THE CHRONIC DISEASE BURDEN IN ETHNIC AND MINORITY GROUPS: COMMUNITY HEALTH WORKERS AS A POTENTIAL SOLUTION FOR IMPROVING AMERICAN HEALTH CARE

A Dissertation

by

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ABSTRACT

Despite many efforts toward prevention, the United States continues to experience high rates of chronic disease, especially among older and ethnically-diverse and minority individuals. Economic, social, and emotional factors affect not only those diagnosed, but also family members and those in the broader community around them. In particular, those from ethnic or minority backgrounds with low income and low education levels are the most likely to have undiagnosed and/or uncontrolled chronic diseases due to the lack of access to quality healthcare, limited health literacy, and scarcity of culturally-competent and relevant information and education.

This dissertation examines how Latinos and other minority groups experience chronic disease and the potential inclusion of community health workers (CHWs) in the continuum of care for chronic conditions, in particular diabetes and breast cancer. Three independent studies, representing different substantive areas and methodological approaches, were conducted. First, a study reported on the construction of a brief survey to assess the status of community health workers in the Gulf coast region, including their roles and professional recognition in the public health arena. Next, a secondary analysis was performed examining existing data to understand the impact of culturally-designed self-management intervention programs in both African American and Latino populations with diabetes. Lastly, a qualitative research study was conducted to address how Latinos experience breast cancer survivorship, their perception of quality of life, and the role of CHWs in this topic.

The results found that the efforts of community health workers provide benefits in the management of chronic disease among ethnic and minority populations. The two different chronic disease research studies conducted suggest the positive value to be accrued when utilizing community health workers as part of the healthcare team. Expanding the use of this vital workforce, CHW's could elevate ethnic and minority patient's health and quality of life due to the enhancement of cultural and linguistic best practices. Both results, along with the status report, solidify the understanding of this concept and provide validation to reduce costs in the health care system, as well as increase compliance and patient satisfaction with incremental health provider support.

DEDICATION

I dedicate this work to the Lord my God. Since being accepted into the public health doctorate program, I have dreamt of the day that I would complete my dissertation. I am so thankful for the opportunity to have returned to school to continue in my field of study. I have been committed to developing a better understanding of science to prepare me for whatever He wants me to be to serve my fellow brothers and sisters.

When I embarked in the program, I made a promise not to study on the Sabbath day. I studied and dedicated many hours, sacrificing vacations, holidays, and time with family. I still did not work on any assignments on the Day of The Lord. I remained committed to my promise even when my personal time was limited due to a full-time job; caring for my parents, husband, a disabled refugee child, and serving in my community and supporting church callings. I have managed to turn in all assignments on time, study for exams, and prepare extensive reading materials, somehow managing from one week to the next. Even when there was sickness or death in the family, or my own health and life caught up with me and time was very constrained, I kept my word and did not study or work on assignments on a Sabbath day.

I am very thankful for faith that has helped me to endure to the end and the gift of having the knowledge that He Lives, that He is My God my Redeemer, my Light in the darkness, and I dedicate this work to Him.

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TABLE OF CONTENTS

	Page
ABSTRACT	ii
DEDICATION	iv
ACKNOWLEDGEMENTS	v
CONTRIBUTORS AND FUNDING SOURCES	viii
TABLE OF CONTENTS	ix
LIST OF FIGURES	xii
LIST OF TABLES	xiii
CHAPTER I INTRODUCTION	1
Health and Demographic Trends	
Growing Population Diversity	
CHAPTER II COMMUNITY HEALTH WORKERS: A STATUS REPORT	
Purpose	7
Background	
Community Health Worker: Definition	
U.S. Department of Labor CHW Definition	
American Public Health CHW Definition	10
About Community Health Worker Certification in Texas: Background	11
Current CHW Texas Certification	12
First Time Certification	12
Certifications	14
Renewals	
CHWs in the Texas Gulf Coast Region: Status Survey	16
Introduction	
Methods Section Background	
Methods	
Developing the Survey	
Pilot Survey Guide	19

Survey Items	21
Feedback from the Original Survey	
Sampling Plan	
Sample Size	
Measurement	
Data Analysis	
Results	
Participants	
Impact	
Discussion	
CHAPTER III DIABETES – A COMPARISON IN TWO MINORITY GROUPS	32
Introduction	32
Methods	35
Recruitment	35
Results	43
Description of Sample	43
Unadjusted Pre-Post Differences	46
Adjusted Pre-Post Differences	47
Discussion	48
Limitations	50
Implications	51
Recommendations for Future Practices	52
CHAPTER IV BREAST CANCER – A QUALITATIVE RESEARCH POTENTIA	L
ROLE OF CHW	54
Introduction	
The Research	
Methods	
Sample and Recruitment	
Interviews	
Pregunta Central	
Central Question	
Otras Preguntas	
Open-ended questions	
Analysis	
Results	
Three Themes	
Conclusions	
Discussion	66
CHAPTER V CONCLUSIONS	68

REFERENCES	70
APPENDIX A WISDOM, POWER, CONTROL. KNOWLEDGE	83
APPENDIX B WISDOM, POWER, CONTROL. SELF-EFFICACY	85
APPENDIX C WISDOM, POWER, CONTROL. SELF-CARE	87
APPENDIX D WISDOM, POWER, CONTROL. PSYCHOLOGICAL	89
APPENDIX E PROTOTYPE SURVEY	90
APPENDIX F FINAL SURVEY	92

LIST OF FIGURES

	Page
Figure 1 Health Status Minority Groups Compared to Whites. Reprinted from https://www.kff.org/report-section/key-facts-on-health-and-health-care-by-race-and-ethnicity-section-3-health-status-and-outcomes/	
Figure 2 CHWs by State. Reprinted from https://nashp.org/state-community-health-worker-models/	16
Figure 3 Pilot Survey Design	19
Figure 4 Survey Revisions	22
Figure 5 Percentage of US Adults Aged 18 or Older With Diagnosed Diabetes, by Racial and Ethnic Group, 2013–2015	32
Figure 6 Comparison Design.	42

LIST OF TABLES

Page
Table 1 Options for CHW to Renew their Certification Every Two Years15
Table 2 Options for CHW Instructors to Renew their Certification Every Two Years 15
Table 3 Pilot Survey Guide
Table 4 Percentage of CHWs with CHW Job Title
Table 5 Participants' Overview
Table 6 Language Percentage
Table 7 Gender and Level of Education by Ethnic Group
Table 8 Racial and Ethnic Background
Table 9 Percentages and Frequencies
Table 10 Characteristics of the Si, Yo Puedo and Wisdom, Power and Control Participants by Program
Table 11 Unadjusted Differences in Knowledge, Self-efficacy, Self-care Behaviors, and Psychological Distress from Baseline to Follow-up Assessment
Table 12 Generalized Linear Model
Table 13 Participant's Demographics

CHAPTER I

INTRODUCTION

Health and Demographic Trends

According to the United Nations, Department of Economics and Social Affairs, the world population is projected to reach a growth of 8.6 billion by 2030. Half of the world's growth will be contributed by just nine countries. Among those, the United States (U.S.) will rank 7th. Within the U.S., the population composition is shifting with trends toward a more diverse society (Mockrin et al., 2018) (United States Population, 2018). This new composition reflects a changing range of diversity in areas such as language, ethnic background, culture, family structure, level of education and many other socioeconomic factors. This diversity must be taken into account when designing and delivering health care programs and interventions (Simpkins, 2017). Statistics reveal health disparities among ethnic and minority groups in terms of access to health care and lower quality of life when diagnosed with a chronic disease (Jasen Chi-Sing, 2016; Luo et al., 2015; Ngo et al., 2016). Cardiovascular diseases and diabetes are chronic conditions that lead to, or worsen other co-existing health conditions (Laditka & Laditka, 2016) Centers for Disease Prevention and Control (CDC), 2014a). These conditions are more prevalent among underserved and minority populations, as well as older populations (Fitzpatrick, Shi, Willis, & Niemeier, 2018; Mariotto et al., 2018; M. L. Smith et al., 2017).

Growing Population Diversity

According to the U.S. Census Bureau 2016 report, the population in the state of Texas was comprised of nearly 40% Hispanic or Latino individuals. In Harris County alone, the Hispanic population is 42%, with a median foreign-born age of 40.7. The most common birth place for this group is Mexico. Harris County ranks the highest in the number of non-English speaking residents in the country, with 30% of the overall population speaking Spanish. Additionally, Hispanics/Latinos are the second highest ethnic group to live under the poverty line in Harris County.

Low income populations from minority or ethnic groups often experience a double jeopardy, facing economic and health disparities, to name a few (Fremont, 2016; Lazar & Davenport, 2018). Cardiovascular diseases, cancer, diabetes and other chronic conditions impose a heavy economic burden in the U.S. (Himmelstein, Woolhandler, Almberg, & Fauke, 2017; Raghupathi & Raghupathi, 2018) CDC, 2018) disproportionately affecting underserved populations who have less access to care (AHRQ, 2017). According to Centers for Disease Control and Prevention (CDC), the treatment expenditure reaches \$3.3 trillion annually in health care (Buttorff, 2017). See Figure 1 for the report of health status in adults by ethnic and minority group. It is, therefore, critical to our society, and its economic well-being, that we recognize and integrate new models of interventions and "interventionists" in our health care delivery system (Payne, Razi, Emery, Quattrone, & Tardif-Douglin, 2017) (Silverman, Krieger, Sayre, & Nelson, 2018), such that we reach out to diverse populations in our own localities.

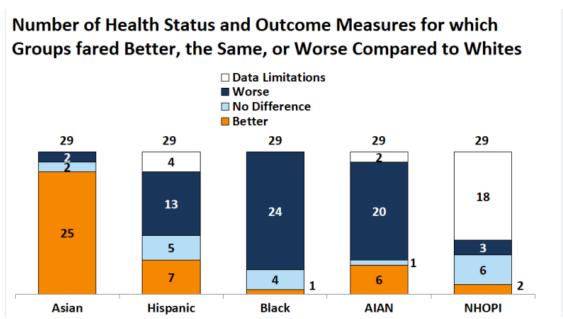


Figure 1. Health Status Minority Groups Compared to Whites. Reprinted from https://www.kff.org/report-section/key-facts-on-health-and-health-care-by-race-and-ethnicity-section-3-health-status-and-outcomes/

Reducing Health Disparities in Underserved Populations

Disadvantaged populations often face many challenges in accessing the healthcare system. A major issue is the lack of knowledge, skills, and comfort in seeking care to identify and manage their chronic diseases (Heiney, Messias, Felder, Phelps, & Quinn, 2017; Sharmeen Shommu et al., 2016). Such patients are also much less likely to pursue health screenings, preventive care exams (e.g., eyes and/or extremities in the case of diabetes) or follow-up consultations due to the lack of knowledge or communication barriers (Chandler & Monnat, 2015; Douthit, Kiv, Dwolatzky, & Biswas, 2015). Compliancy of self-management recommendations, follow-up appointments and

outreach-based or ambulatory care are important elements for successfully managing chronic diseases (Chan et al., 2018; Wharam et al., 2017).

Some of the continuum of care barriers for these patients can be mitigated by interactions with trusted community members who can navigate between patient concerns and the health care system. Community Health Workers (CHWs), or Promotores, can become the link to connect disadvantaged populations and their access and understanding of the healthcare system. Community Health Workers, as defined by the American Public Health Association, are frontline public health workers who are a trusted member of and/or have an unusually close understanding of the community served. Further, "This trusting relationship enables the worker to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery". CHWs are now certified by the Texas Department of State Health Services, and should be considered an integral part of the health care team for persons with less familiarity or access to the health care system or those who need support managing a chronic disease (Powers et al., 2015). Texas introduced this group nationwide first. More interestingly, in the Texas-Mexico border, the term "Promotoras" started to being used for lay health educators, while the term community health workers was used for lay health educators who practice in the rest of Texas. (Nichols, Berrios, & Samar, 2005).

CHWs are often characterized by their culturally sensitivity, fluency in the patients' respective languages, recognition and respect of diversity, and an ability to easily build a rapport with their community members. CHWs' unique position in

reaching out to diverse populations and successfully and measurably improving the community's health, has been documented in substantial literature (Malcarney, Pittman, Quigley, Horton, & Seiler, 2017). However, the integration of this profession within the existing U.S. health care system is still evolving.

As many underserved populations are dealing with unmanaged chronic conditions, many of which are costly, it is critical that CHWs be incorporated into routine healthcare to alleviate the economic impact of healthcare costs due to the exacerbation of untreated chronic diseases. Instead of a pessimistic view of increased burdens of chronic diseases with our growing adult population, we envision a world where diverse populations can live longer, healthier lives with added quality of life years if they get appropriate care and education in a timely fashion (Ory & DeFriese, 1998; Tisminetzky et al., 2017).

