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Ana Villarreal

December, 2017

CONSTRUCTING MEANING: A SYSTEMIC FUNCTIONAL REVIEW OF
TRANSLATED HEALTH TEXTS AND COMMUNITY NARRATIVES

A Dissertation

Presented to

The Faculty of the Department

of Hispanic Studies

University of Houston

In Partial Fulfillment

Of the Requirements for the Degree of

Doctor of Philosophy

By

Ana C. Villarreal

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Abstract

This study uses Systemic Functional Linguistics as a theory and a tool to analyze written text about pediatric cancer that have been translated from English to Spanish. The basic premise is that current translations are not culturally and linguistically adapted for the target community. Based on the work of Halliday, this study analyzes national and local translated texts directed to caregivers with the purpose to shed light on the functionality of the available information. To complement this research, community members were interviewed to present their own construction of the illness and their perceptions on the linguistic services received.

All text and narratives were analyzed using the tools provided by SFL to elucidate the Interpersonal, Ideational and Textual Metafunction as they are realized by the translator's choices. Other tools provided by SFL such as word clouds and pinpointing the choice were also used to show the differences among the English and the Spanish versions of the texts. Translated health texts are used as means of health promotion and dissemination of health information; however, the legibility and the linguistic choices made by translators are not culturally aligned to be of service to the community. This study shows how the translations could use alternative choices, as proposed by SFL, to convey the meaning according to the specific needs of the community. The ultimate goal is the future creation of a computational software capable of translating health material that is culturally and linguistically appropriate to empower the patients in regard to their health decision-making.

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Dedication

To God,
it is well with my soul.

Mom, my hero,
César, my brother,
I will not say goodbye.

Chapter 1

Background Information

1.1 Introduction

The access to healthcare has always been a debatable topic for people living in the United States. Issues such as insurance, corporate lobbying, and allocation of resources have opened a chasm between politics and healthcare access, delegating the responsibility of critical issues such as language equality to different agencies. In a nation of more than 41 million immigrants (Census Bureau, 2015), linguistic minorities have fought their way to be recognized as an inherent part of society and to have full access to all services regardless of the language they speak. In light of the continuous health disparities reports documented across the nation (see the Center for Disease and Control Prevention: Health Disparities and Inequalities Report, 2015), the government has approved several laws and regulations strategized to reduce the bridge between non-English speakers and the health system. The purpose is to facilitate and standardize the creation of linguistic policies and planning to accommodate health services among all residents of the country aiming to diminish disparities in the overall health statistics. Policy makers have taken steps to address the provision of linguistic access; however, the objective of this research is to shed light on how the linguistic planning and application of these policies transfer from the political and institutional realm to the linguistic minority communities by means of the dissemination of translated information.

This chapter provides a review of current laws as they pertain to healthcare access for linguistic minorities. It also explores the linguistic and socio-demographic background information that contextualizes this research located in a rural border region. This area is deeply rooted in cross-cultural communication, yet the access to information in the healthcare system primarily relies on oral interpretation. In addition, issues of health disparities, health literacy, health promotion, and language ecology in minority communities in the United States are discussed in this chapter to outline the premises defining this research. Entrenched in this social, political, and cultural context, this study deals with the access to translated written information as a vehicle for health promotion and dissemination in the field of pediatric cancer. It examines its functionality and the realization of illness experiences through language. The importance of directing the study to this particular medical field resides in the fact that cancer is the number one, illness-related, cause of death among children in the United States.

1.2 Language Policy and Planning

The Office of Minority Health was created since 1986, however, the first law directed to health services that resulted in a national movement to address its requirements was the *Executive Order 13166* signed by president Clinton in the year 2000. This order titled “Improving Access to Services for Persons with Limited English Proficiency” was based on Title VI of the Civil Rights Act of 1964 and required federally funded institutions to provide “meaningful access” to Limited English Proficient (LEP) individuals (Department of Justice, 2000, Section 1). Alongside this *Executive Order*, the

Department of Health and Human Services (HHS) through the Office of Disease Prevention and Health Promotion launched the project *Healthy People 2010* in order to increase life expectancy and reduce health disparities. This project has been extended to *Healthy People 2020* and *Healthy People 2030* (ODPHP: Healthy People 2020, 2017).

In addition, in 2000, The Office of Minority Health (OMH) established the National Culturally and Linguistically Appropriate Services (CLAS) standards to address health disparities. The document is composed of 15 standards from which 4 of them deal directly with language access. Standard 8 of CLAS (see Appendix A for a complete list of standards) applies directly to written translations requiring “easy to understand materials and signage” (HHS: National Standards for CLAS, 2013b, p. 58543). These standards were enhanced in 2013 to be more “action oriented” and “establish congruency with other standards in the field” addressing issues of culture (including religion), patient satisfaction, health literacy, and new technology and terminology (p. 58541). The standards serve as a blueprint for agencies to follow in order to meet the governmental requirement of providing “meaningful access” to healthcare.

Regardless of the efforts made in the early 2000s, disparities among racial and ethnical minorities continued to be a healthcare issue. In 2011, the Attorney General signed a memorandum titled *Federal Government’s Renewed Commitment to Language Access Obligations under Executive Order 13116* (Office of the Attorney General, 2011) requiring agencies to update current guidelines. In order to establish and implement the guidelines of this memorandum, the Department of Justice (2012) initiated the *Language Access Plan*, which is a mandated action plan for all agencies under the Health and

Human Services Department to provide “timely language assistance services to ensure that LEP individuals have substantially equal and meaningfully effective access” (p.2). Following up with this directive, the HHS redacted their *Language Access Plan* (2013) forming the *Language Access Steering Committee*, led by the Director of the Office for Civil Rights. Their mission is to meet every two years to update and oversee the application of the plan in addressing “training, translation, interpretation, and other critical language access issues across divisions” (p.4). While all 10 Elements composing the HHS *Language Access Plan* (see Appendix B for a list of all Elements) ensure non-discriminatory policies, the implementation of each one is rather flexible and discretionary among agencies. For example, Element 3 (p.11) states the following in regard to written documents: “Each HHS agency will identify, translate, and make accessible in various formats, including print and electronic media, vital documents in languages other than English in accordance with assessments of need and capacity conducted under Element 1” (p.11).

This provision guarantees the accessibility to documents; however, due to the many diverse factors involved, it is delegated upon each agency “to determine for its programs and activities what constitutes vital documents, such as applications, and implement a translation strategy” (p. 11). It is a general requirement to ensure the accuracy and the quality of documents, it is stated that, “all vital documents, regardless of language, should be **easy to understand** by target audiences. Matters of **plain language** and **literacy** should be considered for all documents, including vital documents before and after the translation process” (p.11). It is worth noting that this requirement goes a

step forward from previous guidelines that only focused on making translation available. This element not only addresses language barriers, but calls agencies to implement translation strategies taking into consideration the **literacy level** of their target audience.

Other health related organizations have joined the HHS to conduct research and develop standards and recommendations to help healthcare agencies carry out the duty to provide services to linguistic minorities (See Appendix C for a complete timeline of health initiatives). In 2003, the Agency for Healthcare Research and Quality as well as the Institute of Medicine published reports addressing the existence of disparities as an under researched area. As a response to these findings, in 2007, the Office of Minority Health created the *National Partnership for Action to End Health Disparities*. In 2009, the Institute of Medicine published the *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement Report*, which called to identify and categorize the different variables affecting disparities (HHS: Health Equity Timeline, n.d.).

In 2010, president Barack Obama signed the Affordable Care Act (ACA), which included a section to provide services for LEP population. Section 1557 of the ACA requires healthcare institutions to provide language assistance services, such as oral language assistance or written translations of documents (HHS, 2016). This section of the ACA also calls for meaningful access for LEP individuals but it adds the requirement to create a plan of action that ensures that people can “communicate effectively”, “given adequate information”, “understand the services and benefits available” and “effectively communicate the relevant circumstances of his or her situation” (p.31410). This is

another step forward as it focuses on the patient being able to act and respond upon the information given; however, it is again ultimately delegated to every agency to decide on what steps to take upon consideration of the institutional resources and community needs,

It may in some cases be necessary for a covered entity to provide a written translation so that an individual with limited English proficiency can refer back to or study it at a later time. In other cases, however, a covered entity may meet the requirements of this section by summarizing the document orally for a qualified interpreter to then convey to the individual with limited English proficiency, if such approach is sufficient to provide the individual with limited English proficiency meaningful access to the information. (p. 31416)

The stipulation to facilitate written translations so that patients can refer back to them later is one of the main premises of this research because of the cultural implications that Hispanics go through during and after the medical encounter (see Sections 1.4 and 1.5). The Affordable Care Act in its Section 4302 (HHS, 2011) also deals with the elimination of health disparities. It established data collection standards for “race, ethnicity, sex, primary language and disability status” (p. 38397). This is particularly important as it has been documented that Hispanics in the field of pediatric cancer is still an under-researched area (see Section 1.6).

