen un escáner ocular cada año. El escáner es hecho por una máquina que me checa los ojos. Voy al dentista. Los dientes enfermos también pueden causar problemas. Le pido a Dios que me ayude con todo esto y que me ayude a encontrar una manera de mantenerme saludable".

"¿No es mucho tiempo y dinero para ir a hacer todo eso?", Preguntó Anna. Estaba pensando en lo difícil que es encontrar a alguien que te lleve. Tuvo que llevar a sus hijos con ella a la clínica. Era algo más que el dinero. Fue todo el tiempo y el esfuerzo.

María respondió: "Siempre me digo a mí misma que estoy haciendo estas cosas para tener un futuro mejor. Tengo la vacuna contra la gripe. Es mejor mantenerme saludable ahora para poder disfrutar de mis hijos cuando crezcan. Quiero mantener mis pies, mis dientes y mis riñones

Appendix I (continued)

saludables. Son muchas visitas a la clínica, pero todo esto me ayudará a disfrutar de mis nietos cuando vengan".

Anna pensó que su amiga era inteligente. Decidió que quería empezar a hacer cosas para tener un futuro mejor. Tal vez si tuviera cuidado de mantener sus chequeos, podría mantenerse saludable.

Anna dijo, "Tengo una cita la próxima semana para revisar mi A1C. Creo que debería ir. Me ayudará a mantenerme saludable. Y tal vez pueda conseguir un monitor de presión arterial para comprobar mi presión arterial en casa."

María respondió: "Déjame ayudar. Puedo hacer que mi hija cuide a sus hijos. Entonces ambas podemos ir a la clínica en mi auto. Creo que están regalando monitores de presión arterial en la clínica si lo pides. Entonces usted puede conseguir que revisen su A1C también."

Anna le sonrió a su amiga. Se alegró de tener ayuda. Tener problemas con el azúcar en la sangre es difícil. Tal vez un día ambas disfrutarán de sus hijos adultos y nietos.

Story 4

Healthy Coping

Juan and his Anna were talking about his recent diagnosis with type two diabetes. Juan told Anna that some days he felt great. Some days he felt able to manage well. But other days he was worried about getting sick. He would have thoughts like: What would happen to my family if I lost a limb with diabetes? He would want to go drink beer with his friends. He wanted to forget it all. The next day he would feel bad. His blood sugar would be high. Anna was worried he would get sicker. She suggested he keep his routine appointments. She suggested he

Appendix I (continued)

go to the diabetes support group at the community center. At first, he did not want to go, but Anna convinced him to go.

Finally, Juan went to the group. He met some other men who had diabetes. He realized he was not alone. They talked about how hard it was to take care of their families and stay well. One of the men said he made a list of things that would help. Then he made a list of actions that made him sicker. When he wanted to give up, he would choose from the helpful list. He might work in the yard instead of watching TV. Or he might talk with a friend instead of drinking too many beers.

Juan realized there were things he could do to feel better. He realized he could cope with diabetes. Anna helped him to make a list of the things that were hard for him. He wrote about eating regularly after taking his medicine when he was on the job. He wrote about how hard it was to not drink or eat too much at the family fiesta. He thought he could choose better ways to cope. He wrote good things like helping his son play soccer. He wrote how he could go to church with Anna and his family. He shared at the group about the hard days. They gave him more ideas about how to cope with his diabetes. He still had bad days but now he knew he was not alone. He knew he could make choices to cope better.

Grade Level 4: Easy to Read (Readability Formulas, 2020).

Sobrellevando Bien Con La Diabetes

Juan y Anna hablaban de su reciente diagnóstico con diabetes tipo 2. Juan le dijo a Anna que algunos días se sentía muy bien. Algunos días se sintió capaz de manejarse bien. Pero otros días estaba preocupado por enfermarse. Él tenía pensamientos como: ¿Qué pasaría con mi familia si perdiera una extremidad con diabetes? Querría ir a tomar cerveza con sus amigos.