This work addresses several key issues in furthering our understanding of how to mitigate health disparities in underserved populations. It presents research on two chronic diseases states prevalent in underserved minority and ethnic populations, and for which community health workers could help guide patients through screening, diagnosis, treatment, and long-term management. The first section, (Chapter II,) describes the construction of a brief survey for assessing feedback from community health workers. It provides a snapshot of the status of community health workers in one Texas region and a discussion on how community health workers can play a key role in the health care system to help underserved ethnic and minority populations better prevent and manage chronic diseases.

The following two sections showcase two chronic conditions, diabetes and breast cancer, and explore how community health workers can assist their community members and clients who have been diagnosed with chronic diseases. A secondary analysis from two interventions in Hispanic/Latinos and African Americans with diabetes mellitus type II in minority adults was conducted for the first quantitative paper (Chapter III). The primary research question was to understand the effects of two diabetes selfmanagement education (DSME) interventions adapted to two different ethnic and minority groups. For the second chronic disease paper (Chapter IV), a qualitative research study on breast cancer survivorship among Latino women was conducted. The primary research question was to understand how these survivor's quality of life was impacted by their cancer diagnosis and treatment, especially in terms of intimate relationships.

CHAPTER II

COMMUNITY HEALTH WORKERS: A STATUS REPORT

Purpose

U.S. population demographics are changing, drawing attention to the need to address how delivery of health care is modified to support the needs of the community. The prevalence of chronic diseases among minority groups continues to increase, as does the costs of care (Peterson et al., 2018). We must develop a plan to alleviate this crisis because the most impacted by these disadvantages are vulnerable minority populations, who largely have to deal with chronic conditions with limited information and resources (J. Chen, Vargas-Bustamante, Mortensen, & Ortega, 2016). Factors of population change, as well as costs related to caring for the increased prevalence of chronic diseases in the U.S. are two important considerations. Additionally, it is important to understand the concerns of this evolving community and how best to involve them in decision making process.

Reducing health disparities can be approached in three ways: 1).

Improved access to care, 2). Increased workforce of "natural helpers" who can reach minority populations and focus on prevention at reduced costs and 3). Enhanced sense of inclusion by having an advocate in the healthcare system.

In 2010, a newly defined profession in the public health field was added to the Standard Occupational Classifications (SOC) listing for the U.S. Department of Labor (DOL), Community Health Workers (CHWs). Since then, the adoption of CHWs as part

of the team of delivery of care has been provided with an evidence of business case on reducing costs and health disparities have been published (Balcazar & George, 2018; Cross-Barnet et al., 2018). With the rapid growth of the Hispanic population in the Texas Gulf Coast Region, understanding specifics about the attributes and resources available from CHWs in the region is vital to understanding the role they play along with their potential acceptance in the community. The main purpose of the following study is to provide a status report on community health workers in the Texas Gulf Coast Region.

Background

During this last decade, there have been more health-related interventions that include CHWs due to their expertise with closing the gap in health inequalities and creating cost effective interventions among uninsured populations (Balcazar & George, 2018; Jack et al., 2017). Researchers, policymakers, and clinic providers have launched collaborative interventions because they have seen the positive outcomes in reducing disparities among Medicaid holders and other vulnerable groups such as pregnant women (Balcazar & George, 2018; Daviaud et al., 2017).

Community-based participatory research (CBPR) is a framework that stresses the joint participation of community members and researchers to address problematic priorities in a specific community (Purvis et al., 2017; Verney et al., 2016). CBPR allows all parties to unite expertise and knowledge in a democratic process in order to design changes in attitudes, behaviors and outcomes to support the betterment of their own community (Israel, Schulz, Parker, & Becker, 1998). CBPR will continue to be of

value to help in programs and interventions that include community health workers from health issues to advocacy (Ingram, 2015).

This CBPR framework contains two important paradigms: critical theory and constructivism (Denzin & Lincoln, 2000). The paradigm of constructivism is assembled by social, cultural and historical contexts; those contexts are intrinsic characteristics in which community health workers are experts, thus their successful outcomes in community interventions. In this framework, human capital is very important. In the case of CHWs, their skills, sociocultural characteristics and innate cultural competency to the population who they serve, placed them in a unique position to make a great impact in their communities. Moreover, their distinctive advocacy role is to be the voice of their community members in the healthcare system. There has been a long debate about the role that CHWs should play and their credentialing ((Malcarney et al., 2017; Payne et al., 2017; Zavadsky, 2017). In a desire to incorporate CHWs in the system for fee for service and other strategies, is was important to make sure CHWs are meeting the minimum professional standards according to certification.

The purpose of this paper is to: 1) provide background on the definition and roles of community health workers including their special position as a certified workforce in Texas; 2) develop a brief survey vetted with CHWs in line with CBPR principles; and 3) provide a case study of Texas CHWs in one region, the Texas Gulf Coast Region, to assess the status of the CHWs certification in this region.

The definition of a community health worker and their role align with the paradigms part of the CBPR framework thus, it is critical to become familiar with the

definition of a community health worker, the first one is defined by the U.S. government and the second by a leading organization in public health.

Community Health Worker: Definition

The U.S. Department of Labor and American Public Health Association use the following definitions:

U.S. Department of Labor CHW Definition

21-1094 Community Health Workers: Assist individuals and communities to adopt healthy behaviors. Conduct outreach for medical personnel or health organizations to implement programs in the community that promote, maintain and improve individual and community health. May provide information on available resources, provide social support and informal counseling, advocate for individuals and community health needs, and provide services such as first aid and blood pressure screening. May collect data to help identify community health needs. Excludes "Health Educators" (21-1091).

American Public Health CHW Definition

American Public Health Association (APHA) designates the following for CHW definition: A Community Health Worker (CHW) is a frontline public health worker who is a trusted member of and/or has an unusually close understanding of the community served. This trusting relationship enables the CHW to serve as a liaison/link/intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. CHWs also build individual and community capacity by increasing health knowledge

and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support and advocacy (APHA, 2009).

The competencies, roles of practices and even their titles may vary from state to state, however in the history of community health workers, they are essential to addressing present needs and assisting in the future of the healthcare system as they are established as the new workforce in this field (Balcazar et al., 2011).

About Community Health Worker Certification in Texas: Background

In 1999, the Texas Legislature passed an initiative for Community Health Workers (CHW) certification. Included in this was a requirement for the state to create an advisory committee to establish certification of the community health worker training program. The CHW application underwent various revisions and it is currently available in English and Spanish, since many in Texas primarily speak Spanish and serve the Spanish speaking population. In 2001 the Texas Training and Certification Program was implemented; because many CHWs in Texas speak Spanish as their primary language, the official name of the certification and training programs was designated as: "Promotor(a)/Community Health Worker Training and Certification Program." For clarification purposes, Promotores is the Spanish term for Community Health Workers. Promotores speak fluent Spanish and generally work in Spanish-speaking communities

In its conception, this certification program was part of The Department of State Health Services (DSHS), under Office of Title V and Family Health (DSHS, 2013).

In 2003, after implementation of the CHW training and certification program, the advisory committee initiated a draft for CHW Instructor (CHWI) application. In January

2007, Houston Community College offered the first CHW I -160-hour training program, community health workers instructors. CHWI is not a specialization. An individual interested in becoming a CHWI does not necessarily need to become a CHW first. The requirements are to complete a 160 hour-training course or 1,000 hours of CHW experience.

Current CHW Texas Certification

The final version of certification and training program includes an introduction packet with instructions available in English and Spanish, offering the following certifications:

- Community Health Workers/ Promotor(a) CHW
- Community Health Workers/ Promotor(a) Instructor CHWI
- Training Programs

First Time Certification

Regarding certifications, the two options are CHW and CHWI and the requirements are:

- Have 1,000 hours of experience as CHW, within the previous six years prior the application, or
- 2. Receive 160 hours training from a certified training program. Training includes at least 20 hours in the following eight competencies:
 - a. Communication skills
 - b. Advocacy skills
 - c. Interpersonal skill

- d. Service Coordination skills
- e. Organizational skills
- f. Capacity-building skills
- g. Teaching skills
- h. Knowledge base skills

Once the training has been finalized, individuals complete the application form, and submit the certificate of completion and color photo. The application form includes instructions on how to complete the form and is available online by visiting the state's certification website at: https://www.dshs.texas.gov/mch/chw.aspx.

Individuals who have applied for the certification should expect to receive CHW identification and a certificate via regular mail within 90 days, but most of the applications, once approved, are processed within three to four weeks. (DSHS, 2013.)

The process for certification through experience, involves a submission of the application form and then a supervisor or witness who has observed the applicant perform CHW duties will be contacted to verify the 1000 hours. In both cases, CHW and CHWI certification, applications are free of charge.

There are three reasons in which certification is denied:

- 1. Application is incomplete.
- 2. Individual does not meet the requirements, most likely based on experience.

3. Falsified information.

Certifications

There are different categories for training certifications. Programs (training centers) can provide certification courses, continuing education or both, 160-hour certification and continuing education. Also, course and continuing education can be just for CHW or CHWI or a combination of CHW/CHWIs.

For any category, potential training centers should submit a complete application and a curriculum along with future plans to deliver the programs. It is advised that individuals interested in participating in a specific area training program contact the state to ensure there is a need in that location. Sometimes there are limitations in specific regions and the state may not be accepting additional training programs in the area.

Renewals

The process for renewing CHW certification requires 20 hours of continuing education and completion of the renewal application. The renewal application should be submitted before certification expires or it will no longer be valid. Table 1 shows the two options meeting the continuing education requirements for CHW renewal. Table 2 describes the combination options for CHWI renewal. Both renewals, CHW and CHWI, have to meet 20 hours every two years.

Table 1
Options for CHW to Renew their Certification Every Two Years

Renewals could be combination of:	Option 1	Option 2
DSHS approved organization Other Texas license or certification	10 certified hours	5 hours 5 hours
Non-certified hours, verifiable reading/audio/audiovisual material	10 hours	10 hours
Total hours	20	20

Table 2
Options for CHW Instructors to Renew their Certification Every Two Years

Renewals could be combination of:	Option 1	Option 2	Option 3
DSHS approved organization Teaching approved DSHS hours	10 certified hours	5 hours	5 hours 5 hours
Other Texas license or certification Non-certified hours, verifiable reading/audio/audiovisual material	10 hours	5 hours 10 hours	10 hours
Total hours	20	20	20

For both renewal certifications, hours should relate to at least one of the eight competencies which can be found on DSHS's website. (DSHS, 2019).

For renewal certification of training programs, the requirements include a complete renewal application that includes: 1) outlining the sponsoring organization of the training program; 2) the type of training to be delivered, CHW, CHWI or both; 3) a list of affiliated and certified instructors; 4) training information regarding costs, language, evaluation of the programs, updated information regarding the course and the competency areas covering each training/course and 5) contact of the CEO along with their signature. This application is free of charge (DSHS, 2019).

In the fall of 2017, the certification became part of the Health Promotion and Chronic Disease Prevention Section under the Division of Disease Control and Prevention.

Detailed information regarding CHWs in other states can be found on the National Academy for State Health Policy website. The map below, figure 2, is current and interactive with state specific CHW updates on the National Academy for State Health Policy website.

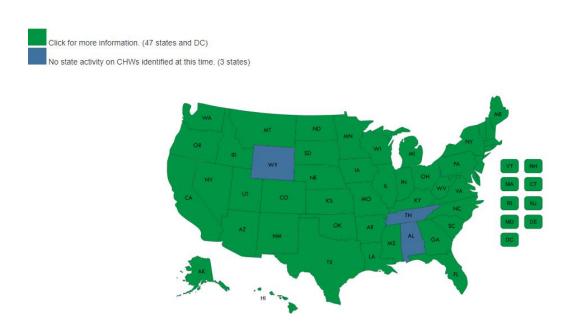


Figure 2. CHWs by State. Reprinted from https://nashp.org/state-community-health-worker-models/

CHWs in the Texas Gulf Coast Region: Status Survey

Introduction

CHWs are part of the community they serve and are trusted members in their communities, thus they have already an established relationship with their communities.

This trusted relationship allows them to help patients make informed decisions with respect to treatment or clinical decisions, because healthcare is very complex for many individuals (Kok et al., 2017; Maryse et al., 2017). Complexity may take on many forms, especially for minority groups. It may relate to language, cultural barriers, limited or no access to healthcare and economic or social limitations among others. Community members have come to rely on the knowledge and experience of CHWs regarding health-related issues (Josiah Willock, Mayberry, Yan, & Daniels, 2015). This relationship is possible because it relies on the previously established relationships built with the community, so that they can relate to the CHWs as peers rather than as intimidating "experts" in their field (Katigbak, Van Devanter, Islam, & Trinh-Shevrin, 2015; Morgan, Lee, & Sebar, 2015).

