

UC Berkeley

UC Berkeley Electronic Theses and Dissertations

Title

Talking Story: A community-developed digital storytelling intervention to promote colorectal cancer screening intention among church-attending Latinos

Permalink

<https://escholarship.org/uc/item/79b7j1js>

Author

Gomez, Vicky

Publication Date

2018

Peer reviewed|Thesis/dissertation

Talking Story: A community-developed digital storytelling intervention to promote colorectal cancer screening intention among church-attending Latinos

By

Vicky Gomez

A dissertation submitted in partial satisfaction of the

requirements for the degree of

Doctor of Public Health

in the

Graduate Division

of the

University of California, Berkeley

Committee in charge:

Professor Joan Bloom, Chair

Professor Amani Nuru-Jeter

Professor Kurt Organista

Summer 2018

© Copyright by

Vicky Gomez

2018

Abstract

Talking Story: A community-developed digital storytelling intervention to promote colorectal cancer screening intention among church-attending Latinos

by

Vicky Gomez

Doctor of Public Health

University of California, Berkeley

Professor Joan Bloom, Chair

Introduction: Although colorectal cancer screening (CRCS) rates have improved for all racial and ethnic groups due to wider availability of screening, Latinos continue to have lower screening rates compared to non-Latino whites. Additionally, Latinos are more likely to be diagnosed with later stages of colorectal cancer (CRC), which can lead to higher rates of morbidity and mortality. More culturally-sensitive interventions are needed to reach this population. The majority of existing CRCS interventions are based in primary health care settings, only targeting a fraction of the Latino population. This pilot study explores the feasibility of developing and introducing a digital storytelling (DST) intervention in a community church setting and its potential to influence CRCS intention among Latinos.

Methods: For the first part of the study, the research team collaborated with ten influential church members to create digital stories about their previous CRC and CRCS experience. They were then interviewed to understand how developing a digital story influences their future screening practices and the promotion of CRCS to others. For the second part of the study, 20 participants were recruited between the ages of 50 to 75 who were not up-to-date with CRCS per United States Preventive Services Task Force (USPSTF) recommendations. They completed surveys assessing their intention to complete CRCS before and after viewing digital stories developed by fellow church members. Participants were then asked to participate in focus groups to understand, qualitatively, how the digital stories influenced their intention to complete CRCS.

Results: The digital story developers were inspired by the digital storytelling process and interested in sharing their digital stories with others in an effort to improve screening beyond the church setting. For those who viewed the digital stories, men and women with previous screening experience were motivated to consider different screening methods for future screening. Furthermore, those who had never completed CRCS reported increased willingness to complete CRCS after viewing the intervention. The DST intervention has potential to influence participants' intention to complete first-time screening as well as the type of screening for those with previous screening experience due to the personal nature of the stories and humanizing of the CRCS process.

Discussion: The introduction of a community-based DST intervention within a church setting is a feasible and novel strategy with the potential to influence more Latinos to complete CRCS and save lives. Future studies should consider this approach to test a DST intervention in multiple settings, topics and diverse populations.

Acknowledgments

First and foremost, I would like to give thanks to God and our infinite universe. Thank you for guiding me on this journey of faith and love!

To my incredible committee: Drs. Joan Bloom, Amani Allen, and Kurt Organista. Thank you for believing me and helping make my dream to become Dr. Gomez a reality. It has not always been easy but so worth it. I have grown tremendously these past five years due to your encouragement and expertise!

Dr. Joan Bloom, without you I would not have made it into this program. Thank you for your assistance with funding and for paying for the digital story development. These stories would not be possible without you.

Dr. Amani Allen, thank you for adopting me. The time you have spent mentoring me and molding me into a scholar will never be forgotten. Thank you for your investment in my potential and giving me fertile soil to grow in. I hope to inspire and encourage my future students the way you have done for me and countless others.

Dr. Kurt Organista, thank you for being so supportive of my work from day one. Thank you for believing in me and this project. I feel blessed to have you on my committee. Your advice and expertise on the Latino population was exactly what this work needed. Thank you for always treating me to tacos and keeping it real!

Dr. Susan Ivey, thank you for your direction in the development of this work. I enjoyed our talks about interventions and life! Thank you for bringing the human connection element to my work.

Dr. Carol Somkin, thank you for being my academic mom from my first day as your intern at Kaiser Permanente's Division of Research. I grew so much during those years as your research coordinator learning from your example what it meant to be a researcher with integrity and good human being. You never gave up on me even when I wanted to give up on myself. Thank you for your unwavering belief in me. Your mentorship has had such a profound impact on my life that I will fully never truly understand the depth of it. Thank you.

Dr. Rena Pasick, thank you for showing me this dream was possible and needed. You believed in me and a host of other underrepresented scholars to change the landscape of research!

DrPH Sensational 7.5 cohort: Drs. Carly Strouse, Anna Summer, Cassie Blazer, Mike Harvey, Leena Singh and Kelechi Uwaezuoke! Thank you for being the most supportive and loving cohort I could have ever asked for!

To the best writing accountability group, TEAM SIML (STAY IN MY LANE), where do I even begin! To my amiga Kelechi, thank you for the endless amounts of laughter and JOY. I can't imagine being on this journey without you. Your love, support and prayers have carried me through on more days than I can count. I will always remember that first taco Tuesday that changed everything! #TeamTWOGETHER. To my amiga Carly, seriously you have been my

rock and the wake-up call when I have needed it. Thank you for our co-working sessions, always being willing to read my work and endless texts of love and support!

Safe Space Crew (SSC): Berke Brown, Drs. Stephanie Fong Gomez, Cassie Marshall, Summer Starling, Melody Tulier and Kelechi Uwaezuoke! Thanks to Amani for putting together such an incredible group of scholars that so kindly loved and supported each other during a full year of seminar. You all made me a better scholar and friend. That we may continue to live our lives with compassionate excellence!

This past year I had the honor of being a Graduate Fellow in the Institute of the Study of Societal Issues. The academic and career guidance I received from Drs. Deborah Lustig, David Minkus and Christine Trost will never be forgotten. I grew tremendously this past year because of your guidance and landed the job of my dreams. Thank you from the bottom of my heart.

To all of my mentors and supporters who have helped make this Mission girl's dream come true, Mission High, CCSF, SFSU Raza Studies, SFSU Health Education BS and MPH: Drs. Vivian Chavez and Lisa Moore for still mentoring me after twenty years and the best little red hen partner a girl could ask for, the incomparable, Sally Geisse. Last but not least, Abby Rincon, my first health education professor and now friend that sparked in me a passion for public health that has only grown stronger since my days at SFSU!

This research would not be possible without the hard work of Nazineen Kandahari, my research project coordinator, who started with me from the inception of an idea and seeing it through to implementation. Thank you for every single thing you did to make this a success. Your sacrifices did not go unnoticed. I am honored that I had the chance to mentor you and can't wait to celebrate you as you become a physician!

For every single person that has been rooting for me since day one. There are too many to mention but you know who you are. I will never forget the countless texts, prayers, phone calls and walks. Thank you for believing in me and knowing this was possible!

Dedication

To my familia: Thank you for all of the sacrifices you have made to support my dream. To my parents, Victoria and Fortunato Gomez, for making the ultimate sacrifice to start your lives in a new country so you could give us opportunities you never had. Thank you. To my sister, Liz Gomez: My best friend and partner in crime. I could not imagine this life without you. You have been my rock and believed in me when I had no hope. Thank you for always loving and supporting us the way you do. To my little brother, Erik Gomez: You are gone but not ever forgotten. This is for you. To my son, Christian Gomez: You have made me a better person and taught me so much about what it means to love unconditionally. We grew up together and you continue to be my son and my best friend. I wish you only the best the world has to offer.

To my church family at Union City Apostolic Church you changed my life and I am so grateful. Pastor Adam Lopez III and Dr. Arnulfo Cedillo, thank you for taking a chance on me and saying yes to conducting this research in your church!

To my angel, Angelica Guevara. There are no words in this world to thank you for the immense support you offered me in the last year of my dissertation. More than that, you were there working with me every single day as my writing and accountability partner in the last month of reaching my goal. Thank you for showing up for me even when I did not know what I needed. I vow to do the same as you work towards the last year of your doctoral program to become Dr. Angelica Guevara. Most of all, thank you for being unapologetically you and choosing love and growth every single day! #teamcantstopwontstop

To Dr. Velia Garcia, who believed that I would be Doctora Gomez one day when I wasn't even sure if I would graduate with my bachelor's degree. You demonstrated what it meant to be an amazing mentor and it has inspired me to be the kind of mentor you would be proud of with my past, current and future students. I am honored to be walking in your footsteps as a professor in the CSU system. Thank you for leading the way. Although it saddens me that you will never have a chance to see me fulfill this dream, I know you are still with me every step of the way.

TABLE OF CONTENTS

Abstract	1
ACKNOWLEDGMENTS AND DEDICATION	i
TABLE OF CONTENTS	iv
CHAPTER I: INTRODUCTION AND OVERVIEW	1
Introduction.....	1
Statement of the Issue	1
Study Purpose and Aims	3
Significance of the Study.....	3
Organization of the Study.....	3
CHAPTER II: REVIEW OF THE LITERATURE.....	4
Latinos in the United States.....	4
Colorectal Cancer and Latinos in the US	4
Disparities in Colorectal Cancer Screening.....	5
Barriers and Facilitators to Colorectal Cancer Screening	5
Colorectal Cancer Screening Interventions	6
Community Faith-based Colorectal Cancer Screening Interventions.....	7
CBPR and Faith-based Cancer Screening Interventions.....	7
Digital Storytelling as a Communication Tool for Reaching the Latino Community	8
Gaps in the Literature.....	8
Theoretical Conceptualization	9
CHAPTER III: METHODS	10
Research Overview and Design	10
Research Questions and Aims	10
Study Setting.....	11
Intervention Design.....	12
Aim 1. Storytellers: Development of the Digital Storytelling Intervention	12
Participants.....	12
Procedures.....	12
Intervention Design Limitations.....	13
Qualitative Study Design.....	14
Aim 1a. Storytellers: Semi-structured In-depth Interviews.....	14
Aim 2a. Storyviewers: Focus groups after Viewing the Digital Stories	15
Participants.....	15
Procedures.....	15
Qualitative Data Analysis	16
Qualitative Study Limitations	16
Quantitative Study Design.....	17
Aim 2. Storyviewers: Assessing the Viewing of the Digital Stories	17
Participants.....	17
Procedures.....	17
Measures	18
Quantitative Data Analysis	21
Quantitative Study Limitations	21

CHAPTER IV: RESULTS	22
Introduction.....	22
Section 1: Aims 1, 1a. Intervention Design and Interviews with Storytellers.....	22
Section 2: Aims 2, 2a. Pre- and Post-surveys and Focus Groups and Interviews	25
Intervention Feasibility and Accessibility	34
CHAPTER V: DISCUSSION	35
Discussion.....	35
Limitations.....	40
Implications for Research and Practice.....	41
REFERENCES	42
APPENDICES	48
Appendix A: Demographic survey	48
Appendix B: Storyteller Interview guide	50
Appendix C: Storyviewer Focus group guide	52
Appendix D: Pre-survey	54
Appendix E: Post-survey	60

CHAPTER I: Introduction and Overview

Introduction

In the United States, cancer is the leading cause of death in the Latino population after surpassing heart disease in 2012 (American Cancer Society, 2012). The top four major cancers in the majority of populations including the Latino population are breast, prostate, lung, and colorectal cancer (American Cancer Society, 2014b). Colorectal cancer is one of the few cancers where screening is effective and can save lives (Siegel, Naishadham, & Jemal, 2013). In 2014, a consortium of 170 major organizations including the Centers for Disease Control and Prevention, the American Cancer Society, and the National Round Table banded together in an effort to increase colorectal cancer screening rates from 60% to 80% by 2018 (“80% by 2018 | National Colorectal Cancer Roundtable,” n.d.). Several racial/ethnic groups are poised to meet this goal while others are farther away; one such lagging group is the Latino population. Although they are the fastest growing ethnic group in the United States, they continue to trail behind in completing screening compared to their non-Latino counterparts. This dissertation is an exploration of providing a community-based digital media intervention in the church

Statement of the Issue

Colorectal cancer (CRC) is the second most commonly diagnosed cancer in Latino men and the third among Latinas; and is the third leading cause of cancer death for both Latino men and women (American Cancer Society, 2015). CRC is one of the few cancers with effective screening (Siegel, Naishadham, & Jemal, 2013). As many as 60% of CRC-related deaths could be prevented if men and women aged 50 to 75 received routine screening (He & Efron, 2011). The United States Preventive Services Task Force (USPSTF) recommends screening for CRC for average-risk adults aged 50 to 75 years old using fecal occult blood tests (FOBT) or fecal immunochemical tests (FIT) every year, sigmoidoscopy every five years, or colonoscopy every ten years (American Cancer Society, 2017). Adults with a family history of CRC are considered to be at higher risk and require screening in shorter intervals (Wilschut et al., 2011).

Although colorectal cancer-screening (CRCS) rates have improved for all racial groups due to wider availability of screening, Latinos have lower screening rates compared to non-Latino whites (American Cancer Society, 2017). In 2015, only 49% of Latinos in the US were up-to-date with CRCS compared to 65% of non-Latino whites (American Cancer Society, 2017). Due to lower CRCS rates, Latinos are also more likely to be diagnosed with later stages of CRC compared to non-Latino whites, which can lead to higher rates of mortality.

According to the literature, there are numerous barriers to completing CRCS among the Latino population, including structural factors such as access to health care, language barriers, and immigration status (Natale-Pereira et al., 2008), cultural constructs such as fatalism and machismo (Getrich et al., 2012; Leyva et al., 2014), and fear of being diagnosed with cancer because it is often considered a death sentence (Ellison, Jandorf, Villagra, Winkel, & DuHamel, 2011; Getrich et al., 2012; Natale-Pereira et al., 2008). Even though different culturally-tailored interventions have been developed and implemented to address these barriers, the CRCS disparity persists (Naylor, Ward, & Polite, 2012). Of the existing interventions, the majority are based in primary care settings with a limited number in community settings. Providing interventions in primary care settings fails to reach this population adequately, mainly because a fraction of the Latino community has limited access to health insurance and those who are

enrolled experience navigation challenges in accessing these health services (Lurie, 1997). Offering interventions in community-based settings has the potential to promote cancer screening and further reach this population to address the existing screening disparity (Allen, Leyva, et al., 2014; Allen, Pérez, et al., 2014).

Another consideration, in addition to location, is the intervention's mode of delivery. When the health promotion and disease prevention field initially emerged, messaging focused on communicating risk with statistics and probability (Briant, Halter, Marchello, Escareño, & Thompson, 2016). This numeric approach did not work for all groups, particularly for those with low-literacy and/or numeracy (Briant et al., 2016). The use of narratives in intervention development is an additional accessible health promotion strategy (Briant et al., 2016; L. K. Larkey & Gonzalez, 2007; L. K. Larkey & Hecht, 2010). A narrative approach is accessible because stories are used daily as a way to communicate with others and to make sense of and understand our lived experience (Briant et al., 2016).

Storytelling is part of a rich oral tradition in the Latino community and is also an accepted form of communication in the field of health promotion as stories are an engaging and accessible way to promote health behavior change (LeBron et al., 2014; Reese, 2012). Health messaging in the form of a testimony from fellow community members has the potential to impact health behavior due to close social ties in the church (Allen, Pérez, et al., 2014). Testimonies are already an accepted form of sharing personal experiences with health issues within the congregation.

The introduction of a digital storytelling (DST) intervention in churches is a potential strategy for promoting CRCS in this population. DST is the process of sharing one's story with the assistance of images, text, and video. Over the last decade, DST has been gaining recognition as a popular education health promotion tool with roots in Community-Based Participatory Research (CBPR) (Gubrium, 2009). DST is a method anchored in CBPR because the digital stories are created collaboratively with community members and integrate the voice of those who have often been underrepresented in research (Briant, Halter, Marchello, Escareño, & Thompson, 2016). Community members develop digital stories with training and technical assistance from a DST professional. Once they complete their digital stories, they are the owners of their stories, and they can choose to share them with their networks and larger church community. DST is a testimony in a digital format; church members who view the stories will be able to see and hear how their fellow community members are motivated to complete CRCS and are potentially influenced to complete CRCS themselves.

Study Purpose

The primary purpose of this feasibility study is to determine if digital storytelling will be a practical church-based intervention for increasing colorectal cancer screening intention among Latinos between the ages of 50 and 75 attending church in Alameda County.

Research Aims

Aim 1. This study aims to develop a faith-based digital storytelling intervention to improve colorectal cancer screening intention among unscreened 50-75 year old Latinos attending church in Alameda County.

Aim 1a. To understand how developing one's own digital story influences continued CRCS intention and to what extent it may serve as an incentive to promote CRCS to others

Aim 2. This study aims to assess the colorectal cancer and screening knowledge, attitudes and beliefs and intention to complete CRCS before and after viewing a digital storytelling intervention created by their fellow church community members.

Aim 2a. To explore how viewing the digital storytelling intervention influences intention to complete colorectal cancer screening among unscreened 50-75 year old Latinos attending church in Alameda County.

Significance of the Study

The contribution of this research has the potential to be significant because a culturally adapted digital storytelling intervention offered in the church setting may impact behavior change and help to improve colorectal cancer screening rates among the faith-based Latino population. Currently, the norm has been to target the Latino population in primary care settings. This research challenges the norm by proposing Latino churches as the point of entry where church members create digital stories targeted specifically to their peers within the church. The proposed research is innovative because a faith-based intervention strategy with the development of a digital storytelling intervention to increase colorectal cancer screening in the Latino population has not been previously tested. The development of a faith-based digital storytelling intervention has the potential to increase colorectal cancer screening rates in the Latino church community of Alameda County and could possibly be used to promote healthy behavior among other Latino populations who live with other chronic diseases such as diabetes and heart disease.

Organization of the Study

Chapter I presents the background and the statement of the issue, its purpose, and specific aims.

Chapter II is a review of the relevant literature and the theoretical foundations of the study.

Chapter III presents the methodology used in the study, including research aims, research design, human subjects' protections, sampling procedures, data collection methods, and a description of the study setting.

Chapter IV presents the findings of the study.

Chapter V presents the discussion, interpretation, implications of the findings, study limitations, significance of the findings, and future directions.