Continuing with the efforts to provide effective language translations, in 2012, The Joint Commission, a non-profit organization that accredits 21,000 health agencies throughout the country, included a condition to require written translated materials of “vital documents” to the accreditation criteria. Their definition of vital documents

included “consent and complaint forms; information about free language assistance programs or services; intake forms that have the potential for important consequences; notices of eligibility criteria, rights, denial, loss, or decreases in benefits” (The Joint Commission, 2008). Nevertheless, regardless of all the governmental and organizational efforts to provide all linguistic minorities with appropriate services in their primary language, several issues are yet to be addressed. While the laws and initiatives by health organizations prove that new policies have indeed taken place and are carefully monitored through actions plans in all federally funded healthcare agencies, still more research is needed to validate the success of the measures implemented by acquiring and publishing data as measured by positive health outcomes and patient satisfaction from the community perspective.

The flexibility in the delivery of language services is sometimes affected by the availability of funding resulting in the use of low-cost, in-house, and ad-hoc translation. A report partially founded by the Joint Commission collected information from 60 hospitals across the country. Their findings concerning written data revealed that, “systems for the provision of language services in hospitals across the country are still a work-in-progress” due in great part to the lack of appropriate training for bilingual staff and the risk of relying on family members as translators (Wilson-Stronks and Galvez, 2007, p.7). They also uncovered that most translations of documents were done in-house by bilingual staff or by computer translators, which, according to the researchers, “the programs they identified do not actually translate documents. As with language service provision, there is a need for greater attention to the quality of translated printed

materials” (p.7). The region where this research takes places is characterized as bilingual; therefore, there is a heavy reliability on in-house translation (see Martinez, 2008).

While services are, undeniably, being provided in languages other than English in all federal health agencies, they have not been authenticated as “meaningful” and “easy to understand” from the patients’ perspective. In order to understand why, regardless of the mandates, health disparities among LEP and minority groups are still visible and on the rise across the health system; it is necessary to take a broader scope into the different factors that affect the effectiveness of language access. One issue that has been brought to light is *health literacy*. As stated, the availability of a language access plan is incomplete if it does not take into account the literacy level of the intended audience. In the next section, a brief historical and conceptual overview of *health literacy* will be provided to review its development and the impact it has in the efforts to shift to a more comprehensive and empowered patient-centered practices. All this is provisioned by Section 1557 of the ACA (2016), which states that the patient can understand and communicate his or her particular situation to healthcare providers. Amid the high levels of illiteracy that characterize the country, linguistic minorities are, most of time, presented with information in their native language but written above their literacy level rendering all efforts to provide language access unfit.

1.3 Health Literacy

As required by the *Language Access Plan* (2013), discussed in the previous section, the concept of literacy should be taken into consideration when planning the establishment of language services addressed to a specific community. However, the concept of *health literacy* seems difficult to define among the complexity of the health system and the diversity of minority groups. The consensual basis of all different arguments is that illiteracy has a profound impact in the health outlook of every person regardless of the language they speak. The Institute of Medicine (IOM) refers to it as a “**silent epidemic**” because of “the lack of understanding by most professionals and policy makers of its extent and effect, and the individual shame associated with it that keeps it even more silent and hidden” (2004, p.xiii). The importance of health literacy ranges from managing preventive medicine, to the actual medical encounter, and the lifestyle after a diagnosis; it includes the ability to read general information about an illness, understand procedures, discern among available treatments, medication usage, and follow-ups. Achieving mutual understanding from patients and medical professionals is vital in order to make informed decisions; nevertheless, “health literacy remains a pervasive, yet under-recognized challenge in health care” (Schwartzberg et al., 2005, p. vii). Regardless of native language, health literacy is a problem that characterizes the nation. In 2003, The National Assessment of Adult Literacy (NAAL), the only large-scale study of literacy in the United States, estimated that over seventy million Americans “have difficulty understanding and acting upon health information” (IOM 2004, p. xiii). These findings are challenging since, according to the Institute of Medicine in the United States, most of the information is given through written documents, “health care systems

rely on printed materials to convey directions and instructions related to procedures, medicines, side effects, and self-care. These materials are, however, often written at readability levels that exceed the reading ability of the average adult” (Schwartzberg et al., 2005, p.76). As a result, the definitions of health literacy have fluctuated around the question of who is responsible for making sure that people effectively participate in their healthcare endeavors, that is, which agent is responsible for managing health related issues: the patient or the system.

The concept of health literacy was first used by Simonds (1974) in his article *Health Education as Social Policy* where literacy was located as a problem swinging around the educational and health systems. Later, the health system put more emphasis on the individuals’ responsibility for managing their own health. This led to definitions such as the one by the American Medical Association, in 1999, that viewed literacy as “a constellation of skills, including the ability to perform basic reading and numerical tasks required to function in the health care environment” (Schwartzberg et al., 2005, p.4). Following this same reasoning, the Joint Committee on National Healthcare Education Standards used the following definition: “the capacity of individuals to obtain, interpret and understand basic health information and services in ways which enhance health” (IOM, 2004, p.36). These definitions draw criticism because the focus was narrowed to the individual and the abilities that he or she could control and was able to demonstrate during the healthcare encounter, suggesting that the system had no responsibility to adjust to the literacy levels of its target population.

In an effort to create a more inclusive definition that would reflect the literacy level of most people living in this country and would make the system an active participant responsible to facilitate health communication, Ratzan and Parker (2002) envisioned a new concept based on the following ideology:

Individuals' health literacy skills and capacities are mediated by their education, culture, and language. Equally important are the communication and assessment skills of the people with whom individuals interact regarding health, as well as the ability of the media, the marketplace, and government agencies to provide health information in a manner appropriate to the audience. (IOM, 2004, p.4)

This idea led to a new definition that was quickly adopted and became one of the most widely used and adopted by all agencies. Ratzan and Parker (2002) defined health literacy as, “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (IOM, 2004, p.4). Regardless of the widespread use of this definition, it was later deemed insufficient. Clancy (2009) found the definition flawed to encompass the current status of health literacy because it still focused on “individual capability” and “imply needed skills”. She proposed a model developed by Orlow and Wolf (2007) in which health literacy “affected by sociodemographic characteristics as well as cognitive and physical abilities, is a determinant of health outcomes” (p. 6).

Following the search of alternative, more inclusive definitions, Baker (2006) developed a model where the individual and the system played an equitable role in health literacy. This model defined health literacy as “a product of individual’s capabilities and

the demands of health information messages delivered by the health care system” that is, “in this model, the health care sector shares responsibility for making sure that individuals can use health information effectively” (Clancy, 2009, p.8). Nevertheless, these definitions are continuously challenged by a complex and fast-paced system that does not seem to foster close relationships with the patients. Cuban (2005) refers to the health system as to one that is “downsized” relying on “self-care, prevention, and with large social distances between providers and patients” (para. 2). Cuban bluntly criticizes a system that does not focus on human relationships and cites Osborne (2004) explaining the idea that “people must be able to advocate for themselves as they are increasingly seen as active consumers rather than passive recipients of treatment and care” (para. 2). A distant health system breaks the standard health model of some cultures where the prototype of medicine is focused on the individual and his or her cultural practices as part of the healing process, thus when medical professionals are not aware of the cultural baggage behind every visit, effective communication with patients becomes very difficult to manage. Considering the different approaches to the health system, health literacy indeed presents a problem to English speakers with low literacy levels; however, it poses a greater issue for immigrants who, besides the fact that they may or may not be literate in their own native language, are indeed not familiar with the particularities of the United States healthcare system.