In Texas, many CHWs, even after receiving certification, are not compensated for the work they do as CHWs and continue to work without pay. The motives for certification are varied. Some individuals seek self-satisfaction and connection with other CHWs. Others seek certification for career advancement and secure employment. Regardless of the motive for certification, it is imperative to evaluate the work of CHWs (Chaidez, Palmer-Wackerly, & Trout, 2018). At the same time, it is important to obtain basic demographic data on CHWs. Lastly, it can be beneficial to identify the different health topics in which CHWs have received training to understand current resources and anticipate additional needs.

Methods Section Background

The need to create an instrument to assess the status of the CHWs certification in the Gulf Coast Region in Southeast Texas was first conceived in the spring of 2012. We designed a survey to test the hypothesis that CHW certification would positively correlate with increased job opportunities and professional recognition. The instrument was pretested with focus groups, both in English and in Spanish, among members of the Texas Gulf Coast CHW/Promotores Association (TGCCPA). Each group included at least five, but no more than seven, certified CHWs (Fern, 1982). The final version collected the data on:

- How many certified CHWs hold a job as a CHW;
- CHWs whose job title is different than CHW, and
- How many health topic trainings were received.

The final survey includes items on each of those three categories. See appendix E for questionnaire.

Methods

Developing the Survey

To develop the prototype survey a guide was created to help with the development of the questionnaire which was ultimately designed to examine the relationship between professional advancement/recognition and trainings for community health workers. The hypothesis states:

Increased training for community health workers/Promotores de salud (CHWs) provides more job opportunities or profession recognition in Texas.

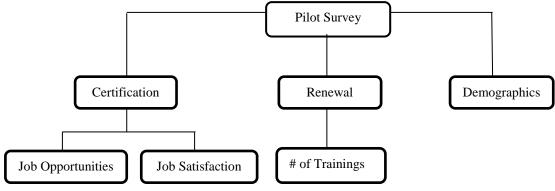


Figure 3. Pilot Survey Design

Pilot Survey Guide

The questions and sections included on the guide, table 3, are directly linked to establish a relationship between training/certification as CHWs and the enhancement of job opportunities and job satisfaction (pay level, practice scope) for CHWs who were, at that time, members of the Texas Gulf Coast CHW/Promotores Association, and attended the annual conference.

Table 3
Pilot Survey Guide

11.Did you attend	Yes, how many?					
any TGCCPA	No, why?	Didn't know Schedule conflict		Not interested Boss would not allow		
events in 2012?						
12.Other reasons:						
CERTIFICATION ITEM	18	•				
1. Certified since			Please specify year			
2. Times that I have renewed my certi		cation:	0	1	2	3 or more
3. I usually obtain my (Please write name of			1			
4. I have received n	·					ining program
by (Select "a" OR "b")		b. performing over 1,000 hours of CHW work				
If are not currently wo	orking as CHW or n	ot workii	ng at all, p	please s	kip to	question 7
5. I work as CHW		a. my j	ob title is	CHW/I	Promo	tor de Salud
(Select "a" OR "b")		b. my job title does not include CHW on the name				
6. If you selected "b"	Please specify your	r job title				
7. JOB STATUS		SELE	CT ONLY	Y ONE '	، س	
a. I have a full/part-t	ime job other than (,	
b. I have not found a	ny job as CHW					
c. I received my cert to receive any con		ole purpos	se to be re	ecognize	ed as C	CHW and not
•	•					

Survey Items

The following explains every section of the survey:

The sample only included certified CHWs, no students (in the process of getting their certifications) or other public health professionals, non-CHW certified. The first independent variable such as "work as CHW or not" as well as "how certification was received."

Within the same section, a dependent category was included "JOB STATUS" which helped identify "job opportunities" as one of the variables of the hypothesis.

The section "HEALTH TOPICS TRAINING RELATED" relates to the other variable of the hypothesis "profession recognition" as well as the following section "ABOUT TGCCPA" helped when coding the reasons of the certification and understand if their employers or other professionals value CHW profession.

Feedback from the Original Survey

After assessing the pilot survey, major changes included formatting for improved understanding and response along with rewording several questions to better reflect the target population, such availability to work in the United States. Another final addition was to change select questions to clarify their perceptions for future opportunities regarding their profession as Community Health Workers vs. merely stating the facts on events since they receive their certification. This was especially relevant for CHWs who

had received their certification within the previous six months and to date had been unable to work as CHWs. See figure 4 for survey revisions.

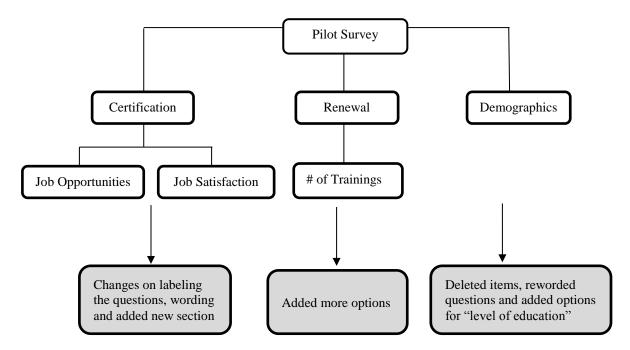


Figure 4. Survey Revisions

The following section lists the items addressing the feedback received from the original version of the questionnaire.

The items on the initial survey were tested, CHWs and other professionals provided feedback regarding format, wording, and optional answers and missing questions. Feedback received was as follows:

1. Do the questions mean the same to the respondents as they do to you?

Yes, for most of them, except one question. The original question was: "Certified since

_____", which most respondents did not answer. They did not remember when they first received CHW certification. The final version for this question was split into two questions: "Are you certified: Yes or No" and "How long have you been certified: _____ years, ____ months".

2. Do the respondents misunderstand some of the words or the way the sentences that make up the question are worded?

One of the sections was titled "Job Status". The intention was to ask about work related questions such as part- or full-time or volunteer CHW work, and what type of setting they currently work or practice in as CHWs, for those who did not receive pay.

However, some of the respondents became concerned with the title "Job Status" that it was about legal or immigration status to work in the U.S.

Regarding formatting of the survey: formatting or space layout were not clear for some of the questions. Below is the feedback reflecting this issue.

3. Have you left out important answer choices?

Yes. More categories under "Health topics training related" should have been included. For example, many CHWS have received training on: "Insurance", "Access to care", and "Navigation". Also, under demographics: Highest level of education, "Graduate" or "Other (specified)" were not included as answer choices.

4. Have you made assumptions about the respondent in your question that may not be true?

The concern about data when participants received their CHW certification was addressed previously. Was assumed that participants will remember the year of their certification.

5. Additional Modifications:

After receiving feedback from the first version, the decision was made to create a new section with questions to determine the recognition-promotion and scope of practice due to the CHW-certifications. This new section was needed in order to test the hypothesis, in particular, to determine how the dependent variables vary with changes in the independent variables.

During other meetings and subsequent focus groups, additional sections and new items were added to the original survey. The end product was Questionnaire Final 2014, as approved by IRB2015-014D, see Appendix E.

Sampling Plan

The sampling frame was all Texas Department of State Health Services certified community health workers attending their annual conference. We were not interested in strata or sub populations; therefore, we used simple convenience sampling (Gravetter & Forzano, 2009) by taking advantage of conference attendance at the Community Health Worker Annual Conference. This convenience sampling was a limitation of this study due to the fact that we would not be including other CHWs in Texas, just CHWs attending the annual Texas Gulf Coast Region conference.

Sample Size

Clark-Carter simplified approach. Clark-Carter simplified approach was used to calculate sample size. A minimum of 120 participants was calculated to have an appropriate sample size for minimal power and effect size. A total of 176 surveys from certified community health workers were collected.

Measurement

The dependent variables in this study included:

- a. Job promotion: Being a certified CHW/Promotor(a) has resulted in a promotion at work. Yes or No
- b. Profession recognition: Being a certified CHW/Promotor (a) gives value to this
 profession (other professionals acknowledge my work as a certified
 CHW/Promotora. Yes or No
- c. Acknowledgment by other health professions: Being a certified CHW/Promotor(a) gives value to this profession (other professionals acknowledge my work as a certified CHW/Promotor --- Yes or No
- d. Is "CHW" your job title? Yes or No

The independent variables were:

- CHW certification: yes or no
- How many years of certification: numeric
- How many training topics: numeric
- Level of education: several nominal options

• Demographics such as age, gender, and job status.

Data Analysis

Dependent and independent variables were descriptively reported. Multivariate logistic regression analyses were computed for each selected dependent variable. This also involved cross-correlations among independent variables and/or control variables.

Results

Participants

Conference attendees were not always CHW certified by the state of Texas, other professionals were in attendance such as vendors and other interested parties. To be counted as a CHW survey participant, the first question was:

"Are you currently a certified CHW? □ Yes □ No → please skip to question 5

A total of 176 surveys were completed, six of those surveys were completed by participants who were not certified by the State of Texas as CHWs, but they have a CHW role or they have a CHW as their job title. 97% of the participants were certified CHW. See table 4 for percentages of participants who answered that were CHW certified and held a "Community Health Worker" job title.

Table 4
Percentage of CHWs with CHW Job Title

CHW as your job title	Respondents	Percent
Yes	27	15%
No	149	85%

Table 5, shows participants' characteristics regarding dependent and independent variables.

Table 5
Participants' Overview

Variable	Obs	Mean	Std. Dev	Min	Max
# of months that has been certified a	167	43.54	38.71	0	160
Number of trainings completed	176	7.51	6.95	0	21
Age	157	45.25	10.80	23	71

a. For this variable, we entered data in months rather than years because some participants who attended the conference had been CHWs for less than a year. Questionnaire asked for years and months for those cases in which participant has been a CHW for few months.

For question number one "How long have you been certified? _____ years or ____ months", 160 months were the maximum number of months entered to comply with the time when the state of Texas implemented the certification in 2001. This was the case for only four respondents who responded that they have been certified over 160 months. After implementing this adjustment, the average of months reported was 43.54, the minimum number of months certified reported was zero. Even when those who responded "yes" to eligible question and answered zero to months. The maximum number of months was 156 months reported with the exception of the other four respondents who reported over 160 months. Surveys were available in English and Spanish, following table 5 shows surveys completed in each language.

Table 6 *Language Percentage*

Language Ferceniag	e	
Language	Respondents	Percent
English	115	65%
Spanish	61	35 %

Other participants' socio-demographic related information is reported on the following tables. Regarding participants' response to education level, 18% completed HS, 29% reported some level of college, 15% reported an Associate Degree and 38% reported at least some level of college. The following table, Table 6, shows a more detailed breakdown by gender, ethnicity and level of education.

Table 7
Gender and Level of Education by Ethnic Group

	Gender		Level of			
Ethnicity	Female	Male	High School	Some College	Associate Degree	College or more
African American	22	3	0	7	4	14
Asian	2	0	0	0	0	2
Caucasian	10	1	1	5	1	4
Hispanic	105	16	27	33	19	39
Total	139	20	28	45	24	59

The total of respondents who completed High School was 18%, 29% reported some college, 15% reported Associate Degree and 38% reported at least some level of completed college.

Table 7, Ethnicity, reflects 76% being Hispanic/Latino, only 35% all the total surveys were completed in Spanish.

Table 8
Racial and Ethnic Background

Ethnicity	Respondents	Percent
African American	25	16%
Asian	2	1%
Caucasian	11	7%
Hispanic/Latino	122	76 %

Table 8, represents results of the frequency and percentage for CHW certification, job title, job promotion, professional recognition, and acknowledgement by other professionals. The table shows that: 1) most respondents (97%) were CHW certified; 2) the majority (85%) did not hold a CHW job title; 3) less than half (46%) perceived that CHW certification provided job promotion; 4) the majority (75%) did not feel that being a certified CHW gives value to this profession; and 5) a large majority (93%) agreed that acknowledgement by other professionals would add value to CHBW status.