Appendix I (continued)

Quería olvidarlo todo. Al día siguiente se sentiría mal. Su azúcar en la sangre sería alta. Anna se preocupaba de que se enfermase. Ella sugirió que fuera a sus visitas en la clínica y sugirió que fuera al grupo de apoyo con la diabetes en el centro comunitario. Al principio no quería ir, pero Anna lo convenció de ir.

Finalmente, Juan fue al grupo. Conoció a otros hombres que tenían diabetes. Se dio cuenta de que no estaba solo. Hablaron de lo difícil que era cuidar de sus familias y mantenerse bien. Uno de los hombres dijo que hizo una lista de cosas que ayudarían. Luego hizo una lista de acciones que lo enfermaron más. Cuando quería rendirse, elegía entre la lista útil. Podría trabajar en el patio en lugar de ver la televisión o podría hablar con un amigo en lugar de beber demasiadas cervezas.

Juan se dio cuenta de que había cosas que podía hacer para sentirse mejor. Se dio cuenta de que podía sobrellevar bien la diabetes. Anna le ayudó a hacer una lista de las cosas que eran difíciles para él. Escribió sobre comer regularmente después de tomar su medicina cuando estaba en el trabajo. Escribió sobre lo difícil que era no beber ni comer demasiado en la fiesta familiar. Pensó que podía elegir mejores maneras de sobrellevarlo. Escribió cosas buenas como ayudar a su hijo a jugar al fútbol. Escribió cómo podía ir a la iglesia con Anna y su familia. Compartió en el grupo sobre los días difíciles. Le dieron más ideas de cómo sobrellevar su diabetes.

Todavía tenía días malos, pero ahora sabía que no estaba solo. Sabía que podía tomar decisiones para sobrellevarlo mejor.

Appendix I (continued)

Story 5

Problem Solving

Jose was sitting at his table after dinner. He was worried. Vanessa, his wife, asked him if everything was ok. He told her he was getting an extra job. Then they would have money to pay for a new car. Jose found out he had diabetes last year. He had a schedule for his medicine. He had a schedule for checking his blood sugar. He knew if he was working the extra hours, it might be hard to remember to take his pills. It might be hard to check his blood sugar. He wasn't sure if the job was worth it. He was feeling better since he started eating better. He was taking his medicine just like the doctor said. Maybe the extra work would make him sick again. Vanessa suggested he use his phone. He could set it to go off when his needed medicine. She could pack him healthy snacks. Eating healthy snacks would help his blood sugar. Jose and Vanessa thought up ways he could keep doing physical activity. He could take steps during breaks. He could walk around the field during his son's soccer practice. Maybe he could do this extra job. Maybe he could take care of his diabetes. He felt better about his choices. He felt able to care for his family.

Jose and Vanessa practiced problem solving. They saw the problem of not remembering to take his meds. They came up with a solution. They saw the problem of eating healthy food. They came up with a solution. They saw the problem of needing to stay active to keep his blood sugar down. They came up with some solutions. When Jose tried these things, he was able to do his extra job. He kept his diabetes under control. He was able to buy the new car for Vanessa and his family. He and practiced problem solving and felt more confident.

Grade Level 4: Easy to Read (Readability Formulas, 2020).

Appendix I (continued)