In regard to literacy among the Hispanic population, the NAAL projected that 41% of the population had a literacy level of below basic (Kutner, 2006, p.11). Some of the factors producing this high percentage of illiteracy are limited English proficiency,

and cultural and demographic factors. These results, however, do not include health literacy. As stated by Allen (2009), “considerations for health literacy measurement should include the capacity of people with LEP and the capacity of systems to respond to them. Currently there are no national data on health literacy for people who speaks other languages or have LEP. This is a major gap” (p.13). The need for a more comprehensive study in LEP communities resides in the fact that health literacy goes beyond the ability to understand the language. In order to successfully attain health literacy, it requires more than receiving and reading information; it implies a “convergence of education, health services, and social and cultural factors” (IOM, 2004, p.2). In an effort to fill this gap and find a common ground between the health system, culture, and language, Zarcadoolas (2006) proposed a definition of health literacy from a theoretical approach involving sociolinguistics, pragmatics, and text theory. She defines it as “the wide range of skills and competencies people use in order to seek out, comprehend, evaluate, and use health information and concepts,” while also labeling health literacy as a “**silent killer**” (Zarcadoolas, 2010, p.339). This idea follows the IOM acknowledgement that defining health literacy from the individual perspective has its limitations:

Most of the tools currently available to measure health literacy primarily measure reading skills, and do not include other critical skills. Furthermore, adults’ reading abilities are often estimated with a ‘grade level’ measure, an estimate that is imprecise at best. Advancement of the field of health literacy requires the development of new measures, which can be used to establish baseline levels and monitor change over time. (IOM, 2004, p.5)

Zarcadoolas' idea is to eliminate the dichotomy of people being literate or illiterate. She proposes a comprehensive approach that makes use of the knowledge that people have acquired throughout life and find a way to act upon available health information.

Zarcadoolas et al. (2003) proposed a model for studying health literacy based on four domains: 1) Fundamental literacy/numeracy, 2) Science and technology literacy, 3) Community/civic literacy, and 4) Cultural literacy (p.120). The premise to use these four domains of literacy is that every person has some kind of previous knowledge in each one of them that can be resourcefully applied to health communication. Zarcadoolas defines her new approach as one that is socio-ecological in the sense all the experiences of the individual can be used to act upon their health.

Different agencies and programs continue to work on a definition of health literacy that encompasses the reality of every sector involved in everyday healthcare activities. For example, The Office of Disease Prevention and Health Promotion, through its program *Healthy People 2010/2020*, have created the National Plan to Improve Health Literacy. This plan is based on the following two principles: “(1) all people has the right to health information that helps them make informed decisions and (2) health services should be delivered in ways that are easy to understand and that improve health, longevity, and quality of life” (ODPHP, 2017b). After reviewing all the different approaches to health literacy, the assurance is that only through shared responsibility the dissemination of health promotion and the rendering of services can be successful. As Paasche-Orlow notes, “health literacy is clearly an important core value for increasing equity, addressing disparities, promoting patient-centeredness, improving outcomes and

quality, and reducing costs” (The National Academies of Sciences, 2015, p.28). The effect of addressing health literacy has a positive impact in both the people and the system; people become empowered in managing their health, and the system can effectively allocate resources, as it will diminish costs and the probability of medical errors.

Health literacy applies to the broad spectrum of illnesses and healthcare; however, because the focus of this research is pediatric cancer, it is important to review the development on the concept of cancer literacy. Diviani (2013) refers to how health literacy can be specifically applied to cancer literacy. The importance of cancer literacy in health communication is that “more than half of all new cancers and cancer deaths are potentially preventable” (p.70). When dealing with cancer, as chronic illness, literacy is rather crucial as information can make the difference between life and death. A well-informed individual has a greater opportunity for early diagnosis. It is more difficult for people with low literacy to have the same opportunities as their literate counterparts when faced with cancer-related decisions. The lack of cancer literacy skills, as explained in Diviani (2013), poses “a disadvantage in their capacity to obtain, process, and understand cancer information to make appropriate decisions, resulting in increased cancer risk, poor participation in cancer control programs, limited understanding of cancer screenings and symptoms of cancer, and late-stage diagnosis (pp.70-71). Bevan and Pecchioni (2008) did a review of the literature about the literacy of cancer of caregivers and concluded that their health literacy level is important because “families want to be involved in health related, decision-making, but they also require health-related information to provide

adequate and appropriate support to the cancer patient” (p. 357). When diagnosed with cancer, the family not only provides emotional support, they have to be able to perform a range of duties such as, “interpreting language; offering additional viewpoints, explanations, and interpretations of medical diagnoses; collaborating to offer personal care to the patient and learning technical procedures; taking part in therapeutic regimens; and encouraging patients to comply with the medical treatments” (p. 357). Receiving news about cancer is overwhelming for everyone surrounding the individual; therefore, information should be easily shared and understood among all parties involved in the process. It is utterly important to have information about the illness from the early symptoms, to be able to choose between the treatments available, and to carry out long-term care.

Health literacy is, certainly, an indicator of health disparities. However, other aspects also need to be considered in order to explain, understand, and address disparities. In addition to literacy, the environment in which an individual develops carries information that researchers can use to make accurate predictions of health determinants. It has been gradually established by the major health agencies that issues such as immigration, culture, primary language, socioeconomic and demographic status play a big role in health literacy. The IOM (2004) explains how the issue of culture is particularly important for immigrants:

Individual, families, and communities have belief systems, religious and cultural values, and group identity that serve as powerful filters through which information is received and processed. These concepts of cultural process and

lived entities replace more traditional concepts such as “acculturation” and present measurement challenges to researchers and health services providers.

(p.111)

In order to successfully attain health literacy, it requires more than receiving and reading information; it implies a “convergence of education, health services, and social and cultural factors” (IOM, 2004, p.2). Mackey (cited in Ruiz, 1984) recognizes that “language problems are inherent in the multilingual situation” (p.6). The United States is a multilingual nation with different migration patterns that affect the sustainability and mobility of resources. Every health agency finds the need to accommodate linguistics services for multiple ethnic minorities; therefore, a look to different socio-cultural and ecological factors, what is known as social determinants of health, can give a more comprehensive understanding of the issues of language in healthcare. In this next section, the different factors that play a role in the health outcome of every community will be reviewed. These social determinants of health are embedded in every health-related activity and define the health behavior of a particular region. A thorough understanding of these factors, along with language access, could allow the health system to build an efficient and resourceful bridge between medical professionals and community health disparities.

1.4 Social Determinants of Health and Social Ecology

It is not enough for people to have a common understanding of the illnesses in order to have complete control over their health status, there many other factors playing a

role. In addition to health literacy, the environment where an individual spends his or her life span has an effect on health-related predispositions and outcomes. Existing literature have been explaining the existence of health disparities through a broader community-based perspective, finding patterns and variables that, along with language and literacy, characterize the health of communities. This research area is particularly important in Hispanics communities because the concept of family and community is deeply entrenched in the social and cultural experience; therefore, intrinsically manifested in health communication and outcomes. Border regions, such as the one where this study takes place, have a significantly different socioeconomic mobility status compared to other areas in the country.

The World Health Organization defines social determinants of health as “the conditions in which people are born, grow, live, work, and age” (WHO, 2017). More specifically, *Healthy People 2020* defines the 5 key areas that determine the health of a community: 1) economic stability, 2) education, 3) social and community context, 4) health and healthcare, and 5) neighborhood and built environment (2017, para.11). Some examples of social determinants of health according to the project *Healthy People 2020* (2017) are:

Access to educational, economic, and job opportunities; access to healthcare services; quality of education and job training; transportation options; public safety; social support; social norms and attitudes; exposure to crime, violence, and social disorder; socioeconomic conditions’ residential segregation;

language/literacy; access to mass media and emerging technologies; culture.

(para.7)

Health disparities cannot be explained alone by the medical services provided and received. From the environment to the administration of drug treatments and follow-up care, many variables affect the health outcome and the living conditions of a community. Data collected has proven the existence of disparities (see Section 1.6); however, researching the determinants of health is important to the developing of new treatment protocols to reduce health disparities. The Centers for Disease Control and Prevention (2014) states,

Addressing social determinants of health is a primary approach to achieving health equity...when everyone has the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of their social position or other socially determined circumstances...social determinants of health such as poverty, unequal access to health care, lack of education, stigma, and racism are underlying, contributing factors of health inequities. (para. 3)

Schiavo (2014) makes a list of some of the social disadvantages and non-biological factors that affect health:

The absence of adequate transportation to reach such services; limited health literacy or poor education levels; living in violent neighborhoods or geographical communities that do not include recreational facilities, parks, community centers, or other kinds of services that may be conducive to a healthy and active life; high

levels of stress, which may be linked to a history of low socio-economic or social discrimination; cultural bias and lack of social support; or inadequate policies, just to make a few examples. Given the many different factors that may affect health outcomes among different groups and populations, the roots of health disparities are often community or group-specific. (p.71)

As mentioned, all these factors are not controlled by the individual, but rather defined by external circumstances. According to Freudenberg et al. (2008), some of the social determinants of health that have been found to affect cancer disparities are “poverty, less formal education, racism, and limited access to healthcare” (p.29). Social determinants of health have been the focus of research in less developed countries. However, as it will be reviewed in Section 1.7, the region where this research focuses meets many of the characteristics of a high-poverty area. That is why understating the environment is a central part of this study. The Dana-Farber/Boston Children’s Cancer and Blood Disorders Center (2016) is proposing the need for new research to explain the existence of health disparities in children with cancer regardless of the medical attention received. K. Bona, their lead researcher, acknowledges the need to consider the environment, “these children are getting the same best possible care at well-resourced institutions from highly trained clinicians, and we’re still seeing disparities...in trying to improve cure rates, we, as a field, have focused almost exclusively on biology. If we want to move forward, we also have to look at social determinants” (para. 5). Their research is opening the path to a new debate based on data about the different variables causing disparities beyond the medical services.

