

STRESS MANAGEMENT/COPING: LIMITED-ENGLISH PROFICIENT  
MEXICAN AMERICAN FAMILY CANCER CAREGIVERS

by

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MEXICAN AMERICAN FAMILY CANCER CAREGIVERS

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## ABSTRACT

The health literacy of minorities in the United States is of major concern to citizens and healthcare providers alike. Low health literacy, coupled with limited-English proficiency (LEP), leads to poor healthcare outcomes for Mexican Americans (MAs), particularly those with critical illnesses like cancer. This population faces vulnerability due to limited healthcare access and continuing cultural stigmas that affect healthcare outcomes.

Mexican American family cancer caregivers (MAFCCs) who provide assistance to an ill family member are a population that suffers from low health literacy. Low health literacy and LEP increase role stress in caregivers' lives, yet few healthcare interventions exist to provide needed culturally sensitive care to these women. The student author collaborated with two experienced researchers in the field of MA cancer caregiving, Drs. Jo Nell Wells and Carolyn Spence Cagle, to extend a previously developed multi-disciplinary action program of support (MAPS). The student's focus was on developing a low health literacy and LEP educational booklet in Spanish to help MAFCCs manage role strain and stress management. The student author participated alongside Drs. Wells and Cagle to implement role-play situations with MA caregivers and state-certified health promoters (*promotoras de salud*) to evaluate the efficacy of the student-developed stress and coping booklet. Feedback indicated that the booklet effectively met MAFCC needs and *promotora*-desired ease of implementation. The booklet, titled *Viva su vida: Manejando el estrés*, is a pocket-sized guide that supplements the larger researcher-developed stress and coping module of the MAPS intervention.

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## INTRODUCTION

Low healthcare literacy plagues the United States with 90 million adults scoring low on health literacy tests in the National Assessment of Adult Literacy survey (Singleton & Krause, 2009). Low health literacy, coupled with a limited understanding of English language, results in many Mexican Americans (MAs) lacking understanding of their healthcare. With the MA population the fastest growing minority group in the United States and approximately 40% speaking little or no English, low healthcare literacy is an increasing threat to overall health disparities facing MAs (Singleton & Krause, 2009). The scarcity of healthcare materials written in Spanish amplifies these health disparities (Siegel, 2012; Wells & Cagle, 2010). The MA population currently faces poverty, limited access to healthcare due to lack of health insurance, low healthcare literacy, and limited-English proficiency (LEP) (Siegel, 2012). These factors create healthcare inequalities and late stage-poor prognosis cancer diagnoses among many MAs (Siegel, 2012). Low healthcare literacy also has financial implications due to limited use of preventative care services by MAs who may overuse emergency services for primary care with costly hospital stays to stabilize their health (Literacy Coalition of Central Texas, 2012). Limited health literacy of MAs also influences their inability to follow treatment instructions, further leading to more costly care (Literacy Coalition of Central Texas, 2012).

*HealthyPeople2020* addresses the topic of low health literacy in the United States but does not offer any recommendations for interventions in this specific ethnic group (U.S. Department of Health & Human Services [USDHHS], 2013b). Although a MA cancer patient suffers from healthcare literacy barriers, the patient's family caregiver also

struggles. A family cancer caregiver experiences role strain in day-to-day duties even without the involved language barriers. Mexican American family cancer caregivers (MAFCCs) experience an increase in stress when there is lack of clear health information resources in an understandable language or format. MAFCCs also face complications with their own health related to lack of culturally specific resources that address role-related stress in their lives.

A gap in literature exists on the topic of health literacy in MAFCC stress management and related health disparities. Honors project committee members, Dr. Jo Nell Wells and Dr. Carolyn Spence Cagle, addressed this gap by conducting research with MAFCCs to evaluate their caregiver experiences. The researchers' long-term goal is to provide support services for MAFCCs to improve the quality of life of the MA cancer patient (Wells & Cagle, 2014). Their team developed a multi-disciplinary action program of support (also known as MAPS) that is culturally specific in the Spanish language (Wells & Cagle, 2014). MAPS is a four-part series of sessions between caregivers and *promotoras de salud*, MA community-health advocates. The researchers' first study began with an open-ended, facilitated conversation with MAFCCs to learn about their unmet learning needs and resources needed to care for their loved ones with cancer (Wells & Cagle, 2013). Study data supported Drs. Wells and Cagle's development of the first two modules of the MAPS series. The first MAPS module focuses on ways for MAFCCs to improve communication with healthcare professionals. The second MAPS module aims to empower the MAFCCs with stress management and coping techniques.

This honors project extends Dr. Cagle and Dr. Wells' MAPS Module 2 on caregiver stress management and coping skills for MAFCCs. The honors student author

aims to fill the apparent gap in Spanish-language reference tools for the *promotoras* to use with MAFCCs during MAPS sessions by presenting content in an interactive, culturally relevant, easy-to-use, and understandable format. The student author developed a pocket-sized guide, or *guía*, to facilitate learning during the MAPS Module 2 intervention (prototype in Appendix B). To date, the student author implemented the prototype model of the guide in two role-play sessions involving MAFCCs and *promotoras de salud*. In July of 2014, the student author attended the 39<sup>th</sup> Annual Conference for the National Association of Hispanic Nurses (NAHN) in Miami, Florida with Drs. Wells and Cagle to present their findings from those sessions. Since then, the student author has received additional feedback from her honors committee member, Mrs. Karla O'Donald, to ensure cultural congruency of the *guía* with the MA culture to refine the final product presented in this paper.

#### STATEMENT OF CLINICAL QUESTION

Both clinical and research nurses strive to develop an evidence-based practice (EBP) question to organize a clinical proposal for investigation (Fineout-Overholt, Levin, & Melnyk, 2004). The PICO, or statement of clinical question, clearly identifies key terms that drive the evidence search for a specified problem (Newhouse & Poe, 2012). A PICO format helps narrow and specify an EBP question in the following way: “P” represents a patient, population, or problem needing exploration; “I” represents an intervention or issue; “C” represents a nursing action compared to an existing intervention; and, “O” represents measurable outcomes to drive efficacy of nursing interventions or actions (Newhouse & Poe, 2012).

The PICO question for this honors paper is the following: In limited-English

proficient (LEP) Mexican American family cancer caregivers (MAFCCs) (*population*), what is best practice to guide development of a low-literacy culturally sensitive booklet focused on stress and coping (*issue*) and delivered by a *promotora de salud* (*intervention*) to improve MAFCC role stress (*outcome*)?

The PICO statement lacks a “C” component because the author’s literature review found no other interventions that addressed alleviation of stress to improve coping of the identified group. This fact supports the author’s project and further research in this area of study.

### THEORETICAL FRAMEWORK

When beginning their study, Drs. Wells and Cagle interviewed caregivers to learn MAFCC perceived needs following a qualitative research methodology, grounded theory approach (Wells & Cagle, 2013). The aim of grounded theory in nursing studies is to analyze how a social process influencing health (e.g., caregiving) works in the context of people’s lives (“Nursing Research and Theories,” 2011). Grounded theory focuses on reciprocal actions by observing social interactions, conducting informal interviews, keeping field notes, and identifying useful written materials (Brown, 2011). Through interviews with MAFCCs, Drs. Wells and Cagle listened to caregivers’ personal experiences, used individual words as data, observed nonverbal cues, coded data for analysis, performed a selective sampling of literature, and developed relevant key themes for their study (Wells, Cagle, & Bradley, 2006).

With the help of their team, Drs. Wells and Cagle developed the Theory of “Becoming Stronger” to define the MAFCC experience based on study findings (Wells et al., 2006). This theory forms the foundation for this research study and the honors

project. The theory supports that cancer in the MA family causes life restructuring (Wells et al., 2006). Life restructuring occurs on a continuum; the two ends include “strategizing by prioritizing the patient” and “struggling by hurting too much.” If the caregiver has social support, “strategizing” will occur (Wells et al., 2006). “Hurting too much” and a failure to cope lead to “struggling” because of lack of caregiver support (Wells et al., 2006). Support that caregivers receive varies. The purpose of this honors project study is to increase the support team available to the MAFCC population. To achieve this, the study utilizes *promotoras de salud*, or community health teachers, to deliver a MAPS study intervention (Wells et al., 2006).

In addition to *promotra*-delivered coping support, MAFCCs’ beliefs in spirituality, or “Duty to God,” and duty to family both influence the continuum of possible caregiver outcomes. The theory’s ultimate outcome is for the caregivers find a sense of “becoming stronger” and to feel empowered (Wells et al., 2006). Other factors affecting the Theory of “Becoming Stronger” include language barriers, LEP, and limited resources for support. These factors generate more stress, which leads to “hurting too much.” Figure 1 in Appendix A depicts this Theory of “Becoming Stronger.”

Lazarus and Folkman’s Cognitive Stress Theory (1986) supports that increased stress causes mood changes, altered perceptions of burden, and negative caregiver health consequences. The Cognitive Stress Theory describes that stress results from an imbalance of supply and demand (Lazarus & Folkman, 1986). In the case of the caregiver, the burden of caregiving often outweighs her ability to care for her loved one; many times she reaches her physical limit or her own resources of time, money, and energy (Lazarus & Folkman, 1986; Scott, 2012). Lazarus and Folkman describe two

types of choices for personal coping: one in which a person perceives control and one in which a person feels little control (Scott, 2012). Needed family role changes due to a diagnosis of family cancer may lead to limited perceptions of life control by caregivers and a sense of uncertainty that leads to stress (Lobcchuk, McPherson, McClement & Cheang, 2012). The Cognitive Stress Theory also describes the importance of personal appraisal. This technique, recommended by various researchers, supports one's evaluation of internal and external factors and options to respond more positively to stressful and uncertain situations (Cagle & Wells, 2008; Scott, 2012). Lazarus and Folkman's theory specifically frames the stress management and coping skill acquisition goal of the PICO statement for MAFCCs the student author proposes.

The student author's *guía* focuses on educating adult MAFCCs about stress and options to alleviate that stress for improved quality of life. Relevant to that focus, it seems appropriate to also include in this paper the Theory of Adult Learning that addresses how adults learn best. This theory supports that learning should be both problem-based and collaborative (Queensland Occupational Therapy Fieldwork Collaborative [QOTFC], 2007). Malcolm Knowles originally designed the theory, identifying six principles of adult learning: internal motivation and self-direction; life experience application; goal-oriented behavior; focus on relevancy; practical thinking; and respect (QOTFC, 2007). As indicated by the adult's internal motivation, rapport is an important aspect of education in order to maximize the approachability of the learner (QOTFC, 2007). *Promotoras de salud* reflect this quality in the utilization in the MAPS sessions approach. By drawing on the caregiver's past experiences, the *promotora* understands the caregiver's voiced concerns and needs. The adult desire to be practical

with education reflects the importance of understanding the benefits of learning to cope with caregiver stress. Respect, or *respeto*, is a key value found in both the Theory of Adult Learning and in the MA culture (Crist, Ruiz, Tores-Urquidy, Pasvogel & Hepworth, 2013; QOTFC, 2007; Wells et al., 2006). The PICO statement (see above) supports the inclusion of the Theory of Adult Learning in this project paper.

### PROJECT DEFINITIONS

The key concepts of this honors paper include MAFCCs, cultural sensitivity, LEP, health literacy, *promotoras de salud*, caregiver role-strain, and stress.

*Mexican American female cancer caregivers (MAFCCs)* are any females in the MA culture who provide care for an ill family member with cancer in the home. For this project, the caregivers are women who live in the Fort Worth, Texas area, have a history of living in Mexico, and use Spanish as their language of choice for verbal and written communication. Additionally, they have completed no more than a high school education. Specifically, they are the primary home caregivers for a family member with cancer. MAFCCs are the principal population in this study, because there is such a pronounced lack of knowledge about their struggles and meaningful interventions to alleviate their caregiving stress.

The student author identified that a culturally sensitive approach was essential for this project. As described in “A Primer for Cultural Proficiency: Towards Quality Health Services for Hispanics” (2001), cultural proficiency is one of the ultimate goals of healthcare equality for minorities. However, one must be culturally sensitive to attempt proficiency. Cultural sensitivity holds cultures in high esteem to close cultural gaps to improve healthcare relationships, even if one does not speak the same language as the

patient (“Primer,” 2001). Cultural competency is a stepping-stone on the lifetime journey to becoming culturally proficient. Cultural competence enables healthcare providers to deliver in a respectful manner that is “responsive to the health beliefs, practices and cultural and linguistic needs of diverse patients” (USDHHS, 2013a, para. 1). One who practices cultural competence evolves from acceptance and respect for differences between cultures, continuing self-assessment of bias, expansion of cultural knowledge and resources, and adaptations of service and care (“Primer,” 2001).