CHAPTER II: Review of the Literature

Latinos in the United States

Latinos are the largest and fastest growing ethnic group in the US. They currently constitute 17% of the US population (53 million) and are projected to grow to 31% (128.8 million) by the year 2060. In California, proportions are even greater; Latinos are the largest ethnic/racial group in the state, comprising approximately 40% of the population and are projected to grow to 50% by the year 2060 (Lopez & comments, n.d.). Alarming, Latinos are least likely to have health insurance compared to all other racial/ethnic group in the US due to numerous barriers including immigration status, language barriers, and underemployment (“Cancer Facts & Figures for Hispanics/Latinos 2012-2014,” 2012).

In 2009, approximately 30% of all US Latinos lacked access to insurance (“Population Bulletin Update: Latinos in the United States 2010 (con’t.),” n.d.). Foreign-born Latinos fared much worse than their native-born Latino counterparts with 54% lacking health insurance (“Population Bulletin Update: Latinos in the United States 2010 (con’t.),” n.d.). The implementation of the Affordable Care Act (ACA) has improved health care access for many documented Latino adults and undocumented Latino children, but does not offer health insurance to the 11.4 million undocumented Latino adults who still need health insurance coverage in the US (ASPA, 2013). Unfortunately the future of the ACA is uncertain due to our current political climate.

For Latinos who do have access to health services, there are secondary access issues such as difficulty navigating within the health system that function as barriers.(Lurie, 1997) Examples of these barriers include: access to a physician with continuity of care, ease of obtaining health services, availability of a professional interpreter, access to providers and staff fluent in Spanish or of Latino descent.(Lurie, 1997) These factors can hinder the use of health services by individuals who have access to health insurance who may not be fully utilizing health care services. Limited access to health services among Latinos leaves them at risk for a multitude of health issues, one of which is colorectal cancer.

Colorectal Cancer and Latinos in the United States

Colorectal cancer (CRC) is the third most common diagnosed cancer and the third leading cause of all cancer-related deaths for both men and women in the US (American Cancer Society, 2014a). Among the US Latino population, CRC is the second most common cancer diagnosed, the second leading cause of cancer-related death for Latino men and the third leading cause of cancer-related death for Latinas (Siegel, Naishadham, & Jemal, 2012). The American Cancer Society estimated a total of approximately 12,000 new colorectal cancer cases and approximately 4000 deaths in 2015 (“American Cancer Society,” n.d.). Latinos are more likely to be diagnosed with later stages of colorectal cancer compared to non-Latino whites due to lower screening rates and less access to health care (“American Cancer Society,” n.d.). It is important for Latinos to get screening because the CRC 5-year-cause-specific survival rate among Latinos at the localized stage is 89% compared to 15% for those diagnosed at a later stage. Research shows that colorectal cancer screening (CRCS) is effective in reducing colorectal cancer mortality (Siegel et al., 2013).

Importance of Colorectal Cancer Screening

The United States Preventive Services Task Force (USPSTF) recommends screening for colorectal cancer for average risk adults aged 50 to 75 years old using fecal occult blood tests (FOBT) or fecal immunochemical tests (FIT) every year, sigmoidoscopy every five years, or colonoscopy every ten years (American Cancer Society, 2014b). A person is considered “up to date” if they are compliant with one of these recommended screening methods. Because precancerous polyps take years to transition into cancer, this provides a window of time for individuals to get screened and have precancerous polyps removed. As many as 60% of colorectal cancer related deaths could be prevented if men and women between the ages of 50 to 75 completed routine screening (He & Efron, 2011).

The FOBT and FIT are both stool kits that can be done at home and sent to the laboratory directly by the patient to detect blood in the colon and/or stool. Only if the test is positive will the patient be required to follow-up with a diagnostic colonoscopy. These home stool tests are inexpensive and non-invasive which make them an appealing population screening tool (Gorin, 2005). The sigmoidoscopy and colonoscopy use endoscopes to enter all or parts of the colon to detect and remove precancerous and cancerous polyps. Although these types of tests provide a much more accurate form of screening, they are invasive, the preparation is time consuming, and they can be off-putting and overwhelming to the patient, potentially leading to a fear of screening.

Disparities in Colorectal Cancer Screening

Delayed screening can result in late diagnosis and can have serious implications for morbidity and mortality (American Cancer Society, 2014b). Even though colorectal cancer screening rates have improved for all racial groups due to wider availability of screening, Latinos continue to have lower screening rates compared to non-Latino whites (American Cancer Society, 2012). In 2012, only 47% of Latinos in the US were up to date with CRC screening compared to 62% of non-Latino whites (American Cancer Society, 2012). When focusing on the uninsured, the gap widens with Latinos being 11% up to date with CRC screening compared to 30% non-Latino whites. Latinos are more likely to be diagnosed with later stages of colorectal cancer compared to non-Latino whites due to lower screening rates (Natale-Pereira et al., 2008). Several of the barriers associated with lower screening rates include low knowledge and awareness of CRC, cultural barriers, language issues, limited access to health care, and immigration status (Natale-Pereira et al., 2008).

Barriers to Colorectal Cancer Screening

The main barrier to completing colorectal cancer screening in the Latino population is the lack of health care access (Aragones, Schwartz, Shah, & Gany, 2010; Cokkinides, Bandi, Siegel, & Jemal, 2012; Ellison, Jandorf, Villagra, Winkel, & DuHamel, 2011; Getrich et al., 2012; Goel et al., 2003; Natale-Pereira et al., 2008; Shih, Elting, & Levin, 2008). With such limited health care access, when the Latino immigrant population seeks health care services, it is usually in the emergency department for serious and acute conditions; therefore, cancer screening is not considered an important priority (Aragones et al., 2010; Goodman, Ogdie, Kanamori, Cañar, & O'Malley, 2006; Natale-Pereira et al., 2008). Furthermore, colorectal cancer can also be asymptomatic; many with colorectal cancer do not develop any symptoms that would help them identify the need to screen (American Cancer Society, 2014b). The undocumented Latino population, in particular, can live in fear of accessing health care services due to their

immigration status (Natale-Pereira et al., 2008). For Latinos that have access to health care services, many experience obstacles that make navigating our current health care system overwhelming to access much needed health services and preventative screenings. Another substantial barrier highlighted in the literature is limited English proficiency among this population, particularly in the area of health literacy (Cokkinides et al., 2012; Diaz, Roberts, Goldman, Weitzen, & Eaton, 2008; Ellison et al., 2011; Goel et al., 2003; Natale-Pereira et al., 2008).

Fear of screening in general for both men and women is another barrier for the Latino community (Ellison et al., 2011; Getrich et al., 2012; Natale-Pereira et al., 2008). This is largely due to limited knowledge of colorectal cancer and its screening methods (Natale-Pereira et al., 2008). There are also many misperceptions about cancer screening and being diagnosed with cancer in the Latino population (Diaz et al., 2008; Natale-Pereira et al., 2008). One particular misperception spread throughout the community is the fear of initiating screening, which many feel can lead to directly being diagnosed with colorectal cancer with no recourse because it is considered a “death sentence” (Natale-Pereira et al., 2008).

Cultural factors such as fatalism and machismo can also play a role in colorectal cancer screening practices (Getrich et al., 2012; Natale-Pereira et al., 2008). Fatalism is the belief that health outcomes are predetermined by God, and therefore there is no need to be proactive if life is predestined (Natale-Pereira et al., 2008). Fatalistic attitudes can be a barrier to improving screening rates within the Latino population. Machismo refers to the attitudes, behaviors, and qualities associated with masculinity/manhood in Latino men (Getrich et al., 2012). Some Latino men fear completing a colonoscopy because they are afraid they will be transformed sexually by the experience (Getrich et al., 2012). These fears are rooted in homophobia and can pose a major barrier to complete colorectal cancer screening (Getrich et al., 2012; Goodman et al., 2006). Addressing these misperceptions can aid in increasing awareness about colorectal cancer and screening in the Latino community.

Although the above factors have been shown to affect colorectal cancer screening practices negatively, the role of acculturation has played a positive role and has increased colorectal cancer screening rates in the Latino population. Acculturation is the process of adopting the attitudes, values, customs, beliefs and behaviors of another culture (Brenner, Ko, Janz, Gupta, & Inadomi, 2015). Studies that have examined the impact of acculturation on CRC screening completion consistently show that individuals who report greater levels of acculturation are more likely than those less acculturated to complete a CRC screening (Brenner et al., 2015). As Latinos are exposed to American culture, they are likely to adopt the cultural norms of the dominant culture such as health service utilization which can account for one of the reasons acculturated Latinos have higher screening rates.

Colorectal Cancer Screening Interventions

Despite the prevalence of colorectal cancer and the lack of screening in the Latino community, there are relatively few colorectal cancer screening interventions targeted specifically for this population. Of the existing interventions, the majority targeting Latinos are based in primary health care settings with only a few based in community settings. Due to the barriers discussed above, providing interventions in primary care settings may not be the best strategy for fully reaching this population and addressing this disparity in screening rates. Several studies suggest that in addition to primary care interventions, community-based interventions may be an effective strategy for promoting cancer screening in the US Latino

population and may help to close the disparity gap (Allen, Leyva, et al., 2014; Allen, Pérez, et al., 2014).

Community Faith-based Colorectal Cancer Screening Interventions

One example of a relevant community-based setting for Latinos is the church. Religion plays a central role in the Latino population; 88% of US Latinos are religiously affiliated, particularly those between the ages of 50 to 75 years old, the recommended CRCSC age range (“Survey | 2013 Hispanic Values Survey,” 2013).

Cancer education interventions delivered in a church based setting are one recommended way to reach underserved populations such as Latinos (Campbell et al., 2007). Many churches view health promotion as their mission and are highly motivated to collaborate on programs to improve the health of congregants (Campbell et al., 2007). In addition, churches have the infrastructure and space needed to deliver programs to a captive audience (Allen, Pérez, et al., 2014).

The majority of faith-based cancer screening interventions have been in partnership with African American churches, particularly in the areas of breast and prostate cancers (Holt et al., 2009; Lumpkins, Coffey, Daley, & Greiner, 2013; Saunders et al., 2013). Recently, more researchers have begun to examine faith-based cancer screening interventions in the Latino community. In 2013, a study examining the feasibility of a multiple cancer screening intervention supported the church as an acceptable setting for promoting cancer screening to Latinas. Current research has focused on Catholic and Protestant churches on the East Coast and, most of all, their findings justify the need for further research (Allen, Leyva, et al., 2014; Allen, Pérez, et al., 2014; Leyva et al., 2014). Colorectal cancer screening interventions provided in community-based settings such as churches can be an effective strategy for increasing screening rates in the Latino community (Allen, Leyva, et al., 2014; Allen, Pérez, et al., 2014). This approach targets a sector of the population that may not be reached in primary care clinic settings (L. Larkey, 2006; L. K. Larkey et al., 2012).

CBPR and Faith-based Cancer Screening Interventions

Community-based participatory research (CBPR) has been proposed as a potential strategy to help reduce health disparities by building collaborations between researchers and community members/organizations (Minkler & Wallerstein, 2008). Contrary to popular belief, CBPR is not a research methodology, but an orientation to research with a set of guiding principles for conducting community-generated and community-centered research with the ultimate goal of social action and change (Minkler & Wallerstein, 2008). One of the goals of CBPR is to give voice to communities that are often left out of the research conversation (Minkler & Wallerstein, 2008).

Faith-based settings such as churches are one way to reach a target population using a CBPR approach. In many communities, the church continues to be a trusted institution in the community. In the African-American community, faith-based interventions have been successful in utilizing a CBPR approach to achieve positive results such as increasing mammograms among African-American women by 38%, successfully improving knowledge of risk factors associated with cancer and increased interest in participation of cancer research (Colon-Otero et al., 2012; Powell et al., 2005; Woods et al., 2013). A true CBPR collaboration would allow the community to decide which issue to focus on, and, unfortunately due to the nature of research funding, this is not usually the case (Minkler & Wallerstein, 2008).

Of the limited amount of faith-based cancer screening interventions using CBPR, the majority have focused on African-Americans, several have been focused on the Latino population, and only a few have focused on other populations such as Afghan, Appalachian and Samoan populations. Only in the past 5 years, have researchers begun to focus on the Latino faith-based communities for cancer screening interventions and not necessarily from a CBPR approach as highlighted in the Latino faith-based studies discussed in the previous section. The majority of the studies utilizing a CBPR approach highlighted the importance of the church as a proper place for offering health promotion activities (Campbell et al., 2007; Harmon et al., 2012; Powell et al., 2005; Rodriguez, Bowie, Frattaroli, & Gielen, 2009; Saunders et al., 2013; Schoenberg et al., 2009; Shirazi, Shirazi, & Bloom, 2013; Wilcox et al., 2010; Woods et al., 2013). Several articles mention churches as a central setting for introducing innovative health promotion activities directly to the communities they serve and influence (Harmon et al., 2012; Powell et al., 2005; Saunders et al., 2013; Schoenberg et al., 2009; Woods et al., 2013).

Many studies viewed the combined approach of CBPR with cancer screening health promotion activities in a faith-based setting as a strategy to reduce cancer health disparities (Campbell et al., 2007; Colon-Otero et al., 2012; Corbie-Smith et al., 2003; Harmon et al., 2012; Rodriguez et al., 2009; Wilcox et al., 2010; Wynn et al., 2011). According to Jones and Wells, CBPR can be used as a strategy to bring researchers and communities together to address health disparities for a more effective approach (Jones L & Wells K, 2007). In the past, many communities of color have not had a voice in the research that is done on their behalf; CBPR supports that all voices are equally important and this is one way to bring a broader range of voices back into the research conversation (Minkler & Wallerstein, 2008).

Digital Storytelling as a Communication Tool for Reaching the Latino Community

In addition to location, mode of delivery is an important component of intervention effectiveness. Digital storytelling is receiving increasing recognition as a popular education health promotion method with roots in CBPR (Gubrium, 2009). The introduction of digital storytelling within the church is one potential strategy that may have the ability to influence more members of the Latino community to complete screening. Digital storytelling is the process of telling one's story with the assistance of images, text, and video. Community members develop the short stories with the technical assistance of a digital storytelling guide.

The use of storytelling in the Latino community is a part of their rich oral history (Reese, 2012). In the area of health promotion, stories are an engaging way to share health messages in an accessible way (LeBron et al., 2014). In addition, stories are often shared among people, and health messages are passed among community members, thus the digital story not only impacts those who tell their stories, but everyone the story is shared with (Cueva et al., 2013).

Gaps in the Literature

The majority of literature available on colorectal cancer screening interventions is limited in scope and based primarily in clinical settings. It is critical to find other ways to address the disparity in screening rates among Latinos. Utilizing CBPR as a research approach with the Latino community may be one way of helping to address this health disparity. Another gap is the limited amount of literature focused on faith-based interventions in the Latino population. The proposed research aims to fill this gap by linking together church-based interventions along with digital storytelling as a potential way of reaching this population and increasing colorectal cancer screening rates.

Theoretical Conceptualization

The Social Ecological Model is the framework being used to highlight the three theoretical levels of this proposed study. The first individual level is a combination of the health belief and theory of reasoned action models, which speak to the individual thought process that occurs when making a behavior change. The second interpersonal level highlights Social Cognitive Theory, which provides a rationale for a vicarious learning model that can guide behavior change. The third organizational level stresses the importance of the church as a relevant organization to the Latino population with the capacity to normalize colorectal cancer screening within the church.

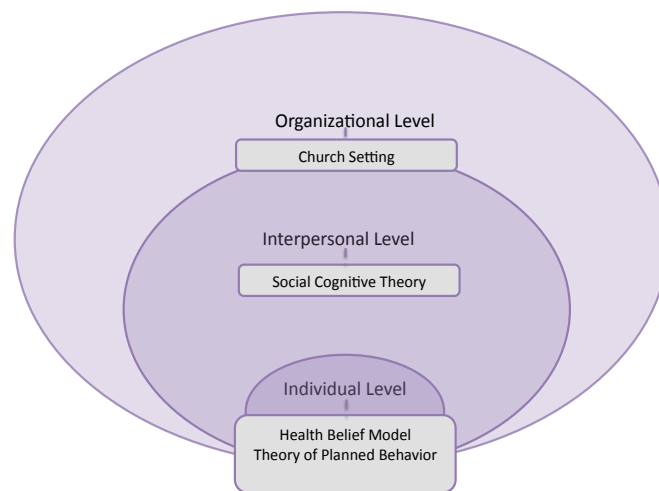
The first behavior theory being highlighted in the individual level of the framework is the Health Belief Model (HBM). HBM posits that individuals will engage in a health behavior, such as colorectal cancer screening, if they perceive themselves to be susceptible to colorectal cancer, if they perceive the consequences to be severe if they don't get screened, if they recognize both the benefits and minimal colorectal cancer screening barriers, if they receive positive cues to get screened and ultimately believe in their own ability to complete screening (Glanz, Rimer, & National Cancer Institute (U.S.), 1997). HBM has been applied extensively in public health interventions as a guiding theoretical model for health issues that are geared towards prevention and are asymptomatic in nature such as colorectal cancer where beliefs can be just as important or even more important than experiencing actual symptoms (Glanz & Bishop, 2010).

The second theory being highlighted in the individual level of the framework is the Theory of Planned Behavior (TPB). TPB posits intention as an important precursor to a health-related behavior change as it outlines the influence of attitudes and social norms on a health behavior (Ajzen, 1991). Because we will not be able to measure actual completion of a screening method after the intervention, behavior intention will be used as a proxy for measuring the participant's intent to complete colorectal cancer screening in the future. Because individual theories cannot explain human behavior change alone, a second level of interpersonal theory is needed to explain how behavior change occurs when the individual interacts with others and their environment.

The Social Cognitive Theory (SCT) is situated on the interpersonal level of the socio-ecological framework. SCT posits that human behavior occurs in a dynamic model where the person, environment, and behavior are constantly interacting with each other (Glanz & Bishop, 2010). Key constructs of SCT that are relevant to health behavior change interventions include observational learning, reinforcement, self-control, and self-efficacy (Glanz & Bishop, 2010). The construct of observational learning highlights the importance of learning from the experience of others and the results associated with those experiences (Glanz & Bishop, 2010). This is important because an important facet of the church experience is the role of testimony among church members. Personal experiences of overcoming life's challenges are shared among members in private and public forums. Often these testimonies include overcoming health challenges such as a cancer diagnosis. These testimonies are a form of observational learning and reinforcement of behavior by learning from the experiences of others and their actions. Another key construct that is important to this research is reciprocal determinism, which means that a person can be both "an agent for change and a responder to change" (Glanz & Bishop, 2010). This is important because as church members develop digital stories they are helping to reinforce their own screening behavior but also have the potential to influence the screening of others. Role models can be an important reinforcement of behavior and can be utilized to promote health behavior such as colorectal cancer screening.