Resolución de Problemas

José estaba sentado en su mesa después de cenar. Estaba preocupado. Vanessa, su esposa, le preguntó si todo estaba bien. Le dijo que estaba consiguiendo un trabajo extra. Entonces tendrían dinero para pagar un **carro** nuevo. El año pasado, José se enteró de que tenía diabetes. Tenía un horario para su medicina y un horario para revisar su nivel de azúcar en la sangre. Sabía que si trabajaba las horas extra podría ser difícil recordar tomar sus **pastillas**. Puede ser difícil controlar su azúcar en la sangre. Él no estaba seguro de si el trabajo valía la pena. Se sentía mejor desde que empezó a comer mejor. Estaba tomando su medicina como dijo el doctor y tal vez el trabajo extra lo enfermaría de nuevo. **Vanessa le sugirió que usara su** teléfono. Podría **poner la alarma** para tomar su medicina. Podría empacarle bocadillos saludables. Comer bocadillos saludables ayudaría a establecer los niveles de azúcar en la sangre. José y **Vanessa** **pensaron en** maneras en que podía seguir haciendo actividad física. **Jose podría** caminar durante los descansos. Podría caminar por el campo durante la práctica de fútbol de su hijo. Tal vez podría hacer este trabajo extra. Tal vez podría cuidar de su diabetes. Se sentía mejor con sus decisiones. Se sentía capaz de cuidar de su familia.

José y **Vanessa** practicaron la resolución de problemas. Vieron el problema de no recordar tomar sus medicinas. Se les ocurrió una solución. Vieron el problema de comer alimentos saludables. Se les ocurrió una solución. Vieron el problema de tener que mantenerse activo para mantener su azúcar en la sangre baja. Se les ocurrieron algunas soluciones. Cuando José probó estas cosas, fue capaz de hacer su trabajo extra. Mantuvo su diabetes bajo control. **Pudo comprar el nuevo auto para Vanessa y su familia**. El practicó la resolución de problemas y se sintió más seguro.

Appendix J: IRB Approval Forms

1/15/2021

Mail - Virginia Cadenhead - Outlook

IRB-FY2021-76 - Initial: Exempt

do-not-reply@cayuse.com <do-not-reply@cayuse.com>

Thu 1/14/2021 2:19 PM

To: Beth Mastel-Smith <bmastel-smith@uttyler.edu>; Virginia Cadenhead <vcadenhead@patriots.uttyler.edu>



INSTITUTIONAL REVIEW BOARD

uttyler.edu/research • 903-565-5858

Jan 14, 2021 4:19:18 PM CST

Dear Virginia Cadenhead,

Your request to conduct the study: Focused Ethnography: Storytelling for Hispanics with Low Health Literacy and Diabetes, IRB-FY2021-76 has been approved by The University of Texas at Tyler Institutional Review Board as a study exempt from further IRB review subject to Category 2.(ii).

Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording).

Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation.

While this approval includes a waiver of signed, written informed consent, please ensure prospective informed consent is provided, if applicable, unless special circumstances are indicated in the approval email. In addition, please ensure that any research assistants are knowledgeable about research ethics and confidentiality, and any co-investigators have completed human protection training within the past three years, and have forwarded their certificates to the Office of Research and Scholarship (research@uttyler.edu).

Please review the UT Tyler IRB Principal Investigator Responsibilities, and acknowledge your understanding of these responsibilities and the following through return of this email to the IRB Chair within one week after receipt of this approval letter:

- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity.
- **Prompt reporting to the UT Tyler IRB and academic department administration will be done of any unanticipated problems involving risks to subjects or others.**
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.
- Any change in proposal procedures must be promptly reported to the IRB prior to implementing any changes except when necessary to eliminate apparent immediate hazards to the subject.
- Submit Progress Report when study is concluded.

<https://outlook.office.com/mail/deeplink?version=20210103002.07&popup=2-1>

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Appendix J (continued)

External IRB Application

This form is for individuals who are (1) not affiliated with CBU, but wish to conduct research approved by their home institution with CBU students, staff, or faculty, or (2) affiliated with CBU, but seeking to do research at CBU that has been approved by another IRB.

Principal Investigator (PI) Information

PI Name: Virginia Hamilton Cadenhead

PI Preferred Salutation: Mrs.