*Limited-English Proficiency (LEP)* describes a lack of English language understanding and used by an individual not native to the U.S. This person does not speak English as a primary language and has a limited-ability to understand information either written or spoken in English (LEP.gov, n.d.). For this project, MAFCCs have LEP because Spanish is their primary language in the household. In a study completed by Wells et al. (2006), 22 caregivers spoke Spanish only and 3 were bilingual in a sample of 34 women. Because of LEP, caregivers have difficulty communicating with healthcare providers and understanding literature, because the vast majority appears in the English language. Researchers Leyva, Sharif, and Ozuah (2005) emphasize that only 22% of MAs with LEP in their study could correctly dose medications after reading a prescription label in English. The danger of incorrectly dosing medications is one concrete example of how LEP can affect the overall health of MAs. Misunderstanding medical documents such as consent forms (Wells & Cagle, 2010), difficulty ordering hospital meals, and the inability to read medication instructions are problems facing the MAFCC population due to both LEP and low healthcare literacy.

*Health literacy* is the sixth vital sign in healthcare due to its crucial importance to

the overall holistic healthcare experience (Heinrich, 2012). The Institute of Medicine (IOM) defines health literacy as the ability of individuals to obtain, process, and understand basic health information and services in order to make pertinent decisions about healthcare (Singleton & Krause, 2009). Because healthcare institutions write literature at complex scholarly levels, the average American has difficulty understanding the information. In regards to the MA population, 68% function at a level below the basic level of health literacy, according to the National Assessment of Adult Literacy (Singleton & Krause, 2009). Health literacy includes reading, comprehending, analyzing, decoding, reading instructions, weighing risks and benefits, and reading charts and diagrams (U.S. Department of Health & Human Services, 2013b). Health literacy is a description of the ability of the MAFCCs to understand medical resources related to their caregiver role.

The *promotoras* played a key role in this honors research project as deliverers of information on stress and coping to MAFCCs. They provided the intervention as outlined in the PICO statement. Anders, Balcazar, and Paez (2006) describe *promotoras de salud* as community health workers who are residents of a local community and provide an opportunity to more effectively address health disparities associated with MA health outcomes (2006). The *promotoras* provide outreach to the MAFCC community in a way that is culturally appropriate, comfortable, and welcoming to help MAFCCs. In this honors project, the *promotoras de salud* utilized the MAPS program developed by Drs. Wells and Cagle to educate and increase awareness about cancer caregiver struggles to improve low literacy and LEP caregiver coping. Utilizing *promotoras* aids in understanding LEP MAFCC needs. An incomparable advantage of using the *promotoras*

is that the researchers can assess the caregiver's current level of health literacy as well as simultaneously implement an effective intervention.

### LITERATURE REVIEW

The student author utilized databases CINAHL Complete, MEDLINE, and ProQuest Nursing & Allied Health Source, as well as print resources and government healthcare websites, to review current literature published on this topic. The inclusion criterion for this literature review included: MAFCC, LEP, female, caregiver stress, caregiver role strain, simple language, and health literacy. The majority of located articles appeared in the past five years, and most used qualitative research methodology.

The student author found an inadequate amount of literature specifically written about LEP MAFCCs struggling with role-strain. This lack of published research about LEP MAs caring for loved ones with cancer further indicated the need for this honors project study and intervention. Research on caregiver stress in the majority of studies was based on Caucasian caregiver populations. More information about cancer caregiver stress appeared when omitting the key terms "Mexican American" and "LEP," including literature published from the National Cancer Institute. The deficit of literature on this specified topic described in the student author's PICO statement indicated an information gap and the need for more research and quality interventions.

"A Primer for Cultural Proficiency: Towards Quality Health Services for Hispanics" describes aspects of the MA culture are crucial to understanding needed context for this honors project study (The National Alliance for Hispanic Health [NAHH], 2001). Primer chapters include an understanding of MA culture and language, ethnic group, history in the U.S., current Hispanic health status, the essential role of

community-based organizations, and the importance of healthcare intervention. The Primer (2001) explains that many persons overlook the need to reach out to MA individuals in the community, but that community-based intervention, such as the use of *promotoras de salud*, provide significant opportunity to expand outreach efforts. The Primer (2001) clarifies that health information translated to Spanish from English does not ensure that the message will be delivered. The NAHH argues that available resources must be appropriate and culturally relevant as well. Unfortunately, these resources remain limited in low-income and underserved MA communities. This lack of available, appropriate, and culturally proficient resources represents a need for change.

The primary sources for this research project were published literature about MAFCCs written by Drs. Wells and Cagle, the faculty heading the MAPS research studies in the Department of Nursing at the student author's undergraduate institution.

The article "Voices of Mexican American Caregivers for Family Members with Cancer: On Becoming Stronger" (Wells, Cagle, Bradley, & Barnes, 2008) used a grounded theory approach to describe the caregiver experiences of 34 MAFCCs. This article also supported development of the student author's PICO statement for this honors project. The researchers Wells et al. (2008) used interviews to gather qualitative data and axial coding as a part of a grounded theory approach to analyze the data. Additional quantitative data isolated the following variables: marital status, relationship to caregiver, caregiver education level, caregiver perception of her health status, and caregiver roles responsive to patient needs (Wells et al., 2008). The researchers found trends in MAFCC qualitative data to support development of the Theory of "Becoming Stronger." This theory centers on life restructuring as addressed earlier (see page 4) (Wells et al., 2006).

“Becoming Stronger” was a caregiving outcome identified by many of the 34 MAFCCs and included “discovering personal feelings of importance, life values, appreciation by others, and internal rewards for caregiving” (Wells et al., 2008, p. 227). In addition to the caregivers’ “renewed connection with God,” they reported a sense of duty to family (Wells et al., 2008, p. 227). Some helpful strategies for the caregivers included being present for the patient, dealing one day at a time, moving forward with optimism, suffering apart, and looking to God (Wells et al., 2008). Most importantly, the caregivers found that the more knowledge they possessed, the “better care they could give” to their loved one (Wells et al., 2008, p. 229). The caregivers’ desire to learn more and the lack of access to learning materials highlighted the importance of a readily available, easy-to-use reference guide. A structured grounded theory approach supported study rigor despite the small sample size of 34 MAFCCs.

“Building on Mexican-American Cultural Values,” authored by Wells, Cagle, and Bradley (2006), also supports understanding the MA culture to better meet the needs of cancer patients. The article identified and explained key values of the MA culture such as *respeto*, *personalismo*, *familismo*, *marianismo*, and *machismo*, which are essential to understanding the culture (Wells et al., 2006). Important aspects of this article included explaining the significance of developing a warm but modest approach to care to establish rapport among all parties and the importance of healthcare providers learning everyday terms in the Spanish language. Also, Wells et al. (2006) explain that teaching materials should be provided in Spanish. Incorporating family and religious practices into decision-making is key (Wells et al., 2006). This study embraced the valuing of holistic healthcare, an aspect of the MAPS sessions.

Another valuable study is “Blending Voices of Mexican American Cancer Caregivers and Healthcare Providers to Improve Care” (Cagle & Wolff, 2009). The purpose of this article was to “identify and categorize healthcare provider perceptions of the meaning of cancer to Mexican American female family caregivers” (Cagle & Wolff, 2009, p. 555). The researchers tied information in their study to that found in Wells et al. (2008). This study is unique by exploring the perspective of healthcare providers on issues of language and healthcare barriers to MAFCCs. The Cagle and Wolff study further emphasizes the MA culture’s value of denying caregiver burden, traditional gender roles such as *machismo*, holistic care, strong ties to faith, and socioeconomic aspects of care (2009). Themes resulting from the content analysis included fear of the cancer diagnosis, interpretation of cancer as a punishment, values of maintaining hope, selective disclosing of medical information, strong Catholic beliefs, and trust in the doctor (Cagle & Wolff, 2009). Cagle and Wolff emphasize the necessity to “generate needed knowledge for a culturally sensitive care intervention” (2009, pg. 556). However, this article has limitations such as a small sample size of 20 healthcare providers. Most importantly, this was an indirect study on the proposed population because the healthcare providers were interviewed instead of the MAFCCs themselves. This provided a different perspective on the topic.

The article “Informed Consent in Mexican American Family Cancer Caregivers: Strategies to Promote Diverse Community Research” (Wells & Cagle, 2010) also provided foundational ideas for this honors project paper. This article focuses on the implementation of strategies to overcome LEP barriers, literacy issues, and address cultural beliefs and values in MAFCCs. This specified population is vulnerable, as

described by Wells and Cagle (2010), because of poverty, lack of insurance, low health literacy, LEP, and language differences. The study explains the need to create culturally appropriate consent forms for this vulnerable population by pilot testing consent forms with MAs and using MA clinical experts. Similarly, the honors project was assessed for contextual cultural congruence in the Spanish language and deemed both culturally sensitive and appropriate. Wells and Cagle's study stressed the need for further research to be done on this topic to truly understand cultural disparity complicated by inappropriate study consent forms, lack of cultural sensitivity in communication materials, and an overall shortage of health education materials written in Spanish.

The article titled "Perceived Mood, Health, and Burden in Female Mexican American Family Cancer Caregivers" combined both quantitative and qualitative aspects of research to yield impressive results about MAFCCs. The authors Wells, Cagle, Marshall, and Hollen (2009) explained the lack of literature available on this population and their desire to use a multi-method approach to data collection. The researchers utilized not only interview techniques, but also quantitative measures such as the Profile of Mood State, F-12 Health Survey, the Burden Interview, and a Short Acculturation Scale for Hispanics to yield valued results (Wells et al., 2009). As with other studies by Wells and Cagle, life restructuring and "Becoming Stronger" define the MAFCC experience (Wells et al., 2009). This study is unique in that it quantitatively described negative caregiving outcomes such as tension, depression, anger, vigor, fatigue, and confusion, whereas in other studies caregivers described this information qualitatively. Even with a small sample size (n=34), study findings were congruent with other published studies present in the current literature.

An evident literature gap exists related to MAFCC stress and thus indicates that more research is necessary. Thus far, Dr. Wells and Dr. Cagle lead research on this topic and represent the vast majority of available materials. Although their contributions are essential to MAFCC healthcare outcomes and fundamental to the student's honors paper project, it remains essential for healthcare providers to propose interventions that will increase positive outcomes for MAFCCs in the future.

### SUMMARY OF LITERATURE REVIEW

The literature review supported the need for a solution to the clinical question proposed: In limited-English proficient (LEP) Mexican American family cancer caregivers (MAFCCs) (*population*), what is best practice to guide development of a low-literacy culturally sensitive booklet focused on stress and coping (*issue*) and delivered by a *promotora de salud* (*intervention*) to improve MAFCC role stress (*outcome*)?

After reviewing literature, there is a definite lack of research on the MAFCC population. Development and evaluation of a culturally sensitive, accessible educational intervention delivered by *promotoras de salud* to meet perceived coping needs of low literacy and LEP MAFCCs was the goal of this student author's honors project. This intervention aimed at improving both caregiver health and that of the ill family member with cancer.

### OVERVIEW OF THE INTERVENTION

The student author developed easy-to-use reference information to provide LEP MAFCCs a support tool to manage stress and decrease role strain. Specifically, the resource created through the honors project includes easily-accessible community resources, interactive confidence building portions, easy-to-understand facts about stress

management, and useful easy-to-integrate coping skills for the caregivers. The guide was written in Spanish at a low-literacy level that is easily understood. The caregiver can write-in her own thoughts and opinions about the information provided so that she may refer back when needed. The tool is also small in size to fit into a purse or other travel bag for convenience. This resource, coupled with the MAPS sessions guided by *promotoras*, aims to decrease caregiver role strain in an oral tradition format compatible with the MA culture.

### PROCESS OF DESIGN

Conceptually, the student-created guide (also known as the *guía*) is easy-to-use, portable, and supplemental (see Appendix B). During the *promotora* sessions, the student author observed that the caregivers learned through auditory learning, as per oral tradition. However, many times during the sessions the caregivers would try to refer back to various aspects of the MAPS 2 module but would forget the specifics. Without papers to organize their thoughts, the caregivers struggled with remembering. As educators and students alike recognize, written learning highly supplements auditory learning. The student author realized this need in the MAPS intervention, creating the inspiration for the honors project.

The student author used the MAPS framework for the Module 2 session to develop the outline of the stress-coping guide to format into a booklet. The guide highlights the various topics addressed by the *promotora* in the role-play sessions. In addition to providing relevant information drawn from the module, the guide provides space for the caregiver to write her own ideas. This provides the caregiver room for reflection while she processes coping skills and stress management strategies from the

*promotora*. At the end of the session, the caregiver is able to keep her guide as a reference for coping strategies and stress management to remind her of the topics reviewed by the *promotora*.

### THE GUIDE

The U.S. Department of Health and Human Services (USDHHS) devised *The National Action Plan to Improve Health Literacy*. The national stance includes that everyone has the enumerable right to health information in order to make informed decisions and that health services should be delivered in methods that are easily understandable and beneficial to one's health, longevity, and quality of life (USDHHS, 2010). The USDHHS supports lifelong learning and the acquisition of skills to promote overall health outcomes. According to the USDHHS analysis of various literature, "the impact of limited health literacy disproportionately affects lower socioeconomic and minority groups" (2010, p. 4). It highlights that those who earned less than a high school diploma or GED, non-native English speakers, and immigrants are more likely to experience limited health literacy (2010). These characteristics reflect those of the MAFCC population in the honors student's project. There is a strong indication for change, and USDHHS claims that there is a "link between limited health literacy and poor health" as evidenced by studies done by the Agency for Healthcare Research and Quality (AHRQ) and IOM (2010, p. 9). If health literacy does not improve or actions are not taken, the real present-day healthcare cost may be \$1.6 – 3.6 trillion (Feinberg, Reinhard, Houser & Choula, 2011). Preventive steps are necessary to avoid this burden on the national budget and overall health outcomes of patients and their caregivers.