In addition to the individual and interpersonal health behavior theories, the socio-ecological model emphasizes that health behaviors influence and are influenced by their surrounding environment similar to Social Cognitive Theory. This ecological framework highlights that there are factors operating at other levels that are involved in the decision to obtain screening such as the individual, interpersonal, organization, community, and public policy levels (“CDC - Social Ecological Model - CRCCP,” n.d.). Only the first three levels are relevant for the purposes of changing behavior in this research. Although there is no organizational theory that has been assigned to this level, the organizational level is of particular importance to this research project as it highlights the church as a relevant organization to the Latino community as an avenue for promoting behavior change and creating an environment that normalizes colorectal cancer screening.

Figure 1.1 – Conceptual Framework



CHAPTER III: Methods

Research Overview and Design

The main purpose of this feasibility study is to determine if digital storytelling is a practical church-based intervention for increasing colorectal cancer screening intention among Latinos between the ages of 50 and 75 attending church in Alameda County. A feasibility design was chosen to provide the foundation for further intervention research if the intervention is deemed feasible and acceptable to the community and if the initial impact shows promise. Feasibility studies are often conducted to determine if a study is worthy of additional resources because it has the potential to be effective and sustainable (Bowen et al., 2009). We selected a mixed methods design because it incorporated both quantitative and qualitative methods to illuminate a richer understanding than what would be found by either approach alone. This study employed a quasi-experimental one-group pre-/post-evaluation design, without control group, which assessed the feasibility, acceptability, and preliminary impact of a digital storytelling intervention, along with qualitative approaches to understand the process of creating and viewing the digital stories. This chapter includes a description of the process and procedures utilized in this study including research design, research aims, study setting, participant recruitment, data collection and analysis. The chapter is organized into three sections: intervention development, qualitative and quantitative study design.

Research Aims

Aim 1. This study aims to develop a faith-based digital storytelling intervention to improve colorectal cancer screening intention among unscreened 50-75 year old Latinos attending church in Alameda County.

Aim 1a. To understand how developing one's own digital story influences continued CRCS intention and to what extent it may serve as an incentive to promote CRCS to others

Aim 2. This study aims to assess the colorectal cancer and screening knowledge, attitudes and beliefs and intention to complete CRCS before and after viewing a digital storytelling intervention created by their fellow church community members.

Aim 2a. To explore how viewing the digital storytelling intervention influences intention to complete colorectal cancer screening among unscreened 50-75 year old Latinos attending church in Alameda County.

Study Setting:

Union City Apostolic Church (UCAC) is a Pentecostal church located in Union City, a middle-class suburb of the San Francisco Bay Area in California. This church was selected due to its size, diversity, and large Latino population. UCAC has a registered church population of over 400 congregants with up to 600 attendees with a predominantly Latino population where both English and Spanish services are offered. Due to the limited scope of the research study, the intervention was primarily offered in English.

The research team has been collaborating with UCAC as part of a larger community-based participatory research project for the past five years, incorporating church leadership and members in the research design process with the assistance of a Community Advisory Board (CAB) consisting of church leadership, congregants, community lay health workers, and public health researchers to guide the research with a diverse, community-centered perspective. As a CBPR study, it is important to give back to the community collaborators and reciprocate the good will and support they have offered during the research process with an action that is beneficial for their community (Minkler & Wallerstein, 2008). As an act of goodwill we offered a \$500 honorarium as a thank you for all of the indirect services they provided, including, but not limited to, church space for the intervention events, unlimited announcements during church services, and the permission to recruit members after services in the church lobby every week. This study received approval from the Committee for Protection of Human Subjects in January of 2017.

Storytellers Digital Storytelling Intervention Design – Aim 1

To develop a faith-based digital storytelling intervention to improve colorectal cancer screening intention among unscreened 50-75 year old Latinos attending church in Alameda County.

Participants

A non-probability, purposive sampling strategy was used to recruit the ten church members to participate in the development of the digital stories. The main goal of purposive sampling is to choose participants with particular characteristics on purpose (Aday & Cornelius, 2011). The following eligibility criteria was used for recruiting participants to develop digital stories: men and women who attended Union City Apostolic Church regularly, identified as Latino, were between the ages of 50-75, had previously completed a recommended form of colorectal cancer screening, and were willing to share their experience in a digital storytelling format.

Procedures

The research team recruited participants to develop digital stories by posting and handing out flyers in the church from February to June of 2017. Church leadership made announcements during weekly Sunday service with the research team making themselves available after service to answer any questions and recruit interested church members to participate in the study. If a member was interested in participating they filled out the contact information, which gave the researchers permission to contact them directly to ask several questions to determine their eligibility to participate.

Originally the study design incorporated recruited participants attending a three day digital storytelling workshop facilitated by StoryCenter, in Berkeley, California. We quickly realized this would not be feasible due to logistical issues and scheduling constraints. The research team worked with StoryCenter staff to devise a solution. The facilitator agreed to conduct the training at the church over a period of two Saturdays during the month of July. Women in the church were more proactive in participating in the group training sessions. On the contrary, the men in the church were not able to make those dates instead they preferred to meet individually to develop their digital story.

A total of four church members (all women) participated in the group sessions facilitated by StoryCenter on two Saturdays, July 15th and 29th. During the first session, participants were

guided step by step through the participatory process of developing digital stories beginning with a story circle where participants shared their colorectal cancer (CRC) and colorectal cancer screening (CRCS) stories in a group setting. As participants shared their experience, we began as a group to conceptualize the stories that would become scripts for the digital stories. The research team recorded the story circle with a digital recorder and also took notes on a laptop to assist in script development. The research assistant went through the audio recording and transcribed anything that was missed in the notes and shared the file with the facilitator who drafted an initial script from the notes. She sent the initial scripts to the participants for their feedback for the next session where we would finalize the scripts and begin the recording and picture selection process. The goal was to have a final script with no more than 400 words in order to produce a 2-3 minute digital story. Participants were instructed before the end of the first session to review their scripts and to gather pictures for the next session. The second session involved working with each of the participants to finalize their scripts and begin the recording process as well as scan any photos they wanted to help illustrate their digital story. By the end of the session, every participant completed the recording of their script and were ready to work with the research team over the next few months to finalize their digital stories.

The remaining six participants (5 men, 1 woman) opted to participate in one on one digital story development with the research team. Beginning in July, the research team met with participants on an individual basis at UCAC. Similarly to the group facilitation, participants were asked to share with the research team about their previous experience with CRC and CRCS in order to conceptualize their story and finalize their script. We met for a total of two sessions, the first for a participant to share their story and begin their scripts, the second session to finalize their scripts, complete the recording and decide on which pictures they wanted to help illustrate their digital stories. Once these two sessions were completed, participants worked directly with the research team electronically to complete their digital stories.

A total of ten digital stories were created for the intervention. The digital story content was chosen specifically to capture the range of stories including those that have completed a form of recommended colorectal cancer screening with differing outcomes to those that have received a colon cancer diagnosis and undergone treatment and finally those who have lost a loved one due to CRC. Each participant signed a consent form and filled out a demographic survey (Appendix A). Participants received a \$20 Target gift card after each of the two sessions and then again once the digital story was finalized for a total of \$60 in gift cards as an incentive for their participation.

Intervention Development Limitations

Recruitment for this portion of the study was originally difficult. Potential participants expressed embarrassment and were not sure if they wanted to share their story in such a public forum. Once several leaders in the church agreed to participate and share their story, and others saw they would not be alone, more participants signed up. Even those who originally had said no, changed their minds. We originally set out to develop a total of six stories but ended up with ten as more church members were interested in sharing their stories. We had to turn some participants away due to not having the capacity to include them in our intervention. There was the potential for stronger digital stories to exist in the church but we were not able to accommodate everyone who was interested due to limited capacity of research funds and resources.

Another obstacle in developing the intervention was figuring out how to make the training process work for everyone. Although the research team did not recognize this as an issue at first, we realized that the men did not want to participate with the women in the group setting due to the sensitivity of the topic. They did not want to share their CRCS experience with other men much less women. We made amends for this by providing them with individual sessions to develop their stories. The men may have received more from the sessions if they were willing to participate in the group setting with the StoryCenter facilitator.

Last but not least, in the original proposal, participants would have been a part of a three day digital storytelling workshop which would train them to develop a digital story themselves. Due to logistical issues, participants were only willing to meet for two sessions and were not interested in further training.

Qualitative Study Design – Aims 1a and 2a

Storytellers Semi-Structured In-depth Interview – Aim 1a

To understand how developing one's own digital story influences continued CRCS intention and to what extent it may serve as an incentive to promote CRCS to others.

Semi-structured interviews were chosen because they allowed for the participant to share, in-depth, about their experiences of their digital storytelling development process, their previous and future cancer screening practices, and how the process influenced how they will promote colorectal cancer screening to others. One of the advantages of semi-structured interviews is that although a guide is used to direct the interview, there is still an opportunity for the interviewer to delve further and ask questions beyond the guide that are prompted by the interviewee's responses.

Participants

The same sampling population, strategy and eligibility criteria were used from the intervention development from Aim 1, because all ten participants who developed a digital story were recruited and participated in a semi-structured in-depth interview.

Measures - Interview Guide

An interview guide was developed to elicit discussion on participant's digital storytelling development process, their previous and future cancer screening practices, and how the process influenced how they will promote colorectal cancer screening to others. The guide was pilot-tested with members of the CAB before beginning the interview process (Appendix B).

Procedures

After the digital storytelling intervention was completed, the participants were invited to participate in a semi-structured in-depth interview within the follow-up period of four weeks. We chose this time frame because we wanted to give participants time to process their experience as digital story developers but also prevent waiting too long such that recall bias might become an issue. The interviews were conducted in a location of the participant's choosing such as the church, a cafe or library setting. Interviews were recorded with the consent of the participant and lasted approximately 60 minutes. After the culmination of the interview, participants received a \$20 Target gift card as an incentive to thank them for their time.

Storyviewers Focus Groups/Interviews – Aim 2a

To explore how viewing the digital storytelling intervention influences intention to complete colorectal cancer screening among unscreened 50-75 year old Latinos attending church in Alameda County.

Aim 2a employed a qualitative study approach and explored how participants interpreted and assigned meaning to particular experiences and understood and described processes such as intention to complete colorectal cancer screening. Focus groups were conducted with participants who viewed the digital storytelling intervention to understand *how* viewing the digital stories influenced their intention to complete or not complete colorectal cancer screening. Focus groups were initially chosen because they elicited detailed information about personal and group feelings, perceptions, and opinions about both process and content.(Morgan, 1993)

Participants

A non-probability, purposive sampling strategy was used to recruit the twenty church members to participate in the viewing of the digital stories and focus groups conducted after the storytelling viewing. Congregants were eligible to participate if they attended UCAC, self-identified as Latino, were between the ages of 50-75, were enrolled in health insurance, and were not considered up-to-date with CRCS per USPSTF screening recommendations.

Data Collection - Focus Group/Interview Guide

A focus group guide was created to elicit responses on understanding *how* viewing the digital stories influenced participant's intention to complete or not complete future colorectal cancer screening. The guide was pilot tested by members of the CAB before the focus group process began (Appendix D).

Procedures

Participants were recruited before and after English services on Sundays from October 2017 to March 2018. The research team and church leadership made pulpit announcements before the sermon to invite church members to learn more about the study after the service, where the research team distributed recruitment flyers, answered questions about the study, and screened interested church members for eligibility before collecting their information. Recruitment flyers detailed the study procedures, eligibility requirements, compensation, and research team contact information. If church members expressed interest in participating, they provided their contact information to be called back at a later time to confirm their eligibility and availability to participate. Digital announcements promoting the study were also projected on the church screens for all congregants to view during the announcement segment of the service. In addition, the research team was invited to participate in the annual church Ministry Fair to set up a table as another way to recruit participants.

All participants were informed ahead of time about participating in a focus group immediately after the viewing. The participants were separated into male and female focus groups because of potential topic sensitivity. Due to logistical scheduling issues, the focus groups ranged from one to six participants per session. Where a session consisted of one participant, it was considered a one-on-one interview. A total of eight sessions were conducted. Participants were offered a \$20 Target gift card for participating in the individual and group sessions, which lasted approximately 30 minutes to an hour and a half.

Analysis of Qualitative Data

At the end of each interview and focus group the research team reflected and wrote a field memo describing first impressions and any additional information about the session that might help make sense of the interactions as they prepare for the analytical process.

A UC Berkeley undergraduate research assistant transcribed all of the digital audio recordings. The main researcher listened to each audio recording, cleaned the transcript and wrote preliminary analytical memos before uploading the de-identified transcripts into qualitative data analysis software, MaxQDA2018. Each interview was analyzed using thematic analysis, a common form of qualitative data analysis (Guest, MacQueen, & Namey, 2011). Thematic analysis is used to identify, analyze and locate patterns within the data (Guest et al., 2011). An exploratory analysis of this nature utilizes an inductive approach while continuing to be guided by the research aims. For the purposes of this research, an inductive and deductive thematic analysis approach is needed to elucidate themes from the data. The following steps are used to conduct a thematic analysis: a) familiarization of the data, b) generation of initial codes, c) theme search, d) theme revision, e) theme definition and f) report production (Braun & Clarke, 2006).

As the lead researcher, I followed the steps for thematic analysis by beginning with the reading of the transcripts while listening to the audio recording at least once in order to be immersed in all of the data. To maximize the validity of the study findings, I penned analytical memos when reviewing the data to reflect on potential biases and identify emergent themes. I began with open coding and identified major categories in all of the transcripts. Next, I moved onto axial coding in order to identify connections and relationships between the initial open codes. As a final step, I displayed the codes in mind-mapping software as a visual map to complete the identification of theme and sub-theme patterns and connections and selected quotes to illustrate the findings.

Qualitative Study Limitations

On a logistical level, we did not anticipate the focus groups needing to be conducted as interviews. Even though this was not the original study design we were able to obtain the data we needed by interviewing the participants. In our original proposal we recognized offering individual interviews may have been too time consuming and costly. Although this was the case, we made the decision to move forward in order to collect the data we needed for this portion of the study.

In qualitative research, there are multiple threats to validity in the data collection process. The goal of maximizing validity in qualitative research is to provide a truthful and reliable account of the data that reflects the actual experiences of the participants (Maxwell, 2012).

In this portion of the study we experienced social desirability and reactivity to the researcher. This became most apparent in the focus groups/interviews with the Storyviewers. In certain cases, participants who were not as comfortable being vocal would say they felt the same way as someone did if they felt their response was well received by the research team. In these instances, the facilitator would use triangulation to come back to the participant and ask different and similar questions about what they actually thought. In other cases, participants were hesitant to give critical feedback on the study and we had to assure them that this was the only way for us to improve. They would need to get comfortable and trust this was true and then they would let us know how we could make this study stronger. We always made sure to follow up with participants if we felt they were telling us what we wanted to hear.

Another important aspect of addressing multiple threats to validity is determining external validity once the data has been analyzed. In order to determine external validity, we consulted with the CAB to ensure respondent validation with our findings. As a study with elements of CBPR, it was critical for the research team to always consult with the CAB to ensure credibility, accuracy and validity of our findings.

Quantitative Study Design – Aim 2

Storyviewers: Assessing the Viewing of the Digital Stories

The quantitative portion of the study was a quasi-experimental one-group pre-/post-evaluation no control group design. Aim 2 assessed both the feasibility of the study by observing different elements of the intervention implementation, as well as the feasibility of measuring the preliminary impact of the intervention with pre- and post-tests with unscreened members of the church.

Participants

A non-probability, purposive sampling strategy was used to recruit the twenty church members to participate in the viewing of the digital stories. Congregants were eligible to participate if they attended UCAC, self-identified as Latino, were between the ages of 50-75, were enrolled in health insurance, and were not considered up-to-date with CRCS per USPSTF screening recommendations.

Procedures

Participants were recruited before and after English services on Sundays from October 2017 to March 2018. The research team and church leadership made pulpit announcements before the sermon to invite church members to learn more about the study after the service, where the research team distributed recruitment flyers, answered questions about the study, and screened interested church members for eligibility before collecting their information. Recruitment flyers detailed the study procedures, eligibility requirements, compensation, and research team contact information (Appendix). If church members expressed interest in participating, they provided their contact information to be called back at a later time to confirm their eligibility and availability to participate. Digital announcements promoting the study were also projected on the church screens for all congregants to view during the announcement segment of the service. In addition, the research team was invited to participate in the annual church Ministry Fair to set up a table as another way to recruit participants.

The research team guided the participants through the informed consent process per human subjects protocol. The first pre-survey (Appendix E) was administered before the unscreened members viewed the digital stories and included questions on their socio-demographic characteristics, current colorectal cancer screening practices, knowledge, attitudes and beliefs about colorectal cancer and screening, and their intention to obtain screening. The participants then viewed a total of 6-10 digital stories (approximately three minutes each). The post-survey (Appendix F) was administered immediately after the viewing of the digital stories and included the same topics in the pre-test along with additional questions on the acceptability of the intervention. The printed pre- and post-tests were self-administered in person with the availability of the researcher to assist with any questions and took approximately 20 minutes to complete. The total time between participants taking the pre- and post-tests was 20 minutes.

Participants were offered a \$15 Target gift card as an incentive for their participation in the viewing of the study, which lasted approximately one hour.

Measures

Colorectal cancer screening intention (Included in pre- and post-tests)

CRCS intention, the dependent variable, was measured at baseline and in the follow-up survey with the following question: “Do you plan to be screened for colon cancer?” (yes, no, don’t know) (Emmons et al., 2008). These data were used to create a new variable, “change in CRCS intention”. In order to implement this, we first recoded every “don’t know” response on both surveys as no. Based on the work of Greaney et al., we created four categories that indicated change in CRCS intention: 1) consistent positive intention (answering yes at baseline and at follow-up), 2) new intention (answering no at baseline and yes at follow up), 3) discontinued intention (answering yes at baseline and no at follow up) and 4) consistent negative intention (answering no at baseline and at follow up) (Greaney et al., 2014).