Table 9
Percentages and Frequencies

	CHW	Cert.	Is CHV	V your	Jo	b	Profe	ssion	Ackno	wledge
			Job T	itle?	Prom	otion	Recog	nition	by othe	er Prof.
	Freq.	%	Freq.	%	Freq.	%	Freq.	%	Freq.	%
No	6	3	149	85	90	54	127	75	12	7
Yes	170	97	27	15	78	46	42	25	157	93
Total	176	100	176	100	168	100	169	100	169	100

Impact

CHWs in the Texas Gulf Coast Region have received training in several health related topics and can provide great benefit in reducing health disparities. In this study, CHWs indicated the importance of having others recognize their profession and valuing their role as part of the healthcare system in Texas. Further impact can be realized if CHW's role is expanded throughout the U.S. healthcare system. As the composition of U.S. population changes, CHWs can be included in more delivery of care for groups with specific needs as is the case of aging population to assist them managing their chronic diseases. Also more work is needed to reach out to diverse populations and approach with a style which will mesh with their culture, ethnic values and language of preference (F. D. Williams, Osorio, & Castaldi, 2017).

Professionalization is very important to help expand CHWs opportunities in the workforce and inclusion in the healthcare system (L.-S. Chen et al., 2018; Payne et al., 2017). Effort is needed on continuous status reporting in order to understand whether or not the current CHW certification method is meeting the stated goals regarding professionalization. Ensuring professionalization will help meet the minimum quality requirement of healthcare delivery. Professionalization can bring a recognition by others which helps achieve the goal of an expanded CHW workforce as well.

Discussion

This study fulfilled the purpose of: 1) utilizing existing records to provide background on the definition and roles of community health workers including their

special position as a certified workforce in Texas; 2) and constructing and implementing a survey to provide a case study of Texas CHWs in one region, the Texas Gulf Coast Region to assess the status of the CHWs certification in this region.

This status report underscores the importance of professional development and acknowledgment. We recommend that public health and health-related professions support the CHW field as a legitimate health workforce. This is important not only to comply with certifying organizations, but also for professional development and recognition. Raising the standards of the profession is critical for an expanded CHW role that will make a difference for serving minority groups, reducing health disparities, and enhancing population health.

CHAPTER III

DIABETES - A COMPARISON IN TWO MINORITY GROUPS

Introduction

Diabetes continues to be widespread in the United States with a total of 30.3 million people who have diabetes and 84.1 million adults with prediabetes. (CDC, 2017). The disparity concerning minority groups affected by diabetes is even greater with African American and Hispanics being disproportionally affected (CDC, 2018). The high prevalence of diabetes among adults aged 18 or older is alarming (CDC, 2018). Resent estimates show minority groups are of greatest disadvantaged when compared to whites (Echouffo-Tcheugui, Caleyachetty, Muennig, Narayan, & Golden, 2016).

According to this report, minority groups are of greatest disadvantage when compare to whites. African-American are the second highest minority group affected by diabetes.

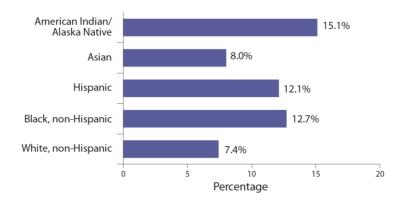


Figure 5 Percentage of US Adults Aged 18 or Older With Diagnosed Diabetes, by Racial and Ethnic Group, 2013–2015.

Notes: Percentages are age-adjusted to the 2000 US standard population. Figure adapted from the *National Diabetes Statistics Report*, 2017. Data sources: 2013–2015 National Health Interview Survey and 2015 Indian Health Service National Data Warehouse (American Indian/ Alaska Native data).

The federal government established a national science-based agenda in December of 2010 to improve the Nation's health. The program was titled, Healthy People 2020, and its objectives included "increase the proportion of persons with diagnosed diabetes who receive formal diabetes education." Researchers and health professionals suggest focusing on diabetes self-management education, specifically, education that will impact health outcomes (Campbell et al., 2015). Diabetes education can provide individuals burdened with diabetes the necessary knowledge and essential behavioral skills to successfully manage their illness.

A continued effort to increase self-management skills to control glycemic levels is critical; thus, programs to assist with diet, regular exercise and medication adherence are of crucial importance.

One important factor for diabetes self-management education (DSME) implementation is the need for cultural appropriateness when targeting different racial and ethnic populations (N. R. M. C. Smith, 2018; Woten & Richards, 2018). For African Americans, places of worship have been shown to be a preferred location for recruitment and implementation (L. B. Williams et al., 2016). Latinos prefer interventions that are delivered in Spanish language and incorporate their culturally-appropriate dietary patterns (Reininger, Lee, Jennings, Evans, & Vidoni, 2017). Tailored DSME interventions developed for Hispanic/Latino, African American, and other minority groups have been proven successful (Peña-Purcell, Boggess, & Jimenez, 2011; Peña Purcell, Jiang, Ory, & Hollingsworth, 2015). For example, compared to non-tailored interventions, tailored interventions have demonstrated greater program benefits

in terms of diabetes knowledge, improved health status and self-care behaviors, to name a few. (Peña-Purcell et al., 2011; Peña Purcell et al., 2015). Community-based DSME interventions that are delivered in community settings and led by community-trained members, such as Community Health Workers (CHWs), are the recommended practices for community-based interventions (Golden et al., 2017; Spencer et al., 2018). CHWs have been a bridge between community members and the healthcare system. Their innate skills help lay people engage and/or adopt healthier behaviors. Using CHWs to assist with DSME delivery is a recommended approach (See ADA 2019 Standards of Care p.2), because CHWs are the intrinsic component within the community support system. Delivering DSME services, specifically among the underserved and minority groups, is vital to achieving the goal of increased healthy outcomes.

While efficacy and effectiveness of DSME have been widely studied, little is known about the comparative effectiveness of tailored DSME that were adapted from the same curriculum (Ricci-Cabello et al., 2014). Thus, this secondary analysis study aimed at comparing the effects of *Sí*, *Yo Puedo Controlar Mí Diabetes* (*Sí*, *Yo Puedo*) and *Wisdom, Power and Control*, which are the DSME interventions adapted for Hispanic/Latino and African Americans respectively (Peña-Purcell, Boggess, & Jimenez, 2011; Peña Purcell, Jiang, Ory, & Hollingsworth, 2015). In Texas, *Sí*, *Yo Puedo* and *Wisdom, Power and Control*, two evidence-based DSME programs that were disseminated based on the Cooperative Extension Service (CES) systems' model of diffusion has been used to disseminate health programs such as DSME interventions (Peña-Purcell,

Boggess, & Jimenez, 2011; Peña Purcell, Jiang, Ory, & Hollingsworth, 2015). Contents of these two interventions are equivalent, but were adapted to be culturally appropriate for the target racial and ethnic groups (Ehrlich, Kendall, Parekh, & Walters, 2015; Kumpfer, Magalhães, Xie, & Magalhães, 2017). These interventions included adapted dietary food preferences, normative values, and beliefs regarding diabetes and disease self-management for each ethnic group.

Methods

Recruitment

Data Source

This study is secondary research using secondary data from two separate evaluation studies of DSME programs: *Sí, Yo Puedo* (Peña-Purcell, Boggess, & Jimenez, 2011) and *Wisdom, Power and Control* (Peña Purcell, Jiang, Ory, & Hollingsworth, 2015). Details of the original studies and data collection were described previously (Peña-Purcell et al., 2011; Peña Purcell et al., 2015). The total number of study participants used for this secondary data study was 250 (n=129 from *Sí, Yo Puedo* and n=121 from *Wisdom, Power and Control*). The data was collected at Week 1 and Week 7 for *Sí, Yo Puedo* and at Week 1 and Week 7 for *Wisdom, Power and Control* intervals of the interventions. Participants completed pre- and post-questionnaires assessing four outcome measures: 1) knowledge, 2) self-efficacy, 3) diabetes self-care, and 4) psychological distress. See appendix A, B, C, D for more details about the outcome measures. The Spanish version of the questionnaires were used among *Sí, Yo Puedo* participants. For this secondary analysis study, there was no consent process. Both

original studies received institutional review board ethical approval from the Texas A&M University. This secondary research also obtained an approval from the same institution.

Participants

The inclusion criteria for *Sí*, *Yo Puedo* and *Wisdom*, *Power and Control* were self-identified Hispanic/Latino or African Americans, respectively, adults over the age of 18, self-reported diagnosis of type 2 diabetes, and willing to remain for the duration of the research study.

Recruitment

Participants were recruited from counties in rural areas in Texas where the Texas A&M AgriLife Extension Services (Extension), had local offices. To recruit participants, research staff conducted community outreach, distributed flyers and posters, and placed newspaper announcements. For both studies, *Sí*, *Yo Puedo* and *Wisdom, Power and Control*, potential participants interested in participating in the program, were enrolled in their local county Extension Office. All who enrolled would receive the education, but data was collected only for those who met the eligibility criteria (i.e. adults over 18y. Hispanic/Latino or African American). Extension offices assisted in the recruitment effort and each county formed a coalition that would help with recruitment. This study only included those who completed both pre- and post-test surveys (n = 98 were excluded).

Intervention

Sí, Yo Puedo and Wisdom, Power and Control were 7-week DSME programs founded on the American Diabetes Association's standards of diabetes care (Beck et al., 2017). Dr. Purcell and her colleagues developed a patient-centered, empowerment-based approach for these curricula. The empowerment refers specifically to knowledge and life skills that would help adults with diabetes and the management of their disease. The programs were designed to be delivered in community-based group settings, for cost effectiveness, vs. individual interventions, and also to promote social modeling, while improving engagement in lifestyle behaviors such as regular physical activity and healthy diet. Both programs, Sí, Yo Puedo and Wisdom, Power and Control, were composed of 7 weekly meetings. The first meeting was an orientation session. While Weeks 2-7 centered on diabetes education, self-care and nutrition. The programs were initially designed to be delivered by a registered nurse, a dietitian, or a certified diabetes educator. After the completion of Sí, Yo Puedo pilot program, as mentioned before, CHWs model continued to be included among the approved class leaders to implement the program.

Sí, Yo Puedo and Wisdom, Power and Control pilot studies were evaluated using prospective quasi-experimental design with repeated measures for internal validity (Peña-Purcell et al., 2011; Peña Purcell et al., 2015). For both, Sí, Yo Puedo and Wisdom, Power and Control, program participation was positively associated with behavioral and psychological outcomes (Peña-Purcell et al., 2011; Peña Purcell et al., 2015). Sí, Yo Puedo was developed and evaluated first for Hispanics/Latinos, and then a translated,

adapted curriculum, *Wisdom, Power and Control*, was developed for African Americans (Peña-Purcell et al., 2011; Peña Purcell et al., 2015). A focus group was established to assess diabetes educational needs for African Americans with diabetes (e.g. eating habits and preferences, traditions, beliefs regarding diabetes, and how best to manage this chronic disease). Based on the results from the focus group (Purcell & Cutchen, 2013), cultural adaptations of Sí, Yo Puedo were made to best fit the African American group.

Measures

The four primary outcome measures were: 1) knowledge, 2) self-efficacy, 3) diabetes self-care, and 4) psychological distress. All instruments are included at the end of this work. See Indexes 1 through 4.

Knowledge

For this outcome measure, the survey used was the Spoken Knowledge in Low Literacy in Diabetes (SKILLD) Scale, work by Rothman (Rothman et al., 2005) and adapted to minority populations (Garcia, Zuniga, Reynolds, Cairampoma, & Sumlin, 2014). The SKILLD scale included 10 items about their basic knowledge related to diabetes. For example, participants were asked to identify symptoms of high and low blood sugar. The responses were dichotomized as acceptable (=1) or not acceptable (=0). Weighted scores were calculated by calculating the percentage of correct items divided by the number of items answered. The weighted score was not calculated for participants who did not answer 3 or more SKILLD items (n=31, 10.2% for pre-test and n= 9, 3.0% for post-test). The composite score ranged from 0 to 1 with a higher score indicating more knowledge.

Self-Efficacy

The second outcome measure, self-efficacy, was assessed using a Likert scale that was composed of eight 4-point items by Stanford (Lorig, Ritter, & Gonzalez, 2003) asking about how confident the participant felt about engaging in healthy diet, physical activity and other diabetes management behaviors, such as managing blood glucose levels. The composite score of self-efficacy was the average of the items and was not calculated for those who did not respond two or more items (n=32, 10.6% for pre-test and n=17, 5.6%). Higher score indicates higher level of self-efficacy. The Cronbach's alpha was were 0.77 at pre-test and 0.85 at post-test assessment.