Bronfenbrenner (1994) is considered “the architect of social ecological models”. He came up with a model that describes how a person’s development is affected by the different levels of their surrounding environment. The level closer to the individual is the microsystem “the immediate environment...includes family, school, peer group, and workplace” (p.39). The next level is the mesosystem, which involves “two or more settings... (e.g., the relations between home and school, school and workplace, etc.)” (p.40). The third level is the exosystem, in which two or more settings are indirectly involved “(e.g. for a child, the relation between the home and the parent’s workplace; for a parent, the relation between the school and the neighborhood peer group)” (p.40). The fourth level is the macrosystem, which is comprised of the first three levels; it is “characteristic of a given culture or subculture, with particular reference to the belief systems, bodies of knowledge, material resources, hazards, and life course options that are embedded in each of these broader systems” (p.40). The fifth and last level consists of the chronosystems, which are “not only the characteristics of the person but also of the environment in which that person lives (e.g. changes over the life course in the family structure, socioeconomic status, employment, place of residence, or the degree of hecticness and ability in everyday life)” (p.41). All these dimensions and relations allow researchers to understand and locate patterns about how particular groups interact in a community and identify risk factors in the development of health issues and the healing process. An example showing the importance of the information provided by these layers to obtain health information can be found in a research conducted by Meeske et al. (2013). They tried to determine the effects of living with childhood cancer in the mental

health of caregivers; it was discovered that Hispanics were more resilient to suffer mental problems “due to familism and social support” (p. 1474). Family plays a very important role in some cultures and how they deal with illness. A study conducted by Gray et al. (2014) surveyed literature and identified how issues such as full disclosure about the illness were managed very differently by families from different cultures who chose to filter what information to communicate to children opposing the full disclosure view of the United States system.

Stokols (1996) applies social ecology to issues of health communication and health promotion. He proposes two principles concerning health. In one, the environment is seen as “having multiple physical, social, and cultural dimensions that can influence a variety of health outcomes, included physical health status, developmental maturation, emotional well-being, and social cohesion” (p. 285). The second principle states that “human health is influenced not only by environmental circumstances, but also by a variety of personal attributes, including genetic heritage, psychological dispositions, and behavioral patterns” (p.285). Health researchers and policy makers have to pay specific attention to each one of these dimensions to understand the different ways in which a patient and his or her environment become an integral part of the healing process. McCormack et al. (2017) argue that by following this model it is possible to engage the patient at all levels, from the individual to the to the community, the institutional, and policy level. Planning health literacy interventions at all levels “shifts some of the burden of responsibility off the patient” who can then become an active agent in the discussion and decision-making process because, as McCormack explains,

When information is well-designed, understandable, and accessible to patients and family members, the dialogue is based on shared language...consequently patients can authentically engage in decisions about their health and healthcare and be less impacted by potential issues of shame, perhaps leading to more of a partnership approach to health. (p.12)

The linguistic planning to address health disparities has to be based on a theoretical framework in order to be well directed and meaningful. It is a common practice to focus on individual behavior as characteristic of health. However, McLeroy and Wendel (2011) point out that, “even when there is a strong link between a behavior and a health outcome, some behaviors are not entirely under the control of the individual, and even those under individual control may be strongly influenced by social and structural factors” (p.1). That is the reason why Krieger (2014) calls the use of ecosocial theory a “painful awareness”, because society and the environment, together, ultimately define the distribution of health (p.653). This ecological approach to health promotion (McLeroy et al., 1988; Green et al., 1996; Stokols, 1996; Golden and Earp, 2012; Golden et al., 2015) appeals to create a joint effort by policy makers, community, institutions, and individuals to improve health in any given environment.

Sociodemographic, economic, and cultural factors have a deep impact in health access and each community faces its own challenges. Therefore, researchers have turned to community-based evidence projects to help reduce disparities. One example is the Community-Based Participatory Research (CBPR) (see the Agency for Healthcare Research and Quality, 2009; Wallerstein and Duran, 2006, 2010; Minkler and

Wallerstein, 2010; Smith and Blumenthal, 2012; Burke and Albert, 2014), an interdisciplinary movement that strives to identify and give voices to the needs of at-risk communities to make them active participants in the healthcare system. The project is rooted on the cultural and ideological characteristics of the community. Wallerstein and Duran (2010) define it as “a transformative research paradigm that bridges the gap between science and practice through community engagement and social action to increase health equity” (p.40). However, O’Toole et al. (2003) mention how this initiative is still limited to some programs under the public health professional field (p.592). In the past decades the National Institute of Minority Health and Health Disparities, the Center for Disease Control, the National Cancer Institute, among other agencies, have started initiatives to collect health data following the CBPR model (Israel et al., 2013). The aim of CBPR is to create partnerships among community and institutions of power in order to provide evidence that could result in changes and adjustments to current policies. The National Cancer Institute use of CBPR methods reflects back to Zarcadoolas’ definition of health literacy where she proposed to take advantage of the different skills individuals possessed. The NCI states that “an assumption of CBPR is that research will be more successful and yield more meaningful findings if it respects community values and capitalizes on the cultural assets and resources of the community” (Braun et al., 2012, p. 1200). In other words, biological and medical research alone is not enough to eliminate disparities as they continue to be on the rise.

Another effort to close the gap between the system and the community and facilitate the diffusion of medical information is by relying in the field of health promotion, a worldwide effort to create healthier communities. The World Health Organization defines health promotion as “the process of enabling people to increase control over, and to improve their health. It moves beyond a focus on individual behavior towards a wide range of social and environmental interventions” (WHO, 2017). Larkey and Hecht (2010) describe health promotion efforts as “designed to address cultural values through culturally adapted messages” (p. 114). Health promotion strategies are designed to reach out to the community and understand health from their perspective. Health promotion tries to “incorporate narrative theory, locating culture within the narratives of cultural members, and suggesting that narrative may provide a central, grounded medium for expressing and shaping health behavior” (p.114). Professionals in this field rely in community based approaches to develop, implement, and evaluate projects of preventive medicine and public health. Crosby et al. (2015) describe health promotion as “a cornerstone” for preventable health related issues (p. 3). The successful implementation of health promotion tasks is evidence-based; however, all efforts to better health in the communities with limited access have not been able to eliminate the disconnection between research and practice.

After a review of the definition of health literacy and the initiatives based on social determinants of health, it can be summarized that eliminating health disparities requires not only a continuous effort and commitment among all entities involved but also data collection and monitoring of the interdisciplinary aspects that affect the

community health outlook. A transdisciplinary approach is needed to study all interconnected factors found in the different communities because there is a multidimensionality to health, a set of elements that have not been extensively researched. This section provided a panoramic review of the different disciplines involved in health disparities; however, Hispanics communities, in addition to a very particular ecosocial environment, face the issue of language barriers that hinders communication between the community, researchers, and medical professionals. In the next section, the impact of language barriers in the health will be reviewed.

1.5 Language Barriers in Health Communication

There is a bridge between the complexity of the health system in the United States and the diversity of ethnic and racial minorities living in the country. However, one of the main issues faced by Hispanics in healthcare is the language barrier. According to the Robert Wood Johnson Foundation, “language services are frequently provided by self-declared bilingual clinic providers and ad-hoc interpreters, such as family members, friends, or staff who have not been trained and assessed in medical interpreting” (Regenstein, 2008, para.2). To rely on translation from interpreters that have not been trained or lack understanding of the culture has a negative impact on safety resulting in medical errors that have both human and monetary cost for the medical institutions. In addition to the language barrier of communicating in a different language, there is another issue, the way that language is used may or may not be deemed appropriate for Hispanic culture. For example, Hispanics do not expect the doctor to just tell them

information and leave the room without further interaction. As Solomon et al. (2005) point out; some cultural issues need to be taken into consideration while providing linguistic services. For example:

Familialism, the significance of the family over the individual; collectivism, the importance of friends and extended family in helping to solve problems; *simpatía*, the need for smooth interpersonal relationships in which criticism and confrontation are discouraged; personalismo, the preference for relationships with members of the in-group [people sharing same values]; *respeto*, the need to maintain one's personal integrity and allow for face-saving strategies; and power distance, the special deference shown to certain persons, such as the powerful, the elderly, and the educated. (p. 406)

Language barriers not only reside in the abilities to understand the other language but in the cultural values that are deeply embedded within the use of language as they relate to health. Health and illnesses are constructed through language; therefore, communication is key to provide integral healthcare services.