Previous Colorectal Cancer Screening Experience (Included in pre-test only)

Independent variables included previous colorectal cancer screening experience beginning with the question “Have you heard of any of the screening tests for colorectal cancer listed below? (Please check all that you have heard of.); answers include home stool kit, colonoscopy and sigmoidoscopy. Next the respondents were asked if they have ever had a screening test for CRC and if yes, which screening test along with the approximate date of their last test; answers included yes, no, unsure. The respondents were also asked if anyone in his/her family have been diagnosed with CRC; answers included “yes”, “no” and “unsure”. Lastly, the respondents were asked if they have ever been diagnosed with colorectal cancer; answers included “yes”, “no” and “unsure”.

Colorectal cancer screening knowledge, attitudes and beliefs (Included in pre- and post-test)

Respondents were also asked about their current knowledge, attitudes, and beliefs (KAB) about cancer, colorectal cancer and screening. A complete validated survey on colorectal cancer screening KAB administered to the Latino population was not found in the current literature; instead, a combination of validated and non-validated scales were found for each of the areas. A combination of these scales was used to assess current knowledge, attitudes and beliefs around colorectal cancer and screening.

The knowledge questions were used from the CRC Knowledge Assessment Survey (KAS) used with at-risk Latinos in New Mexico (Sanchez, Palacios, Thompson, Martinez, & O’Connell, 2013). The knowledge questions were developed originally on CRC risk information from the National Cancer Institute along with existing health survey literature used with underserved populations (Sanchez et al., 2013). A total of 14 knowledge questions were used, two yes/no questions on general knowledge of CRC (Cronbach’s alpha 0.74), five true/false questions on knowledge of CRC risk factors (Cronbach’s alpha 0.88), and seven questions (two true/false and five yes/no questions) on knowledge of screening (Cronbach’s alpha 0.89). The survey’s readability level was determined to be 7.9 and all 14 knowledge questions had a total composite score of 0.94 (Cronbach’s alpha). After piloting the survey with the CAB, we decided to only ask nine of the 14 questions on the pre- and post-surveys.

The attitudes, beliefs and intention questions were adapted from a study that measured cancer KAB among Chinese, Korean and Vietnamese subgroups (Le et al., 2014). Survey

questions were initially developed with the guidance of the Theory of Planned Behavior which is one of the theories informing this research. The original survey contained a total of 42 questions, 11 assessing behavioral beliefs (Cronbach's alpha 0.76), fourteen assessing attitudes toward behavior (Cronbach's alpha 0.81), three assessing control beliefs (Cronbach's alpha, 0.69), six assessing behavioral controls (Cronbach's alpha, 0.71) and four assessing behavioral intentions (Cronbach's alpha 0.87). These variables were assessed using a 5-point Likert scale with the answer options: "strongly disagree", "disagree", "neutral", "agree" and "strongly agree". The original survey was pilot-tested using cognitive interviewing techniques and revised several times until each of the target groups completed the survey with ease (Le et al., 2014).

In order to adapt the survey for the purposes of this research study, we deleted the questions that did not reflect the Latino community and we ended up with seven questions on behavioral beliefs, twelve questions on attitudes towards behaviors, three questions on control beliefs, six questions on behavioral controls and four questions on behavioral intentions.

We chose this survey for being clear with a reading level that could be understood by a majority of study participants. This helped as we had a range of participants with different reading levels complete the surveys. The CAB pilot tested the survey and revised it several times to ensure the correct reading level and the appropriateness of the questions and instructions for target survey group.

Measure of acceptability of the intervention (Included in post-test only)

Respondents were asked about the acceptability of the intervention with an open ended question, "Are digital stories an acceptable way of receiving information on CRCS, why or why not?".

Table 4.1. Demographic Background Characteristics

Variable	Demographic Questions	Variable description
Gender	What is your gender? Responses: Male or Female	<ul style="list-style-type: none"> • Binary
Age	What is your age group? Responses: 50-54, 55-59, 60-64, 65-69, 70-75	<ul style="list-style-type: none"> • Ordered categorical
Ethnicity	Do you consider yourself to be of Latino or Hispanic origin? Responses: Yes, No, If yes, please specify.	<ul style="list-style-type: none"> • Categorical
Race	What is your race? Responses: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Pacific Islander, White or European-American or other	<ul style="list-style-type: none"> • Categorical
Education	What is the highest level of school you have completed? Responses: Grade school grades 1-8, Some high school grades 9-11, High School degree or GED, Some college – vocational/technical school, College degree, Graduate School degree or other	<ul style="list-style-type: none"> • Ordered categorical
Marital Status	What is your marital status? Responses: Single, Married or partnered, Separated, Divorced and Widowed	<ul style="list-style-type: none"> • Categorical
Employment Status	What is your current employment status? Responses: Full-time employed, Part-time employed, Retired, Disabled, Full-time student, Homemaker, Unemployed, and Other	<ul style="list-style-type: none"> • Categorical
Insurance coverage	What best describes your current insurance coverage? Responses: Employer provided insurance, Spouse's/partner's employer provided insurance, Pay for insurance out of pocket, Medicare, Medical, Medical/Medicare and other.	<ul style="list-style-type: none"> • Categorical
Income	What is your yearly income before taxes? Responses: Less than \$30,000/year, \$30,001 to \$70,000/year, \$70,001 - \$100,000 and \$100,001 or more/year.	<ul style="list-style-type: none"> • Ordered categorical

Quantitative Data Analysis

All survey data was analyzed using Excel. First, descriptive statistics (e.g., proportion, standard error, 95% confidence interval) were calculated to describe the socio-demographic characteristics of the sample. Next, differences in Likert scale responses were calculated to assess KAB and measure differences in order to see patterns.

Quantitative Study Limitations and Threats to Validity

A key limitation to the survey design is that the sample was not large enough to achieve statistical power. Because this study employed a feasibility design, our goal was to determine the feasibility of measuring the impact of the intervention and not the effectiveness of the intervention itself. We wanted to see preliminary impact before testing this intervention in the future with a control group with sufficient power to detect results. Another limitation of the study is that data was collected at one particular time point without a follow up period. Due to the limited scope of the study, a three to six month follow up period was not feasible due to timing issues.

Additionally, the results of the survey have limited generalizability to Latinos in other churches not included in the survey sample. Another limitation is the reliance on self-reported data for colorectal cancer screening status. The research team was not able to verify the information with their medical provider due to the limited scope of the proposed study. Another similar issue is the measure of intention to complete screening as it is a self-reported measure that was not verified in this study. Finally, due to the use of existing scales, the constructs measured by these scales were not in the exact form the researcher would have chosen. An alternative strategy would have been to develop the survey questions and to complete the validation process; unfortunately this would be unrealistic given the costs and time constraints of the proposed study. Instead the survey was pilot tested with CAB members before we administered the surveys to our participants. The CAB pilot tested the survey for length and readability.

CHAPTER IV: Results

Introduction

The results of this study are divided into two subsections. The first includes the findings from the development of the digital stories and the interviews with the Storytellers. The second section highlights the findings of the Storyviewers completing the pre-and post-surveys and focus groups/interviews after viewing the DST intervention.

Section 1: Intervention Development and Interviews with Storytellers - Aims 1 and 1a

Storyteller Sample Description

The average age of the digital story developers, referred to as Storytellers, was 61.1 (SD=12.0) years. Five out of ten (50%) of the participants were male. All participants identified as Latino, predominately second generation from Mexico. The entire sample was married and the majority (90%) of the participants completed high school and above, with several having completed graduate school. Only three of the participants were retired, the rest of the participants had some form of employment. Approximately half of the sample (5) made \$70,000 or above in annual income. All of the sample had some form of health insurance coverage and more than half of sample was enrolled in private insurance. The Storytellers included the pastor, two assistant pastors, two ministers other prominent church congregants.

Table 5.1 Storyteller Demographics

Characteristic	N = 10 (%)
Age, years (SD)	61.1 (12.0)
Gender	
<i>Men</i>	5 (50)
<i>Women</i>	5 (50)
Ethnicity	
<i>Latino</i>	10 (100)
Marital status (%)	
<i>Married or partnered</i>	10 (100)
Education level (%)	
<i>Some high school</i>	1 (10)
<i>High school graduate or GED</i>	5 (50)
<i>Some college</i>	1 (10)
<i>College graduate</i>	1 (10)
<i>Graduate school</i>	2 (20)
Employment (%)	
<i>Full-time</i>	4 (40)
<i>Part-time</i>	3 (30)
<i>Retired</i>	3 (30)

Income (%)	
<i>\$30,001 - \$70,000</i>	2 (20)
<i>\$70,001 - \$100,000</i>	3 (30)
<i>> \$100,001</i>	2 (20)
<i>Missing</i>	2 (20)
Health insurance (%)	
<i>Private</i>	6 (60)
<i>Private/Medicare</i>	3 (30)
<i>Medicare</i>	1 (10)

Storyteller Interview Findings

General experience with developing a digital story

Each Storyteller experienced their own emotional journey while developing their digital story. For some participants, it was a cathartic experience finally being able to come to terms with family members and their cancer. For others, it was time to be reflective about their own life experiences and be the center of the story instead of being a supportive actor.

I thought it was pretty cool because this made me reflect on everything, you know, I hadn't thought of it like that before. Like my story, to me it was my mom's story, my wife's story. And I was part of that. But this made me realize, no, that this is my story too. So it made me look at it differently which was a good thing. Participating in this is a big deal and it made me even more motivated to do more to take care of myself. It really did that because it gave me a different perspective that was there but I didn't look at it that way. I didn't see it that way. I saw it as my mom's story. My wife's story. What they are going through. But, it made me look at it more from my eyes which sounds crazy because I should have been looking at it like that but I didn't. – Male interview participant

It was a little emotional. It brought back some memories. [pause] [breathes in] I think, you know, tapping into it I think of what my father was dealing with in having colorectal cancer during that time when it wasn't talked about like it is now. – Male interview participant

First of all I wanted to carry on what my sister initially set out to do. So, that kind of inspired me to do it. But then also I mean I know how important it is because I'm in the healthcare field. And the more I researched it the more I realized how Hispanics don't get screened. So I thought that was important and if I could make a difference in someone else's life and have something come out of a tragedy for our own family, you know, it's something that I wanted to do. – Female interview participant

Potential influence on future screening behavior

The purpose was to better understand if creating a digital story helped to influence their own colorectal cancer screening intention. For some, the digital storytelling process acted as an important reminder to continue getting screened. For others, it was not going to change the way they were completing screening because they were already activated to complete screening.

Yeah, it just keeps me more aware of it. It keeps me more aware of it, that I need to be stay vigilant on it, can't let it get by, you know, it's, it's especially when we've had family history and then we've had issues already going on in our own bodies we need to, to, to stay on top of that and it's going to, made me very well aware of it. It's almost like a picture, you take a picture of, of, of an occasion or, or experience and this is gonna say, "Hey this is gonna be my picture to remind me that this is something that I need to do." – Male interview participant

Well, every time I see, get that little square envelope in the mail, I'm going to remember you and I'm gonna remember this video and I'm gonna remember the importance of not just throwing it in with a pack of mail and not looking at it and really taking the time to put importance on it because of all of the stories that I've seen. And how important it is to do it, you know. So I'm gonna always remember. It did impact me because I think any other time I probably wouldn't have, you know, you just get something in the mail you throw it to the side, you don't really pay attention to it. But I will. I'm gonna. I'm definitely going to do it every year. – Female interview participant

Promoting of colorectal cancer screening to others

The purpose was to understand if the creation of a digital story helped to influence the Storytellers to promote cancer screening to others. Many of the participants were enthusiastic about spreading the word in an effort to help others.

Yeah, it would be a nice thing to share, you know, even on Facebook. Just say, hey, just wanted to share this, my video story with the general public. This is my experience. For awareness. Especially for topics and cancer-causing areas that are gender specific and are prevalent among the Latino community. – Male interview participant

I choose to share because we're all real people and these are real life stories and they can happen to anyone and no one is exempt. – Female interview participant

Well I'd never done a digital story this was my first time ever doing this. And to me it's almost like you're making a history like a memory. It's like a memory a digital memory. That I can leave for my family. It's almost like a legacy. Cause now my, my children haven't seen this yet and I want them to see it, I want my husband to see it so that he can take health more seriously and he can get his screenings and then my daughter when she becomes of age can get her screenings and my son when he becomes of age can say well Mom, it was important enough for my mother to do it. And he'll watch this video. And so it's like, it's like a legacy that's gonna go on. It's a positive because it's, it's, it can prevent death. – Female interview participant

I think that it's a good tool for this to get out to other churches and other, you know, other communities not just our but there's Southern California that, I mean, like I said where we have our big convention because this is powerful. And I know that if people saw this they would, they would do that the test. They wouldn't be afraid. Because it's the unknown, it's that we don't talk about that and we don't do that. It's just it's fear it's what

it is, it's fear. And God didn't give us a spirit of fear. But of love, peace, power and a sound mind. So just doing this will give you a sound mind, give you peace because you know that you don't have to worry about, you know, you don't know if you have cancer or not. So I, I, I would want my family to see it. I would want it to go across to all the other churches and to go to the big convention and get a lot of thousands of people to see it and hopefully get screened and save lives. – Female interview participant

Section 2: Pre- and Post-surveys and Focus Groups/Interviews – Aims 2 and 2a

Storyviewer Sample Description

The average age of the participants who viewed the digital stories was 59.2 (SD=8.49) years. Eleven out of 20 (55%) participants were male. All participants identified as Latino predominately second generation from Mexico. The majority of the sample was married (70%) and more than half of participants completed high school and above. Only four of the participants were retired, and the rest of the sample had some form of employment. Exactly half of the sample (10) made \$30,000 or less in annual income.

Table 5.2 Storyviewer Demographics

Characteristic	N = 20
Age, years (SD)	59.2 (8.49)
Gender (%)	
<i>Men</i>	11 (55)
<i>Women</i>	9 (45)
Ethnicity (%)	
<i>Latino</i>	20 (100)
Marital status (%)	
<i>Married or partnered</i>	14 (70)
<i>Divorced</i>	2 (10)
<i>Widowed</i>	2 (10)
<i>Single</i>	2 (10)
Education level (%)	
<i>No school</i>	1 (5)
<i>Grade school</i>	2 (10)
<i>Some high school</i>	1 (5)
<i>High school graduate or GED</i>	6 (30)
<i>Some college, vocational technical school</i>	2 (10)
<i>College graduate</i>	5 (25)
<i>Graduate school</i>	3 (15)

Employment (%)	
<i>Full-time</i>	8 (40)
<i>Part-time</i>	2 (10)
<i>Retired</i>	4 (20)
<i>Self-employed</i>	3 (15)
<i>Other</i>	3 (15)
Income (%)	
<i>< \$30,000</i>	10 (50)
<i>\$30,001 - \$70,000</i>	2 (10)
<i>\$70,001 - \$100,000</i>	4 (20)
<i>> \$100,001</i>	4 (20)
Health insurance (%)	
<i>Private</i>	6 (30)
<i>Private and Medicare</i>	1 (5)
<i>Medicare</i>	2 (10)
<i>Medicare and Medicaid</i>	3 (15)
<i>Pay out of pocket</i>	3 (15)
<i>Uninsured</i>	3 (15)
<i>Other</i>	2 (10)

Pre- and Post-Survey Findings

Previous colorectal cancer screening experience

Participants were asked in the pre-survey about their previous experience with CRCS. Exactly half of the sample had completed some form of CRCS in the past and indicated that they were not currently up to date with screening. Of those ten participants, four completed a home stool kit, four completed a colonoscopy, and two completed a combination of both screening tests. In this sample, men were more apt to have previous screening experience.

Figure 5.1 Previous CRCS experience by gender

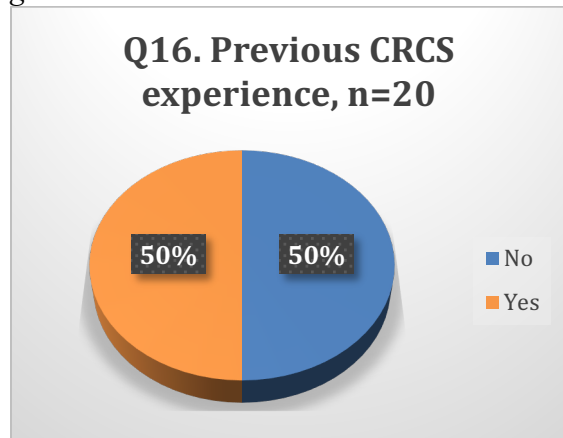
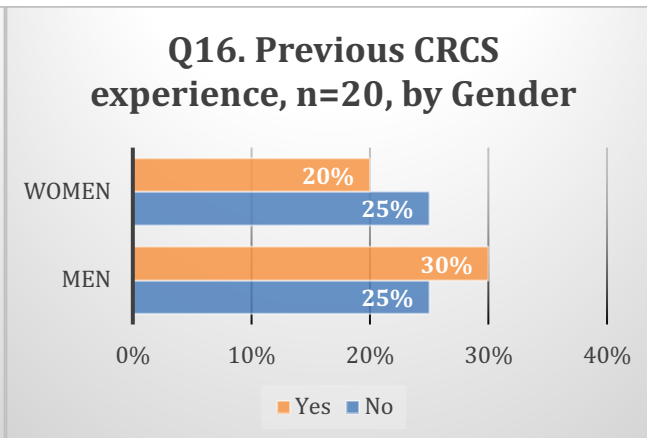


Figure 5.2 Previous CRCS experience by gender



Family history of colorectal cancer

Participants were asked about the history of colorectal cancer in their family. Five of the 20 participants responded with having a family history of colorectal cancer. The men in the sample had a slightly higher family history of CRC.