According to the AARP, informal unpaid family caregivers provide an average of

21 hours of care per week, totaling 1,080 hours per year (2006). Texas has the second greatest number of caregivers by state (over 5 million); this number of caregivers contributing unpaid hours represents an estimated economic value of \$34 million annually in the State of Texas alone (Feinberg et al., 2011). Without MAFCCs such as the women in this study, these family members with cancer diagnoses possibly may suffer high financial burdens from relying on professional medical services and caretakers, or their health may further deteriorate as a result.

Observing this need for healthcare literacy interventions, the student author researched successful evidence-based approaches for inspiration. AHRQ published “Health Literacy Interventions and Outcomes: An Updated Systematic Review,” which analyzes evidence-based practice to support effective learning in LEP and low literacy population learning. Successful ingredients in such practice include using simplified language, few words per page or document, presentation of groups or chunks of ideas, large font sizes, and plenty of white space (2011). These characteristics contribute to document design and readability. “The Health Literacy Style Manual” (Maximus, 2005) reflects many of these same AHRQ recommendations. In addition, Maximus (2005) includes other helpful strategies in creating documents to increase health literacy. Some of these include avoiding making the page too crowded, using similar formats on each page, expressing only two or three key messages or ideas per page, using the active voice instead of the passive voice, and utilizing plain language (2005). Plain language is writing that is clear to most readers the first time they read it, well-organized and streamlined, not wordy or long, simple vocabulary, and uncomplicated sentence structure (Maximus, 2005; USDHHS, 2013c). Also, a simple change of font style can significantly

impact the readability of a document. Maximus (2005) explains that serif fonts like Times New Roman are better for blocks of text, while sans serif fonts like Arial are more effective for titles and headings.

By following guidelines set forth by USDHHS and AHRQ, the student author modeled a prototype booklet to follow the script of the MAPS Module 2 intervention. Overall, the student aimed to achieve the “Three A’s” of health literacy materials developed by the Centers for Disease Control and Prevention (CDC); health information should be accurate, accessible, and actionable (2014). The pages reflect these features as well as small amounts of information per page to not overwhelm the readers, use of images and white space, and plain language. The following section provides an outline sketch for each page in the guide (*guía*). Appendix B exhibits each page.

#### Title/Cover – Viva su vida: Manejando el estrés

The title cover of the guide is *Viva su vida: Manejando el estrés*. This means “Live your life: Managing stress” in English. The subtitle states the target population “A guide for women who are caregivers for a family member with cancer.” The image of an open sunflower on the title page signifies hope and warmth for the caregivers.

#### Page 2 – Relationship between Caregiver Health and Family Health

The second page represents the relational cycle of health between the caregiver and the family member with cancer. This conceptual model exemplifies the theme and purpose of MAPS Module 2. The caregivers must see that their own health and the health of the family members that they care for affect one another. By caring for themselves, the caregivers will then have more strength both emotionally and physically to care for their loved ones with cancer.

### Page 3 – Value of Role

This page emphasizes the value of the caregiver. The title expresses the idea “I am important,” and that the caregiver is irreplaceable in her role within the family. The question asks the caregiver what are some of the specific tasks she performs in her caregiver role. This is significant because many of the caregivers, as witnessed during the intervention sessions, appear to not realize the significant amount of work they do every day. They question why they are fatigued and exasperated in their role as caregiver; this page in the guide interactively asks them to reflect on their daily tasks. Examples provided are cooking, cleaning the home, caring for the children, and visiting the doctor. The guide provides lines for the caregiver to write-in more tasks.

### Page 4 – Life Stresses and Interventions

This page expresses the idea of identifying specific stresses in the caregivers’ lives. Previously explored literature, such as Lazarus and Folkman’s Cognitive Stress Theory, states the factors influencing caregiver stress. These stresses include uncertainty about the diagnosis, lack of sleep, low funds, lack of family support, and no energy. The image of the empty fuel tank symbolizes these aspects of the caregivers’ lives that are seemingly lacking or empty. There is a section where the *promotoras* lead the caregivers to begin to think positively and constructively about their situation. A question appears to seek caregiver ideas about what they can do to improve their situations. The caregivers and *promotoras* then talk through ideas of stress-relieving interventions the caregivers can take.

### Page 5 – Signs and Symptoms of Stress

This portion of the MAPS intervention session guides the *promotoras* to teach the

caregivers about the physical manifestations of stress. The caregivers most commonly present these symptoms, as found in previous studies by Cagle and Wells. The symptoms listed include depression, worry, high blood pressure, loss of restful sleep, chest tightness, and headaches.

#### Page 6 – Support: Lending a Hand

The focus of this page is to reassure the caregiver that she is not alone during this struggle of caring for a loved one with cancer. This is one of the most crucial aspects of the module. Many caregivers respond that they feel alone during this time in their lives and that they are drowning in stress. This page emphasizes that the caregivers are not alone in this struggle and that social support is there. Support is all around – the MAFCCs are assisted to identify it.

The *promotoras* express in this module and page that asking for help is crucial. In previous interventions and studies in the MAPS series, many women were nervous or scared to ask for help from other family members or friends when functioning in the role of caregiver. This page works through the hesitancy of asking for help. The *promotoras* present scenarios for the caregivers and asks whom the caregivers would go to for support in that situation. For example, a question posed to the caregivers is, “Whom would you call to go shopping with?” The image of the outstretched hand grasping another hand implies that a helpful hand is lending itself to the caregivers. They just need to take it.

#### Page 7 - Primary Contact

After reviewing various resources and contacts available to the caregivers, the *promotoras de salud* ask the caregivers to identify a primary contact person for help.

Many times this individual is difficult for the caregivers to identify, so organizing the previous page is advantageous to assisting the caregivers with identifying their social support system.

#### Page 8 – Deep Breathing Exercises

Content and questions in this portion of the MAPS Module 2 intervention offer a time for caregiver relaxation. The *promotoras* lead the caregivers to step away from the lesson plan for a hiatus filled with deep breathing exercises. For the next few minutes, the *promotoras* lead the caregivers through a series of deep breathing techniques. The image on the page represents tranquility and the peacefulness that accompanies deep breathing. The words express the idea that while deep breathing, the body becomes oxygenated and that oxygenated blood flows from the lungs to the heart and brain. This process strengthens the body as a whole, bringing caregiver peace and clarity.

#### Page 9 – Natural Remedies

Congruent with the MA culture, natural remedies are heavily present and influential in the management of stress and promoting relaxation. In this portion of the module, the *promotora* allows the caregiver to express her thoughts about helpful natural remedies. Many times the *promotora* prompts the caregiver by providing examples such as hot chamomile tea. This page allows for the *promotora* and caregiver to share and write ideas for other natural remedies.

#### Page 10 – Stress Alleviation Methods

This page of the guide expresses the theme of “Breathe, Relax, Think.” The question prompts, “In what ways can you alleviate stress?” The *promotoras* encourage the caregivers to reflect back a few pages in the *guía* when they engaged in deep

breathing exercises. As an example of a way to alleviate stress, deep breathing allows the body to relax. The *promotora* expresses to the caregiver that this allows one to think more clearly. Next, the *promotora* and caregiver review other methods to alleviate caregiving stress.

#### Page 11 – Stress Alleviation Methods (Continued)

This page is a continuation of the previous page on specific methods of stress management that the *promotoras* review with the caregivers. Along with the specified interventions for stress management and coping throughout the module including natural remedies and deep breathing, the caregivers write other methods appropriate to their lifestyles. Examples caregivers generated in past sessions include taking long walks, speaking with community religious leaders and counselors, listening to music, journaling, and simply speaking with friends and loved ones about the role strain they are experiencing as caregivers for family members with cancer.

#### Page 12 – Certificate of Completion

This page signifies the caregiver completion of the module. Too often caregivers do not receive recognition for their efforts in caring for a family member with cancer. The caregiver may also be the head of the household and the main source of income, along with being a caregiver. Many in the family ignore this role strain, and the caregiver resorts to internalizing this isolation, thereby augmenting stress. The simple act of recognizing the caregiver's strength in her passion to care for the family member with cancer relieves some of that stress. This page represents a certificate for completing MAPS Module 2. The caregiver will sign her name in the space. Following her name are the phrases, "Thank you for your participation; you are valued in your role as caregiver;

value your health.” This idea traces back to the main theme of the module that if the caregiver cares for her own health, the overall health of the family member suffering from cancer will benefit. The health statuses of both are interrelated.

#### Page 13 – Additional Information

This final page of the guide is a reference list of established organizations related to caregiver support and includes phone numbers and websites. The list includes the U.S. government’s contact for women’s health information, the Third Generation, Medicare and Medicaid services, the Alliance for Family Caregivers, the National Association of Family Caregivers, the National Services for Respite Locations, and Family in Action.

#### PROCESS OF IMPLEMENTATION

The student author participated as a research assistant and Spanish interpreter during two MAPS Module 2 sessions on November 12, 2013 and April 22, 2014. Two *promotoras de salud* and two MAFCCs participated in each session. Each session included two groups involving one *promotora de salud* and one caregiver, a lead researcher (Cagle or Wells), and one or two Spanish student interpreters. Each session was two hours in duration; the first hour was for the intervention to take place and the second hour was to review findings and receive feedback from all participants to achieve a holistic perspective of the experience.

Researchers explained the goals and expectations before beginning the intervention. The *promotora de salud* and the caregiver were to interact in a role-play scenario as if the *promotora* were arriving at the home of the caregiver. The researchers previously provided the *promotoras* with a detailed outline of the module from which they were to teach (listed in Appendix C). Once the interventions began, the observers

recorded field notes of the experiences. Such field notes are included in Appendix D and Appendix E.

Following the interventions, *promotora* and caregiver participants received certificates validating their study involvement. The image below is an example of the role-play setting and award distributed on November 12, 2013.



**Figure 1.** Group Session

### PROCESS OF EVALUATION AND MODIFICATIONS

Qualitative feedback from caregivers and *promotoras* in the role-play sessions and from session attendees at the National Association of Hispanic Nurses (NAHN) conference in Miami, Florida allowed for evaluation of content and process of the *guía*. The reviewers positively noted aspects of coloration, word-choice, organization, and overall style. Along with those aspects, the viewers analyzed cultural congruency and appropriateness for the population.

After the completion of the role-play interventions, the team regrouped for discussion. Each individual shared her experience and opinion of the intervention. The student author shared her plan in the November 12, 2014 role-play session to develop a pocket-sized guide to supplement learning materials for a previously developed script on

MAFCC stress and coping. All parties enthusiastically endorsed this idea. During the April 22, 2014 role-play experience, use of the first prototype of the pocket-sized guide created by the student author occurred and further participant feedback gained to refine the *guía* for the NAHN presentation. Presentation of this *guía* occurred as part of a larger presentation by Drs. Wells and Cagle at a NAHN plenary session in July 2014. The conference audience expressed opinions of the cultural congruency and overall satisfaction with the guide. Continued refinement of the *guía* to insure cultural congruency and ease of delivery occurred via student author work with Mrs. Karla O'Donald, an honors project committee member. The most updated prototype appears in this honors project paper (Figure 2, Appendix B).

#### CLINICAL SIGNIFICANCE

The pocket-sized guide, or *guía*, represents an aspect of teaching materials lacking in the current literature and educational materials available to MAFCCs. The student author achieved successful outcomes from her implementation of the supplemental pocket-sized guide for the pre-existing module. The guide received positive and constructive feedback throughout its development. Currently, the student author has not implemented concrete methods of measurable resources to determine the guide's efficacy. The aspired future outcomes of this intervention include increased confidence of the caregivers, increased coping skill attainment, increased stress management, and increased understanding of her life situation. As the student author continues her research with Drs. Wells and Cagle, she plans to create pre- and post-assessment tools as measures for determining these outcomes as met or unmet.