Muturi (2005) (cited in Schiavo, 2014) states that the goal of health communication should be “to increase knowledge and understanding of health related issues and to improve the health status of the intended audience” (p.8). However, the question is how to measure understanding from the patients' perspective. Data from The Joint Commission (2007) exposed that 65% of medical errors ending in an adverse outcome for the patient reside in communication mistakes. This same report explains that 49.2% of LEP patients reported physical damage resulting from miscommunication,

while English language speakers only reported a 29.5%. The range of probability to suffer permanent damage or death is 3:7 in LEP people and 1:4 for English speakers. These alarming data put together by The Joint Commission reflects the disadvantage of not speaking the language, keeping in mind that (as discussed in Section 1.3) the health system is so complex that not only requires an average ability to speak the language, it does require a high literacy level.

The Agency for Healthcare Research and Quality in a report about LEP parents established that the lack of ability in the language severely impede the interaction within the healthcare context. The information they received was minimal in comparison to other groups. This same agency concluded that “pediatric patients with Spanish-speaking LEP families have a much greater risk for serious medical events during hospitalizations than patients whose families are English proficient” (AHRQ, 2012). Jacobs et al. (2006) summarize the consequences of language barriers in LEP patients based on previous research:

1. People with limited English Proficiency are less likely to receive the care they need
2. Patients whose primary language is not English have a poorer understanding of the care they have received and are less likely to follow recommendations
3. Patients are more likely to be admitted to the hospital and have longer hospital stays
4. LEP patients are less satisfied with their health care (pp. 116-117)

The National Association for Health Care Quality (2014) identifies three common causes for medical errors.

1. The use of family members, friends, or non-qualified staff as interpreters.
2. Clinicians with basic foreign language skill who try to communicate without using qualified interpreters.
3. Cultural beliefs and traditions that effect health care delivery.

This is one of the reasons why disparities caused by language continue to exist despite the existence of linguistic services. Even when the translation occurs, it often results in medical errors with consequences for the patients.

Flores et al., (1998, 2003, 2005) have published several articles about the impact of language barriers on Hispanics and children's health, calling it the greatest barrier to healthcare access. In some cases, it even leads to wrong diagnosis and careless information. Flores concludes that the fact that children go to school in the United States does not help the problem, if anything, it makes it worse, since children are often used as translators. Even if children can communicate in English, they lack all the resources to understand the medical terminology and the implications that are dealing at the medical encounter; children are unequipped to function as interpreters. Flores (2006) has found some examples of patient safety concerns due to language barriers. He refers to the following high-profile medical errors: in one situation, a 3-year-old girl went to the emergency department complaining of abdominal pain because of the language barrier it resulted in a delay that caused peritonitis and a severe infection; the second case involves the misinterpretation of the words "*se pegó*" which was understood as someone hitting a

little girl instead of the girl hitting herself by a falling accident; this resulted in the 2-year-old girl sent to protective custody. Another misinterpretation is cited by Wilson (2013) involving the word “*intoxicado*” which was understood as intoxicated when the patient meant feeling sick to the stomach causing in the patient being treated for an apparent overdose instead of the aneurysm he was suffering. This resulted in the patient being quadriplegic (p. 252).

For parents or caregivers dealing with cancer the struggle increases as they also deal with the stress of the situation. The National Institute of Health talks about communication when matters of life and death are being discussed because, when talking about cancer, it “requires clinicians to draw on a distinct set of communication skills”. This is because patients and caregivers “are dealing with the emotional impact of a life-limiting illness, treatment decisions that are complex and frequently involve consideration of clinical trials, and the challenges of sustaining hope while also having realistic goals” (Back et al., 2008, p.1897).

Access to healthcare is a matter of equality and justice; however, the language barrier is still visible for minorities despite the existence of interpreters. This is because interpreters and medical personnel need to know more than the conversational aspect of the language; they need to be trained to understand the cultural and social baggage that accompanies each medical encounter. This is where the field of health promotion and community-based research take a role. There has to be a bridge of information connecting the system and the community. The negative health outlook shown by reports of health disparities allows this research to put into perspective the real risk that LEP

patients confront in the medical settings. The sum of all factors, the determinants of health, including language barriers and cultural appropriateness, results in health disparities in many different chronic illnesses. However, the focus of this research is pediatric health disparities, as it will be explained in the next section.

1.6 Pediatric Cancer Disparities

Before establishing the data for pediatric cancer specifically for Hispanics, it is essential to look at the current panorama of childhood cancer in the United States. These reports are the basis of this research as they state the importance of focusing in this illness. Pediatric cancer is an area that has been overlooked when talking about cancer, yet, it is the second leading cause of death in children, after accidents. The cancer incidence in children keeps increasing and it is an under-researched, under-funded, area in the United States. The general data is, by itself, quite remarkable and concerning, without adding the risk factors for Hispanics and other minority groups. St. Baldrick's Foundation, an organization dedicated to provide funding for research in childhood cancer, provides the following national data: only 4% of U.S. federal funding is exclusively dedicated to childhood cancer research. The funding from pharmaceutical companies is almost none, as it is not a highly profitable area. Most of the funding that is provided from non-profit cancer organizations is spent providing transportation and accommodations to families to be close to their child during hospital stays, making it less than 5% of funds available dedicated to research ("Filling the Funding Gap", 2016). The National Pediatric Cancer Foundation and the Coalition Against Childhood Cancer Fact

Library (2016) give more alarming data. According to their fact library, 1 in 285 children will be diagnosed with cancer setting the total at 15,780 cases per year; that is a 24% increase in the past 40 years. Furthermore, it has been reported that 95% of survivors will have significant health problems related to the cancer or as a result of side effects of the cancer and/or the treatment. Nevertheless, since 1980, the Federal Drug Administration (FDA) has only approved three new drugs, which add up to only 10 available treatments. In addition to this data, the average cost of a hospital stay is 40,000 dollars (Coalition Against Childhood Cancer, 2016).

Now, the outlook for Hispanics is even more concerning. A 2012 report by the National Cancer Institute states that, “Hispanic children with cancer are slightly less likely to survive 5 years after their diagnosis than non-Hispanic white children” (“A look at Childhood Cancer” para. 3). According to the report *Cancer Facts and Figures 2015-2017*, by the American Cancer Society (ACS), “an estimated 2,700 Hispanic children (ages 0-14 years) in the US will be diagnosed with cancer in 2015, accounting for about 2.1% of cancer in Hispanics. In contrast, childhood cancer accounts for 0.5% of new cancer cases in non-Hispanic whites” (p.14). While most of the children survive this illness, the rate of survival is lower for Hispanics (ACS, 2015, p.15). According to this report, the reason for this discrepancy is based on the following barriers faced by this group,

Financial barriers include inadequate health insurance, low personal income, and high rates of poverty...structural barriers include poor geographic access and lack

of transportation to providers. Personal barriers to care include cultural and linguistic factors, as well as discrimination and provider bias. (p. 27)

The ACS reports that approximately 300 to 400 children will die in 2015 (p.14).

Following the issue of survival for Hispanics, Jones et al. (2010) cite the limited access to healthcare poverty as well as cultural and language barriers to the lack of follow up care “when Latino children do receive a cancer diagnosis, there is evidence that they have poorer outcomes and receive more inconsistent care” (p.75). Aristizabal (2016), a pediatric oncologist and researcher at the University of California, has taken on different projects to understand the disparities among cancer in Hispanic children. She also points out at cultural and language issues recognizing that “recent immigrants may not have a cultural reference points for advances in U.S. medicine. Some see participation in clinical trials as being asked to use their children as ‘guinea pigs’ instead of the reality of improving their chance for a cure” (para. 8). Bhatia (2011) also pinpoints to cultural factors as main contributors to ethnic/racial disparities to survival, identifying the following: 1) socioeconomic status and health insurance coverage, 2) diagnosis delays, 3) enrollment on cooperative group trials 4) knowledge about cancer diagnosis, treatment and toxicities 5) cancer surveillance 6) risky health behaviors 7) disease biology 8) pharmacogenetics and 9) adherence to therapy (pp. 6-10).