Self-Care

For this variable, diabetes self-care, a 12-item questionnaire was used to measure general and diabetes self-care behaviors. An example of general self-care behavior was: "On average, over the past month, how many days per week have you followed your eating plan?" An example of diabetes self-care behavior was: "Did you test your blood sugar?" Appendix C presents the complete set of self-care questions. This measure scale was a slightly-modified version of the Summary of Diabetes Self-care Activities (SDSCA) scale that was revised by Toobert and her colleagues (Toobert, Hampson, & Glasgow, 2000). Each item was scored "None of the days (=1), "Some of the days" (=2), "Most of the days" (=3), or All of the days (=4). Scores for some items were recoded as appropriate. The composite score for this section was calculated by the average of the responses with the higher score indicating the better self-care behaviors. The composite score was not calculated for those who did not response two or more items (n=26, 8.6%

for pre-test and n=25, 8.3% for post-test). The Cronbach's alpha was 0.74 at pre-test and 0.78 at post-test assessment.

Psychological Distress

To collect data regarding psychological distress, 6-items were used to assess their mental well-being or psychological distress. The complete set of items are available in appendix D. Each item was scored "None of the time" (=1), "A little of the time" (=2), "Some of the time" (=3), "Most of the time (=4). The composite score calculated the average response of the 6-items, and the respondents score was not calculated if two or more items were missing (n=24, 7.9% for pre-test, and n=40, 13.2% for post-test). Participants with the lowest value scores felt the least psychological distress. The Cronbach's alpha for this section was 0.88 at pre-test and 0.83 at post-test assessment. *Background Information*

Demographic data included date of birth, and it was converted to years by subtracting the year of birth from the year data was collected. For self-identify race/ethnic group (categorical) variable, the following options were provided: "African American"; "Asian"; "Hispanic"; "Native American"; "White"; "Other". Sex variable was a dichotomized Male/Female (categorical). Level of education (categorical), was collected in terms of "Less than high school", High school, GED or equivalent", "Vocational", College degree" Graduate/professional", and "Other". Employment was another dichotomized, Yes/No, variable. For household income (categorical) were three options, "Under \$20,000"; \$20,000 - \$50,000'; \$50,000 or more". Self-reported health (categorical) variable was collected by selecting one of the following options:

"Excellent"; "Very good"; "Good"; "Fair"; "Poor". Years of diabetes (categorical) variable, was collected by: "Less than 1 year"; "Between 1 and 2 years'; "Between 2 and 3 years"; "Between 3 and 4 years"; "Between 4 and 5 years"; "5 or more year". The following variable were dichotomized (categorical) Yes/No variables: Feet exam, eye exam, dental checkup, and A1C test.

Analysis

An approved Institutional Review Board (IRB) was granted by the Texas A&M University for this secondary analysis (TAMU IRB 2012-0052). All statistical analyses were performed using SAS Version 9.4.

First, we used descriptive statistics such as measures of frequency (e.g. percentage and counts) and measures of central tendency (e.g. mean) to describe the sample of the secondary analysis. To measure the reliability for Likert scales, Cronbach alpha tests were performed. Second, independent group comparisons (e.g., Chi-square tests for categorical variables and independent t-test for interval variables) were performed to examine any statistical differences in the background and baseline characteristics of the two intervention groups. Paired t-test was used to determine changes between pre and post intervention. To compare the pre-post changes in knowledge, self-efficacy, self-care, and psychological distress the two intervention groups, *Si*, *Yo Puedo* and *Wisdom*, *Power and Control*, separate generalized linear regression models were employed for each pre-post differences in the outcome variable, and were adjusted for the corresponding baseline score, sex, education, and years with diabetes. Adjusting for level of education was considered to ensure that tailored

programs were addressing the sociodemographic factors (i.e. level of education) that should be part of aiming needed populations (Adjei Boakye et al., 2018). Controlling for years with diabetes was important because it is linked to patients' attitudes towards the intervention (Fan & Sidani, 2018).

Figure 6 then shows the final variables, WPC Knowledge, WPC Self-Efficacy, WPC Self-Care, WPC Psychological, SYP Knowledge, SYP Self-Efficacy, SYP Self-Care, SYP Psychological, used to perform the comparison between the two groups.

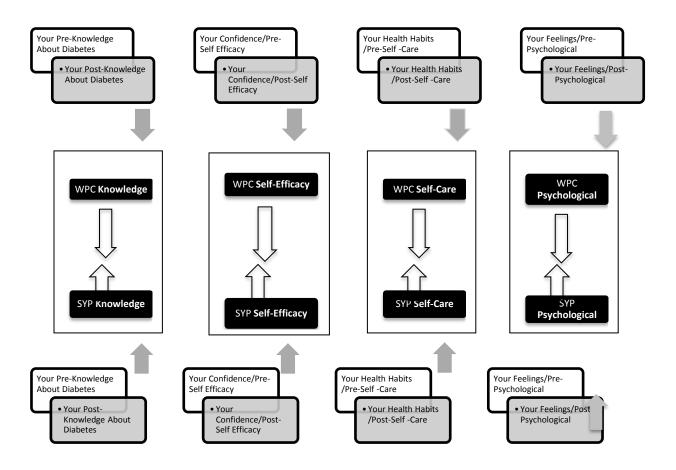


Figure 6 Comparison Design.

This figure the design of the analyses process for Sí, Yo Puedo (SYP) and Wisdom, Power and Control (WPC).

Results

Description of Sample

The following table 10 shows participants demographics used in this secondary analysis. A total of 129 Sí, Yo Puedo (SYP) and 121 Wisdom, Power and Control (WPC) respondents were used for the completion of this secondary analysis. Below are the demographics for each program. Table 10 shows, on average, participants were 50 years old for Sí, Yo Puedo and 66 years old for Wisdom, Power and Control. The age difference for the groups was 13 years, reporting the minimum age of 26 and max 90 years old for Sí, Yo Puedo and for Power and Control minimum 32 years old and maximum of 92 years old. Average years with diabetes was 48 months for Sí, Yo Puedo and 58 for Wisdom, Power and Control at time of the intervention. Most subjects were female, with 77 out of the 129 participants for Sí, Yo Puedo being female and 97 out of the 121 for Wisdom, Power and Control being female. Regarding level of education, Sí, Yo Puedo participants highest frequency was 53 (23%) in the first category "Less than high school" while their counterparts, and Wisdom, Power and Control the highest mean was for the second category "High school or GED" with 41 (18%). Both groups, Sí, Yo Puedo and Wisdom, Power and Control, predominately reported "had not worked for pay during the last 12 months." As the previous variable, both groups by large selected the income category "Under \$20,000", 28% for Si, Yo Puedo and 26% for Wisdom, Power and Control. The baseline assessment for the component variables reported knowledge with a p = .9070, self-efficacy p = 9244, self-care p = 2681, and psychological distress reported a statically significance with a p = .0031. Other variables

showing statistically significance were health insurance p < .0001, years with diabetes p = .0019; annual feet and eye exams both p < .0001, and A1C p = .0027.

Table 10 Characteristics of the Si, Yo Puedo and Wisdom, Power and Control Participants by Program

	Mean (SD) o	_	
	Sí, Yo Puedo	Wisdom, Power	
	(N=129)	and Control	Difference
Program		(N=121)	
Background			
characteristics			
Age	50	66	p > .0001
Sex			p = .2738
Male	27, (26%)	24, (20 %)	
Female	77, (74%)	97, (80%)	
Education			p > .0001
Less than high school	53, (45%)	12, (10%)	
High school or GED	39, (33%)	41, (36%)	
Vocational or some	16, (14%)	27, (23%)	
college			
College	6, (5%)	22, (20%)	
Graduate/Professional	4, (3%)	13, (11%)	
training or degree			
Employment (work for pay			p = .1455
during the last 12 months?)			_
Yes	46, (45%)	41, (35%)	
No	57, (55%)	76, (65%)	
Annual household income			p = .0367
Under \$20,000	55, (60%)	50, (49%)	
\$20,000 - \$50,000	32, (34%)	33, (32%)	
\$50,000 or more	6, (6%)	19, (19%)	
Have health insurance			p < .0001
Yes	52, (46%)	101, (88%)	•
No	62, (54%)	14, (12%)	
Self-reported health			p = .0762
Good-to-excellent	62, (56%)	80, (67%)	-
Poor-to-fair	49, (44%)	39, (33%)	

Table 10 Continued

	Mean (SD) or		
	Sí, Yo Puedo	Wisdom, Power	
	(N=129)	and Control	Difference
Program		(N=121)	
Background			
characteristics			
Diabetes			p = .0019
Less than 1 year	12, (13%)	13, (13%)	
Between 1 and 2 years	20, (22%)	4, (4%)	
Between 2 and 3 years	12, (13%)	7, (7%)	
Between 3 and 4 years	5, (5%)	7, (7%)	
Between 4 and 5 years	7, (8%)	10, (10%)	
5 or more years	35, (38%)	60, (60%)	
Feet exam			p < .0001
Yes	46, (39%)	78, (68%)	
No	73, (61%)	37, (32%)	
Eye exam			p < .0001
Yes	41, (35%)	86, (74%)	
No	76, (65%)	31, (26%)	
Dental check			p = .9712
Yes	54, (45%)	52, (46%)	
No	65, (55%)	62, (54%)	
A1C test			p = .0027
Yes	59, (60%)	87, (80%)	
No	38, (40%)	22, (20%)	
Baseline assessment			
Baseline knowledge	0.776, (0.190)	0.773, (0.160)	p = .9070
Baseline self-efficacy	2.833, (0.632)	2.825, (0.664)	p = .9244
Baseline self-care	2.415, (0.513)	2.487, (0.468)	p = .2681
Baseline psychological distress	1.8803, (0.711)	1.6052, (0.702)	p = .0031

NOTE:

a. Number of available responses were 70 out of 143 among Si, Yo Puedo (SYP) participants and 117 out of 160 among Wisdom, Power and Control (WPC) participants.

Unadjusted Pre-Post Differences

Table 11 shows mean values, along with p values from the paired t-tests for comparing the pre-post improvements in four outcome variables (knowledge, selfefficacy, self-care and psychological distress) between the two groups, Sí, Yo Puedo and Wisdom, Power and Control. With the exception of psychological distress, our null hypotheses was that (post-scores) - (pre-scores) = 0, meaning that the examined scores remain same before and after the interventions. For psychological distress, the null hypothesis was (post-scores) – (pre-scores) = negative result increase, as higher negative numbers were indicating less depression or less psychological distress. So, when the pvalues were <.05, the null hypothesis was rejected, thus concluding that the scores were different before and after the program. All four variables improved significantly for both interventions. In the case of knowledge difference, Sí, Yo Puedo effect size was 0.80 and 0.53 for Wisdom, Power and Control. As this first component variable, the other three, self- efficacy (Cohen's d (d) = 1.10), self-care (d=1.04), and psychological distress (d=0.60), Sí, Yo Puedo had greater effect when compared to Wisdom, Power and Control with (d=0.76), (d=0.78), (d=0.31) respectively.

Table 11 Unadjusted differences in Knowledge, Self-efficacy, Self-care Behaviors, and Psychological Distress from Baseline to Follow-up Assessment.

SYP			WPC					
Program outcomes	N	Mean (SD)	Cohen's d	<i>p</i> -value	N	Mean (SD)	Cohen's d	<i>p</i> -values
Mean Knowledge difference ^a	107	0.1525, (0.1902)	0.80	>.0001	113	0.0858 (0.1611)	0.53	<.0001
Mean Self- Efficacy difference ^a	109	0.7439, (0.6783)	1.10	<.0001	108	0.5486, (0.7219)	0.76	<.0001

Table 11 Continued

SYP				WPC				
Program outcomes	N	Mean (SD)	Cohen's d	<i>p</i> -value	N	Mean (SD)	Cohen's d	<i>p</i> -values
Mean Self- Care difference ^a	108	0.6175, (0.5940)	1.04	<.0001	109	0.3774, (0.8444)	0.78	<.0001
Mean Psychology difference ^a	106	0.4192, (0.6952)	0.60	<.0001	101	0.693, (0.5450)	0.31	p = .0023

SYP = Sí, Yo Puedo; WPC = Wisdom, Power and Control

Adjusted Pre-Post Differences

Table 12 shows program-wide differences (i.e., SYP vs. WPC) in the pre-post differences in terms of knowledge, self-efficacy, self-care, and psychological distress, after controlling for the baseline score, gender, education, and years with diabetes.

Results in Table 12 shows that three (knowledge p <.0020, self-care p = .0186, and psychological stress p = .0269) out of the four program outcomes were scored significantly differently between Si, Yo Puedo and Wisdom, Power and Control participants, after controlling for other variables. Si, Yo Puedo program showed greater effect difference when compared to Wisdom, Power and Control. Variables reporting significance were knowledge (p <.0020), self-care (p = .0186), and psychological stress (p =.0269). These three previous variables with scores 0.069, 0.238, and 0.276, were respectively, points higher among Si, Yo Puedo participants when compared to those from Wisdom, Power and Control. While being marginally significant (p = .052), this adjusted analysis also showed that predicted pre-post differences in self-efficacy score

a. Positive values indicates improvements.

was 0.253 point higher among participants from *Sí*, *Yo Puedo* compared to those from *Wisdom, Power and Control*.