This pocket-sized guide intervention aims to directly benefit the MAFCC

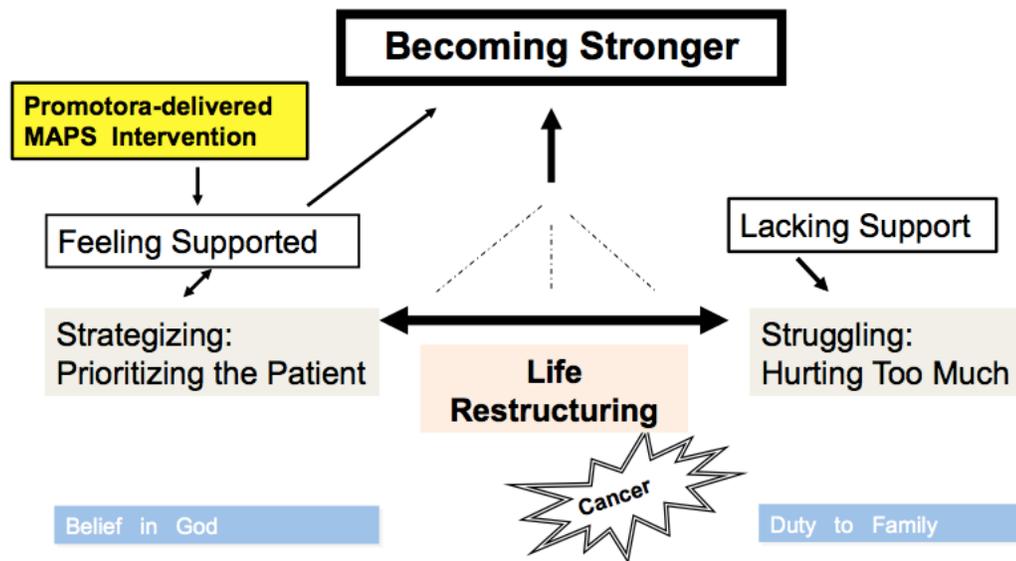
population undergoing role strain. The reviewed evidence, i.e. literature, pilot study and qualitative data suggest that this pocket-sized booklet supports best practice to guide MAFCC's in stress-coping. Furthermore, the guide addresses a need for resources available in the Spanish language and at a low health literacy level to address the LEP population in Fort Worth, Texas, and perhaps surrounding areas.

### CONCLUSION

Low health literacy exists throughout the nation but specifically affects minority groups, especially in those with LEP. Due to the deficit of easily attainable culturally sensitive supportive materials available for MAFCCs, many suffer from increased levels of stress and lack coping skills to manage role strain. As evidenced by the literature, there is a clear need for intervention in this specified population. The student author, with collaboration from her honors committee, developed an easy-to-use culturally-sensitive instructional guide (*guía*) to respond to needs for improved coping skills and stress management among MAFCCs. Based on this project, the student author aspires to further collaborate with researchers involved in MA caregiving work and *promotoras de salud* in the Fort Worth, Texas community to implement interventions to support constructive and instrumental change in the health literacy rates of the MAFCC population.

## APPENDIX A

## Theory of Mexican American Family Cancer Caregiving

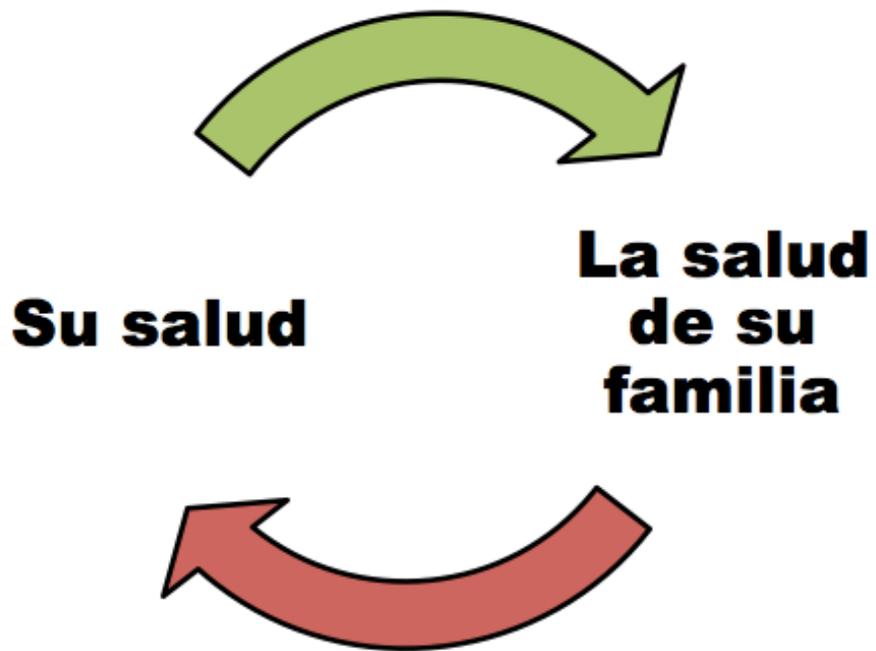


Wells, Cagle, & Bradley, September 2006

APPENDIX B

**Viva su vida:  
Manejando el estrés**

Una guía para mujeres que cuidan  
de familiares que sufren de cáncer



# Soy importante

Todo lo que usted hace es importante al cuidar a un familiar que tiene cáncer. ¿Cuáles son algunas de las actividades que **usted hace**?

- ✓ cocinar
- ✓ limpiar la casa
- ✓ cuidar a los niños
- ✓ citas con médico
- ✓ \_\_\_\_\_
- ✓ \_\_\_\_\_
- ✓ \_\_\_\_\_
- ✓ \_\_\_\_\_

## ¿Qué le causa el estrés?

**Ejemplos**

- incertidumbre sobre la diagnosis
- falta de descanso
- falta de dinero
- falta de apoyo familiar
- falta de energía



## ¿Qué le gustaría mejorar en si misma?

---

---

---

---



# Apoyo

Aquí estoy ofreciendo una mano



## ¿A quién puedo llamar...

## Contactos

- Para ir a una cita conmigo?
- Para dar un paseo a algún lado/lugar?
- Para ayudar a preparar una comida/limpiar la casa?
- Para ayudar como cuidador mientras tomo un descanso?
- Para apoyo espiritual/para platicar?
- Para ir de compras conmigo?
- Para responder a las preguntas que tengo sobre medicamentos/como cuidador?

# Contacto Principal

¿Quién es esta  
persona para usted?



Nombre:

---

Número de teléfono (de casa):

---

Número de teléfono (celular):

---

Correo electrónico:

---

## Su Apoyo Principal



Tener buena **oxigenación** en nuestro cuerpo ayuda a nuestro sistema de **inmunológico**, hace nuestro **CORAZÓN MÁS FUERTE**,

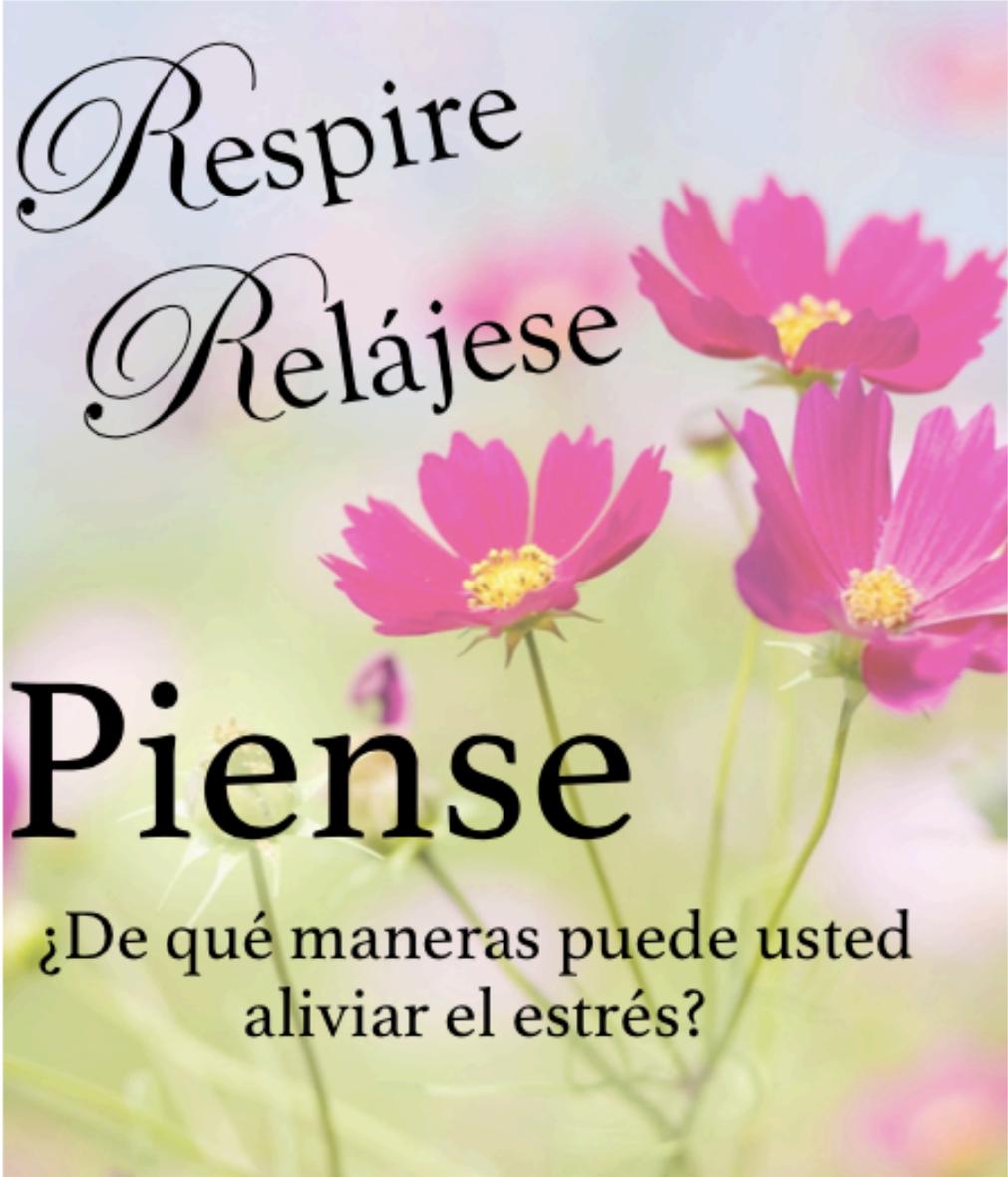
promueve **la digestión** y nos lleva a

*la paz y la claridad*  
*Respira*<sup>mental</sup>

# Remedios Naturales



A white notepad with ten horizontal lines, set against a background of green leaves. The notepad is positioned in the center of the page, and the lines are evenly spaced, providing a space for writing notes or a list of natural remedies.

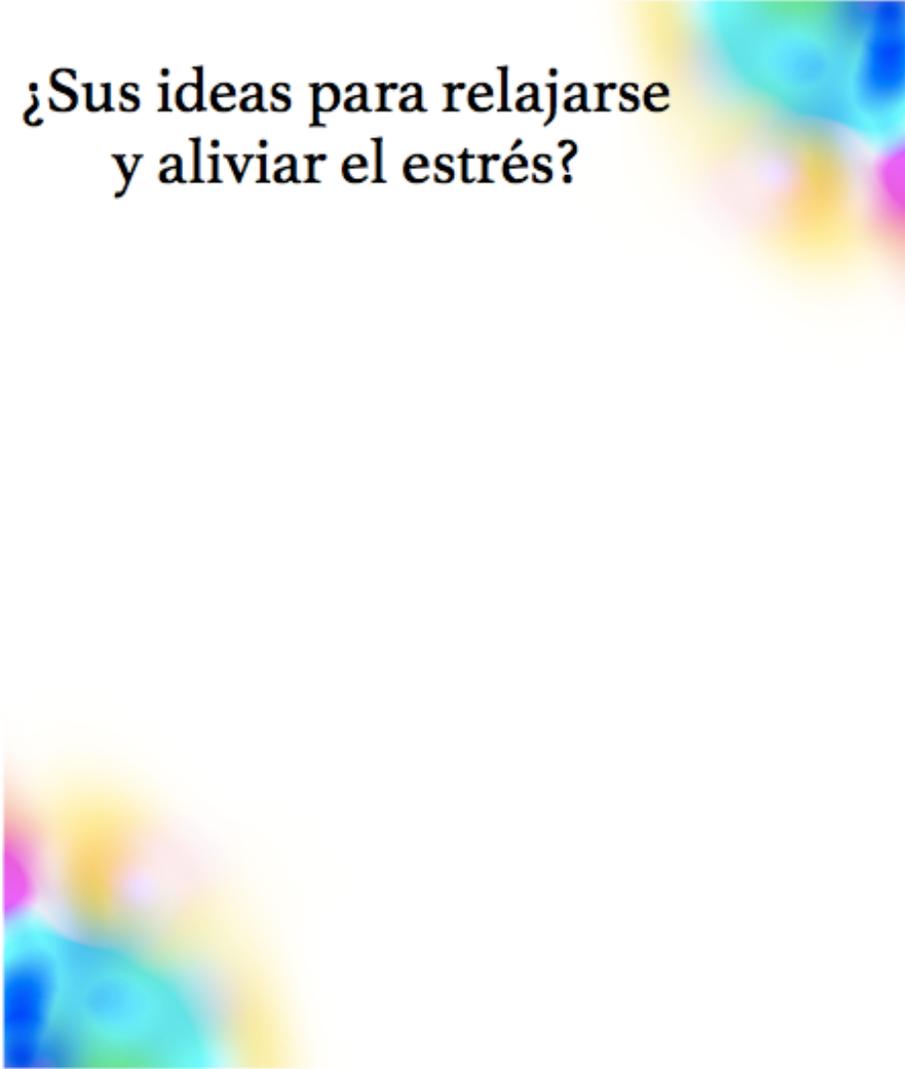
A photograph of several bright pink cosmos flowers with yellow centers, set against a soft, out-of-focus background of more flowers and green foliage. The text is overlaid on the top half of the image.