In addition to these factors, there is still one more issue that Hispanics face. Some parents are considered illegal residents of the United States and they keep children in hiding, afraid that taking them to the doctor will get them in trouble with immigration agents. Zamora et al., (2016) conducted a study among primary caregivers of pediatric

cancer children. In his study, 32% “reported feeling that their child would have received better care if English was their primary language” (p.2173). Additionally, they found that “75% of them reported that at least one member of their household had ‘undocumented’ legal status” and “11% of them avoided or delayed care due to their immigration status” (p. 2173). Moreover, 73% of the Spanish caregivers accepted to be enrolled in a clinical trial. However, researchers found this information to be incorrect in 56% of the cases. This could be attributed to confusion about the treatment since “21% report having falsely claimed understanding a healthcare provider because they were ashamed they did not speak English” (p.2177).

While the ACS (2015) states that symptoms are non-specific to any group, regular children’s medical checkups are vital for early detection. Some symptoms “include an unusual mass or swelling; unexplained paleness or loss of energy; a sudden tendency to bruise; localized pain or limping; unexplained fever or illness; frequent headaches, often with vomiting; sudden eye or vision changes; and excessive, rapid weight loss” (p.14). All these symptoms can be easily overlooked by parents who, scared of the health system and the government, would rather rely on self-medication and/or cultural healing practices that inevitably result in an advanced-state diagnosis. As Freudenberg et al. (2008) explain, “most cancer research has focused on secondary prevention and treatment. The evidence base for developing policies for the primary prevention of cancer is limited, making it more difficult to achieve significant progress toward the goal of reducing cancer disparities” (p.26). Parents are going too late to seek specialized medical attention because of all the barriers they face, which makes Hispanic children

even more vulnerable to cancer than other children making it harder to survive, regardless of the fact that the symptoms are the same for every racial group.

As mentioned previously (see Section 1.4), there are different non-biological factors outside the control of the parents that could drastically predispose a child to get ill. However, there is also a biological factor directly involving Hispanics and it is still under-researched. This is genetics. Researchers at the St. Jude Hospital (Xu et al., 2012) have found a gene called ARID5B that was traced back to a gene resulting from a combination of genes present in Hispanic ancestry which resulted in “higher risk of ALL [acute lymphoblastic leukemia] in Hispanic children” (p.751). In addition to the barriers, there is also a genetic predisposition that affects Hispanic children; however, aside from this study done at St. Jude Hospital there is no more data on the issue. Moving away from the biological and continuing with the ecosocial factors affecting children, another factor that predetermines health outcomes of children is the place where they live. The ACS (2017) acknowledges that minority communities are often living at the margins and are more disposed to die of cancers that could have been prevented because they are being diagnosed at a later, more advanced, stage and they tend to be more likely to not receive pain medication. Furthermore, they are also faced with the financial factor. The Intercultural Cancer Council (2008) explains that about 13 million children in the United States live below poverty level (below 200% poverty). This same report says that Hispanic children have a higher incidence (30% greater) in acute lymphoblastic lymphoma as well and Hodgkin and Non-Hodgkin lymphomas, while they have a 15% higher incidence of lymphoid leukemia and a 17% in leukemia. Moreover, Hispanics

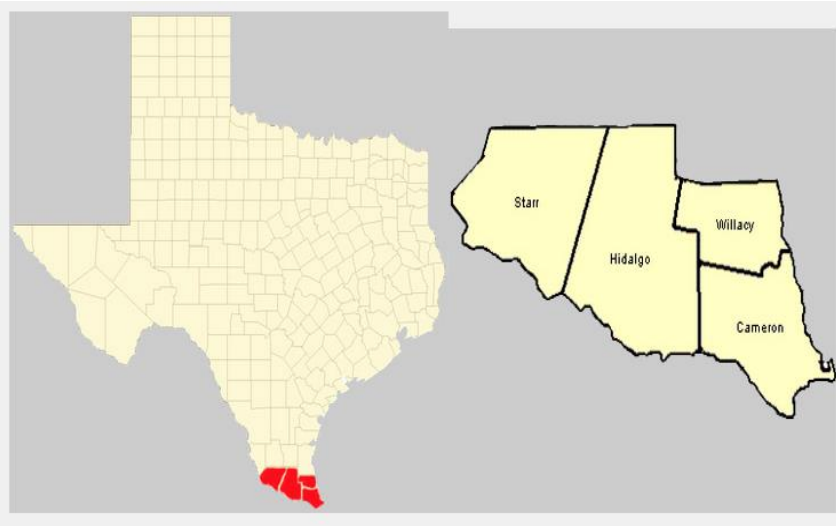
have the highest incidence of acute lymphoblastic leukemia (p.2). This report corroborates what has been already mentioned in other studies, Hispanic children are more likely to die from these cancers than the non-Hispanic counterparts. Patel et al. (2015) in a study to determine the effects of socioeconomic status on neurocognitive outcomes in children with cancer explain that even though survival rates for children with cancer have improved “there are disparities in outcomes for children from lower socioeconomic status (SES) and/or racial and ethnic minorities” (p.115). While some other studies have tried to elucidate the impact of poverty, race and ethnicity in childhood cancer outcomes (Bhatia et al., 2002, 2012, 2016; Liu et al., 2016; Pan et al., 2010; Wang et al., 2017; Lim et al., 2013) there is still much research needed in the field. A diagnosis of cancer has an effect in the whole family; therefore, the socioeconomic status of the family has an effect in how to cope with the health of the children. Research suggests that “overall levels of distress are higher among parents of pediatric cancer patients versus their children, given the evidence that a family’s sociodemographic disadvantage can have significant effects on children’s psychosocial well-being, more attention should be given to these constructs among pediatric cancer patients” (Bemis et al., 2015, p.734).

This research is based in a particular area on the border of the United States and Mexico, deep in South Texas. While the incidence of cancer in this area will also be reviewed; first, it is important to contextualize the geographical region and its demographic and socioeconomic status while keeping in mind how all the social determinants of health, the social and demographic panorama and the language access barriers that are characteristic of the region have an impact in health.

1.7 The Rio Grande Valley

The Rio Grande Valley (RGV) is a territory of unique socio-demographic and linguistic characteristics. Because of its location at the southern border of the state of Texas, it is a focal point for language researchers. The RGV is a place of contrasts, for some people it offers a thriving international commerce, while it is still considered one of the poorest places in the state. This border area is also a passing point for immigrants looking to move up north; however, many never make the journey out of *the Valley*, as it is known, and stay here in the invisibility of being illegal and alone in an unknown area. This region has been defined as “the most misunderstood region of North America” (Arispe and Acevedo, 2009, p.39).

Figure 1.1: Map of the Lower Rio Grande Valley Counties



Map showing the four counties location in the State of Texas. Picture taken from The Center of Community Health Development (<https://cchd.us/about-our-communities/>)

The RGV is comprised of four main counties: Hidalgo, the mainstream area, Starr to the West, and Willacy and Cameron, to the East. The location of these counties is at the lower South-East border of Texas. Figure 1.1 shows the exact location in the map of Texas. This area has for long been described as a third space, a space in-between (see Homi Bhabba, 1994). It has also been the subject of numerous works of narrative, novels, and short stories because of the uniqueness found at the intersection where two worlds, two languages, two cultures collide in family-centered makeshift houses. To summarize the enrichment of these cultures, the Rio Grande Valley is well known by its residents by a phrase commonly used in advertisement, “Magic Valley”, (in Spanish, *El Mágico Valle del Río Grande*). However, regardless of the richness of culture it has to offer and being considered one of the most sought locations because of the proximity to border commerce; there is a negative stigma associated with living in the Valley. Governor Gregg Abbot referred to it as “a third world country” (Planas, 2014, para.1), while a report on the Michigan Journal of Sustainability calls this population “the forgotten Americans” (Rivera, 2014).

A recent report about *colonias* refers to this community lifestyle as “living in the limbo” (Hilfinger Messias et al., 2016). The US Census Bureau (2015) data gives more information about the demographic situation of the RGV (see Table 1.1). This data demonstrates the population of this area is characterized by all the at-risk factors in the **social determinants of health** (see Section 1.4).

Table 1.1 Demographic Characteristics of the Rio Grande Valley

Counties:	Hidalgo	Starr	Cameron	Willacy
Population	842,304	63,795	422,156	21,903
Persons under 18 years	33.4%	33%	31.3%	25%
Hispanic/Latino	91.3%	95.8%	88.8%	87.7%
Foreign Born	28.8%	33.1%	24.4%	16.7%
Language other than English at home	84.7%	96.1%	74.5%	54.2%
High school graduates	62.1%	46.3%	64.8%	62.9%
Bachelor's Degree	16.7%	9.1%	16.4%	8.3%
Persons without health insurance	33.8%	32.4%	32.8%	25.5%
Persons in poverty	31.1%	30.9%	32%	35.4%

Note: Table adapted from *U.S. Census Bureau* Data as of July 1, 2015.