PI college/school at CBU: College of Nursing

PI college/school if unaffiliated with CBU: University of Texas at Tyler

PI Position (Asst. Prof, Undergraduate student, etc.): Assistant Professor at California Baptist University

PI email: vcadenhead@calbaptist.edu

PI phone: 9038046445

PI Date of most recent CITI HSR Certification: 7/26/2020

Date of Application to CBU: 1/15/2021

Research Project Title: Focused Ethnography: Storytelling for Hispanics with Low Health Literacy and Diabetes

The approved protocol was reviewed/approved as (select one and complete category of determination/approval; e.g., exempt category 2(ii)):

Category of approval		Criteria met and subcategory
<input checked="" type="checkbox"/>	Exempt	Your request to conduct the study: Focused Ethnography: Storytelling for Hispanics with Low Health Literacy and Diabetes, IRB-FY2021-76 has been approved by The University of Texas at Tyler Institutional Review Board as a study exempt from further IRB review subject to Category 2.(ii). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including

Appendix J (continued)

IRB Modification

IRB #: IRB-FY2021-76 Title: Focused Ethnography: Storytelling for Hispanics with Low Health Literacy and Diabetes Creation Date: 2-18-2021 Status: Review Complete Principal Investigator: Virginia Cadenhead Modification *required Are you making changes to the project? Yes Please make your changes in the sections to the left. No *required Justification Please provide the reasons for the modifications. Due to Covid 19 there are no face-to-face worship services, and the churches are meeting mostly online. I was unable to recruit as planned simply by contacting the pastors. I have made modifications to include snowball sampling within the Hispanic churches. The wording in the sample recruitment procedures has been changed to reflect this modification.

Chapter 5: Summary and Conclusion

Summary of Research

The reviews in Chapters 2 and 3 and the original research in Chapter 4 added to the body of knowledge about storytelling in health communication and identified knowledge gaps.

“Concept Analysis - Storytelling as a Teaching Strategy in Health Communication” clarified storytelling in the research literature. The concept analysis identified the types of storytelling and discussed its purpose in health communication. “Storytelling - An Educational Intervention for Oral Learners” included a scholarly overview of storytelling literature and its application to nursing practice. This state of science review presented orality and its relationship to low health literacy.

The articles revealed that storytelling has been studied as a cultural adaption for ethnic minorities (Bertera, 2014; Goddu et al., 2015; Houston et al., 2011) including the Hispanic population (Larkey et al., 2015; Larkey et al., 2007; Moran et al., 2016; Njeru et al., 2015). Experts recommended storytelling for low health literate populations (Day, 2009), but few studies measured the health literacy of the participants (Bertera, 2014; Moran et al., 2016). First person storytelling improved self-efficacy, health knowledge, and health outcomes in chronic disease management (Bertera, 2014; Campbell et al., 2013; Lipsey et al., 2020). Fictional storytelling had not been reported for chronic disease management.

Chapter 4, “Focused Ethnography: Storytelling for Hispanics with Low Health Literacy and Diabetes”, applied storytelling to a specific health issue and population. The problem of low health literacy and health disparities related to diabetes in the Hispanic population was addressed by the development of a storytelling intervention for diabetes education. Five community-dwelling volunteers with diabetes and low health literacy experienced focused ethnographic

interviews that included a fictional storytelling experience followed by a structured interview. Through qualitative analysis of the interviews, the five fictional stories were revised as culturally adapted educational tools for diabetes education. The story revisions included changes to improve (a) comprehension, (b) cultural acceptability, (c) identification, and (d) realism. The research suggested that stories could communicate diabetes knowledge and theoretically influence health behavior, but unlike previous research, it did not have a clear impact on self-efficacy. The findings were not generalizable due to the small, homogenous sample and research design.

Next Steps in Storytelling Research

The research was useful for story development, but the next step would be to verify the stories' educational validity. To establish their efficacy as educational interventions, the stories should be part of a quantitative interventional study to measure their impact on diabetes knowledge, self-efficacy, and health behaviors. A randomized controlled trial could be done to compare storytelling in diabetes education with didactic education for Hispanics with low health literacy. Follow-up research is needed to investigate the stories as part of an educational adaption within a larger diabetic education program.