*Respire*  
*Relájese*

**Piense**

¿De qué maneras puede usted  
aliviar el estrés?

¿Sus ideas para relajarse  
y aliviar el estrés?





Se reconoce la participación de

---

Gracias por su participación

Usted está llena de valor

Valore su salud

## Para obtener más información

del estrés del cuidador, llame a [womenshealth.gov](http://womenshealth.gov)  
al 1-800-994-9662 o comuníquese con las siguientes entidades:

### **Administración de la Tercera Edad**

Número telefónico: 1-800-677-1116 (EN/SP)

Dirección en Internet: <http://www.aoa.gov>

<http://www.eldercare.gov>

### **Centros para Servicios de Medicare y Medicaid**

Número telefónico: 1-800-633-4227(EN/SP)

Dirección en Internet: <http://www.cms.hhs.gov>

### **Alianza de Cuidadores Familiares**

Número telefónico: 1-800-445-8106 (EN/SP)

Dirección en Internet: <http://www.caregiver.org>

### **Asociación Nacional de Cuidadores Familiares**

Número telefónico: 1-800-896-3650(EN/SP)

Dirección en Internet: <http://www.nfcacares.org>

### **Servicio Nacional de Localización de Servicios de Relevo**

Número telefónico: 919-490-5577 (EN/SP)

Dirección en Internet: <http://www.respitelocator.org>

### **Familias en Acción**

Número telefónico: 503-201-9865 (EN/SP)

Dirección en Internet: <http://www.familiasenaccion.org>

## APPENDIX C

1

MAPS2STRESSCOPING/WELLS/CAGLE/ 9/19/2013

### **Multi-disciplinary Program of Support (MAPS) for Mexican American Family Cancer Caregivers**

#### **Stress and Ways to Cope**

**English and Spanish Version—Spring 2013**

**Authors: Dr. Carolyn Cagle, Dr. Jo Nell Wells, Desiree Ortiz & Arnoldo Cabral**

#### **0-5min Step 1: Introductions**

CHW says: "Hello Señora \_\_\_\_\_."

"I am \_\_\_\_\_. It is so good to see you from the last time I visited."

"How are you feeling today?"

"How is \_\_\_\_\_ (ill family member) doing today?"

CHW says, "Hola Señora \_\_\_\_\_".

Yo soy \_\_\_\_\_. Me da mucho gusto de verla. ¿Como se siente hoy? ¿Cómo está su ser querido?

"I would like to just discuss once again (?) why I am excited to be here today. I am a Certified Community Health Worker. Sometimes I am called a promotora. This means that I am very fortunate to work with people from my own culture. I help those people learn about ways to promote their health and cope with illness. The last time we met you told me, as a family caregiver for a patient at the JPS Center for Cancer Care, that you agreed to be in a program to help MA cancer caregivers gain skills and knowledge to provide care to their loved one with cancer. I am employed by that Program (?)"

"Me gustaría discutir de nuevo porque me da tanto gusto de estar aquí con usted hoy, este día. Yo soy un promotor de salud, certificado, también me llaman Promotora. Esto quiere decir que afortunadamente tengo la oportunidad de trabajar con gente de mi propia cultura, para enseñarles diferentes maneras de promover la salud y ayudarles a enfrentar diferentes enfermedades. En mi última visita, le explique que usted, cómo cuidador primario de su familia, de la clínica JPS, dio su consentimiento de estar en este programa, diseñado para darle apoyo a usted mientras que cuida a (NOMBRE DE PACIENTE).

"As you remember, there are 4 sessions in this Program and they will occur in your home. The Program also involves calling you at home between the home-based sessions.. The purpose of the home visits is to help you, as the caregiver, to care for yourself so you can care for your loved one with cancer".

"The last time, I spoke with you about ways to talk with others about \_ (patient's name) \_\_\_\_\_ and his/her cancer."

"How has the last lesson helped you?"

"Como recuerda, habrán 4 sesiones como la última vez, en su hogar, y también llamadas por teléfono entre medio de las visitas. El propósito de estas visitas es para ayudarle como el cuidador primario, de cuidarse a sí mismo(a). "

"La última vez que hablamos, le mencione maneras de hablar con otros sobre (PACIENTE) y su enfermedad."

"Como le ayudo esa lección?"

"For session two of the Program, I want to visit with you today for about an hour to an hour and a half. I want to discuss stress related to being a caregiver and ways to decrease some of that stress to allow a more comfortable caregiving experience for you."

"para a la segunda sesión de este programa que es la lección de hoy, quiero hablar sobre el estrés que resulta con cuidar a un ser querido con enfermedades, y maneras de aliviar partes de ese estrés".

#### **5-6 min Step 2: Importance of the Caregiver**

"Señora \_\_\_\_\_ I would like to begin by asking you a personal question. I want you to feel very comfortable with sharing your answer. I promise you, as a promotora in the community, I am not here to judge. I just want to give you information and skills to help you comfortably deliver care to your sick family member."

"Señora, me gustaría empezar por hacerle una pregunta personal. Quiero que se sienta muy cómoda, y le aseguro que, como promotora comunitaria no estoy aquí para juzgar, sólomente para ayudarle ser cuidador del paciente".

Have you ever felt overwhelmed in your caregiving job? Or have you been unable to express your emotions while providing care for \_\_\_\_\_?"

"It is normal to feel overwhelmed or stressed during moments of caregiving. Sometimes in providing care to a sick family member, we deny (?) our own health needs. It is very common to want to make others happy when they are ill. But, as a caregiver you must also take time to care for your body, mind and spirit. This care will help you become strong for your loved one and provide the best care."

"¿Alguna vez se ha sentido abrumado como cuidador o incapaz de expresar sus emociones mientras cuida a su ser querido?"

"Es normal sentirse estresado en algún momento en que cuida su ser querido. De vez en cuando, mientras que tenemos el trabajo valiente de ser un cuidador, descuidamos nuestras

The focus of this icebreaker is to identify that the promotora and caregiver may share some of the same stressors (stresses?). This common experience may empower the caregiver by revealing she is not alone in how she feels about stressors. This may help the caregiver feel more comfortable working with the promotora.

Activity: Have the caregiver write down her top ten stressors on a worksheet. The promotora will also take part in this activity and can offer some examples of stressors such as too little income to meet family food, housing, health care needs; long work hours that prevent caregiving desires; fatigue related to multiple roles of caregiver; lack of family support for caregiver or sick family member; uncertainty about cancer diagnosis (is there content from the first MAPS module that could be reinforced here?)

The promotora and caregiver will share their stressors and how they influence their life and goals for daily work and family.

El propósito de este rompehielos es de identificar que la promotora y el cuidador tienen en común algunos factores que causan el estrés. Esto quizás dará poder al cuidador, al revelar que no están solos en cómo se sienten acerca de su estrés, y puede ayudar a que se sientan más cómodos trabajando con la promotora.

Haga que el cuidador escriba diez factores principales de su estrés en una hoja. La promotora también participe en esta actividad, y puede ofrecer algunos ejemplos de factores de estrés como las finanzas, las horas de trabajo, conflictos con miembros de la familia, etc.

La promotora y el cuidador discutirán sus estresores (?).

CHW: "At this time I would like to begin this second lesson with a small activity. Here is a notebook for you. It is a gift from the Program. You can use the notebook to write anything down that needs to get off your mind. These things may be stresses that make you feel unhappy, overwhelmed, or ill. When you feel these stresses, you may want to write about them in the notebook when you take a rest from providing care to your loved one.

Ahora me gustaría comenzar la lección con una actividad pequeña. Aquí tiene una libreta, es un regalo para que cuando usted sienta el estrés, tome un descanso de cuidar a su ser querido y escriba del el estres para cuitarle el estrés de la mente...

It is important to do something about the stresses you may feel as a caregiver. Stress can begin to have an effect on our body. Some signs of stress include chest pain, headache, changes in blood sugar and blood pressure, feeling depressed or angry, being unable to sleep or just feeling constantly worried."

Es importante de reconocer y manejar los estresantes como cuidador. El estrés puede empezar a tener un efecto en nuestro cuerpo. Señales de esto incluyen dolores de pecho, cabeza, cambios en la presión de la sangre y de la azúcar en la sangre, sentirse deprimida o enojada, perder sueño, o sentirse preocupada constantemente.

propias necesidades por satisfacer a los demás. Como cuidador también debe tomarse el tiempo para cuidar de su propio cuerpo, mente y espíritu para ser fuerte para su ser querido y poder dar una atención óptima. "

"I reassure you – it is very common to feel alone, fatigued, depressed or angry when you are a caregiver. Our time today will focus on those feelings and how to prevent and respond to them if they happen. Your job as a caregiver is very important. I am honored to spend time today with you to tell you how much your hard work and dedication to your loved means to that person and others.

"During our lesson today we will talk about ways for you to manage stress. We want you to stay healthy and continue to provide the best care for \_\_ (patient name) \_\_\_\_\_."

"Quiero asegurarle que sentirse sola, fatigada, deprimida o enojada son emociones muy comunes entre los cuidadores. Yo me siento honrada de tener la oportunidad de decirle lo mucho que su trabajo y dedicación a su ser querido es valorada."

"En nuestra lección de hoy, hablaremos de varias maneras de manejar su estrés para que usted pueda mantenerse saludable y que pueda seguir dando atención a su ser querido."

"During our talk, feel free to ask questions. In fact, I would love to talk to you as a friend (?). I want to provide support that feels comfortable to you."

"We will do some activities to discover some of the stresses in your life. We will also take time to focus on our breathing. We will also make a soothing tea to calm our nerves. You may wish to use that tea during your day to decrease your stress with caregiving".

"If at any time you feel uncomfortable with sharing your thoughts in the lesson, please let me know. I want to make sure this lesson helps you feel relaxed and safe and gives you some ideas of how to manage caregiving stress."

"Durante la lección, con confianza haga preguntas. Me encantaría hablar con usted como amiga para poder darle un apoyo significativo".

"También vamos a hacer algunas actividades para descubrir las tensiones en su vida. También tomaremos algún tiempo para concentrarse en la respiración y hacer un té calmante para calmar los nervios".

"Si en algún momento usted se siente incómoda con participar en la lección, por favor dígame. Quiero asegurarle de que este es un ambiente muy relajado y seguro durante la lección. "

### **6-12min Step3 Activity: Identifying Your Stress**

¿Le gustaría mostrarme su lista?

CHW: "As we share our lists of stresses, we see there are different things that cause stress in different persons. One of the reasons for stress may be there is never enough time in the day to do what we want. . Stress may also result from taking care of our loved ones when we cannot manage our other family roles. Money issues (not enough money and the need to ask family members for money, etc.) may also cause personal stress."

En compartiendo nuestras listas de estrés, podemos ver que hay muchas causas de estrés en cada persona. Algunas de las causas de estrés pueden ser relacionados con el pensamiento que nunca hay suficiente tiempo para hacer las cosas durante el día, o quizás estamos tan ocupados cuidando a nuestros seres queridos que no podemos manejar nuestros deberes con la familia. Otra tema que puede causar el estrés es la falta de suficiente dinero y tener que pedirles dinero a la familia.

"What are some things you have done to manage stressful situations (stresses) in the past?"  
*Allow caregiver to share*

Cuales son algunas de las cosas que ha hecho para manejar estas situaciones estresantes en el pasado?"

*Deje que el cuidador hable*

#### **12-20 min Step 4: Identifying Support Your Support Network**

CHW: "I understand that being a caregiver is very overwhelming. Often times you can feel so alone. However, it is important to know that your role is very important and it is normal to feel a bit stressed."

"A good way to deal with stress is to ask for help from those you trust. You should be honest about your ability to meet your caregiver demands. It is very important to know when you need to ask for help."

Entiendo que ser una cuidadora puede a ves en cuando sentirse abrumada, y sola. Sin embargo, es importante reconocer que su trabajo como cuidadora es muy importante y es completamente normal de sentirse un poco estresada.

Una buena manera de manejar su estrés es pedir ayuda a los quien usted les tiene confianza. Usted debe ser honesta acerca de sus habilidades para satisfacer sus demandas como cuidadora y darse cuenta cuando es necesario de pedir ayuda.

"Who are people that you think of when you feel lonely or stressed? Let's make a list of useful names and phone numbers in case you needed help." *(allow caregiver to create a list, use supplemental worksheet)*

"Have you experienced any of these signs of stress señora?"

*Allow care giver to share*

*"Alguna vez ha sentido estas sintomas señora?"*

*Dejar que la cuidadora hable.*

"Now I want you to use your notebook and write down any daily stresses (?) you experience now. These are stresses you want to "throw away" or at least decrease because they "wear you down" or cause symptoms of stress like I told you earlier. Please do not limit yourself in anyway. Feel free to write down your thoughts as we meet in your home, a safe place for you to express your thoughts that will strengthen you as a caregiver. You may want to look at the worksheet that lists types of stress. Feel free to draw a picture if that is easier to express your thoughts."