Figure 5.3 Family history of CRC

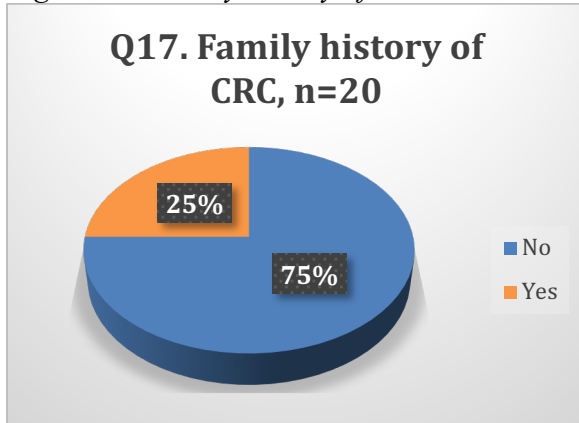
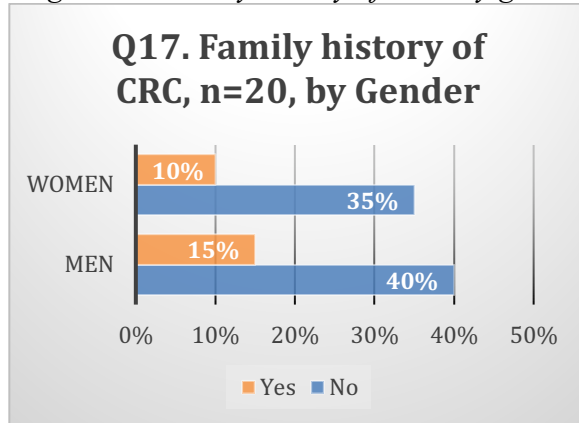


Figure 5.4 Family history of CRC by gender



Intention to complete colorectal cancer screening

When participants were asked their intention to complete screening before and after viewing the intervention, 12 out of 20 participants maintained consistent positive intention, six out of 20 participants indicated a new intention to complete screening and two out of 20 maintained consistent negative intention (Figure). When we focused in on gender, the women in the sample were more apt to indicate new intention to screening, and the men in the sample were more apt to continue with their initial positive intention to complete screening (Figure).

Figure 5.5 CRCS Intention Before and After DST

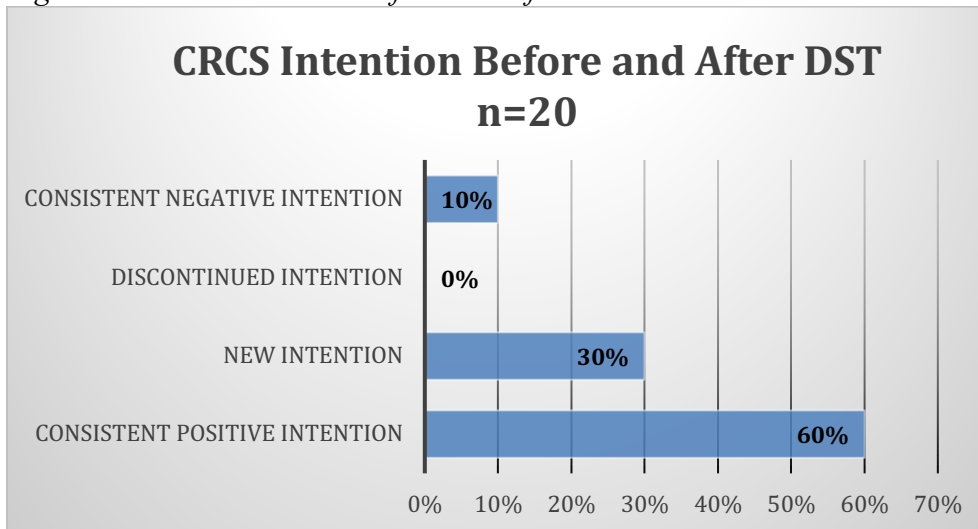
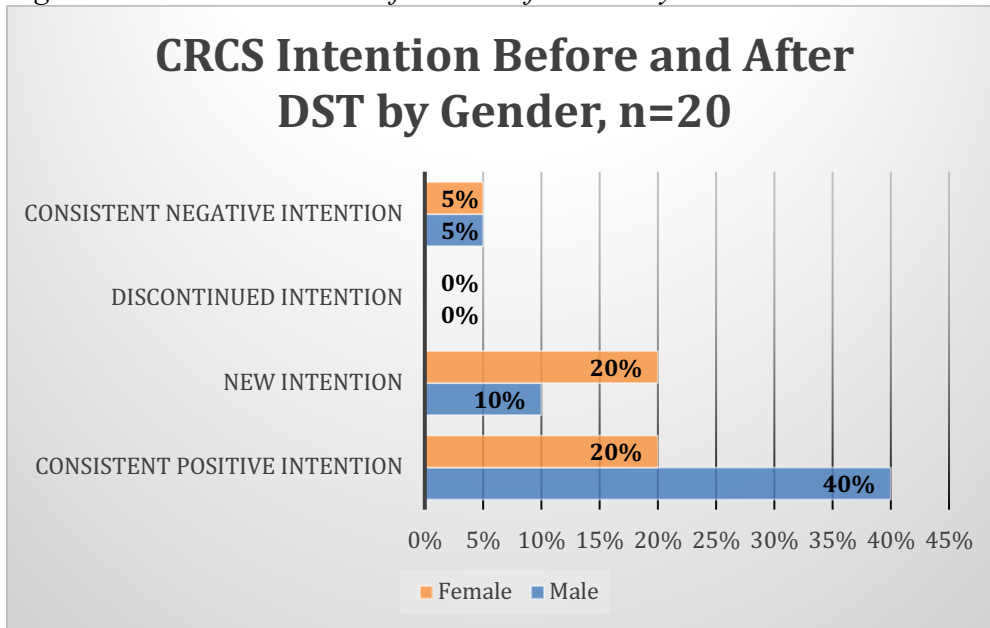


Figure 5.6 CRCS Intention Before and After DST by Gender



Knowledge, Attitudes and Beliefs

Knowledge was assessed by asking yes/no and true/false questions about colorectal cancer and screening. The majority of participants (64%) answered the questions correctly in the pre- and post-survey while 14% of participants answered the questions incorrectly in both surveys. 13% of participants answered the questions incorrectly in the pre-survey and then correctly in the post-survey after watching the digital stories. Only six percent of participants answered the knowledge questions correctly and then in the post-survey answered them incorrectly. When viewing the answers to the knowledge questions by gender, there is little difference between the groups. Only the “Continued Knowledge” category was slightly higher for the men in the sample.

Figure 5.7 Knowledge Questions Pre- and Post All Participants

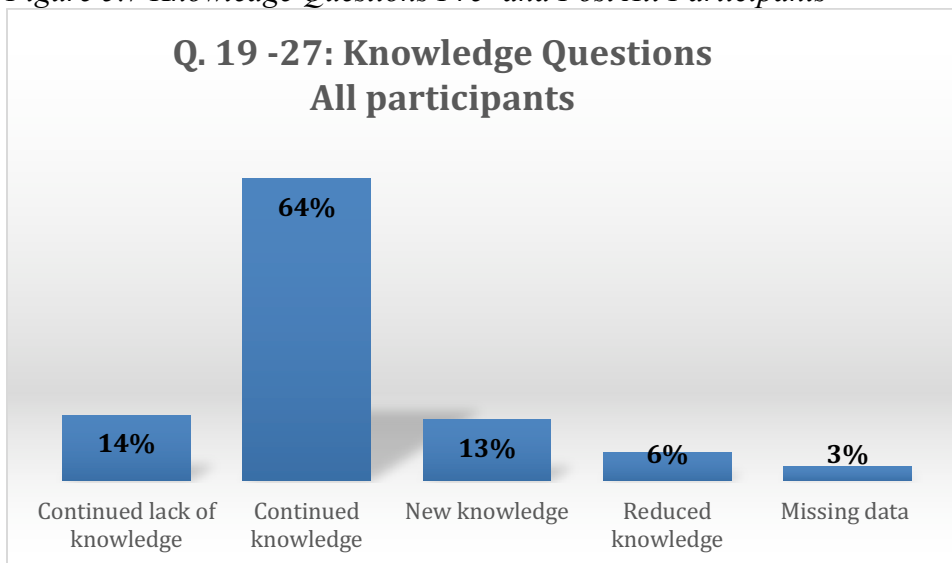
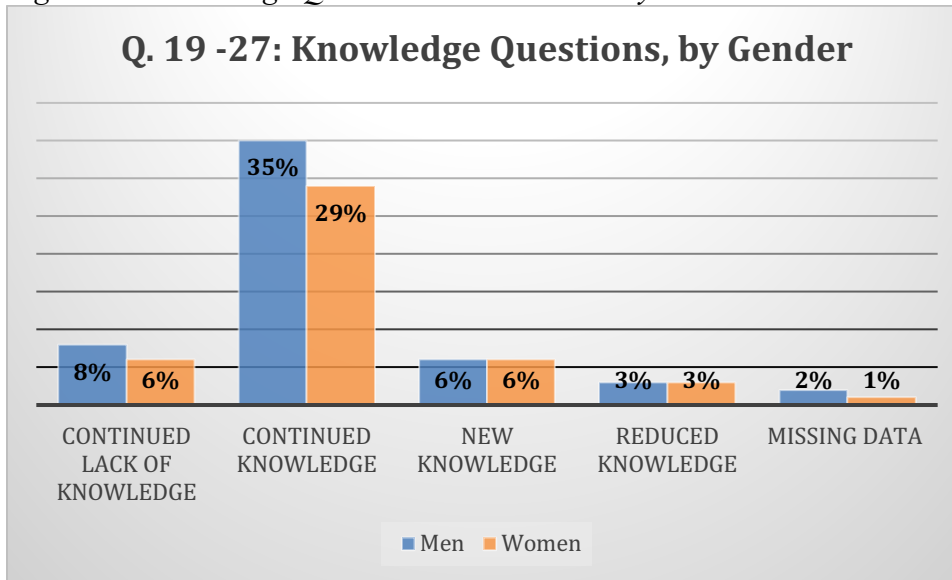


Figure 5.8 Knowledge Questions Pre- and Post by Gender



Next, participants were asked a total of 12 questions on their attitudes toward cancer screening behavior. For many of the questions, there was no difference in how they answered in the pre- and post-survey. For example, participants understood the importance of completing screening in order to detect cancer early in both the pre- and post-survey. There were a few questions where responses yielded differences between the surveys. In question 12c, we asked participants to answer “strongly disagree”, “disagree”, “neutral”, “agree” and “strongly agree” with the statement, “I am afraid of getting screened for cancer.” In the pre-survey for those who had not been screened before, participants expressed greater fear of screening and in the post-survey their perception of fear decreased. For those who had previously completed screening, they disagreed with the statement and their answer remained the same in the post-survey indicating they were not afraid before or after; possibly because they had completed screening previously.

Participants were asked a total of seven questions to assess behavioral beliefs. Participants’ responses on three questions stayed the same: they expressed positive agreement before and after the survey with questions 11a, “Cancer can be prevented by living a healthy lifestyle”, 11d, “Cancer screening is a good method of finding cancer early” and 11e, “Cancer can be treated if it is found early”. Participants’ answers changed on two questions, 11b and 11c, “Cancer can be prevented by regularly exercising” and “Cancer can be prevented by eating certain foods.” After watching the digital stories, participants who initially answered on the lower scale chose the neutral, agree and strongly agree options indicating a change from pre to post of greater agreement.

The pre- and post-survey was a preliminary way to engage with the participants; we used interviews and focus groups to gain a deeper understanding of how the digital stories influenced intention to complete screening in a way that the pre- and post-surveys would be unable to attain.

Focus Groups/Interviews

During the focus groups/interviews, participants highlighted four factors that helped to influence their intention to complete CRCS as a result of viewing the digital stories: individual, family, peers, and leadership.

Individual motivation

Each of the Storytellers shared a message about the importance of taking better care of themselves and making an effort to put themselves first even though it has not been their custom. They made connections between taking care of themselves as being biblical and treating their body as a temple of God.

The Bible says that we are the vessels of God, we are the temple of God. So, God has given us a mind to try to take care of ourselves, as best as we can, so we can live life to help ourselves and others. – Male focus group participant

Uh, they made me feel that, that I need to take more care of myself. You know, of my health. Because I don't eat healthy even though I'm on that diabetes borderline for probably more than four years. I still don't eat healthy. I still don't take care of myself. I'm not making any effort to you know. To do good. And, and, you know, eating healthy and exercising and doing all the things that are going to be good for me for my health. – Female one-one-one interview participant

Even though, some may not have children, or may not even be married, but it doesn't matter because we need to be an example. We need to show that hey how, how important we are because we matter. We do matter. So we have to show that, hey this is very important, not take it lightly, and not be that selfish because it is selfish, when we decide not to do nothing. And so we need to take notice of that and say you know what, I want to be an example, I don't want to be selfish and I want to show hey, you know, we do matter. We do matter. – Male focus group participant

I mean now that I'm here and listening to all that I mean this is very important for us to take care of ourselves and do the best we can with our health, you know, because if we don't do it ourselves who else is going to do it for us. – Female one-one-one interview participant

Personal responsibility. I learned that I have to be a little bit more responsible especially when it comes time to take care of my own body because it's something that sometimes we don't really do. And personally I never really thought about it. – Male focus group participant

Familial motivation

Each digital story contained a message about completing CRCS for their families, even though the Storytellers were not prompted to include this message. Participants who viewed the digital stories were motivated to complete CRCS because being there for their families is also a powerful motivator for them.

I like them [digital stories] pretty much all saying that because see to me family is the most important, you know. My kids and my husband. And my brothers and sisters, nieces and family is more important to me so if anything I would do, I would do it for family, you know, instead of me because I'm like second, I'm like on the back burner compared to my family. I'll go out of my way to help my kids and I'll go without sleep, food, whatever it doesn't matter to me as long as my family comes first. So that's why I would do it. So that's what touched me that they're all about, it's all about family because it is but God knows so he knows my family needs me. – Female focus group participant

And to me that's what I saw in those videos. I saw family, that care for their loved ones. It mattered to them, they fought in that battle with them, that was impressive, man. That was impressive. – Male focus group participant

That talking about health since all the stories had a common meaning that is to want to live healthy and live a long life to see their grandchildren and great grandchildren and live a healthy life. That is what I want. – Female one-on-one interview participant

The Bible says, "Our people perish from lack of knowledge." Okay, and it's very important that we be educated on what we need to do with ourselves so that we can be around a little longer for our loved ones. Our church, our family, our community. – Male focus group participant

Doing it for our families -- doing it for ourselves but doing it for our families. – Female focus group participant

I would have to say for myself, um, we need to be good stewards with our body, you know. It's not just a principle that we think of day to day, but it's biblical. And um one of the things that I think of, I want to be around for my wife a little longer, for my grandchildren. And to me that's very important. So it's vital for me to take try to take care of myself as much as I can and so whatever preventative measures that I need to take concerning my health, such as what we are doing today, is important. So yes, I do believe that we should be on top of our health and what we need to do to take care of ourselves. You know, no matter what the cost, no matter what it is. – Male focus group participant

And that's when I said, wait a minute, I've got to take care of myself, that opened me, my eyes, I never go to the doctor, I went like once every six years, seven years, I waited until I was sick and this time now when they call me and say it's time for my screenings, I am going to go even though I don't like doing them, you know, but I do go, because it's important to me to be here for my husband, my children, my grand babies now, even more so, for my grand babies. – Female focus group participant

As a result of the familial motivation, several of the male participants had completed the home stool kit before viewing the stories and, after viewing the digital stories, they were more willing to consider undergoing a colonoscopy.

I don't care for the hospital, I don't care for doctors or none of that but, but if I have to do it, I mean, it just, makes a lot of sense, I mean you know, hey I want to be around a little longer. So yeah, I would, now after viewing that I, I would consider it, I would consider it [a colonoscopy]. – Male focus group participant

Fellow church member influence

In the church, sharing testimonies with fellow congregants is already an acceptable form of health communication. Many of the participants were touched by seeing someone in their community sharing such personal information with them in this public format.

Personally I liked everyone's and we know the families of those who are in the videos. I have had several close encounters with the families and well, I know how healthy they are and I want to be like them. They have already gone through a situation that maybe I have to go through then we are prepared and emotional, I am very emotional, I was very motivated by the videos. – Male focus group participant

I think what opened my eyes is several, to a lot, knowing that other people have done it in our church, they've kept it to themselves, but they were able to feel free to express it to help us and then the aftermath is talking about it [in the focus group], that was very important because a video can tell you a lot that you really, for me, I really needed to learn more about it, and I thought hand-in-hand both of them [viewing and focus group] worked out really well. – Female focus group participant

How, how these stories reveal how connected we are to this disease. All of us. – Male focus group participant

I appreciated the ladies, but I really, really appreciated the men because I think that us as women we're more open to speak about things than the men, hearing them come out and be so honest, I think it's really refreshing especially with the colorectal, you know. – Female focus group participant

But then again I know him that's why it was effective to me so I now. I guess maybe these stories when they're personalized like this by your friends they just kind of, they're more real for you because they're your friends. – Male focus group participant

Well, I thank them for what they have done, they have taken this important step. It is very important what they gave us the information they gave us, to talk about their own testimonies of their own situations that happened. That is the most important thing because they are real stories and that has to be in our consciousness that we have to act. – Female one-on-one interview participant

What I liked is to see people that I know. That I work with, that I've known for a while, you know, it's real. You see that, you know, they went through that and somethings happen, you know, but they won the battle. – Male focus group participant

The digital stories humanize the information and because I know the folks that personalizes it in a more powerful way. – Male one-on-one interview participant

One member felt the impact of the stories because the message carried more weight since he knew those telling their stories. He questioned whether these exact stories would have the same impact in another church population where these Storytellers are not known.

I don't know if it would have the same effect when these videos are shown to another group that don't know these people. But I think that with this group these videos would be very useful in our environment because everybody knows these people. So there's a trust that's built in when knowing the characters, you know. So, I don't know if that would have would affect their effectiveness outside of our group but inside our group they would certainly affect a lot of people . – Male focus group participant

In a different male focus group, a participant felt that it does not necessarily need to be someone you know.

One thing that I can say is that seeing, I mean to be fair -- not to be fair -- to be honest with myself, it's not a commercial, it's not a portrayal. And I bring that because if I see somebody, if I see a story but I know this is the actual person that went through something about that, it's still impacting, it still has, I mean, I still, you know, it's the same thing like you know you see somebody with the child and it's just like, I think of my child and it's you know, and you go and you grab them and go “no, no, no, not my child!” So I'm saying the fact that it's real stories, real testimonies so I mean, when I give it a thought, it didn't have to be somebody I knew to be impactful. – Male focus group participant

Leadership influence

The involvement of church leadership from the beginning of this research and having them share their CRCS experience in a digital story helped to influence CRCS intention among participants. A majority of participants shared that the most influential stories were from the Pastor and Assistant Pastors.