Another next step in research would be to apply the model developed to other situations and settings. The researcher plans to use the model in community-based participatory research in Guatemala, a country with a 25% rate of diabetes among its indigenous peoples (Bream et al., 2018). Studies reviewed in the state of science article indicated storytelling had a global application (Lamb et al., 2017; Nguyen et al., 2018; Sabaretnam et al., 2019), therefore, further research should be done to determine if fictional storytelling is a valid tool in other cultures and locations.

For storytelling to be a reliable educational tool, further theoretical and qualitative research is recommended. The state of the science review revealed a lack of clarity between orality, storytelling, and low literacy. A better conceptual definition of orality could lead to development of tools to measure the concept. The additional theme of reciprocity was not addressed in the theoretical model, but it was similar to the defining attribute of interaction in the concept analysis (Cadenhead, 2021). Further qualitative research should be done to identify themes and meanings within the participants' reciprocal stories and the impact on storytelling as an educational tool.

Conclusion

Storytelling is an adaptable communication tool that can be applied to diverse settings and health issues. This dissertation included a concept analysis and a state of the science review to answer questions about storytelling as an educational tool and its application to health communication. The original research, "Focused Ethnography: Storytelling for Hispanics with Low Health Literacy and Diabetes," presented a model for fictional story development to be used in further research establishing storytelling as an educational tool to decrease health disparities among at-risk populations.

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BIOGRAPHICAL SKETCH

Provide the following information for the Senior/key personnel and other significant contributors.
Follow this format for each person. **DO NOT EXCEED FIVE PAGES.**

NAME: Virginia Hamilton Cadenhead, MSN, RN, CNM

INSTITUTION: University of Texas at Tyler

POSITION TITLE: Assistant Professor, California Baptist University

EDUCATION/TRAINING *(Begin with baccalaureate or other initial professional education, such as nursing, include postdoctoral training and residency training if applicable. Add/delete rows as necessary.)*

INSTITUTION AND LOCATION	DEGREE <i>(If applicable)</i>	Completion Date MM/YYYY	FIELD OF STUDY
Texas Christian University	BSN	08/1980	Nursing
Southwestern Baptist Seminary	MA	07/1986	Religious Education
Parkland School of Nurse-Midwifery	Diploma	10/1990	Certified Nurse Midwife
University of Texas at Tyler	MSN	12/2016	Nursing Education
University of Texas at Tyler	PhD	enrolled	Nursing

A. Personal Statement

I have been a nurse for over 40 years working with women and underserved populations. I am fluent in Spanish, having lived in Spanish speaking countries for over 20 years. I presently teach maternal child nursing and transcultural nursing at California Baptist University. My experiences living and working in other cultures have given me a desire to learn how to communicate health information for low literate populations.

B. Positions, Scientific Appointments, and Honors

- 1980-1986 Staff Nurse Labor and Delivery
- 1987 Community Nurse Educator
- 1987 Nurse Educator/ Baptist School of Allied Health in Occupied Territories/ Israel
- 1989 Staff Nurse Educator
- 1991-1993 Certified Nurse Midwife- Private Practice
- 1993-2005 Community Development/ Transcultural Nursing in Spain and North Africa
- 2006-2008 Community Health Nurse
- 2008-2015 Medical Coordinator- International Mission Board

(B., continued)

2016-2017 Staff Nurse Labor and Delivery

2017 Diabetes Nurse Educator

2017- Present Assistant Professor of Nursing

Member- Sigma Theta Tau Nursing Honor Society

Member -Christian Nurse Fellowship

C. Contributions to Science

Effective Health Teaching for Immigrant Women- Evidence-Based Change Project Fall 2016

unpublished

“Storytelling an Educational Intervention for Oral Learners” accepted for publication in the *Journal of Christian Nursing*.