*"Quiero que use su libreta para escribir cualquier estresante actual que siente diariamente de que le gustaría aliviarse. Por favor, no se limite en cualquier caso. Con confianza, escriba lo que siente ya que usted esta en un lugar seguro y con el propósito que esto le dara mas fuerza como cuidadora. Talves le gustara ver la lista de estreses. Quizás quiera hacer un dibujo si es más fácil de aclarar sus pensamientos.*

"While you think, I will also list stresses in my life. Once we are done, we can share our lists and thoughts. Maybe we share some of the same stresses?"

*"Mientras que usted piensa, yo también voy a enumerar las tensiones en mi vida. Una vez que hayamos terminado, podemos compartir nuestras listas y pensamientos. Tal vez compartimos algunas de las mismas tensiones?"*

CHW: "Thank you for taking the time to complete this activity with me. I hope this activity shows you that we share many of the same stresses even though our lives may be different. I would like us to work together to build a strong relationship to improve your health. This may help you manage your caregiving stresses.

*Gracias por tomar el tiempo para completar esta actividad conmigo. Espero que esta actividad revele si tenemos algunos estresores similares, con la esperanza de construir una relación más fuerte de amistad y descubrir formas en que juntos podamos manejar estos factores de estrés.*

"Is it ok if I share my list with you at this time?"

"Would you like to share yours?"

*¿Puedo mostrarle mi lista?*

Reflection: "Look at how many people are available to help you! Now let us identify the special person who you can call to talk to, ask for a ride to run an errand, or take your loved one to a doctor's appointment. What are other things can you ask for? Some examples of tasks that friends or family may be willing to help you with include making dinner, helping take care of your children, going shopping or cleaning the house."

"Quiénes son las personas en quien usted piensa cuando se siente sola o estresada? Vamos a hacer una lista de nombres y números que pueden ser utilizados en caso de que necesite ayuda.

*Dejar que cuidadora construye su lista*

Reflejo: Mire cuantas personas están disponibles para ayudarle! Ahora vamos a identificar una persona en la lista quién puede usted llamar para hablar sobre algo que le preocupa, pedir asistencia de manejo para hacer un mandado, o llevar a su ser querido a una cita médica. Que son otras cosas que usted pueda pedir o necesita? Algunos ejemplos de tareas en que sus amigos o familiares pueden ayudarle incluyen preparar la cena, ayudar a cuidar sus hijos, ir de compras, o limpiar la casa.

"The help that you receive from your support system benefits your loved one. If you receive help, you will feel supported and energized. Your sick family member may feel less guilty about needing your help by seeing that others help you. Remember there are people who will support you and help you! Listen to them and accept the help that they offer."

"Keep the list of people you have identified in an easily visible place. This may be on the kitchen refrigerator. This will remind you that there are people to call upon when you need help."

Su ser querido beneficia de la ayuda y apoyo que usted obtenga. Si usted recibe ayuda, se sentirá apoyada y con energía, y quizás su ser querido se sienta menos culpable de necesitar su ayuda, al ver que los demás le están ayudando. Recuerde que hay personas que la apoyan y están dispuestos a ayudar. Escúchelos, y acepte la ayuda que le ofrecen.

Mantenga esta lista en un lugar visible, como la refrigeradora en la cocina, para que recuerde que hay gente disponible cuando usted necesite ayuda.

## **20-30 min Lesson 2: Part I: Deep Breathing exercises**

### **Ejercicios de Respiración Profunda**

HCW: "We have identified a list of friends/family that can help you in meeting your caregiving and role tasks. Now let's focus on ways we can decrease any stress in our bodies to allow us to do our jobs better!"

"Are you familiar with deep breathing exercises? " This is a part of the lesson I am very excited about! These exercises make me feel very peaceful and at ease. I really would like to share these exercises with you."

"Deep focused breathing is a form of meditation. Have you heard of meditation? It has many health benefits, including reducing stress." Once we practice mindful (?) breathing together, you can do the breathing at any time during the day you feel stressed. You can use breathing exercises when you pray, go on walks, or as you lay in bed before you go to sleep."

HCW: Ahora que hemos identificado una lista de amigos y familiares que le puedan ayudar en el cumplimiento de sus tareas, ahora podemos concentrarnos en formas en que podemos aliviar el estrés en nuestro cuerpo.

"Está familiarizada con los ejercicios de respiración profunda? Esta es la parte de la lección que me excita mucho porque me hace sentir muy tranquila y me gustaría compartir esto con usted."

"La respiración profunda es una forma de meditación que tiene muchos beneficios para la salud, incluso, ayuda a reducir el estrés." Cuando practiquemos la respiración profunda, sabrá que es algo que se puede hacer en cualquier momento del día cuando se siente estresada. Usted puede incorporar ejercicios de respiración en el momento de rezar, ir a caminar, o en su cama antes de dormir. "

"In addition to relieving stress, there are many amazing benefits of deep breathing."

"Some of the benefits of deep breathing include detoxification of your blood. When you exhale (when you breathe out) air from your body, you release carbon dioxide that has been passed through your bloodstream into your lungs. Carbon dioxide is a natural waste product of your body's metabolism. Breathing deep with a focus on the present moment will help clear any uneasy feelings out of your body."

"Además de aliviar el estrés, hay muchas ventajas asombrosas de la respiración profunda."

"Algunos de los beneficios de la respiración profunda incluyen la desintoxicación de la sangre. Cuando usted exhala el aire de su cuerpo se libera dióxido de carbono que se ha transmitido a través del torrente sanguíneo a los pulmones. El dióxido de carbono es un desecho natural que el cuerpo dispone. Respirar profundamente ayudará a aclarar cualquier sentimiento inquieto de su cuerpo. "

"Deep breathing releases tension from your body. Think of how your body feels when you are stressed, angry, or worried. It gets really tense, right? Your muscles get tight and your breathing

becomes shallow and not deep. This tension prevents you from being able to get all the oxygen your body needs."

"By practicing breathing exercises, we bring good oxygenation into our body that will increase our immune systems, make our hearts stronger, promote digestion, and also bring peace and clarity to our minds."

"La respiración profunda libera la tensión de su cuerpo. Piense en cómo se siente su cuerpo cuando usted está estresada, enojada o preocupada. ¿Se pone muy tensa, verdad? Sus músculos se ponen tensos y su respiración es superficial y no profunda. Esta tensión le impide ser capaz de obtener todo el oxígeno que el cuerpo necesita."

"Al practicar los ejercicios de respiración podemos traer buena oxigenación en nuestro cuerpo que aumentará nuestro sistema de la inmunidad, hacer nuestro corazón más fuerte, promover la digestión, y también llevar la paz y la claridad a la mente."

"I know it may seem awkward if you have never participated in deep breathing exercises before. But let us have fun with doing this deep breathing. Relax and try! If you have any questions during our practice, let me know."

"First, let us sit up straight. Then, we will place our hands in a comfortable position. We can place them on our lap or on our stomach or chest. With our breathing, we feel our stomachs or chests rise. We feel air and oxygen passing through our bodies."

"Now let us close our eyes and breathe in slowly through our nose. We will count to four in our heads, and then release the air for four seconds through our mouths."

"Sé que puede parecer extraño si nunca ha participado en ejercicios de respiración profunda antes, pero vamos a divertirnos. ¡Relajese y prebe! Si usted tiene alguna pregunta durante nuestra práctica, por favor no deje de preguntar. "

"En primer lugar vamos a sentarnos con la espalda recta y coloque las manos en una posición cómoda. Podemos colocarlas en nuestro regazo o en el estómago y el pecho para sentir que la respiración hace subir el estómago y el pecho. Sentimos el aire y el oxígeno que pasa a través de nuestros cuerpos."

"Ahora vamos a cerrar los ojos y respirar lentamente por la nariz. Vamos a contar hasta cuatro mentalmente, y luego suelte el aire por cuatro segundos a través de la boca. "

"Focus on something soothing and calming. Maybe this is a special place or picture of a loved one? Relax all the muscles in your body and, if you like, smile. Take this time to reflect on how valued your work as a caregiver is."

"Take your time repeating the taking in and letting out of air (oxygen); do this "in and out" exercise 3-4 times. Open your eyes when you are ready."

"How did this make you feel? Do you feel more relaxed?" Remember "breath is life" – when we breathe deeply, our lives become stronger."

"Enfocue en algo relajante y calmante. Talves esto es un lugar especial o fotografia de un ser querido. Relaje todos los músculos de su cuerpo y si gusta, de unasonrisa. Tome este tiempo para reflexionar sobre que tan valoroso es su trabajo como cuidador.

"Tóme su tiempo repitiendo la inhalación y la exhalación 3-4 veces y abra los ojos cuando esté lista".

"Cómo hizo sentirse los ejercicios de respiración Se siente más relajada "Recuerde "respirar es vida" - cuando respiramos profundamente, nuestras vidas se vuelven más fuertes. "

### **Lesson 2 Part II: Preparing Herbal Teas**

"If you are ready, I would like to share some knowledge of teas that can soothe your nerves as a caregiver. The following teas can be bought at a local grocery store or herbaria. They are not very expensive and are easy to prepare. I have brought \_\_\_\_\_ and would like to share a cup of tea with you as we continue our discussion."

#### **Preparando Te Herbal**

"Si usted está listo, me gustaría compartir algunos conocimientos de tés que pueden calmar sus nervios como cuidador. Los siguientes tés se pueden comprar de una tienda de comestibles o herbarios. No son muy caros y son fáciles de preparar. He comprado \_\_\_\_\_ y me gustaría compartir una taza de té con usted mientras continuamos nuestra discusión. "

#### **Prepare tea**

"A few of the teas I suggest help calm your body, mind and spirit. These teas are peppermint, 7 Azarez, tila flower, valerian root, and chamomile."

"You may be familiar with some of them. They are commonly used among Latinos as healing medicine. You can drink these in the morning to start your day on a peaceful path. You can also share these herbs with \_\_\_\_\_ to promote a feeling of tranquility."

#### **Preparar té**

"Algunos de los tés que sugiero para ayudar a calmar a su cuerpo, mente y espíritu son la menta, Azarez 7, flor tila, valeriana, y manzanilla."

"Usted posiblemente reconozcaalgunos de ellos. Son de uso común entre los latinos como la medicina curativa. Usted puede tomar estos tés en la mañana para comenzar su día en un camino tranquilo. También puede compartir estas hierbas con \_\_\_\_\_ para promover una sentimiento de tranquilidad."

"Just be sure to share with your doctor all herbal teas that you and \_\_\_\_\_ use. You want to make sure there is no interaction of the tea with medication you or the patient may be taking."

"Peppermint tea has strong relaxing effects. Peppermint tea benefits mental, and emotional wellbeing. In addition to easing stress, it promotes digestion by lowering gas in the intestines. Peppermint can also soothe the stomach and help discomforts of diarrhea and vomiting."

"Sólo asegúrese de compartir con su médico todos los tés de hierbas que usted y \_\_\_\_\_ usan. Usted quiere asegurarse de que no hay interacción del té con la medicación que usted o el paciente están tomando."

"El té de menta tiene fuertes efectos relajantes. El té de menta beneficia el bienestar mental y de la emoción. Además de aliviar el estrés, el té de menta promueve la digestión mediante la reducción de gas en los intestinos. Menta también puede calmar el estómago y ayudar a molestias de diarrea y vómitos."

"7 Azarec is a traditional Mexican tea that has been used as a natural remedy for many years. It has been reported that this tea will help with relaxation and sleeplessness."

"Tilia Flower/Linden Tea is used to treat issues of indigestion, and abdominal pain. It also has a calming action to increase blood flow, take away headaches, and is useful for nervousness and inability to sleep."

"7 Azarec es un té tradicional mexicana que ha sido utilizado como un remedio natural por muchos años. Este té ayuda con la relajación y el insomnio."

Tilia Flor / té Linden se utiliza para tratar los problemas de indigestión y dolor abdominal. También tiene una acción calmante que estimula el flujo de sangre, alivia los dolores de cabeza, y está indicado para el nerviosismo y el insomnio."