*One thing that I really appreciated too was that **you picked people from our congregation that I think the majority have a lot of respect for**, be it because, not just because there are spiritual people in our church but education-wise or like our church leadership, and, and maybe there might be some things that people didn't know about each one there, you know, their stories, and you made it really personal, you know and I think that if our congregation would just see something like this that it would like, you know, it would touch them just as much as much as it touched me, but I think that just the fact that you picked key respectable people. [emphasis added] – Female focus group participant*

Having a testimony of people who have a very high degree of spirituality is respectable. I take it with all the, with all the certainty that deserves the case in my heart, my mind took it and seeing how this disease attacks everyone for more spiritual or less spiritual that

one is, the disease attacks. It moved me, it impacted me more that people with a great degree of spirituality have testified that the cancer has passed through them or their families. – Male focus group participant

They shared those things to show us that we can take care of ourselves, and if we take the time, we should take care of ourselves and I think that was very encouraging, because we see them as ministers, we don't see their personal lives. – Female focus group participant

Well, you know what, you know, you've got a good mix because of Assistant Pastor. He stayed true to his ministry because first and foremost he's a minister and he spoke to the damage that he did to himself when he was young. He spoke to the corrective measures. Turning his life around and then taking care of his body by taking vitamins and supplements. He's been a very healthy man. When you have a very healthy man telling you I got to do this. – Male focus group participant

The story of my pastor, that made an impact on me because he is so young and he decided to take that exam. I consider him very, very brave, with a lot of courage and that means a lot. – Female one-on-one interview participant

Intervention Feasibility and Acceptability

All participants expressed that the digital stories were a powerful way of humanizing the CRCS process and felt they would be well received by other church members. Most felt they would be well received in other church settings, though one person thought they would not be as effective in other church settings where the Storytellers are not know. When asked at the end of the group discussions what would improve the digital stories, several participants suggested the intervention would be strengthened by the development of an educational digital story with specific details about CRC and CRCS. Several also suggested that the discussion as a group or one on one was an important aspect of the intervention and recommended viewing the digital stories and then including a facilitated discussion afterwards. The discussion was an opportunity to learn further from peers and the research team.

The following chapter discusses the findings of this research and their implications for research and practice, as well as providing recommendations for future research.

Chapter V: Discussion

The purpose of this study was to explore the feasibility of developing and introducing a digital storytelling (DST) intervention in a community church setting and understand its potential to influence CRCS intention among Latinos. The majority of CRCS interventions tailored towards the Latino population occur in primary health care settings. Since Latinos are often deemed as a hard to reach population with limited access to health care for multiple reasons, it is vital to provide outreach in community settings where they can be reached.

Developing a digital storytelling intervention in a church is feasible

The first goal of the study was to determine if developing a DST with church members about their previous CRC and CRCS experience was feasible. We found the church to be a feasible setting. Although health promotion research in the African-American church has been the norm for many years, researchers have recently begun to look at the Latino church as an audience primed for health promotion activities with the infrastructure to provide such services (Allen, Leyva, et al., 2014; Allen, Pérez, et al., 2014). We found this to be the case in this community. The church had the infrastructure and a large and cooperative congregation to pursue this line of study. The one component missing from this particular church was an organized health ministry similar to that of many African-American churches to provide health promotion programs to improve the overall health of the church.

We also found the digital storytelling intervention was feasible although it was initially difficult to recruit church members to tell their story due to the sensitivity of the topic. Once we were able to recruit prominent members and leaders in the church with previous colorectal cancer screening experience to be a part of the intervention development, we needed to make adjustments to the digital storytelling development process to accommodate the scheduling and capacity needs of the participants. The literature highlights many of the concessions that need to be made when working with community partners particularly with a method such as digital storytelling that can be time intensive (Gubrium, 2009).

Overall the Storytellers enjoyed the process of creating their digital stories. The average age of the Storytellers was 61, yet the technology was not a barrier for them due to the research team and StoryCenter staff assisting with all the technological aspects of the intervention. Everyone who began the digital storytelling process completed it.

A total of ten stories were developed by the Pastor, two Assistant Pastors, two ministers and five influential women from the church. Because of the Storytellers' previous experiences with colorectal cancer and screening, they included that taking care of themselves was vital in order to be healthy in order to take care of others. For example, the Pastor of the church shared his story of having to take care of his wife due to suffering a stroke and leaving her disabled more than twenty years ago. Because he is the primary caretaker of his wife, he needs to make sure he is in good health in order to provide her with the care she needs. The Storytellers included messages about their families being an important reason they completed screening. Without being prompted to do so, they organically shared how being there for their children and future grandchildren in the long term was a motivating factor for completing screening. Several

of the Storytellers expressed belief that God gave doctors the knowledge to take care of His people and thus getting screened is consistent their belief and trust in God.

The process turned out to be a reflective and emotional process for many of the participants. The literature illuminates an emotional transformation that happens when choosing the story you will share and turning it into a digital story (Briant, Halter, Marchello, Escareño, & Thompson, 2016; Gubrium, 2009). Several Storytellers were grieving the loss of a family member and it was cathartic for them to share in the group story circle their experience with losing her to colorectal cancer. This intimate and vulnerable sharing among the participants present helped to create a safe space along with a deeper level of understanding and artistry. In fact, because of the cathartic sharing of their stories two of the participants in the story circle suggested the creation of a grieving ministry in the church to help those experiencing loss in their lives, thus an unintended benefit of the intervention was that it prompted the church leaders and members to talk about how the church could better meet the needs of the congregation.

Unfortunately, not all Storytellers had an opportunity to experience the group story circle due to the one on one accommodations we had to offer since all of the male participants did not feel comfortable sharing their CRCS experience in a group setting. Several remarked during the interviews that they would have kept quiet and not felt comfortable sharing in a group setting. Although it was not ideal, it was essential to include these male voices into the intervention and part of the intervention tailoring process. This is quite common in the literature; many researchers have found that Latino men tend to be more private and guarded especially when it comes to sensitive health topics (Getrich et al., 2012). Because of our flexibility, we found a way include these critical voices in the intervention.

A digital storytelling intervention is a promising approach to influence health behavior among those who create the stories

In addition to determining if the development of the intervention was feasible, we sought to understand if developing a digital story influenced the Storytellers' intention to continue future screening and several of the Storytellers shared that because of this experience, it would serve as an even more vital reminder for future CRCS. The remaining Storytellers did not feel the digital story development process influenced their future screening behavior because they were already activated to complete screening, which is why they chose to participate in our study in the first place. In other digital storytelling studies, participants have been more proactive to completing future screening as a result of the intervention (Cueva, Kuhnley, Revels, Schoenberg, & Dignan, 2015).

We also wanted to know if developing their digital story would influence the Storytellers to promote their stories to others inside and outside of their immediate networks. Other studies have found those who develop their stories as activated to continue promoting cancer screening behavior by sharing their stories with broader audiences (Cueva et al., 2015). Because each of the Storytellers were content with their final stories, many of them felt proud of what they accomplished and wanted to share them immediately with others. One Storyteller downloaded his story to his smart phone so he could show others at a moment's notice. Because we were still testing the intervention we asked that Storytellers wait to share their story with others until we were done testing the intervention in the church with unscreened church members. Now with the completion of the intervention, the stories are theirs to share however they choose. During the interviews with the Storytellers, many expressed excitement to spread the word in their larger

networks. First and foremost, they would like to share their stories with their immediate friends and family either in person or on social media, next with their fellow church members as well as other churches in their district and ultimately at the yearly district convention with thousands of conference attendees from the Apostolic Assembly. We were surprised by the reach these Storytellers hoped to make with their digital stories especially considering their initial hesitation and the sensitive nature of sharing something normally considered private in such a public arena.

A digital story intervention is a promising approach to influence health behavior among those who view the stories

The second goal of the study was to have the unscreened members of the church, Storyviewers, view the digital stories and see if they influenced their intention to complete future colorectal cancer screening. We encountered recruitment difficulties for this group due to many of the congregants being up to date with screening due to our presence in the church for the past five years. And in fact, midway through the intervention, during the focus groups, four participants (two men and two women) out of the 20 total, realized they had completed screening with a home stool kit in the past year. It was not until they viewed the digital stories and saw the examples of FIT kits in the stories that they started to remember. Because they were only equating completing screening with a colonoscopy, they did not deem the home stool kit as a form of screening.

Once we had recruited the viewers, we needed to make adjustments due to logistical and scheduling issues, just as with the Storytellers. For example, one evening when we had eight members of the church scheduled to participate in the intervention viewing, the Pastor called an emergency meeting of all ministers in the church which included three of the men participating in the intervention viewing that evening. We were unable to find a time to reschedule all three participants at one time so we had to separate them into one group of two and then the other in a one-on-one interview format. For others who wanted to participate but were not able to make it to the group sessions, we were able to offer them the one-on-one interview option as well since they intended to make the group session but were unable to attend due to unforeseen circumstances. Although this was not ideal, we learned to be flexible and accommodate the schedules of the church members and made it a point not to interfere with existing church activities.

The main outcome of our study was intention to complete future screening. A majority of the participants (12 of 20) were already activated to complete screening due to understanding the importance of screening and their CRCS previous screening experience. Only a small fraction of the sample (2 of 20) indicated they were not interested in completing screening before the digital stories and after and none of the participants experienced discontinued intention where they had an intention to complete screening before the digital stories and then decided against it afterwards. One of our most interesting findings is that a total of six participants indicated their new intention to complete screening. They initially said they were not interested and then as a result of viewing the digital stories indicated their intention to complete future screening. This was the desired outcome we were hoping for. Unfortunately, the finding would be refuted after the focus group discussion with participants. When we initially surveyed the participants half of them answered they had never completed screening before. So instead of 15% (3 of 20) of participants, falling into the “New Intention” category only as one of the participants indicated in the pre-survey his intention to complete screening in the future.

The literature cites that low knowledge of CRC and CRCS is a major issue as to why many Latinos are not completing screening (Natale-Pereira et al., 2008). More culturally tailored awareness and education is needed in this area for this target population. During the focus groups, we found those who were initially resistant to colonoscopies (but willing to be screened with home stool kits) changed their minds as a result of viewing the digital stories and participating in the group discussion. While the study was about CRCS in general, colonoscopy is the clinical gold standard of screening methods. Future research should investigate whether DST is effective in changing not just levels of screening but which screening methods are used.

The participants enjoyed the discussion as it was an opportunity to learn from each other. Future interventions would benefit from including an education discussion to provide a space for these sensitive conversations where peers can learn from each other.

In regards to the acquisition of knowledge as a part of the intervention, the majority of participants (64%) were in the “Continued Knowledge” category meaning they marked the correct answer before and after the viewing versus (14%) of participants with a “Continued lack of knowledge.” A small percentage of the sample (13%) acquired “New Knowledge” after viewing the intervention while (6%) were in the “Reduced Knowledge” category. There were no major differences between knowledge types between men and women. The majority of the sample answered correctly potentially because of their previous experiences with CRC and CRCS. What is more concerning is the (20%) who answered incorrectly pre- and post-survey as well as those who initially answered correctly and then answered incorrectly after the viewing. One possible explanation is the length of the surveys. All of the intervention viewings happened in the evening, and the intervention took two hours total including the consent process, the pre-survey, the viewing and the post survey. Although we had chosen questions due to their average 7th grade reading level, there were just too many questions. Additionally, we had some participants who spoke English but preferred to read and write in their first language, Spanish. Although we did pilot test the surveys, we did not take into account that the intervention would happen in the evening with participants with limited English literacy. Future studies should be mindful of this and consider cutting down the number of questions to make the surveys more manageable and less time consuming.

For the attitudes and beliefs questions, participants answered similarly before and after the viewing. The majority of the sample agreed with the importance of completing screening to detect cancer early, that colorectal cancer screening is a good method for finding cancer early, and that cancer can be prevented by living a healthy lifestyle. For those who did not have previous CRCS experience, they were more apt to react to the statement, “I am afraid of getting screened for cancer”, with fear. Only after the digital stories did they respond with less fear. Watching their peers share their CRCS experience may have helped to reduce fear in those participants.

All of the participants shared in the survey and the focus groups/interviews that the digital stories touched them as the personal narratives hit home and they learned something new about their fellow church members. Several Storyviewers expressed their surprise that often private church members and leaders shared their personal screening experience in such a public way. Based on the focus groups and interviews, I found that the digital stories motivated and influenced the Storyviewers in four different ways: individual motivation, familial motivation, fellow church member influence and leadership influence.

The Storyviewers were inspired to focus on their own health realizing how they often sacrifice taking care of themselves in order to take care of others. As mentioned above, the

Pastor shared his story of taking care of himself in order to take care of his wife, who has a disability. The Storyviewers were touched by being able to see their Pastor in a new light and how important it was for him to take care of himself so that he could be there for his wife and children. This inspired several participants to consider putting their health first instead of focusing all of their attention on everyone else.

This leads directly to the next factor of familial motivation being an important motivator to complete screening. A desire to complete screening so they can be around for their family. The literature cites the family as an important motivator for completing CRCS and our results confirm this motivation (Natale-Pereira et al., 2008).

In addition to the familial motivation, participants were also inspired by their fellow church members particularly church leadership to pursue future screening. Each participant mentioned in their surveys and focus groups/interviews how much it meant to them to have someone they knew sharing their story. More importantly how much it meant for them to see their current church leadership sharing their private experiences and encouraging screening. In the clinical intervention literature, champions in the clinical setting have a high influence in helping others to adopt new behaviors. This was the case in this community-based setting too, where the Pastor, Assistant Pastors and ministers are held in high esteem and in a position of power. This was also the case for the members of prominent families who developed a digital story. Storytellers mentioned what it meant for them to see these families who had been in the church for generations and highlighted how the tide had changed in the church where it was no longer taboo to seek medical services for fear of not allowing others to see their distrust in God. Several of the Storyviewers echoed the Storytellers in their belief that God gave doctors the knowledge to take care of His people and thus church members should not sacrifice going to the doctor due to their belief and trust in God.

Although the majority of Storyviewers felt this way, one particular participant insisted that although she enjoyed the stories and the messages from the digital stories that she would never be screened because her trust in God was too great. Other participants were getting uncomfortable because it made them feel as if they did not have as strong of faith as this participant. Fortunately, the other participants made sure to clarify with her that they understood where she was coming from but they believed in a slightly different way. Her refusal to ever complete screening may be due to her being raised in the church since birth and being a part of one of the original families to start this church. She was raised under strict leadership where doctors were criticized and your only way to salvation was to have complete trust in God. This is an extreme example of fatalism, the belief that all events in life are predestined and therefore inevitable, because the participant is convinced that no action in the area of her health is required because if God wants her die, he will let her die. Participants who are not easily swayed by the intervention are vital to include in research because it is important to understand the strong motivations someone has to not change health behavior and figure out innovative ways to remove barriers for this particular type of participant.

Another related and important aspect of this was revealed during the focus groups/interviews, where many described faith as a motivator to pursue health screening and one participant saw faith as a barrier to health screening. Many of the participants quoted Bible passages to support their position. Although there are many passages that support pursuing good health, there are also many examples in the Bible where it can be used to refute the need for medical intervention. In future faith-based health interventions, it's essential to be prepared to deal with these opposing points of view, if they emerge.

Both the Storytellers and Storyviewers felt strongly about sharing these digital stories to promote CRCS within the church and the larger community. One participant, a health professional and a member of national cancer awareness organization within the church suggested we connect with her organization to disseminate these stories on a larger scale. We believe the reason why participants are eager to share such personal narratives with others in an effort to spread cancer awareness is because they felt the power of storytelling and personal connection when they watched the digital stories created by their fellow church members. In fact, the most important finding of this study is the power of storytelling and human connection. The digital stories humanized an often humiliating screening experience and offered participants a platform to discuss this taboo subject. The act of storytelling evokes empathy and understanding from listeners and communicates more than information about a disease; the stories provide courage, strength and reinforcement (Natale-Pereira et al., 2008).

Last but not least, when we asked participants how we could improve the intervention, several mentioned the creation of an educational digital story describing CRC and CRCS in greater detail. This is an important finding because it shows that more education on CRC and CRCS is needed in the Latino church community and that in addition to peer stories, an expert (but accessible) digital story should be included in future interventions.

Limitations

The study was limited in scope because of its quasi-experimental no control group design. Because of our limited time and resource constraints we chose a feasibility design with the goal of learning if this concept would be worth implementing on a larger scale. Future studies should include a control group and randomized design with the goal of measuring the effectiveness of the intervention.

Our Storyviewer sample size was smaller than we originally anticipated due to our five-year presence in the church having an intervention effect on church members. For example, over the years, many congregants who were not previously up-to-date with CRCS recommendations have over time completed screening because of conversations they have had with the research team. We felt it unethical to keep CRCS information from members who wanted to learn more about screening. Our enrollment might have been higher if this were not the case.

Another reason for a small sample size was our exclusion of Spanish monolingual speakers from the Spanish congregation. Many of the members from this part of the church have never completed CRCS¹. Several participants who were bilingual suggested to us how this intervention could serve the Spanish congregation with greater reach due to their limited cancer screening awareness. In fact, two participants returned their incentives after participating in the intervention event because they would rather we gift it to other Spanish-speaking congregants instead. Although we originally hesitated in accepting the returned gift cards, the participants insisted and would be upset if we did not accept the gesture. We are already planning to apply for Institutional Review Board (IRB) approval to record the stories in Spanish, translate all study materials, and recruit church members to view the intervention.

Another important limitation is that the outcome of the intervention is intention to complete screening, not completed screening. Although intention is a proxy for behavior change, it does not guarantee the participant will follow through. Future studies will be able to address

¹ When we recruited before the English service, we would come in contact with Spanish congregation members who wanted to participate and said they had never been screened.

this by offering screening services and following up three to six months after the intervention was viewed.

There may also have been a group discussion effect on influencing participants' willingness to complete future screening that we were unable to measure due to time constraints and inability to obtain IRB approval in time for our data collection timeline. Although the participants reported the digital stories as the motivating factor to obtain CRCS, we cannot minimize the influence of the focus group discussions as the participants shared their experiences and potentially influenced each other's intention further. In future studies, we will include a post-focus group survey to measure the impact. Last but not least, social desirability was a limitation of this study due to the long term collaboration and relationships built in the church and the desire for participants to please the research team. Although the intervention participants were not necessarily well-known to the research team, there may have been the desire to appease the researchers. We tried to avoid this by collecting different measures via the surveys and the focus groups. In future studies, we would like to offer this intervention in a church that has not had such a long term collaborative relationship with the research team to see if the intervention has the same potential to influence CRCS intention.