It is important to keep in mind that some undocumented people do not participate in the census. According to the Migration Policy Institute (2014) there are approximately 100,000 undocumented people living in Hidalgo County alone.

After looking at the demographics, some things that stand out are the low level of education and the high levels of poverty. Perkins et al. (2001) argue that some of the reasons for low education are “first, many of the families are unaware of the available educational opportunities. Secondly, while many parents indicate they want their children to be educated, any level of education the children attain beyond their parents’ achievements is considered a success” (p.34). The poverty levels are explained, in part, because of the large number of *colonias* that have been established along the border.

Barton et al., (2015) explains the term *colonias* comes from a Spanish term meaning community or neighborhood in Texas; however, they are defined as

A residential area along the Texas-Mexico border that may lack some of the most basic living necessities such as potable water, septic or sewer systems, electricity, paved roads or safe and sanitary housing. An estimated 500,000 people live in 2,294 *colonias* in Texas. (p.1)

There are more than 1,400 *colonias* in Texas and most of them can be found in the border where “local public funds and other resources are often limited and unable to provide services to the current and growing population. Hidalgo County, which has the most *colonias* and largest number of *colonia* residents in Texas, is typical of many border counties...[it] does not have a large enough local tax base to provide water and sewer services to the 129,888 people living in its 868 *colonias*” (p.4).

All four counties that make up the Rio Grande Valley are categorized under the poorest counties of Texas. This has a direct impact on the access to health care. Looking back at Section 1.3, it can be sustained now, with statistical information, that all the indicators categorized by the 2003 National Assessment of Adult Literacy as red flags for lack of health literacy and poor health outcomes are found in this data. The NAAL report mentions that the most at-risk groups are: 1) adults living under poverty levels, 2) Hispanics, 3) adults that spoke only Spanish before going to school (Kutner et al. 2006, p. v-vi). Table 1.1 and Table 1.2 show that these descriptors are true in all counties, and even more evident in *colonias*. The following are the demographics found in Texas *colonias* compared to the country.

Table 1.2 Demographics of Colonias in the Nation and the State of Texas

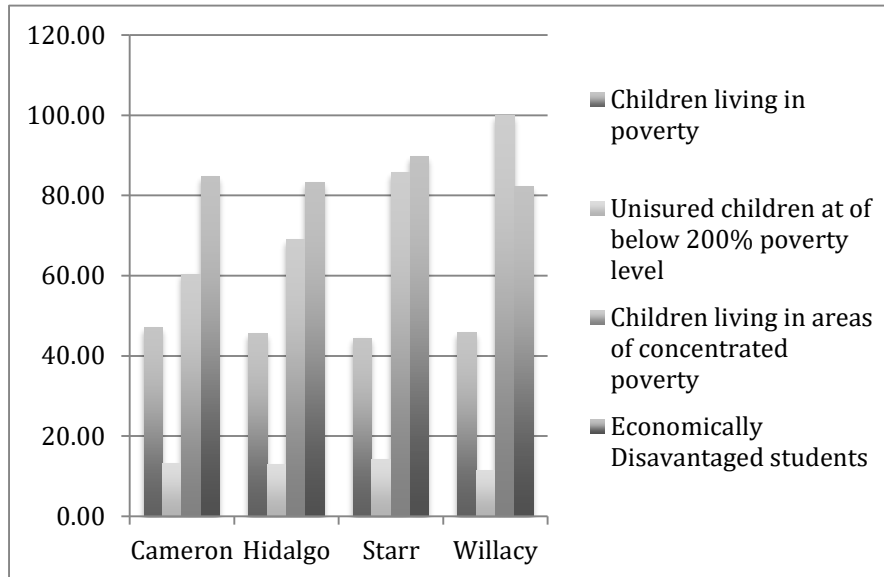
	Colonias	Texas
Median Age	27	33.6
Hispanic/Latino	96%	37.6%
Speak English less than very well	43.3%	14.5%
Less than High School Diploma	54.8%	19.6%
Poverty Rate	42%	17%

Note: Table adapted from Barton et al., 2015.

The HHS, through the office Health Resources and Services Administration (2017), has classified these four countries as a medically underserved area and a health professional shortage area. Cameron and Hidalgo counties have been under this classification since 1994, Starr and Willacy counties since 1978 (HRSA, “MUA Find”). The poverty and the lack of access has taken a toll on children’ lifestyle. According to the organization Community for Children (2017) the percentage of children under 17 years old living in poverty in the RGV is 48.5% (the rate is 24.3% in the state). The ratio of physicians is 1:1,394 (1:606 in the state). Figure 1.2 addresses the poverty levels for children. This data justifies and gives the foundation to the focus of this research.

The health disparities of childhood cancer taken into consideration and the defining high percentage of children living in the RGV under poverty level, exhibit an area of concern that has not been fully addressed. That is, the opportunities of survival that these kids have when diagnosed with cancer while facing all the health determinants that historically have led to adverse health outcomes.

Figure 1.2 Demographics of Children Living in the Rio Grande Valley



Data taken from The Center for Public Policy Priorities, Kids Count (2017): Data Center, 2010-2014.

The next section will explain the information that exists about the incidence of pediatric cancer in this region.

1.8 Pediatric Cancer in the Rio Grande Valley

According to the Texas Department of State Health Services (2014), approximately 1,200 children are diagnosed with cancer each year and 200 of them will die. This makes cancer the leading disease-related cause of death in the state. The situation in the Rio Grande Valley, a medically underserved area (as explained in Section 1.7), is not favorable for children diagnosed with cancer. Considered a rural area, this region did not have any specialized medical center to treat childhood cancer. The most

basic services were being provided in the general pediatric sections at local hospitals. However, for diagnosis and specific treatments patients had to travel to the primary location of the Texas Children's Hospital in Houston, Texas at approximately 350 miles of distance. The traveling distance positioned families in a difficult situation, as they were required to find transportation and often leave their jobs to be able to be with their child far away from home during a lengthy hospital stay. Some families, nevertheless, found themselves in a more excruciating circumstance. Approximately 75 miles to the North, in the only highway out of the Valley, there is a permanent location of the U.S. Customs and Border Protection, a full-stop checkpoint at Falfurrias, Texas. This means that undocumented children or undocumented caregivers cannot go to Houston, Texas or any other main city outside of this region.

In the year 2001, the Vannie E. Cook Jr. Children's Cancer and Hematology Clinic (2017) was built in the city of McAllen, Texas, right in the heart of all four countries. This clinic was founded by the non-profit organization Vannie E. Cook Jr. Foundation and the Baylor College of Medicine. The establishment of this medical institution has enormously changed the health outlook for children in the RGV. According to the clinic's webpage no children have been denied services for lack of medical insurance. This place is located within 37 miles of the closest international bridge. Therefore, it also serves children coming from the Mexican side of the border.

According to an article published by St. Baldrick's Organization, it was them who provided the funding and support to the clinic to become part of the Children's Oncology Group (COG) which allows them now to participate in cutting-edge clinical trials

Interviewed in this article, Dr. David Poplack, director of the Texas Children's Cancer Center said that "these children just weren't getting optimal care". He also recognized the obstacles to fund the clinic since most of the children are uninsured (Jessop, 2015). This organization also facilitated the hiring of a research nurse working for COG trials, Jill Hartley, who describes the region as "a demographic that's grossly underrepresented in childhood cancer research" (para. 12). The number of children that have been able to receive care has increased throughout the years; nonetheless, the incidence of cancer has also increased. In an interview realized back in 2014 for Valley Central, a local news media, Victoria Guerra, the Director of Development at the clinic said there has been a constant increase in cases. According to Guerra, in the previous year they had about 700 cases, which was "an alarming rate in a population of our size" (Avila, 2015, para. 7). In this same news report oncologist Lorimar Ramirez warns the community to seek medical attention as soon as something looks not right and trust that "they have the latest technology in detecting cancer early" (para. 17). Since the clinic opened its doors in 2001 more than 8500 children have received medical attention "four times the number expected" ("About the Vannie E Cook Jr.", 2016).

It is undeniable that the opportunity that this clinic has created for residents in both sides of the border could have an effect in the disparities this region faces. They have the resources necessary for diagnosis and most of the treatments. Moreover, they are aware of the demographics and the needs of the majority of the population and through funding events they outreach to the community. However, it is not enough. As it was discussed before, the amount of people living in the shadows and afraid to seek

medical attention is still very high. That is why the focus of this research is to analyze how materials for the dissemination and promotion of health are being received by the communities through the Rio Grande Valley in hope that this data will provide a path to close the informational gap between the available resources and the social determinants of health that negatively impact this area. The RGV, a border region, provides its residents with a rich cultural and linguistic environment, a unique blend of people striving to survive at the farthest South edge of a first world country, the leader of the free world; however, the access to the mainstream systems seem to alienate certain groups. It is the objective of this study to open paths of communication via interdisciplinary theories that take into consideration the particular situation and culture of the individuals and the institutions creating a bridge of information among both entities. In the next chapter, a thorough review of the theories and their history, as they have been applied to research, will be presented.