Table 12
Generalized linear model. Regression coefficients between SYP and WPC, differences in knowledge, self-efficacy self-care behaviors, and psychological distress from baseline to post-test assessment after adjusting for baseline, sex, education, years with diabetes, and education

	Coefficient (Standard	t-value	p-value
	error)		
Knowledge	0.069 (0.022)	3.14	<.0020
Self-Efficacy	0.253 (0.13)	1.96	p = .0518
Self- Care	0.238 (0.10)	2.38	p = .0186
Psychological Stress	0.276 (0.12)	2.24	p = .0269

SYP = Sí, Yo Puedo; WPC = Wisdom, Power and Control

Discussion

Diabetes self-management education (DSME) group programs have shown to improve knowledge, skills and attitudes towards this prevalent chronic disease as showed in other studies (Fløde, Iversen, Aarflot, & Haltbakk, 2017). In this study, the efficacy of the two culturally appropriate DSME interventions were compared (AADE, 2013). Our secondary analysis results showed that while both programs had positive impacts on diabetes care, the tailored program for Hispanic/Latino populations were more effective than the tailored program for African Americans.

In the previous studies, both tailored DSME programs showed positive effects in their targeted ethnic groups (Peña-Purcell, Boggess, & Jimenez, 2011; Peña Purcell, Jiang, Ory, & Hollingsworth, 2015). The findings of this secondary analysis are

consistent with the literature that show culturally tailored diabetes program for Hispanics/Latinos have beneficial outcomes (Hu, Amirehsani, Wallace, McCoy, & Silva, 2016). *Sí, Yo Puedo* and *Wisdom, Power and Control* DSME programs included the four components that we analyzed: 1) knowledge, 2) self-efficacy, and 3) diabetes self-care, and 4) psychological stress. Those components coincided with other successful interventions that usually include like components as standard for other DSME interventions (Page-Reeves et al., 2017). Moreover, *Sí, Yo Puedo* and *Wisdom, Power and Control programs* followed the recommendations by the American Diabetes Association regarding the best practices for diabetes self-management (ADA, 2018). African-American patients also benefit from a culturally specific diabetes program (Whitney et al., 2017).

The comparison effect on these two interventions, *Sí*, *Yo Puedo* and *Wisdom*, *Power and Control*, prove participants' success by showing improvement in both groups. However, *Sí*, *Yo Puedo* showed greater effects when compared to *Wisdom*, *Power and Control*. Participants, African Americans in the *Wisdom*, *Power and Control* group, reported higher compliance, when compared to the Hispanic group, on the following characteristics: having insurance, having regular feet and eye exams, and completion of A1C testing. Thus, reporting greater access to health care resources, they were more likely to have their eye and feet exam by a doctor or health professionals.

When analyzing this data, we do agree with other studies that there was a positive outcome effect for the psychological distress component on both interventions. There are few studies such as *Sí*, *Yo Puedo* and *Wisdom, Power and Control* that address

the psychological well-being of adult self-management diabetes programs (A. P. Gutierrez, Fortmann, Savin, Clark, & Gallo, 2018). Although, as found in the same systematic review by Gutierrez, we agreed that greater samples participating in these types of interventions are needed in order to generalized the positive effect regarding psychosocial components (A. P. Gutierrez et al., 2018).

Findings in the secondary analyses sample were also according as reported by similar interventions regarding age and gender, where in previous studies the majority of the participants were females and age mean for Hispanics and African Americans coincide with *Sí*, *Yo Puedo* and *Wisdom*, *Power and Control* (Garcia et al., 2014; Mezuk et al., 2018). More research is needed to understand if age makes an impact regarding program outcomes when comparing two populations. Other studies with average age of 60 years and younger, have shown improvement on health outcomes (Adjei Boakye et al., 2018; Rhodes et al., 2018). Furthermore, secondary analysis sustained what previous literature has found regarding other demographics, such is the case of sex, specifically males (Adjei Boakye et al., 2018). According to Adjei Boakye, males were less likely to be a part of DSME programs and Hispanics in general were less likely to engage in DSME programs. This could very well be due to factors such as lack of insurance and the lack of Spanish DSME programs that are also culturally tailored.

Limitations

Due to the nature of the data, secondary analysis, not all of the data was usable for this study. For example, the age variable could not be used for the regression as control variable because there were many respondents who did not answer or answered

incorrectly. The response rate for age was 97% (117 out of 121) for Wisdom, Power and Control and 58% (70 out of 129) for Sí, Yo Puedo. Another interesting data collected was A1C values, but not all the participants were tested due to limited funds. Furthermore, there were some limitations pertaining to original study designs and processes. The original studies were designed to be quasi-experimental studies. From all interested individuals, a waiting list (control group) would be created and those would only receive standard care. Due to difficulty maintaining numbers of recruited people to for the waiting list, it was not achievable to have control groups that later would be able to compare with the intervention group. Additionally, the original study design was a 5 week-intervention and after the completion of the Sí, Yo Puedo pilot test period, session two was divided due to the amount of information covered during that session. A total of six-week education sessions and first week for orientations. Wisdom, Power, Control evolved to a 7-week program, that is, week-1 was orientation, followed six weekly educational sessions. Additionally, there was no documentation on the number of classes/programs delivered by CHWs, county agents and/or healthcare professionals. Thus, another limitation could be data collection challenges.

Implications

This secondary analysis showed that both DSME interventions, *Sí*, *Yo Puedo* and *Wisdom, Power, Control*, were effective and not only was there improvement on diabetes self-management behaviors; but also improvement on psychological distress.

Even when *Sí*, *Yo Puedo* had greater effect than *Wisdom, Power, Control*, this study

finding cannot generalize and is limited by multiple factors. We need to continue implementing tailored DSME programs and be consistent on the implementation (i.e. who delivers the programs, length of the program, etc). As there is an increasing need to reduce diabetes related cost, DSMS interventions will continue to not only demonstrate that individuals improved their diabetes management; but also improve their quality of life by reducing the stress burden of the disease.

Recommendations for Future Practices

There is a need for more culturally competent health interventions, especially as the population of minorities grow, to close the gap in health outcomes (Whitney et al., 2017). Specifically tailored health interventions may offer an opportunity to close some of those health gaps created by systemic problems (Hu et al., 2016). Literature shows that culturally appropriate, team-based interventions led by a person who looks and belongs to the target group, show greater impact than generic programs (Pérez-Escamilla et al., 2015). In 2014, *Sí*, *Yo Puedo* and *Wisdom, Power, Control*, community health workers were included in the program delivery as class leaders. This was done to expand and enhance the cultural and linguistic recommended best practices for these types of interventions (Ehrlich et al., 2015; Njeru et al., 2017; F. D. Williams et al., 2017).

We understand the value of culturally appropriate DSME for Hispanics/Latinos and African Americans, this approach can be further enhanced with Community Health Workers (CHWs). *Sí*, *Yo Puedo*, and *Wisdom, Power and Control*, are great examples to include CHWs on the delivery of these types of programs. Further, this explorations

illustrates opportunities for Cooperative Extensions to scale-up reach to underserved racial/ethnic groups. Furthermore, the healthcare system in the United States, restricts the time for health education in clinic settings, and fails to provide substantial community support and resources. More can be done by including community health workers offering DSME program in the communities.

Additionally, as a part of this dissertation, we identified the role of community health workers, and how they assist their communities by working with minorities who suffer with a chronic disease burden, such as diabetes. Thus the use of CHW in intervention has shown to be effective when implementing culturally adapted programs (Murayama, Spencer, Sinco, Palmisano, & Kieffer, 2016). Training more community health workers (CHWs) to match the needs of cultural and language barriers is vital. If an individual has the ability to be educated by someone who understands and shares common language, culture and life experiences, that individual may more easily relate and embrace health information and procedures (Egbujie et al., 2018). For example, when being educated on sensitive topics, individuals may prefer a health professional of the same gender to feel more comfortable. CHWs are in a unique situation to expand their role for those situations. This study supports other similar research showing the effectiveness of including CHWs in the healthcare system to reach healthy outcomes. (Shahbazi, Kumar, Mawson, Lavigine, & Dove, 2018). We should attempt to include community health workers as part of the healthcare delivery team, especially when serving minority population and people in disadvantage communities.

CHAPTER IV

BREAST CANCER – A QUALITATIVE RESEARCH POTENTIAL ROLE OF CHW

Introduction

As cancer treatments have advanced considerably in recent years, new therapies, drugs, chemotherapeutic agents, and other management protocols are achieving great success (Khan, 2019). Because of these advancements, we are experiencing an improved rate of cancer survivors. The American Cancer Society has reported that we have more than 14 million cancer survivors in the United States (this figure includes children and adults). It is estimated that at least 10 percent of those survivors are between 20 and 30 years old thus, in the prime of their reproductive/productive lives.

Scientific advancement provides cancer patients with increased chances for survival. However, survivors and their loved ones are left alone to suffer the burden of post-cancer treatment. The life of cancer survivors is forever changed after diagnosis and treatment. Research about health-related quality of life (QOL) themes in this population remains an important research topic (Bajpai & Shylasree, 2018). Because remission starts an uncertain and emotional journey, where physical challenges are inevitable among cancer survivors, it merits further study.

At present, we know little about the aspects of the quality of life of Latino women who are cancer survivors. Research regarding quality of life (QOL) in cancer survivors explores life changes in their daily activities after cancer treatment, including sexual intimacy with the patient's partner (Mehta et al., 2019; Turner, 2019). If we

combine the growing Latino ethnic population in the U. S. with the increase in cancer survivor rate, we are faced with the need to learn more of QOL issues among Latinos, specifically among female cancer survivors.

Most studies of Latino women and quality of life after cancer treatment have reported low scores for mental, physical, and social QOL (McNulty, Wonsun, Thurston, Jiwon, & Larkey, 2016). A concern among Latino women and their heterosexual partners is that they may encounter difficulties in communication and/or involvement in their relationships (D. Gutierrez, Barden, Gonzalez, Ali, & Cruz-Ortega, 2016; Segrin, Badger, & Sikorskii, 2019). Little is known about the perceptions of Latino cancer survivors on sexuality and intimacy after cancer treatment. Particular consideration is needed for issues of QOL and communication in a heterosexual relationship among Latino cancer survivors. Therefore, I conducted this research to address the sexual issues faced by Latino women after cancer treatment to obtain qualitative information about the concerns that Latino women experience when they resume their sexual life after treatment.

The Research

To obtain qualitative information about the concerns that Latino women experience when they resume their sexual life after cancer treatment, in-depth interviews using seven open-ended questions were conducted.

"Yo estaba como tranquila hasta que... me dijo [el doctor], bueno ya se puede levantar y la voy a dar de alta porque ya está muy bien..., me dijo el doctor. Y cuando fui a verme en el espejo, me sentí... como... Empecé a llorar. Entonces mi marido agarro lo que tenía a mano, así haciendo un puño con su mano, a y me puso aquí... (Señalando en el lado del seno) y entonces yo salí y todo."

"(I was calm until the doctor told me: "You are fine, you can get up now. You will be discharged [from the hospital] because you are doing well now." When I saw myself in the mirror...I felt like.... I started to cry...

Then my husband took what he had in [his] hand, making a fist with it, and put it here (making a motion to her missing side of the breast) and then I left and that was it."

Methods

Sample and Recruitment

The sampling data in this qualitative research was a sample from a city in the south central United States with a high concentration of Latinos. To obtain this sample, a combination of *criterion*, *snowball* and *convenience* sampling was used (Patton, 2015). A sample size of 10 was chosen, which in qualitative phenomenology research is considered appropriate to account for variability (Moustakas, 1994). Table 13 shows a participants' sample demographics, to keep confidentiality, not all the participants were included in the sample nor are the comments necessarily matching those of the participants in the table.

Table 13 Participant's Demographics. Selected Sample, n = 5

Age at time	Children	Marital Status at	Marital Status at	Level of
of diagnosis		Time of Diagnosis	Time of Interview	Education
Early 30s	One	12 years married	Continues married to the same person	Some college
Almost 40	Three	Married	Continues married to the same person	Did not mention
Over 35	Two	Married; lived together and married before oldest child was born	Continues married to the same person	Advanced degree
Over 30	Two	Married	Divorced after treatment	High school or GED
46	Two	Divorced for few years	Remains single with steady partner met before diagnosis	College degree

During an informal gathering for breast cancer survivors, potential participants were recruited in-person. To be eligible for inclusion, women had to be Latino female breast cancer survivors over 18 years of age who had engaged in sexual activity with a heterosexual male partner after cancer treatment. The only exclusion criterion was pregnancy at the time of the interview. A signed informed consent form was obtained from each participant. The Texas A&M University Institutional Review Board approved the study.