Additionally, although these stories were developed by church members who the viewers knew, the next step would be to explore if the stories would have a similar impact being watched by people who do not know those who created the stories. A few variations of this study should be investigated: viewing the stories in another church collectively, in another community setting collectively, and individually.

Implications for research and practice

The findings of this dissertation study illustrate the value of developing a digital storytelling intervention to communicate health messages in a culturally tailored way. There are several considerations that need to be made when developing digital storytelling interventions with future Latino populations. One is that the process must be tailored to work with them, including a flexible process so that their voice is what shines through to make an authentic story.

The use of champions in clinical interventions is not much different than in a community setting. We found the power of working with leaders in the community and how much stronger that connection is with the participants. Leadership buy-in was essential for recruiting, and the development of the stories of those influential members seemed critical, though future research could compare the effect of stories of leaders and those of church attendees who are not in a leadership role. In addition, more education on colorectal cancer screening awareness in the Latino population is needed to reduce stigma and influence more members of the community to complete screening. Removing CRCS barriers and motivating people to complete screening could lead to a better quality and quantity of life and reduce the burden of CRC on public health. Community-engaged intervention designs have the potential to reach participants that are often deemed hard-to-reach instead of using a top-down approach without involving the expertise of the community.

This is a feasible low-cost, simple -to-disseminate intervention that is a promising approach to increase CRCS intention. Future studies should consider this approach to test a DST intervention in multiple settings and diverse populations for a range of topics. This novel intervention approach has the potential to be scaled-up, disseminated, and implemented on a wider scale in a variety of settings for a variety of health topics such as diabetes and health disease and other populations.

REFERENCES

- 80% by 2018 | National Colorectal Cancer Roundtable. (n.d.). Retrieved March 20, 2015, from <http://nc crt.org/tools/80-percent-by-2018/>
- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50(2), 179–211. [https://doi.org/10.1016/0749-5978\(91\)90020-T](https://doi.org/10.1016/0749-5978(91)90020-T)
- Allen, J. D., Leyva, B., Torres, A. I., Ospino, H., Tom, L., Rustan, S., & Bartholomew, A. (2014). Religious beliefs and cancer screening behaviors among Catholic Latinos: implications for faith-based interventions. *Journal of Health Care for the Poor and Underserved*, 25(2), 503–526. <https://doi.org/10.1353/hpu.2014.0080>
- Allen, J. D., Pérez, J. E., Tom, L., Leyva, B., Diaz, D., & Idali Torres, M. (2014a). A pilot test of a church-based intervention to promote multiple cancer-screening behaviors among Latinas. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 29(1), 136–143. <https://doi.org/10.1007/s13187-013-0560-3>
- Allen, J. D., Pérez, J. E., Tom, L., Leyva, B., Diaz, D., & Idali Torres, M. (2014b). A pilot test of a church-based intervention to promote multiple cancer-screening behaviors among Latinas. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 29(1), 136–143. <https://doi.org/10.1007/s13187-013-0560-3>
- American Cancer Society. (2012). *Cancer Facts & Figures for Hispanics/Latinos 2012-2014*. Atlanta: American Cancer Society.
- American Cancer Society. (2014a). *Cancer Facts & Figures 2014*. Atlanta: American Cancer Society.
- American Cancer Society. (2014b). *Colorectal Cancer Facts & Figures 2014-2016*. Atlanta: American Cancer Society.
- Aragones, A., Schwartz, M. D., Shah, N. R., & Gany, F. M. (2010). A randomized controlled trial of a multilevel intervention to increase colorectal cancer screening among Latino immigrants in a primary care facility. *Journal of General Internal Medicine*, 25(6), 564–567. <https://doi.org/10.1007/s11606-010-1266-4>
- ASP. (2013, June 7). *Affordable Care Act (2010) Read the Law*. Retrieved December 7, 2013, from <http://www.hhs.gov/healthcare/rights/law/>
- Bowen, D. J., Kreuter, M., Spring, B., Cofta-Woerpel, L., Linnan, L., Weiner, D., ... Fernandez, M. (2009). How we design feasibility studies. *American Journal of Preventive Medicine*, 36(5), 452–457. <https://doi.org/10.1016/j.amepre.2009.02.002>
- Brenner, A. T., Ko, L. K., Janz, N., Gupta, S., & Inadomi, J. (2015). Race/Ethnicity and Primary Language: Health Beliefs about Colorectal Cancer Screening in a Diverse, Low-Income

- Population. *Journal of Health Care for the Poor and Underserved*, 26(3), 824–838.
<https://doi.org/10.1353/hpu.2015.0075>
- Briant, K. J., Halter, A., Marchello, N., Escareño, M., & Thompson, B. (2016). The Power of Digital Storytelling as a Culturally Relevant Health Promotion Tool. *Health Promotion Practice*, 17(6), 793–801. <https://doi.org/10.1177/1524839916658023>
- Campbell, M. K., Hudson, M. A., Resnicow, K., Blakeney, N., Paxton, A., & Baskin, M. (2007). Church-based health promotion interventions: evidence and lessons learned. *Annual Review of Public Health*, 28, 213–234.
<https://doi.org/10.1146/annurev.publhealth.28.021406.144016>
- Cancer Facts & Figures for Hispanics/Latinos 2012-2014. (2012). Retrieved December 7, 2013, from
<http://www.cancer.org/research/cancerfactsfigures/cancerfactsfiguresforhispanicslatinos/cancer-facts-figures-hispanics-2012-2014>
- Cancer Facts & Figures for Hispanics/Latinos 2015-2016. (n.d.). Retrieved April 27, 2016, from
<http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-046405.pdf>
- CDC - Social Ecological Model - CRCCP. (n.d.). Retrieved April 19, 2015, from
<http://www.cdc.gov/cancer/crccp/sem.htm>
- Cokkinides, V. E., Bandi, P., Siegel, R. L., & Jemal, A. (2012). Cancer-related risk factors and preventive measures in US Hispanics/Latinos. *CA: A Cancer Journal for Clinicians*, 62(6), 353–363. <https://doi.org/10.3322/caac.21155>
- Colon-Otero, G., Albertie, M., Lesperance, M., Weis, J. A., Coles, A., Smith, N., ... Rajkumar, S. V. (2012). A pilot program in collaboration with African American churches successfully increases awareness of the importance of cancer research and participation in cancer translational research studies among African Americans. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 27(2), 294–298. <https://doi.org/10.1007/s13187-011-0288-x>
- Corbie-Smith, G., Ammerman, A. S., Katz, M. L., St George, D. M. M., Blumenthal, C., Washington, C., ... Switzer, B. (2003). Trust, benefit, satisfaction, and burden: a randomized controlled trial to reduce cancer risk through African-American churches. *Journal of General Internal Medicine*, 18(7), 531–541.
- Cueva, M., Kuhnley, R., Revels, L. J., Cueva, K., Dignan, M., & Lanier, A. P. (2013). Bridging storytelling traditions with digital technology. *International Journal of Circumpolar Health*, 72. <https://doi.org/10.3402/ijch.v72i0.20717>

- Cueva, M., Kuhnley, R., Revels, L., Schoenberg, N. E., & Dignan, M. (2015). Digital storytelling: a tool for health promotion and cancer awareness in rural Alaskan communities. *International Journal of Circumpolar Health*, *74*, 28781.
- Diaz, J. A., Roberts, M. B., Goldman, R. E., Weitzen, S., & Eaton, C. B. (2008). Effect of language on colorectal cancer screening among Latinos and non-Latinos. *Cancer Epidemiology, Biomarkers & Prevention: A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology*, *17*(8), 2169–2173. <https://doi.org/10.1158/1055-9965.EPI-07-2692>
- Ellison, J., Jandorf, L., Villagra, C., Winkel, G., & DuHamel, K. (2011). Screening adherence for colorectal cancer among immigrant Hispanic women. *Journal of the National Medical Association*, *103*(8), 681–688.
- Getrich, C. M., Sussman, A. L., Helitzer, D. L., Hoffman, R. M., Warner, T. D., Sánchez, V., ... RIOS Net Clinicians. (2012). Expressions of machismo in colorectal cancer screening among New Mexico Hispanic subpopulations. *Qualitative Health Research*, *22*(4), 546–559. <https://doi.org/10.1177/1049732311424509>
- Glanz, K., & Bishop, D. B. (2010). The role of behavioral science theory in development and implementation of public health interventions. *Annual Review of Public Health*, *31*, 399–418. <https://doi.org/10.1146/annurev.publhealth.012809.103604>
- Glanz, K., Rimer, B. K., & National Cancer Institute (U.S.). (1997). *Theory at a glance: a guide for health promotion practice*. [Bethesda? Md.]: U.S. Dept. of Health and Human Services, Public Health Service, National Institutes of Health, National Cancer Institute.
- Goel, M. S., Wee, C. C., McCarthy, E. P., Davis, R. B., Ngo-Metzger, Q., & Phillips, R. S. (2003). Racial and ethnic disparities in cancer screening: the importance of foreign birth as a barrier to care. *Journal of General Internal Medicine*, *18*(12), 1028–1035.
- Goodman, M. J., Ogdie, A., Kanamori, M. J., Cañar, J., & O'Malley, A. S. (2006). Barriers and facilitators of colorectal cancer screening among Mid-Atlantic Latinos: focus group findings. *Ethnicity & Disease*, *16*(1), 255–261.
- Gorin, S. S. (2005). Correlates of colorectal cancer screening compliance among urban Hispanics. *Journal of Behavioral Medicine*, *28*(2), 125–137.
- Gubrium, A. (2009). Digital storytelling: an emergent method for health promotion research and practice. *Health Promotion Practice*, *10*(2), 186–191. <https://doi.org/10.1177/1524839909332600>
- Harmon, B. E., Adams, S. A., Scott, D., Gladman, Y. S., Ezell, B., & Hebert, J. R. (2012). Dash of Faith: A Faith-Based Participatory Research Pilot Study. *Journal of Religion and Health*. <https://doi.org/10.1007/s10943-012-9664-z>

- He, J., & Efron, J. E. (2011). Screening for colorectal cancer. *Advances in Surgery*, *45*, 31–44.
- Holt, C. L., Roberts, C., Scarinci, I., Wiley, S. R., Eloubeidi, M., Crowther, M., ... Coughlin, S. S. (2009). Development of a spiritually based educational program to increase colorectal cancer screening among African American men and women. *Health Communication*, *24*(5), 400–412. <https://doi.org/10.1080/10410230903023451>
- Jones L, & Wells K. (2007). Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA*, *297*(4), 407–410. <https://doi.org/10.1001/jama.297.4.407>
- Larkey, L. (2006). Las mujeres saludables: reaching Latinas for breast, cervical and colorectal cancer prevention and screening. *Journal of Community Health*, *31*(1), 69–77.
- Larkey, L. K., & Gonzalez, J. (2007). Storytelling for promoting colorectal cancer prevention and early detection among Latinos. *Patient Education and Counseling*, *67*(3), 272–278. <https://doi.org/10.1016/j.pec.2007.04.003>
- Larkey, L. K., & Hecht, M. (2010). A model of effects of narrative as culture-centric health promotion. *Journal of Health Communication*, *15*(2), 114–135. <https://doi.org/10.1080/10810730903528017>
- Larkey, L. K., Herman, P. M., Roe, D. J., Garcia, F., Lopez, A. M., Gonzalez, J., ... Saboda, K. (2012). A cancer screening intervention for underserved Latina women by lay educators. *Journal of Women's Health* (2002), *21*(5), 557–566. <https://doi.org/10.1089/jwh.2011.3087>
- Le, T. D., Carney, P. A., Lee-Lin, F., Mori, M., Chen, Z., Leung, H., ... Lieberman, D. A. (2014). Differences in knowledge, attitudes, beliefs, and perceived risks regarding colorectal cancer screening among Chinese, Korean, and Vietnamese sub-groups. *Journal of Community Health*, *39*(2), 248–265. <https://doi.org/10.1007/s10900-013-9776-8>
- LeBron, A. M. W., Schulz, A. J., Bernal, C., Gamboa, C., Wright, C., Sand, S., ... Caver, D. (2014). Storytelling in Community Intervention Research: Lessons Learned From the Walk Your Heart to Health Intervention. *Progress in Community Health Partnerships : Research, Education, and Action*, *8*(4), 477–485. <https://doi.org/10.1353/cpr.2014.0066>
- Leyva, B., Allen, J. D., Tom, L. S., Ospino, H., Torres, M. I., & Abraido-Lanza, A. F. (2014). Religion, fatalism, and cancer control: a qualitative study among Hispanic Catholics. *American Journal of Health Behavior*, *38*(6), 839–849. <https://doi.org/10.5993/AJHB.38.6.6>
- Lopez, M. H., & comments, J. M. K. (n.d.). Will California ever become a majority-Latino state? Maybe not. Retrieved August 21, 2015, from <http://www.pewresearch.org/fact-tank/2015/06/04/will-california-ever-become-a-majority-latino-state-maybe-not/>

- Lumpkins, C. Y., Coffey, C. R., Daley, C. M., & Greiner, K. A. (2013). Employing the Church as a Marketer of Cancer Prevention. *Family & Community Health, 36*(3). <https://doi.org/10.1097/FCH.0b013e31829159ed>
- Lurie, N. (1997). Studying access to care in managed care environments. *Health Services Research, 32*(5), 691–701.
- Maxwell, J. A. (2012). *Qualitative Research Design: An Interactive Approach* (Third Edition edition). Thousand Oaks, Calif: SAGE Publications, Inc.
- Minkler, M., & Wallerstein, N. (2008). *Community-based participatory research for health: from process to outcomes*. San Francisco, CA: Jossey-Bass.
- Natale-Pereira, A., Marks, J., Vega, M., Mouzon, D., Hudson, S. V., & Salas-Lopez, D. (2008). Barriers and facilitators for colorectal cancer screening practices in the Latino community: perspectives from community leaders. *Cancer Control: Journal of the Moffitt Cancer Center, 15*(2), 157–165.
- Population Bulletin Update: Latinos in the United States 2010 (con't.). (n.d.). Retrieved April 8, 2014, from <http://www.prb.org/Publications/Reports/2010/latinosupdate2.aspx>
- Powell, M. E., Carter, V., Bonsi, E., Johnson, G., Williams, L., Taylor-Smith, L., ... Husaini, B. A. (2005). Increasing mammography screening among African American women in rural areas. *Journal of Health Care for the Poor and Underserved, 16*(4 Suppl A), 11–21. <https://doi.org/10.1353/hpu.2005.0129>
- Reese, L. (2012). Storytelling in Mexican Homes: Connections Between Oral and Literacy Practices. *Bilingual Research Journal, 35*(3), 277–293. <https://doi.org/10.1080/15235882.2012.734006>
- Rodriguez, E. M., Bowie, J. V., Frattaroli, S., & Gielen, A. (2009). A qualitative exploration of the community partner experience in a faith-based breast cancer educational intervention. *Health Education Research, 24*(5), 760–771. <https://doi.org/10.1093/her/cyp010>
- Saunders, D. R., Holt, C. L., Whitehead, T. L., Atkinson, N. L., Le, D., Wang, M. Q., ... Naslund, M. (2013). Development of the men's prostate awareness church training: church-based workshops for African American men. *Family & Community Health, 36*(3), 224–235. <https://doi.org/10.1097/FCH.0b013e318292eb40>
- Schoenberg, N. E., Hatcher, J., Dignan, M. B., Shelton, B., Wright, S., & Dollarhide, K. F. (2009). Faith Moves Mountains: an Appalachian cervical cancer prevention program. *American Journal of Health Behavior, 33*(6), 627–638.
- Shih, Y.-C. T., Elting, L. S., & Levin, B. (2008). Disparities in colorectal screening between US-born and foreign-born populations: evidence from the 2000 National Health Interview

- Survey. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 23(1), 18–25. <https://doi.org/10.1080/08858190701634623>
- Shirazi, M., Shirazi, A., & Bloom, J. (2013). Developing a Culturally Competent Faith-Based Framework to Promote Breast Cancer Screening Among Afghan Immigrant Women. *Journal of Religion and Health*. <https://doi.org/10.1007/s10943-013-9793-z>
- Siegel, R., Naishadham, D., & Jemal, A. (2012). Cancer statistics for Hispanics/Latinos, 2012. *CA: A Cancer Journal for Clinicians*, 62(5), 283–298. <https://doi.org/10.3322/caac.21153>
- Siegel, R., Naishadham, D., & Jemal, A. (2013). Cancer statistics, 2013. *CA: A Cancer Journal for Clinicians*, 63(1), 11–30. <https://doi.org/10.3322/caac.21166>
- Survey | 2013 Hispanic Values Survey: How Shifting Religious Identities and Experiences are Influencing Hispanic Approaches to Politics. (2013). Retrieved December 7, 2013, from <http://publicreligion.org/research/2013/09/hispanic-values-survey-2013/>
- Wilcox, S., Laken, M., Parrott, A. W., Condrasky, M., Saunders, R., Addy, C. L., ... Samuel, M. (2010). The faith, activity, and nutrition (FAN) program: design of a participatory research intervention to increase physical activity and improve dietary habits in African American churches. *Contemporary Clinical Trials*, 31(4), 323–335. <https://doi.org/10.1016/j.cct.2010.03.011>
- Wilschut, J. A., Steyerberg, E. W., van Leerdam, M. E., Lansdorp-Vogelaar, I., Habbema, J. D. F., & van Ballegooijen, M. (2011). How much colonoscopy screening should be recommended to individuals with a varying degree of family history of colorectal cancer? *Cancer*, 117(18), 4166–4174. <https://doi.org/10.1002/cncr.26009>
- Woods, G., Levinson, A. H., Jones, G., Kennedy, R. L., Johnson, L. C., Tran, Z. V., ... Marcus, A. C. (2013). The Living Well by Faith Health and wellness program for African Americans: an exemplar of community-based participatory research. *Ethnicity & Disease*, 23(2), 223–229.
- Wynn, T. A., Anderson-Lewis, C., Johnson, R., Hardy, C., Hardin, G., Walker, S., ... Scarinci, I. (2011). Developing a community action plan to eliminate cancer disparities: lessons learned. *Progress in Community Health Partnerships: Research, Education, and Action*, 5(2), 161–168. <https://doi.org/10.1353/cpr.2011.0013>

APPENDICES

Appendix A Demographic Survey

Study ID: _____

1. What is your gender (check one)?

- Female
 Male

2. What is your age? _____

3. Do you consider yourself to be of Latino or Hispanic origin?

- Yes, If yes, please specify _____
 No

4. What is your race? (check all that apply)

- American Indian or Alaska Native
 Asian, If yes, please specify _____
 Black or African American
 Native Hawaiian or Pacific Islander
 White or European-American
 Other, please specify _____

5. What is the highest level of school that you have completed?

- Grade school (grades 1-8)
 Some high school (grades 9-11)
 High school degree or GED
 Some college, vocational/technical school
 College degree
 Graduate school degree
 Other (please specify: _____)

6. What is your marital status?

- Single
 Married or partnered
 Separated
 Divorced
 Widowed

7. What is your employment status?

- Full-time employed
 Part-time employed
 Retired
 Disabled
 Full-time student
 Homemaker
 Unemployed
 Other (please specify: _____)

8. What best describes your current insurance coverage?

- Employer provided insurance
- Spouse's/partner's employer provided insurance
- Pay for insurance out of pocket
- Medicare
- Medical
- Medical/Medicare
- Other (please specify: _____)

9. What was your total family income (before taxes) from all sources last year?

- Less than \$30,000/year
- \$30,001 to \$70,000/ year
- \$70,001 to \$100,000/ year
- \$100,001 or more/ year

Appendix B

Storyteller Interview Guide

Introduction

In our interview today, we will discuss your experience developing your digital story, how it influences the way you will get screened in the future, and if you will share your digital story as a tool to promote colorectal cancer-screening to others. I ask for your opinion and feedback. I want to emphasize there are no right or wrong answers to the questions I will ask. I anticipate this interview will take between 60-90 minutes.