Types of Stress

Time-Management stress  
 Mental stress  
 Financial Stress  
 Familial stress  
 Health stress

Effects of stress on Behavior:

Malnourishment  
 Angry outbursts  
 Social withdrawal  
 Crying spells  
 Relationship conflicts  
 Decreased productivity

Effects of stress on your body:

Headache  
 High Blood Pressure  
 Body Aches  
 Fatigue  
 Weight goes up and down  
 Shortness of Breath/Chest  
 Tightness  
 Stomach upsets  
 Constipation  
 Pounding Heart  
 Increased Sweating

Stress relieving activities:

Exercise like walking or stretching  
 Getting a good night's sleep  
 Talking with a friend  
 Maintaining a healthy diet  
 Developing a hobby  
 Developing a support network  
 Keeping a stress or gratitude journal  
 Managing time wisely  
 Practicing relaxation  
 Having fun!  
 Taking breaks

Effects of stress on mental health

Anxiety  
 Restlessness  
 Increased worry  
 Depression  
 Guilt  
 Anger  
 Resentment

Things to avoid to limit stress:

Yelling at loved ones  
 Withdrawing  
 Eating too little or too much  
 Not taking time off from work  
 Dwelling on problems  
 Alcohol abuse  
 Blaming others

**Tipos de estrés**

Estrés del manejo de tiempo  
 El estrés mental  
 estrés financiero  
 El estrés familiar  
 El estrés de la Salud

**Efectos del estrés en su cuerpo:**

Dolor de cabeza  
 Hipertensión  
 Dolores musculares  
 Fatiga  
 Peso sube y baja  
 Falta de respiración/ Presión en el pecho  
 Dolor de estómago  
 Estreñimiento  
 Palpitación del corazón  
 Aumento de la sudoración

**Efectos del estrés sobre la salud mental**

Ansiedad  
 Inquietud  
 El aumento de la preocupación  
 Depresión  
 Culpa  
 Cólera  
 Resentimiento

**Efectos del estrés en el comportamiento:**

Desnutrición  
 explosiones de cólera  
 Aislamiento social  
 Ataques de llanto  
 conflictos en las relaciones  
 Disminución de la productividad

**Actividades para aliviar el estrés:**

El ejercicio como caminar o estiramientos  
 Tener una buena noche de sueño  
 Hablar con un amigo  
 Mantener una dieta saludable  
 Desarrollar un hobby  
 El desarrollo de una red de apoyo  
 Llevar un diario de estrés o la gratitud  
 Administrar el tiempo sabiamente  
 La práctica de la relajación  
 Divertirse!  
 Tomar descansos

**Cosas que debe evitar para limitar el estrés:**

Gritar a los seres queridos  
 Retirando  
 Comer muy poco o demasiado  
 No tomar tiempo libre del trabajo  
 Vivienda en problemas  
 El abuso de alcohol  
 Culpar a otros

Coping with Stress	
To Do	To Avoid
Physical activity	Being a couch potato
Go for a walk	Yelling at your spouse, family, and friends
Sleep at least 7-8 hours per night	Sleeping too little or too much
Talk with a friend	Withdrawing from others
Eat a healthy , well balanced diet	Eating too little or too much
Be open about your own needs	Being aggressive or passive
Ask for help when needed	Try to manage everything on your own
Manage your time	Letting time manage you
Take mini-vacations throughout the day (one-three minute breaks from care giving to stretch, take a walk, etc.)	Not taking a break throughout the day Eating while you work Skipping meals
Build a support network	Feeling isolated
Practice relaxation	Dwelling on problems
Have fun: dance, laugh, and smile!	Not giving yourself recognition for all your hard work.

Enfrentars al Estrés	
Que Hacer	Que Evitar
Actividad Física	Ser un Perezoso
Dar un paseo	Gritarles a su esposo/a, , familia oamistades
Dormir al menos 7-8 horas por noche	Dormir muy poco o demasiado
Hablar con un amigo	Alejarse de los demás
Sea abierto acerca de sus propias necesidades	Ser agresivo o pasivo
Pida ayuda cuando la necesite	Tratar de manejar todo por su cuenta
Administre su tiempo bien	Dejar que el tiempo lo domine
Tome descansos durante el día (descanse de ser cuidador; tome 1-3 minutos de estiramiento o camine)	No tomar un descanso durante todo el día Comer mientras se trabaja Dejar de comer a sus horas de comida
Construya una red de apoyo	Sentirse aislado
Practique la relajación	Vivienda en problemas
Diviértese: baile, riase y sonriase!	No dandose reconocimiento por todo su trabajo duro.

Support Contact List	
Who Can I call?	Contact Information:
To go to an appointment with me	Name: Phone:
	Name: Phone:
	Name: Phone:
To give me a ride	Name: Phone:
	Name: Phone:
	Name: Phone:
To help prepare a meal/house chores	Name: Phone:
	Name: Phone:
	Name: Phone:
To help in caregiving while I take a break	Name: Phone:
	Name: Phone:
	Name: Phone:
For spiritual support/to talk to	Name: Phone:
	Name: Phone:
	Name: Phone:
To go shopping with me	Name: Phone:
	Name: Phone:
	Name: Phone:
To answer questions I have about medication/caregiving	Name: Phone:
	Name: Phone:
	Name: Phone:

Lista de Contactos de Apoyo	
¿A quién puedo llamar?	Información de contacto:
Para ir a una cita conmigo	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
Para darme un paseo a algún lugar	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
Para ayudar a preparar una comida / limpiar la casa	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
Para ayudar como cuidador mientras me tomo un descanso	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
Para apoyo espiritual / para hablar	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
Para ir de compras conmigo	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
Para responder a las preguntas que tengo sobre medicamentos / como cuidador	Nombre:                      Teléfono:
	Nombre:                      Teléfono:
	Nombre:                      Teléfono:

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### Videos:

- <http://www.youtube.com/watch?v=eE6NoYUUVo> food for stress control
- [http://www.youtube.com/watch?v=xrSgA1I\\_uS8](http://www.youtube.com/watch?v=xrSgA1I_uS8) STRESS

APPENDIX D

**Promotoras: MAPS – Stresses and Coping  
November 12, 2013 – 5pm until 9pm – Library B29**

Promotoras: Gabi and Maria  
Housekeepers: Maria and Elena  
Students: Arnoldo, Monica, and Catie  
Professors: Dr. Wells and Dr. Cagle

Upon entering, the promotoras and the housekeepers appeared to be very timid and shy about the role-play. We went around the room and introduced ourselves. Maria speaks little English and commented to me about being very nervous but that Dr. Wells had calmed her by saying it was alright and to not worry about not knowing much English. Elena speaks more English than Maria, but still prefers to speak in Spanish.

We separated into two different rooms; I was in the room with Dr. Cagle, Arnoldo, Gabi, and Maria. I led Maria through the pre-test for stress (temperature gauge of stress). She was confused at first as to what the gauge represented because it is originally designed for patients. She went ahead and wrote down her actual own feeling at the time. *I feel as though we could have used another tool for this moment. Or maybe should have had her write down the current emotions she was feeling instead of give her specific ones to choose from. She was very open about how she was feeling and I think the study would have benefitted from hearing exactly what emotions she was experiencing about the study itself.*

Gabi began the conversation by facing Maria and smiling. She opened the conversation up by explaining what they were going to talk about, saying that “many people have questions.” Maria seemed to open up to Gabi quickly. Maria began to talk about how she has had a history of taking care of a loved one with cancer, not in the U.S. but in Mexico. She feels as though one of the scariest things about having to take care of a loved one is “no hay un ‘despues’” (there is no afterwards). She went into more detail about this thought when prompted by Gabi. Maria explained that she had never known how to talk about the future with her loved one with cancer (her father, we later found out) because for him they all knew that he would not survive and there would not be an “after cancer” life for him in this world. After speaking more to Gabi, Maria began to cry. She was very nervous, it seemed. Maria was wobbling her foot constantly and was moving around uncomfortably in her chair. All the while, Gabi remained calm and kept eye contact. She was listening intently to what Maria had to say. When Maria struggled for words, Gabi offered her some good words to work from to form her thoughts.

Although Maria quickly opened up about herself and changed the direction of the conversation, Gabi soon changed it to bring it back to the topic at hand (MAPS). *I believe it was important though for Gabi to give Maria an opportunity to express herself and her*

worries. *This made the entire conversation more relatable for Maria and for Gabi to understand what some of the pressing concerns that Maria had before they even began going over the MAPS dialogue. This type of interaction in the beginning also seemed to develop a meaningful, genuine relationship between Maria and Gabi where Maria seemed to trust Gabi and rely on her.* Gabi said “vamos a hablar de usted” – “we are going to talk about you” to change the subject of the conversation to focus on Maria. Gabi referred to MAPS1 and how that Module helped cancer caregivers talk to doctors, for instance, what questions exactly should be asked? Maria seemed interested in this Module as well. Gabi then explained what this current module was about. She related the goals of this Module back to their previous conversation about what Maria had experienced when she was taking care of her loved one with cancer. Gabi explained that many become depressed, many don’t know what to do about their futures or if there even is one, how it hurts not only the patient but the caregiver during the cancer process, and that there are many stresses. Gabi said that she wanted to show her how to “manejar el estres.” Maria then explained, agreeing with Gabi, that she wants to be strong, but she doesn’t know how to express herself; she couldn’t help her father or mother in the past and that it was the suffering of her father that caused her mother’s suffering. Gabi then asked what stressors were affecting her life at the time: emotions, economically, physically, etc. Maria agreed that it was a mixture of all of them, including that she was frustrated and angry at the time, she couldn’t sleep, she didn’t even know how to talk to her family at the time, and also that she didn’t know “quien tiene la culpa” – “whose fault it was? Who had the blame?” Maria explained, after Gabi’s guidance, that she was also affected by physical stresses including “hambre se me va, no puede dormer, trabajar mucho” - saying hunger basically left her body and she wasn’t ever hungry, she couldn’t sleep, and yet she was working many hours.

After explaining this to Gabi, Maria seemed very distraught and asked “Donde esta Dios? La Fe?”, asking where is God, faith? She wondered whether it was possible for God to help financially. Gabi then directed all of Maria’s concerns back to her, saying “En SU cuerpo, que puede hacer” – “in YOUR self, what can you do?” *By emphasizing this, I noticed that it set the stage for the entire rest of the conversation. Gabi made the goal of the Module attainable for Maria in this moment by saying basically “What can YOU do?” This seemed to give Maria power in herself and her own abilities. She was able to further focus on what was attainable and what was possible in her life.* Maria answered to Gabi that maybe she should look for help and emotional support, that even words of encouragement are helpful, saying that tomorrow will be better. Gabi smiled at this and said very clearly “PEDIR LA AYUDA!” – “Ask for help!” Gabi stressed this over and over, allowing Maria to repeat it.

Gabi then related to Maria, sharing a bit of her own story and about her stresses that she is dealing with, having a loved one with cancer. She explained also that there are many programs available for support.

Gabi then got out one of the interactive pages of the MAPS. They both sat in silence for a few minutes while they reflected on the activity, mainly about what their goals were. *This*

*also provided a needed break in the conversation. This allowed both to regroup their thoughts and focus on the task at hand.*

Maria immediately wrote something down, as if it was already on her mind. She did not hesitate at all to add to the list. Maria seemed to be very focused on the activity and was very deep in thought. Gabi also participated in the activity, writing down her own personal list. *I think it was important that Gabi also participated because it made the activity more personal and less of a “do this work” kind of assignment. Instead, the activity was a way for the both of them to reflect and grow together on their similarities when they shared their lists.*

When Maria shared her thoughts that she had written down, Gabi was able to adjust the script of the MAPS accordingly. *I believe that this flexibility in the module is very important as to adjust accordingly to the aspects of the module that apply most directly to the current stresses that the caregiver is experiencing. This allows the conversation to also be more interactive and more applicable to the caregiver’s life and to overall hopefully be a more successful and meaningful conversation.* Gabi then went through the list evaluating Maria’s goals and how to achieve them specifically all while keeping the topic related to stress management, as per the module.

Gabi additionally gave recommendations about what helps her personally manage stress. *This adds a dynamic approach that promotoras can add to the conversation to not only make the conversation more personable but to also give advice that they have seen in their own experiences.* She mentioned that it helps her to talk about the future, and whether one is prepared for the future or not. This seemed to hit a soft spot with Maria as she began to cry. Gabi reached over and touched her gently saying “Nos duele” – we all hurt. She also said “we are strong for the ones around us”. Maria agreed by nodding. Gabi then geared the topic towards Maria again saying, “ahorrita” (right now) “let’s focus on us.”

Gabi continually went over the importance of asking for help. They repeated the word “ayuda” over and over again. Gabi stressed this aspect of the Module.

Maria brought up that transportation was a huge aspect of stress. Gabi immediately asked “que harriamos” – “what could we do about that?” This allowed Maria and Gabi to brainstorm together to achieve a probable solution to a problem. Gabi gave her options and opinions, mentioning that there are organizations, friends available, pastors, psychological services, and many more services other than just transportation that are available to Maria.

Gabi then brought up physical effects of stress in life. She told Maria that sleep is important. She stressed that giving yourself time to sleep is important too, by allotting time for it. She then asked “what are YOUR needs?” directing the conversation back to Maria.

Maria brought up other stresses in life that she faces such as working, paying bills... Gabi then directed the solution-finding back to Maria, asking her what she can do about those. Gabi asked what can Maria currently do to fix some of those problems. When Maria had difficulty answering, Gabi offered some suggestions. Gabi suggested creative answers that were manageable such as speaking with a supervisor to make more flexible work hours, lean on her family, make schedules for her days so that she can allot time to her personal relaxation time and time for sleeping and eating. She stressed that Maria needed to make time for herself.

Gabi then brought up the activity in the Module that consist of making a contact list. Maria seemed very receptive to this activity and approached it when excitement. *I believe that the spacing of the interactive activities was perfect to facilitate the conversation and to create breaks during the dialogue.* Maria seemed to have an answer for each of the contacts. She struggled over the transportation contact, but eventually decided on her sister. *I believe that this activity was very helpful in allowing Maria to fully grasp and internalize how much support from family and friends she has available and that she is not alone.* Maria vocalizes that this activity made her feel better. Gabi then explained that during a crisis, this is a “plan” for her to refer to. She stressed that it is important to plan, to be prepared.