Interviews

Semi-structured, in-depth, in-person interviews were conducted. At the beginning of each interview, the participant was given the following printed questions in Spanish.

Pregunta Central

¿Cómo fue la experiencia de su primera vez al reiniciar actividad sexual con su compañero después de su tratamiento de cáncer?

Central Question

What was the experience like the first time you attempted to resume sexual activity with your partner after cancer treatment?

Otras Preguntas

¿Cual, si alguno, fue el cambio más notable en su cuerpo que impactó su actividad sexual?

¿Cuál, si alguno, fue el cambio más notable en su cuerpo que impacto a su compañero en su actividad sexual?

¿Qué planes, si hubo antes del tratamiento- se tomaron para el primer re-encuentro? ¿Qué habría cambiado, si fuera posible, para haber gozado su primer re-encuentro? ¿Qué recomendaría a otras mujeres en su misma situación?

Open-ended questions

What, if any, was the most significant change in your body that impacted your sexual activity?

What, if any, was the most significant change in your body for your partner that impacted your sexual activity?

What plans – if any, prior to the treatment – took place for the first encounter?

What would you change, if possible, to have an enjoyable first experience after cancer treatment?

What would you recommend to other women in your same situation?

All interviews were conducted in Spanish, the native language of all participants. The women were allowed five minutes to read the open-ended questions. Each interview was conducted at the time, date and location of the women's choice. Interviews were recorded and transcribed shortly afterward to effectively link the recording with the interviewer's notes. All Spanish excerpts in this paper were translated by the interviewer.

Analysis

Data were analyzed by a constant comparative method (Lincoln & Guba, 1985) and a simple modality of crystallization (Ellingson, 2009). Open and axial coding were used.

Results

A total of 10 in-depth, semi-structured interviews were conducted. Although the original agreement was for at least 45 minutes of interview time, each woman talked for more than 90 minutes. At the time of the interview, all women had resumed sexual activity after cancer treatment. None of the women mentioned feeling embarrassed to talk about "confidential" information or their experiences regarding sexuality. Three main themes emerged from the interviews: (1) deciding among treatment options based

on post treatment body images, (2) communicating (or not) regarding intimacy after treatment, and (3) needing education on sexuality after cancer treatment.

Three Themes

(1) Deciding among treatment options based on post treatment body images.

Participants started the interview mentioning when and how they were diagnosed. They also commented on what they based their decision on for their treatment. Only one woman, who had previously met a survivor with an advanced stage of breast cancer, knew she would want it "all taken out" if she was ever diagnosed. All the other women clearly said they were greatly concerned, because they knew their partners would not like the physical changes in their body due to the optional treatments.

Yo oré para que mis senos pudieran salvarse... Yo sabía que no tendría apoyo de mi marido si me removían [los doctores] mi seno...

(I prayed that my breast could be saved...I knew that I would not have support from my husband if they [the doctors] would remove my breast...)

Women who did not have partners at the time of diagnosis did not want anyone noticing they had been diagnosed with breast cancer.

[Yo] era divorciada,... Todo esto, pues yo lo afrente yo sola...yo a nadie le dije nada. Era algo muy personal.

Me explicaron que las opciones eran que me quitaban el seno y me hacían radiación... o me dejaban el seno y me daban quimio y radiación. ¡No, es mejor que me lo quiten todo! Ahora, con la experiencia que ya tengo y lo que he visto, tal vez hubiera pensado diferente. Pero en aquella época, no, yo quería vivir... Entonces yo dije, ¡pues que me lo quiten todo!

¡Ahora, la quimio sí me mató! Me dio durísimo... Y yo decía, es tan duro que es mejor uno morirse y no seguir así.

([I] was divorced... I faced all this alone... I never told anything to anyone, it was very "personal" ...

[The doctors] explained to me that my options were to remove my breast and receive radiation or retain my breast and receive chemo and radiation. No, it is better to take everything out! Now with the experience that I had and what I have seen, maybe I would have thought differently. But back then, I wanted to live... Then I said, "Remove everything!"

Well, the chemo really "killed" me. It hit me very hard... I used to say, it was so hard that it is better to die and not continue like this.)

The woman discussed above did have surgery, and during the interview said she received chemotherapy in addition to the surgery.

Most participants, even when they considered the change in their anatomy, decided on treatment options based on the long-term outcome, e.g., less likelihood of reoccurrence. All women stated that at some point they wondered about how they would look after losing one or both breasts. No participants mentioned concern about pain, fear, or the quality of life (QOL) after treatment.

(2) Communicating (or not) Regarding Intimacy After Treatment

For this research, intercourse and intimacy were differentiated (Mehta et al., 2019), because the participants themselves identified intimacy and intercourse as separate concepts. The following are comments regarding the importance of intimacy. By intimacy, women meant having communication, being tender, kind, and using other gestures that denote caring. All participating women preferred intimacy over intercourse.

Some of the couples had previous conversations regarding their sexual life, either because of "getting old" or fertility issues. None of the couples received information or talked about sexuality after cancer treatment diagnosis or during or after treatment. None of the women remembered having conversations or making plans with their partners on how to resume their sexual life.

...Porque el sexo está en la cabeza, obviamente que está en el cuerpo pero es más aquí [señalando la cabeza] en lo que uno experimenta, hace el amor, y ya se da normal.

...Because sex is in your head, obviously it is also in the body, but you experience it more in here [pointing to the head], when you make love, then emotions keep coming naturally.

Three of the women said they had received many subliminal messages about rejection because of physical changes after cancer treatment. One said that she had had no interest in sexual life with her partner since she underwent cancer treatment.

El cree que todo sigue igual. No toma en cuenta que mi vida y mi cuerpo han cambiado. El solo quiere tener "el movimiento" y yo necesito más ternura de su parte y flores... y ayuda en la cocina!"

He thinks everything stays the same. He does not take into account that my life and body have changed. He just wants to have the "movement," and I need more caring from him... some flowersand some help around the kitchen!

One of the participants had no partner at the time of diagnosis and treatment. At the time of the interview she was in a relationship and she that all went well. She said that no one had told her what to expect or what would happen, but her new partner was kind and willing to wait "for a year" before any sexual encounter.

All the women differentiated strongly between sexual encounters and intimacy.

Each said that it is not only the act of intercourse that is important. Rather, they

emphasized that daily interactions, care and support during the cancer journey affect

wanting to resume sexual activity.

(3) Needing Education of Sexuality After Cancer Treatment

All women expressed an immense need for education about resuming sexual life with their partners. They said they would have liked to have known what to expect and

what changes (physical and emotional) might take place after treatment. The women also noted the lack of education available in their native language. They said there should be printed and online educational materials that are readily available, up-to-date and culturally appropriate.

The women also mentioned wanting to receive such information from someone, such as a healthcare provider, who was culturally competent and culturally sensitive.

... todo el mundo (refiriéndose a su equipo de salud) hablaba inglés. Y yo leí mucho y también, todo era en inglés. Tenía mucho para absorber, sin nadie con quien comentar... ¡Estaba desesperada!

(...Everyone [referring to her health care providers] spoke only English. I read a lot, but everything was in English too. I had to absorb many things on my own, without anyone to talk to... I was desperate!)

Even the women who were bilingual and highly educated said they would have liked to have received the information/education in their native language.

Shortly after one interview, the participant said she remembered something important and wanted to continue recording. The woman said that many times she felt alone and did not know whom she could talk to or ask about "personal" matters. She took upon herself the mission of advocating for Latinas with newly diagnosed breast cancer. While working hard to identify and educate these newly diagnosed women, she said, "someone asked me to become a 'Promotora', a community health worker."

Era muy interesante ese programa. Eso hace que a una mujer le da más valor... ¡"empower"!

(It was a very interesting program. It gives to the woman the necessary strength... empower! [using the English word]).

All the women emphasized the lack of education, during and after treatment, about resuming intimacy with their partners. All women would preferred to have had very basic printed materials provided at different times for their benefit and that of their partner.

Mi esposo debería de estar presente cuando yo recibo información importante.
(My husband should be present when I receive this important information.)

Conclusions

This study illuminates the unspoken feelings of Latinas about dealing with sexual intimacy after breast cancer treatment. Interviews were conducted over a period of one year. All the interviews were conducted in a semi-structured form; however, the women appreciated receiving an outline with printed questions.

In our study, we found three major themes: (1) deciding among treatment options, (2) communicating (or not) regarding intimacy after treatment, and (3) needing education on sexuality after cancer treatment.

Regarding treatment options, some women emphasized that when they had to make the decision of which treatment to choose, they remembered previous subtle conversations with their partners regarding physical changes. Those conversations took place before diagnosis. When making the decision of which treatment to choose, none of the participants recall ever having been asked about QOL matters, including those concerns on sexual issues after undergoing treatment.

With regard to communicating (or lack thereof) regarding intimacy after treatment, the women focused especially on the importance of intimacy rather than sex.

All participants said that after diagnosis and treatment for breast cancer, the life of a couple changes. Latino women may encounter difficulties communicating with their heterosexual partners regarding intimacy. Resuming sexual activity treatment was of high concern to the participants; Crowly et al, addressed the same issue regarding sexual health. In their research, they found that survivors are worried about physical changes, the ability to enjoy the experience and changes affecting partner satisfaction.

The women who were interviewed said they wished they had received education about sexuality after breast cancer treatment and called for the availability of such education in Spanish. Even when participants of this study were bilingual, they said they would like to receive sensitive information in Spanish, their native language. Our study findings are consistent with other research projects. Improved outcomes are obtained when utilizing more than English "only" printed materials and supplementing with materials in the patient's native language (Boyle et al., 2015). We found that without formal education on sexual health after breast cancer treatment, the women felt completely alone on how to start their new lives. Even when they had shared some of their personal experiences amongst themselves, they still felt the need to have a "special health provider" educate them on these important topics. As supported by the literature, providers should be properly trained to communicate with their patients regarding QOL matters (Turner, 2019). One participant mentioned that what helped her was becoming a community health worker (Promotora de salud). After training, she embarked on a mission to help other women who had just started their cancer treatment.

Discussion

According to the latest U.S. Census Bureau's Report (2011), Latinos now reside in each of the 50 U.S. states. As populations become increasingly diverse within the same city, in like manner, we should consider providing information in the native language of the populations we serve.

Our study focused on Latino women in a south central US city who had been treated for breast cancer. The findings might not be generalizable to women who have been treated for other types of cancer, who are members of other ethnic groups, or even who belong to other Latino populations. Research similar to ours regarding other types of cancer and other populations appear worth pursuing.

Future studies should look into the sexual identity among minority cancer survivors. We have to make strong efforts to address outcomes about other aspects that may extend to a patient's family structure, such as a marital status change due to a major illness (Polenick, Renn, & Birditt, 2018) and how this outcome may impact financial stability, a well-known burden for cancer survivors (Kim et al., 2015).

As the women in this study shared, a patient's quality of life is impacted by many factors including both physical and emotional. It is important to emphasize that a person's QOL during and after cancer treatment needs to be highly considered in an individualized and tailored approach by health professionals. More resources are needed in the patient's native language, as well as health professionals that speak the patients native language and are culturally sensitive to the needs of the patient (F. D. Williams et al., 2017). In addition to these resources, a member of the care team must be included

who is trusted to deliver, educate and have a natural cultural competency, such as a community health worker (Chalela, Muñoz, Gallion, Kaklamani, & Ramirez, 2018; Meghea & Williams, 2014). Depending on the individuals' specific situation, emphasizing "one size **does not** fit all" is an important discussion to support quality of life "Having access to community health workers to guide Latinos through cancer survivorship issues could be very beneficial for encouraging cancer survivors (Meghea & Williams, 2014; Sprague Martinez, Freeman, & Winkfield, 2017) to address sensitive topics such as impacts on their sexuality (Cheun & Loomis, 2018) and providing a sense of community to reduce stigma and shame, and hence improve quality of life in the post treatment phase.

CHAPTER V

CONCLUSIONS

The CHWs of the Texas Gulf Coast Region already provide valuable services and can expand their role when working with underserved populations with prevalent chronic condition such as diabetes management or cancer survivorship. The main goal of this dissertation proposal was to identify health disparities in underserved populations by providing two examples of relevant health issues for the Hispanic/Latino and minority population in the U. S. This paper documented the status of the CHWs and provided examples of how CHWs can be better integrated in the delivery of standardized chronic disease management training programs in the region in order to reduce health disparities.