Facilitator: Play participant's final digital story. Memo participants' reactions. Offer to show other completed digital stories.

Interview Questions:

1. Let's start at the very beginning. First, I'd like to know why you decided to participate in this study.
 - a. What motivated you to develop a digital story?
 - b. Were you ever hesitant to participate? Is there anything that would have discouraged you from participating?
2. Now let's move on to talking about the digital story development process.
 - a. What was your experience working in a group setting?
 - b. Specifically, how did you feel about the story circle (in which you brainstormed ideas with the other participants and got feedback)?
 - i. What did you like about hearing others' stories?
 - ii. How did you decide what story you would share in the story circle?
3. As part of the process, we also wrote and revised scripts, recorded audio, gathered and ordered photos, and edited the final product.
 - a. Please expand on your experience -- what it was like for you to develop your digital story?
 - i. What did you learn from this process?
 1. What did you like?
 2. What did you dislike?
 - ii. What did you find challenging as you developed your digital story?
 - iii. What kinds of worries or concerns did you have about creating a digital story?
 - iv. Given what you knew about digital stories, how did the digital storytelling process meet your expectations? Or not?
 - v. What can we do to improve the digital storytelling process in the future?
4. Now let's focus on the final product. What are your thoughts on your final digital story?
 - a. How did your final digital story make you feel after you viewed it for the first time?
 - b. How do you feel your digital story could have been improved?
 - c. How did you feel watching the other digital stories?
 - i. First, I'd like you to focus on how you felt after watching the stories in the beginning of the training.

- ii. How did you feel after watching stories from the other church members?
- 5. Now let's slightly switch gears, and focus on impact. Specifically, I'd like to discuss how creating a digital story impacts you. The workshops were in July, so a few months ago.
 - a. How have the workshops influenced your own colorectal-screening?
 - b. How did creating a digital story influence how you choose to get screened?
 - i. How will you choose to get screened from now on, now that you've seen more digital stories from your own church community?
 - c. How regularly will you choose to get screened from now on?
 - i. Is this different from how regularly you used to get screened?
- 6. Why would you choose to share, or not share, your digital story with others?
 - a. How do you think your digital story will impact other people?
- 7. Now let's think bigger picture, specifically, about the digital storytelling skills you learned through this process. How likely are you to use them in the future?
 - a. How might you use these skills in the future?
 - i. Personal use
 - ii. Church use
 - b. If you could choose any topic for a digital story, what would it be? Why?
- 8. As we begin to wrap up, I want to open the floor. What other thoughts did you have on your experience that we haven't covered that you would like to share?

That's it, we're done! Thank you so much for your time today.

Appendix C

Storyviewer Group Discussion Guide

Getting Started

Thank you all for being a part of this health study.

In our group discussion today, we want to ask you for your opinions and feedback about the digital stories you just finished viewing. The purpose of this group discussion is to determine if these stories have the potential to increase colorectal cancer screening rates in the Latino church community.

We want to emphasize that there are no right or wrong answers to the questions. We want your honest feedback and opinions. I anticipate this focus group will take approximately 1 to 1.5 hours.

Ground Rules

Before we begin, we should agree upon a few ground rules [*facilitator point to ground rules posted*]. We want everyone to feel safe speaking. Therefore, we ask that you not talk about what is discussed at today's focus group with anyone outside of the group. Please respect people's opinions, and try not to cut people off when they are talking. We want to hear everyone's opinion, so I may call on you to ask your opinion on a topic if we haven't heard from you. You can absolutely decline to answer any questions you don't feel comfortable discussing. Lastly, please refrain from using your phones to record or take pictures during the group discussion. Are there any questions or other rules we should add to this list?

Focus Group Questions

1. How does your faith influence your health decisions?
2. Before viewing the digital stories what had you heard about colorectal cancer?
 - a. Who has ever recommended screening for this cancer to you? i.e. doctor, family, friend, community member
3. What is your previous experience with colorectal cancer screening?
 - a. *Note to facilitator: if a participant says they've been screened within the USPSTF recommendations, memo it.*
 - b. If not, why not? What were your feelings about getting screened that made you not want to try it?
 - c. If yes, why did you decide to not get screened since then?
 - i. What about your experience was positive?
 - ii. What about your experience was negative?
 - d. What would motivate you to want to get screened?

- e. What would discourage you from wanting to get screened?
4. What did you like about the digital stories?
5. What did you not like about the digital stories?
6. How did you feel about the church members who created the digital stories?
7. You have the list of digital stories in your programs, which ones spoke to you the most and why?
8. How did watching the digital stories make you feel?
 - a. What about the digital stories made you want to get screened?
 - b. What about the digital stories discouraged you from wanting to get screened?
9. What did you learn from watching the digital stories?
10. How can the digital stories be improved?
11. As we wrap up our discussion, I'd like to open the floor now to any thoughts that we might not have covered tonight or anything else you would like to add?

Closing

This concludes the focus group discussion. I would like to thank you again for participating.

Before we leave, I would like to remind you to not share has been discussed in today's focus group with anyone outside of the group. On the bottom of your program you will find my contact information; please feel free to contact me directly at if you have any questions, concerns, or just lingering last thoughts after today's focus group.

Appendix D
Storyviewer Survey 1

Study ID: _____

Section 1. Questions About You

1. What is your gender (check one)?

- Female
- Male

2. What is your age? _____

3. Do you consider yourself to be of Latino or Hispanic origin?

- Yes, if yes, please specify your origin _____
- No

4. What is your race? (check all that apply)

- American Indian or Alaska Native
- Asian, if yes, please specify _____

- Black or African American
- Native Hawaiian or Pacific Islander
- White or European-American
- Other, please specify _____

5. What is the highest level of school that you have completed?

- Grade school (grades 1-8)
- Some high school (grades 9-11)
- High school degree or GED
- Some college, vocational/technical school
- College degree
- Graduate school degree
- Other (please specify: _____)

6. What is your marital status?

- Single
- Married or partnered
- Separated
- Divorced
- Widowed

7. What is your employment status?

- Full-time employed
- Part-time employed
- Retired
- Disabled
- Full-time student
- Homemaker
- Unemployed
- Other (please specify: _____)

8. What best describes your current health insurance coverage?

- Employer-provided insurance
- Spouse's/partner's employer-provided insurance
- Pay for insurance out-of-pocket
- Medicare
- Medi-Cal/Medicaid
- Medi-Cal/Medicare
- Other (please specify: _____)

9. What was your estimated annual household income before taxes from all sources last year?

- Less than \$30,000
- \$30,001 to \$70,000
- \$70,001 to \$100,000
- \$100,001 or more

10. In the space below, please tell us why you have not completed colorectal cancer screening.

Section 2. Questions About How You Feel About Cancer and Cancer Screening (Please read each statement and circle the response that best describes your feelings.)

11. Behavioral Beliefs 7/11	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
11a. Cancer can be prevented by living a healthy lifestyle.	1	2	3	4	5
11b. Cancer can be prevented by regularly exercising.	1	2	3	4	5
11c. Cancer can be prevented by eating certain foods.	1	2	3	4	5
11d. Cancer screening is a good method of finding cancer early.	1	2	3	4	5
11e. Cancer can be treated if it is found early.	1	2	3	4	5
11f. Even if I do not have a family history of cancer, it is important to be checked regularly.	1	2	3	4	5
11g. I am afraid to talk to my doctor about cancer.	1	2	3	4	5

12. Attitudes Toward Behavior 12/14	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
12a. It is better to detect cancer early through screening than to discover it later.	1	2	3	4	5
12b. When I think about getting screened for cancer, I feel good about myself.	1	2	3	4	5
12c. I am afraid of getting screened for cancer.	1	2	3	4	5
12d. Getting cancer usually means the person is going	1	2	3	4	5

to die.					
12e. My risk of getting cancer is about the same as everyone else.	1	2	3	4	5
12f. People are happy to get and complete cancer screening tests.	1	2	3	4	5
12g. Most usually people talk to each other about cancer screening tests they get.	1	2	3	4	5
12h. People feel the same way I do about getting cancer screening.	1	2	3	4	5
12i. I talk to other people about the cancer screening tests I have gotten.	1	2	3	4	5
12j. I talk with other people about the cancer screening tests I need to get.	1	2	3	4	5
12k. I feel uncomfortable talking about my body with a healthcare provider.	1	2	3	4	5
12l. I am uncomfortable letting a healthcare provider touch my body even if it is a health screening exam.	1	2	3	4	5

13. Control Beliefs 3/6	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
13a. People are in charge of getting their own cancer screening.	1	2	3	4	5
13b. People should be in charge of talking to their doctors about what cancer screening they need.	1	2	3	4	5
13c. Doctors should be in charge of talking with patients about their cancer-screening tests.	1	2	3	4	5

14. Perceived Behavioral Control 6/6	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
14a. If a doctor told me to get cancer screening, then I would do it.	1	2	3	4	5
14b. If I could get cancer screening tests for free, then I	1	2	3	4	5

would get them.					
14c. If I had questions about cancer or cancer screening, then I would talk to my doctor.	1	2	3	4	5
14d. I only see a healthcare provider when I am having a problem with my health.	1	2	3	4	5
14e. I rely on my family to advise me about health matters.	1	2	3	4	5
14f. I rely on my family or close friends to take me to see a healthcare provider.	1	2	3	4	5

15. Behavioral Intentions 4/4	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
15a. Even if I were very busy, I would make time to get cancer screening tests.	1	2	3	4	5
15b. I intend to stay up-to-date with cancer screening.	1	2	3	4	5
15c. I feel comfortable scheduling cancer screening tests.	1	2	3	4	5
15d. Even if I were nervous about getting cancer screening, I would make sure to get it.	1	2	3	4	5

Section 3. Questions About Colorectal Cancer and Screening

16. What screening tests for colorectal cancer do you know about? Where did you complete them, or could you complete them? When was the last time you completed it? (Please write in your answers.)

- Test type: _____ Location: _____ Date (mo/yr): _____
- Test type: _____ Location: _____ Date (mo/yr): _____
- Test type: _____ Location: _____ Date (mo/yr): _____
- Test type: _____ Location: _____ Date (mo/yr): _____
- Test type: _____ Location: _____ Date (mo/yr): _____

17. Do you have a family history of colorectal cancer?

- Yes
- No
- Unsure

18. Have you ever been diagnosed with colorectal cancer?

- Yes
- No
- Unsure

Section 4. Your Knowledge, Attitudes and Beliefs About Colorectal Cancer and Screening (Please check one answer.)

19. Do you know what a colon polyp is?
- Yes
- No
20. A low fat and high fiber diet helps decrease the risk of colorectal cancer.
- True
- False
21. The risk of colorectal cancer increases after the age of 50.
- True
- False
22. A family history of colorectal cancer does not increase your risk.
- True
- False
23. Do you know what your risk for colorectal cancer is?
- Yes
- No
24. Finding cancer early will not increase the chances of surviving it.
- True
- False
25. You only need to have a colorectal cancer screening test if you are having symptoms.
- True
- False
26. Getting a colonoscopy is not worth the hassle.
- True
- False
27. If I were beginning to develop colorectal cancer, I would want to know right away.
- True
- False

Section 5. Intention to Complete Colorectal Cancer Screening (Please check one answer.)

28. Do you plan on getting screened for colon cancer?
- Yes
- No
- Don't know
29. How confident are you that you can complete a screening test for colorectal cancer?
- Very confident
- Confident
- Somewhat confident
- Not confident

30. How likely are you to be screened for colorectal cancer using a home stool test in the next year?

- Very Unlikely
- Somewhat unlikely
- Somewhat Likely
- Likely

31. How likely are you to be screened for colorectal cancer by a colonoscopy in the next ten years?

- Very Unlikely
- Somewhat unlikely
- Somewhat Likely
- Likely

32. In the space provided below, please tell us why you would or would not complete screening for colorectal cancer.

Thank you for completing survey 1.

Appendix E
Storyviewer Survey 2

Study ID: _____

Section 1. Intentions to Complete Colorectal Cancer Screening (Please select one answer.)

1. Do you plan on getting screened for colon cancer?

- Yes
- No
- Don't know

2. How confident are you that you can complete a screening test for colorectal cancer?

- Very confident
- Confident
- Somewhat confident
- Not confident

3. How likely are you to be screened for colorectal cancer using a home stool test in the next year?

- Very Unlikely
- Somewhat unlikely
- Somewhat Likely
- Likely

4. How likely are you to be screened for colorectal cancer by a colonoscopy in the next ten years?

- Very Unlikely
- Somewhat unlikely
- Somewhat Likely
- Likely

5. In the space below, please tell us how the digital stories influenced your decision to get screened.

6. Please tell us which digital stories you enjoyed watching and why.

7. Please tell us which digital stories you did not enjoy watching and why.

8. Are digital stories an acceptable way of receiving this kind of information on colorectal cancer screening, why or why not?

Section 2. Your Knowledge, Attitudes and Beliefs About Colorectal Cancer and Screening (Please check one answer.)

9. Do you know what a colon polyp is?

- Yes
- No

10. A low fat and high fiber diet helps decrease the risk of colorectal cancer.

- True
- False

11. The risk of colorectal cancer increases after the age of 50.

- True
- False

12. A family history of colorectal cancer does not increase your risk.

- True
- False

13. Do you know what your risk for colorectal cancer is?

- Yes
- No

14. Finding cancer early will not increase the chances of surviving it.

- True
- False

15. You only need to have a colorectal cancer screening test if you are having symptoms.

- True
- False

16. Getting a colonoscopy is not worth the hassle.

- True
- False

17. If I were beginning to develop colorectal cancer, I would want to know right away.

- True
- False

Section 3. Questions About How You Feel About Cancer and Cancer Screening Please read each statement and circle the response that best describes your feelings.

18. Behavioral Beliefs	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
18a. Cancer can be prevented by living a healthy lifestyle.	1	2	3	4	5
18b. Cancer can be prevented by regularly exercising.	1	2	3	4	5
18c. Cancer can be prevented by eating certain foods.	1	2	3	4	5
18d. Cancer screening is a good method of finding cancer early.	1	2	3	4	5
18e. Cancer can be treated if it is found early.	1	2	3	4	5
18f. Even if I do not have a family history of cancer, it is important to be checked regularly.	1	2	3	4	5
18g. I am afraid to talk to my doctor about cancer.	1	2	3	4	5

19. Attitudes Toward Behavior	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
19a. It is better to detect cancer early through screening than to discover it later.	1	2	3	4	5
19b. When I think about getting screened for cancer, I feel good about myself.	1	2	3	4	5
19c. I am afraid of getting screened for cancer.	1	2	3	4	5
19d. Getting cancer usually means the person is going to die.	1	2	3	4	5
19e. My risk of getting cancer is about the same as everyone else.	1	2	3	4	5

19f. People are happy to get and complete cancer screening tests.	1	2	3	4	5
19g. Most usually people talk to each other about cancer screening tests they get.	1	2	3	4	5
19h. People feel the same way I do about getting cancer screening.	1	2	3	4	5
19i. I talk to other people about the cancer screening tests I have gotten.	1	2	3	4	5
19j. I talk with other people about the cancer screening tests I need to get.	1	2	3	4	5
19k. I feel uncomfortable talking about my body with a healthcare provider.	1	2	3	4	5
19l. I am uncomfortable letting a healthcare provider touch my body even if it is a health screening exam.	1	2	3	4	5

20. Control Beliefs	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
20a. People are in charge of getting their own cancer screening.	1	2	3	4	5
20b. People should be in charge of talking to their doctors about what cancer screening they need.	1	2	3	4	5
20c. Doctors should be in charge of talking with patients about their cancer-screening tests.	1	2	3	4	5

21. Perceived Behavioral Control	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
21a. If a doctor told me to get cancer screening, then I would do it.	1	2	3	4	5
21b. If I could get cancer screening tests for free, then I would get them.	1	2	3	4	5
21c. If I had questions about cancer or cancer screening, then I would talk to my doctor.	1	2	3	4	5

21d. I only see a healthcare provider when I am having a problem with my health.	1	2	3	4	5
21e. I rely on my family to advise me about health matters.	1	2	3	4	5
21f. I rely on my family or close friends to take me to see a healthcare provider.	1	2	3	4	5

22. Behavioral Intentions	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
22a. Even if I were very busy, I would make time to get cancer screening tests.	1	2	3	4	5
22b. I intend to stay up-to-date with cancer screening.	1	2	3	4	5
22c. I feel comfortable scheduling cancer screening tests.	1	2	3	4	5
22d. Even if I were nervous about getting cancer screening, I would make sure to get it.	1	2	3	4	5

23. In the space provided below, please let us know any additional thoughts you would like to share with us about your experience today.

Thank you for completing survey 2. We appreciate your participation!