Next Gabi continues on to the relaxation portion of the Module. Maria seems to already have begun to relax in the conversation. She is no longer tapping or wiggling her foot. She is stretching in her chair. Maria explains that when she becomes stressed or angry, she is no longer hungry. Gabi responds that also a headache can happen, which can affect her overall health.

Gabi first explains about breathing techniques. She explains that when the brain gets more oxygen, one can think clearer and make better decisions. Together they begin to take deep breaths. Gabi first demonstrates how to slowly count and Maria watches. Next, they begin the breathing exercises together and Maria actively participates.

Gabi then explains about tea and how it helps with stress. Maria does not seem very receptive to this idea, joking that her little grandmother would like this. Gabi laughs and agrees that many families have ‘family recipes’ about hot teas that help relax. Gabi also ensures that she is not a doctor, but instead a promotora and that drinking tea is not something that will heal anyone, but that is merely a recommendation to help relax someone. She also emphasizes that none of these suggestions are treatments for stress, but are merely ways that might help. Gabi then leads into a short story about herself about how she got into the promotora role and what it means. She explained her own credentials. *Gabi seems to be a wonderful teacher. She is friendly and uses a very calm voice. Maria was receptive throughout the exercises and engaged in all activities. I believe that the tea portion of the module needs to be adjusted Many cannot relate to the tea method or relaxation or also may already be too familiar with it that it does not seem to be essential to put into the module. Possibly removing, or even expanding on the “tea” portion to also include healthy eating habits that decrease stress such as not eating late at night or that it is healthy to eat breakfast and to snack throughout the day?*

Gabi then asks Maria how she is feeling. Maria smiles and replies that she is feeling so much better compared to when they first met. She also appears to be much more relaxed and is smiling more. She tells Gabi that it has also just been so nice to have someone to talk to. Gabi then expresses the importance of knowing how to relax when alone and stressed. *I thought that this was an important aspect for Gabi to bring up. You will not always have support around you to rely on so it is important to know ways to manage your own stress when you are alone. I thought this was a great thing that Gabi brought up in the conversation and emphasized to Maria.*

The next portion of the conversation was very light and easy to talk about between the two women. This portion was where they looked at the Do's and Don't's hand-out together. *I believe that this resources is a great resource that encompasses many aspects of the entire module and can act a sort of 'wrap up' for the entire conversation about the MAPS module.* Maria was very alert when looking over the hand-out together. She was attentive and her posture was reflective of that. Also, the two were laughing together and seemed to be becoming very comfortable.

Gabi also emphasized the importance of all of these side effects of stress being normal. She stressed that Maria was not the only one going through this and that there was support available to her. She also stressed that Maria needed to make time for herself during the day and to not become isolated. Maria agreed wholeheartedly that when people become isolated that things inevitably become worse for them.

Finally, Gabi turned the conversation to "Peso de Valor." Gabi stressed the importance of Maria's value as a person. She explained that everyone who is a caregiver has so much value and should not be belittled by anyone. She expressed that Maria is valued and valuable, both. *I believe that this was a beautiful way for Gabi to wrap up the entire conversation. She was able to boost Maria's self confidence, not only on her future as a caregiver but also emphasizing the value of her hard work in the past. Gabi was able to value Maria for what she was worth and appreciate her for all the hard work and struggle she has been through. This was a beautiful moment between the two of them because I felt as if they reached a good high-point in the conversation were they were able to talk truthfully to each other and yet still encourage each other do reach higher goals.*

APPENDIX E**Promotoras: MAPS – Stresses and Coping  
April 22, 2014 – 5pm until 9pm – Library B29**

Promotoras: Gabi and Maria  
Housekeepers: Estella and Eva  
Students: Nicole, Monica, and Catie  
Professors: Dr. Wells and Dr. Cagle

At 5pm, I arrived at the library to meet with our research group, the promotoras, and the housekeepers. We sat at a table and shared introductions. At first it appeared that the housekeepers were shy, but soon they started sharing about themselves.

For my session, I was with Dr. Cagle, the promotora Maria and the housekeeper Eva. Our interview session was held in the small office living room of B16E in the basement of the TCU library. Eva seemed to have a very gentle and quiet disposition. Maria spent a little while getting to know Eva, but did not overwhelm her with personal questions. Because Maria has become more experienced with the MAPS series, it appeared as if she had found a good balance of “business” with following the MAPS packet and creating a trusting relationship with the women in the study.

As Eva and Maria learned more about each other, Eva began to feel more comfortable. Her body became more relaxed in the chair and she kept direct eye contact with Maria. She also felt comfortable asking questions she had about promotoras in general. Although she explained that she had heard of promotoras before, Eva said she was curious about exactly what they do and how they get their certification. Also, Eva asked why Maria specifically was interested in getting involved in community health such as through promotora de salud sessions.

Beginning the session, Maria provided a comprehensive overview of the purpose of the session. The purpose of role play was to “Imaginarse” (to pretend) in order to understand that this study hopes to benefit Mexican American women who function as caregivers for a family member with cancer. Eva smiled and agreed that it was a good thing to do. Maria further explained that this session focuses on the struggles facing women in this group. Maria asked Eva if she was specifically stressed about things at the time and Eva responded that she had little stress “gracias a Dios,” (thank God).

They planned to go over the guide together as a form of a guide. As they go through the packet, Maria asks Eva to read the information on the first page in order for her to become engaged in the activity. Maria rereads it emphasizing important aspects. She says that they will write on the guide and fill it out as they go along. The first part asked what are things that the caregiver does each day. Eva was shy with her answer and so Maria coaxed her with easy answers such as “what do you do when you wake up?” and then Eva laughed and said that she does so much during the day that she wouldn’t have enough room on the paper to write everything! After a few minutes of talking about

caregiver tasks, Eva began to tear up remembering when her mother had cancer (uterine cancer 20 years ago). She said that the memories were flooding back to her and she began to gently cry. Maria was comforting but also coaxed her to follow the guide, ensuring that this activity and entire role play session was to bring back those memories but to also help cope with them and relieve stress.

Continuing with the packet, they then came across the stresses page about what things add stress to Eva's life as a caregiver. Maria phrased it as "Cual es que mortifican?" (What terrorizes your sanity/What pains you? – more than just "what bothers you?"). Immediately Eva answered "dinero – money." However, she replied then that her family is very supportive and she gets lots of help from her family, especially 20 years ago when her mother had cancer..

At 6:05pm they began the "signos de estrés" (signs of stress) portion of the MAPS guide. Continually Maria repeated that "este programa es para ti, para ti Eva" – (This program is for you, FOR YOU, Eva). She then reemphasized that if the caregiver – Eva – does not feel good or is not in good health, then she won't be able to have the *confianza* or the ability/inner and physical strength to help others. Further, she explained, this exhaustion from being a caregiver can cause symptoms of her own in her health. Eva identified her lack of sleep as the main symptoms of caregiver stress that she experiences. For a short while the two of them joked about lack of sleep and how busy their lives are. A little while later, Maria asked to return to the MAPS series.

Maria shared personal stories of struggle and this seemed to make Eva become more comfortable about sharing her own struggles. Especially Eva spoke about how the word "cancer" was so impactful. There is just something about the connotation that the word "cancer" holds that frightens people. She said that when the word "cancer" is said, then people automatically assume "I'm going to die." The two women agree to speak truthfully with each other. Eva continues to wipe her eyes.

Next, they spoke about the different types of death and how cancer has so much suffering while accidents in life can end life instantly.

In relation to the MAPS guide, Eva and Maria did not know how to work with the "basura" page (the one with the trashcan on it that speaks about what stresses you want to rid from your life). However, Maria figures out what she wishes to use the page as and guides Eva through by giving her examples. In addition, throughout the time they used the guide, they continued flipping back to pages and referring to them.

Around 6:10pm they move on to the portion of the MAPS guide that talks about support systems. Maria reads aloud as they together go through each section one by one. Maria creates scenarios in which Eva would need a support system. She additionally talks about what kinds of people can actually cause stress in life and which ones can take away stress by being support. Eva at first says that only she can do many of her household chores. She has trouble leaving the house sometimes because of this. Also, as long as the patient or her loved one is not in pain and is calm, she is at peace. a lot of times, she did not want

to leave her loved one at home alone either so she would rarely leave her mother's side during her time with cancer. Now, most of her family doesn't live with her, but they are nearby so they would help and be supportive in times of need. Her father especially aided in care. Maria suggested that they add people to the list of support that did not cause her stress because that was the opposite of what the activity was intended to serve as. Here Eva had difficulty calling to mind people that she would trust with certain tasks. She commented that her husband was very supportive but that he is very busy with his job as well. She included that when she lived in Mexico, she seemed to have much more support and aid because more of her family was around. Here in the U.S., she has less family around and less support.

At 6:23pm, we entered into the topic of "el número uno!" (Who's your number one contact?). Maria smiles and asks who that person is for Eva. Eva struggles with an answer, saying that she doesn't know. Then she thought and tentatively answered her husband or brother would possibly be good ones to write down.

Eva then began to talk about how the diagnosis was scary to share with others. Her mother was embarrassed and afraid to tell others about it. Her mother only told her family. To close friends she would even lie and say it was a stomach infection. She and her mother would pray to God and ask him what to do. When her mother was unable to walk from one room to another, she understood then that they needed help. Her mother then began radiology therapy. Eva spoke about the kinds of side effects that her mother experienced including saying that her mother felt like she was pregnant again. She was very nauseas and vomited much of the time.

At 6:30pm they began the "respire" (breathe) portion of the MAPS series. Maria emphasized that this portion of healing and coping with stress as a caregiver was very important. It was important for both her health and for her mother's. Eva responded that she had never done any sort of breathing techniques and that she was very unfamiliar with them. She did not understand the importance of them. Maria then told Eva that the stress that she is feeling is felt within all caregivers, not just herself, and that she is not alone. She explained then that this was the purpose of this entire packet – to help her understand the she is not alone and that she can make it through this stress and get help as long as she asks. The purpose is to ask "Who can take care of YOU?" because in order to take care of others like her mother, she first needs to take care of herself. She emphasized that "everything you do is important." Eva says that she forgets about herself a lot of the time but that she is thankful to God that she has her husband. Now she only suffers from sinusitis all the time from allergies. She also had a headache frequently, she added that. Maria kept repeating that in order to take care of her mom she had to take care of herself. Maria kept creating imaginary stories to relate thing to. The would refer to other pages and flip back to them. The pages were very accessible for them to refer back to.

Maria continually repeated that the support Eva receives is more important than anything. The then put the paper down and showed Eva how to deep breathe. The movements seemed foreign to Eva at first, but she caught on as Maria explained. She explained to not breathe through your chest but to instead breathe through your stomach. Eva says she

feels a difference and smiles. The emotion in the room even feels calmer. Maria explains that the breathing doesn't fix the problem but it will clear the head, especially when worried or anxious about stress.

At 6:40pm, they begin the Te Herbal section about herbal tea. Immediately Eva smiles and says that she loves hot tea. They both exclaim that "herba Buena" is the best herb to use. They have a good time speaking about herbal teas and sharing ideas. They both smile. Eva said that herbal teas like chamomile and other home remedies helped. Her mother in particular loved using honey in her tea. Her mother would like to have hot tea in the morning and at night. It helped calm her and manage the pain. Tea with lemon, with the flower of oranges. This seemed like a good opportunity for them to talk about ways for her mom to eat, etc. Maria also included diet ideas and what foods to include for a healthy diet.

At 6:45pm, they began the section about what kinds of activities can possibly help to decrease her stress. Eva says that she would like to start to go for walks, pick up a hobby, etc. She really wants to start going back to church, she said. She said that her husband doesn't like to go to church so it has discouraged her to go, but she likes to go with her sister. She feels though that she doesn't have enough time to do many of these activities even though she wants to relax and be calm and at peace with live. She really wants to pick up a hobby. She says that many of her friends play card, but that she doesn't enjoy them. She instead likes the lottery. Maria also suggests her picking up a journal or diary to keep her ideas in. She says that this is for her! No one else. The diary can give you a perspective when you look back. The two of them start laughing and get closer in their chairs. It appears that Eva is more comfortable.

For the next portion of the packet that includes types of foods to integrate in your life, Eva seemed to have trouble thing of ideas. Maria explained that good food for your heart and spirit can help your stress. She explained that her spirit must be at rest for her body to be at rest.

At 6:55pm they reached the Certificate page. Eva seemed to really like and appreciate this page. When they finished the entire MAPS packet, they reviewed the past few pages. Eva spoke about how she is even a caregiver now because her grandson has head and neck cancer at the age of 9 and has been in and out of the ICU for the past few months. She said that it was very, very difficult for her family, especially her son, whose child it is. She said that even though she had fear, she knew that it was in God's hand. Maria says that Eva can use some of these things they have spoken about in the session to apply to her care of her grandson.

At 7:02pm, they finished the session by looking over the contact page on the last page.

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