Specifically, this work explored how Hispanic/Latino women perceive breast cancer and how CHWs can benefit from this information when working with this population. This can help CHWs expand their role in cancer survivorship management. This research is also consistent with prior literature indicating positive health outcomes when CHWs are part of the diabetes management process (Egbujie et al., 2018). Chapter III, Diabetes Self-Management Education – A comparison in two minority groups", addressed the benefits of culturally-sensitive programs for ethnic and minority groups, and the differential impact on different outcomes across two population groups. It provides a case example of how the role for CHWs in diabetes might be expanded for underserved population groups, specifically for Hispanics and African Americans.

CHWs can be trained in many conditions with ready-to-use, evidence-based programs identified by the Centers for Disease Control and Prevention and other federal agencies, such as the Administration for Community Living. Rising health care costs call for a movement to disseminate widely evidence-based programs for chronic disease self-management.

CHWs are a cost-efficient and effective means of reaching populations at a higher health risk who require cultural and linguistic accommodation. CHWs can be integrated into the U.S. healthcare system quickly and inexpensively (Allen, Escoffery, Satsangi, & Brownstein, 2015) to assist with disease management among minorities and help them improve their quality of life, by helping them understand their disease state, discuss treatment options and assist with compliance.

The contribution of this exploration work in the Public Health field, helped to identify and qualify community health workers as they work to reduce health disparities among underserved populations. By "qualifying" the CHW's, we recognize the need to promote CHWs inclusion and reputation among the community. The need exists to explore more regarding training and compensation to enhance and leverage this profession. All of this can be used to understand the burden of health disparities in underserved populations and identify the role of community health workers in reducing health disparities.

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APPENDIX A

WISDOM, POWER, CONTROL. KNOWLEDGE



A1. How often should people with	diabetes have	e an eye exam?		
a) Every month	b)	At least once a year	c)	Not needed
A2. What is a normal HbA1c (hemo	globin A1c) d	or "average blood	test"?	
a) Between 8 to 10	b)	Over 12	c)	7 or below
A3. What is a normal fasting bl	lood glucose	range?		
a) Between 40 to 70 mg/dl	b)	Over 180 to 210 mg/dl	c)	Between 70 to 130 mg/dl
A4. What is one of the sympton	ns of low blo	od glucose?		
a) Shaking	b)	Dry itchy skin	c)	Frequent urination
A5. If someone with diabetes for	eels thirsty, ti	red, and weak, it u	usually means t	heir blood
glucose is:				
a) High	b)	Low	c)	Normal
A6. How often should people w	vith diabetes	check their feet?		
a) Once a day	b)	Once a week	c)	Once a month
A7. Which of the following is u	sed to treat lo	ow blood glucose?	?	

	a)	3 hard candies	b)	Water	c)	1 cup diet soft drink
A8.	Wh	en someone with diabe	tes exercises	, their blood sugar:		
_	a)	Goes up	b)	Goes down	c) St	ays the same
A9.		Which of the following	j is most likely	y to raise your bloo	d glucose the	e most?
_	a)	Carbohydrates	b)	Fats	c)	Proteins
A10.	Wh	ich of the following is a	complication	of diabetes?		
_	a)	Lung problems	b)	Kidney problems	c)	Lower back problems

APPENDIX B WISDOM, POWER, CONTROL. SELF-EFFICACY



Но	w confident do you feel that you	I don't feel sure	I feel a little sure	I feel more or less sure	I feel very sure
1.	can eat your meals every 4 to 5 hours every day, including breakfast every day?	□1	\square_2	\square_3	□4
2.	can follow your diet when you have to prepare or share food with other people who do not have diabetes?	□1	\square_2	\square_3	□4
3.	can choose the appropriate foods to eat when you are hungry (for example, snacks)?	□1	\square_2	\square_3	□4
4.	can exercise 15 to 30 minutes, 4 to 5 times a week?	□1	\square_2	\square_3	□4
5.	do something to prevent your blood glucose from dropping when you exercise?	□1	\square_2	\square_3	□4
6.	know what to do when your blood glucose level goes higher or lower than it should be?	□1	\square_2	\square_3	□4

How confident do you feel that you	I don't feel sure	I feel a little sure	I feel more or less sure	I feel very sure
7. can judge when the changes in your illness mean you should visit the doctor?	□1	\square_2	□3	□4
8. can control your diabetes so that it does not interfere with the things you want to do?	□1	□2	□3	□4

APPENDIX C

$WISDOM, POWER, CONTROL. \ SELF-CARE$



		None of the days	Some of the days	Most of the days	All of the days
1.	On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?	□1	□2	□3	□4
	How many of the last SEVEN DAYS				
2.	have you followed a healthful eating plan?	□1	\square_2	□3	□4
3.	did you eat five or more servings of fruits and vegetables?	□1	\square_2	□3	□4
4.	did you eat high-fat foods, such as red meat or full-fat dairy products?	□1	\square_2	\square_3	□4
5.	did you space your carbohydrates evenly through the day?	□1	\square_2	□3	□4
6.	did you participate in at least 30 minutes of physical activity?	□1	\square_2	\square_3	□4
7.	did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?	□1	\square_2	\square_3	□4
8.	did you test your blood sugar?	□1	□2	\square_3	□4

	None of the days	Some of the days	Most of the days	All of the days
9. did you test your blood sugar the number of times recommended by your health care provider?	□1	□2	□3	□4
10. did you check your feet?	□1	\square_2	\square_3	□4
11. did you inspect the inside of your shoes?	□1	\square_2	\square_3	□4
12. have you smoked a cigarette – even one puff?	□1	\square_2	\square_3	□4
If yes, how many cigarettes did you smoke on an average day? Number of cigarettes				

APPENDIX D

$WISDOM, POWER, CONTROL. \ PSYCHOLOGICAL$

Please read each item carefully and check **ONE** box for each question.

▲TEXAS A&M
GRILIFE
EXTENSION

During the last 30 days, about how often did	None of the time	A little of the time	Some of the time	Most of the time
1. you feel so depressed that nothing could cheer you up?		\square_2	\square_3	\square_4
2. you feel hopeless?	\square_1	\square_2	\square_3	\square_4
3. you feel restless or fidgety?	\square_1	\square_2	\square_3	\square_4
4. you feel that everything was an effort?	\square_1	\square_2	\square_3	\square_4
5. you feel worthless?	\square_1	\square_2	\square_3	\square_4
6. you feel nervous?	\square_1	\square_2	\square_3	\square_4

APPENDIX E

PROTOTYPE SURVEY

TEXAS GULF COAST CHW/PROMOTORES ASSOCIATION (TGCCPA) SURVEY

We would like to get to know you a little more. This is to provide us more information on how best our organization can help you. Your information will be completely anonymous.

CERTIFICATION ITEMS

1.Certified since	Please sp	ecify year:		
2. Times that I have renewed my certification:	0	1	2	3 or more
2. Lygyally abtain my CE's fram.				

3. I usually obtain my CE's from:

(Please write name of agency/ies) _ _

4.I have received my certification by	a. attending a 160 hours training program
Select "a" OR "b"	b. performing over 1,000 hours of CHW work

If are not currently working as CHW or not working at all, please skip to question 7

5.I work as CHW	a.	my job title is CHW/Promotor de Salud				
Select "a" OR "b"	b.	my job title does not include CHW on the name				
6.If you selected "b" Please specify your job title						

7	10	n	C'	ГАΊ	ГΤ	TC

a. I have a full/part-time job other than CHW	
b. I have not found any job as CHW	
c. I received my certification with the sole purpose to be recognized as CHW and not to receive any compensation	
d. I only performed unpaid work as CHW, my own decision	

8.My primary training is related to:	
You can look from the list below to answer this item	

9.I have received training on: (Please check all that apply)

Alcohol use	Disability	Mental health
Asthma	Domestic Violence	Physical activity
Cancer prevention	Emergency preparedness	Prenatal care
Cancer survivorship	Hand washing	Safety belt use
Child Abuse	Healthy eating	Seniors/Geriatrics
Diabetes	Hypertension	Tobacco cessation/cigarette smoking

10	Others	not m	antion	e har	hove.
	1 /1111115			IECI X	11111VE

ABOUT TGCCPA

11.Did you attend	Yes, how many?		
any TGCCPA	No, why?	Didn't know	Not interested
events in 2012?		Schedule conflict	Boss would not allow
12.Other reasons:			

DEMOGRAPHICS

13Gender:	Male	Female	14. Age:		15. Zip code:
16.Race/Ethnicit	y:		17.Highest education leve	1:	<u> </u>
			High School /GED _	Some	College
			Associate Degree	Col	lege
i					

APPENDIX F

FINAL SURVEY

TEXAS GULF COAST CHW/PROMOTORES ASSOCIATION (TGCCPA) SURVEY

Survey

By completing this survey, you agree to participate in a research study to provide information of the status of the Community Health Workers in the Gulf Coast Area. We would like to get to know you a little more and know more about your certification as community health worker.

The survey will take about 10 minutes to complete. If you wish to skip any question, just leave it blank. Information collected from this survey will be share as aggregate (combined) data during professional conferences, publications, etc.

Your information will be completely anonymous and voluntary.

This research is voluntary and you have the choice whether or not to be in this research study. You may decide to not begin or to stop participating at any time. If you choose not to be in this study or stop being in the study, there will be no effect on your relationship with Texas A&M University.

You may contact the Principal Investigator, Dr. Marcia Ory, Ph.D., M.P.H., to tell her about a concern or complaint about this research at (979) 458-1373 or mory@tamu.edu.

For questions about your rights as a research participant; or if you have questions, complaints, or concerns about the research, you may call the Texas A&M University Human Subjects

Protection Program office at (979) 458-4067 or irb@tamu.edu.

Thank you!

TEXAS GULF COAST CHW/PROMOTORES ASSOCIATION (TGCCPA) SURVEY

CERTIFICATION ITEMS

Are you currently a certified CHW? ☐ Yes ☐	No → please skip to question 5
1. How long have you been certified?	years ormonths
2. How many times have you renewed your certification	ition?
☐ 1 ☐ 2 ☐ 3 or More 3. I usually obtain certified continuing education	☐ None hours from (write name of training program(s)):
4. I received my certification by:☐ Completing a 160 hour certification cours☐ Performing over 1,000 hours of CHW/Pro	

EXPERIENCE WITH CERTIFICATION

	Yes	No
Being a certified CHW/Promotor(a) has better equipped me to serve my community and make a difference in the lives of the residents I serve.		
b. Being a certified CHW/Promotor(a) has increased the respect and value shown to me by my community.		
c. Being a certified CHW/Promotor(a) has increased my self-confidence as a CHW/Promotor(a).		
 d. Being a certified CHW/Promotor (a) gives value to this profession (other professionals acknowledge my work as a certified CHW/Promotor(a). 		
e. Being a certified CHW/Promotor(a) has resulted in better job opportunities.		

f. Being a certified CHW/	Promotor (a) has resulted in	increased job responsibilities.		
g. Being a certified CHW/	Promotor(a) has resulted in	a promotion at work.		
h. Being a certified CHW/	Promotor(a) has resulted in	a higher salary.		
i. There are too many rec	quirements to maintain CHW	certification		
j. There is a lack of recog	nition of CHWs/Promotores			
k. There are not enough j	ob opportunities for CHWs/F	romotores		
☐ My job title☐ My job title☐ I have a full/part-ti☐ I am currently not☐ I only perform unp 6. What type of setting do yo ☐ health care	omotor(a) and is CHW/Promotor(a) de Sa does not include CHW. My me job other than CHW working as CHW aid work as CHW, my own o	ud job title is		-
HEALTH TOPICS TRAININ 7. My primary training is rela		the list below to answer this iten	n)	

8. I have received training on: (Please check all that apply)

	is a second an area apply)	
Alcohol use	Disability	Mental health
Asthma	Domestic Violence	Physical activity
Cancer prevention	Emergency preparedness	Prenatal care
Cancer survivorship	Hand washing	Safety belt use
Child Abuse	Healthy eating	Seniors/Geriatrics
Diabetes	Hypertension	Tobacco cessation/smoking
Insurance	Access to care	Navigation

9. Others not me	ntioned above: _				
ABOUT TGCCP	A				
□ No → □	How many? Why not? Didn't know abo	ut them	2013? ☐ Not interested ☐ Other		
DEMOGRAPHIC	s				
11. Gender:	□ Male	□ Fer	male		
12. Age:	-				
13. Zip code:					
14. Race/Ethnicit	y:				
15. Highest educ	ation level:				
☐ High School /C	GED □Some	College	□Associate De	gree l	⊐College