Chapter 2

Literature Review

2.1 Introduction

As health institutions are shifting to an all-inclusive, patient-centered holistic care, the efforts of language policy makers are focused on developing a culture of effective communication across all levels in the health system; yet, the implementation of an

effective language planning that incorporates diverse low-literacy populations and cultural backgrounds in the nation has yet to be proven functional. As it was discussed in Section 1.2, the government of the United States has passed different laws and regulations to address health-disparities issues; however, extensive research is still needed to identify the extent and efficacy of these policies from the community perspective. This research is based on a language-in-context approach that addresses the functionality and meaning potential of language as it travels from the context of health institutions to the community. Hence, the need to apply a sociolinguistic theory that provides the fundamentals to study the characteristics of the written text as it is embedded in the cultural context where the message is being exchanged. Systemic Functional Linguistics (SFL), as an applied theory, provides the tools to shed light about the implications of translating health documents as a vehicle of health promotion and health information to linguistic minorities.

Some of the most renowned writers of Systemic Functional Linguistics such as M.A.K. Halliday and Christian Matthiessen have proposed the use of SFL as a practical and viable tool to analyze language as it relates to healthcare. In 1998, Halliday wrote what is considered a pioneer article on the topic, “On the Grammar of Pain” expanding the focus of his theory to the health field. Years later, Matthiessen continued to apply SFL key terms to healthcare. Matthiessen (2013), inspired by the work being done in emergency room communication by Slade in Australia and Hong Kong, validated the use of SFL in healthcare because of its “theoretical and descriptive resources.” SFL, says Matthiessen, has an interdisciplinary aspect that “empowers researchers to undertake

projects of investigation and intervention in many contexts that are critical to the workings of communities and the quality of human life” (p.437). This permeability feature has open a path for the theory to make its way from linguistics to other fields such as translation, computational linguistics, artificial intelligence, second language acquisition, among others. It is worth noting that research outcomes in all these disciplines are focused and ultimately measured by their impact in society.

In this section, a description of the SFL theory and methods will be described as well as their relationship with the field of translation and health communication. In addition, a review of translation theories as they merge with SFL principles will be provided. Previous research in these fields will also be reviewed as the premises from where this research project takes on the objective to identify the gap between the linguistic planning, implementation, and the reception of such information by means of how the health narratives are constructed in translated texts and the community.

2.2 Systemic Functional Linguistics

Systemic Functional Linguistics is a theory that was formally developed by the British Linguist M.A.K Halliday during the 1960s. J.R. Martin (2016) considers the article “Categories of the Theory of Grammar” published by Halliday in 1961 as the “founding paper” for SFL (p.35). Certainly, Halliday is the father of the SFL, as it is known today; however, it has been extensively indicated that Halliday’s theory is based on the work published by J.R. Firth during the 1950s. It was through Firth that he became interested in the study of language as a complete functional system in context in

contrast to Chomsky's Universal Grammar (see Martin, 2016; Choi, 2013; Coffin and Donohue, 2012; Matthiessen, Teruya, and Lam, 2010; Matthiessen, 2012; Hasan, 2014; Halliday and Hasan, 1985). Firth rejected Saussure's concepts of "langue" and "parole" as well as Chomsky's "competence" as he did not see language as a "mental system;" but rather, "as a set of events which speakers uttered, a mode of action, a way of 'doing things'" (Chapman and Rutledge, 2009, p.82). Halliday took the idea of language as a system from Firth and integrated it with the ideas of "context of situation" and "context of culture" previously proposed by Polish anthropologist, Malinowski, in 1935 (Choi, 2013, p.16). Australian SFL researcher and writer, Eggins (2004), makes a historical recount of SFL explaining Malinowski's influence as follows:

The linguistic events were only interpretable when additional contextual information about the situation and the culture was provided. Malinowski claimed that language only becomes intelligible when it is placed within its context of situation...Malinowski developed an account of language that is both functional (makes reference to why people use language) and semantic (deals with how language means). (p. 88)

While Malinowski developed the notions of *context of situation* and *context of culture* as "necessary for the adequate understanding of the text", Firth broadened the concept of *context of situation* (Halliday and Hasan, 1989, p.7). He embraced the possibility of creating a "theory of meaning-in-context" that could be extended "to the more general issue of linguistics of predictability"; he believed that knowledge of the context would allow to "predict what language will be used" (Eggins, 2004, p.89). Undoubtedly,

Malinowski's ideas opened a new way of thinking about linguistics but they were not conclusive enough to be considered a theory. With Firth's input, a framework that could be used as a theory was created. Some of his students, such as T.F. Mitchell and Hymes conducted studies based solely on this framework (Halliday and Hasan, 1989, p.8). In summary, SFL redefined the ideas of Malinowski and Firth elevating them in order to form a theory that could be applied to language and society. In a recent definition, Miller describes SFL as much as a linguistic theory as it is a "social theory" (Manfredi, 2014, p. iv).

A starting point to follow the development of Halliday's ideas into a functional theory is by positioning the concept of text as "both the product and the generator of social context" (Lukin, 2013, p. 523). Text is described by Halliday and Hasan (1989) as,

Language that is functional...language that is doing some job in some context, as opposed to isolated words or sentences that I might put on the blackboard. (This might also be functional, of course, if I was using them as linguistics examples.)

So any instance of living language that is playing some part in a context of situation, we shall call a text. It may be either spoken or written, or indeed in any other medium of expression that we like to think of. (p.10)

This definition goes back to Firth's idea of language being defined by its *context of situation*. However, Halliday sees this context as "only the immediate environment", as from there it integrates a deeper context "a broader background against which the text has to be interpreted: its *context of culture*" (Halliday and Hasan, 1989, p. 46). Texts cannot be studied as isolated signs due to the fact that meaning is always specifically anchored to

its *context of situation* and *context of culture*. Halliday (1956) outlines three primary functions of text as a socio-cultural component: “The functions to establish, maintain, and specify relations between members of societies. The function to transmit information between members of societies and the function to provide texture, the organization of discourse as relevant to the situation” (as cited in Halliday and Kress, 1976). Hasan says these new Hallidayan views about text led to “a new way of thinking about language” which matters so much to society because “there is simply no other modality as far reaching, as pervasive, as good at externalizing human experience as language” (as cited in Hasan, 2015, p. 132). The information embedded in the choices made while producing the text is far more reaching than a forthright human interaction. It carries information that reveals the most intrinsic components of the message being exchanged amid its sociocultural background.

The fundamental premise of Systemic Functional Linguistics is based on the linguistic choices that human beings make to create meaning. Halliday (1993) describes the innate human interactions as “acts of meaning” which, in a later state, become “systems”; hence the term *systemic*. These systems are comprised of the choices made from a set of alternatives. He explains, “if there is a meaning ‘I want’, then there can be a meaning ‘I don’t want’, perhaps also ‘I want very much’ as alternatives” (p.96). The choice is, however, always subjective by its context. Achugar and Colombi (2008) explain that language is a form of social action where:

Context influences the type of language used and users further shape the type of language used in different contexts. The system constrains the possible choices

and it is changed by the choices speakers make. The actual language that occurs in a particular setting is therefore probabilistic; that is, in certain contexts users tend to make certain choices. (p. 38)

Regardless of the medium of communication, when an individual takes part in a communication exchange, there will be language choices that will shape how the experience and the relations are being constructed and structured by the surrounding context. Most situations follow socially pre-established patterns, which perhaps set a parameter of probable choices. Halliday (1973) gives the following example:

Buying and selling in a shop, going to the doctor, and many of the routines of the working day all represent situations types in which the language is by no means restricted as a whole, the transactional meanings are not closed, but nevertheless there are certain definable patterns, certain options which typically come into play...conversation on the telephone does not constitute a social context, but the entry and the closure both do: there are prescribed ways of beginning and ending the conversation. (p.302)

SFL identifies the functional uses of meaning choices from patterns found in everyday contexts to the more precise use of meaning for specific contexts. Matthiessen (2013) says one of the “key points” in Halliday’s (1964) vision of linguistics is to close the gap between the different approaches to language from academics to that of the “different ‘consumers’ or community needs” (p. 440). As a result, from the SFL point of view, it is virtually impossible to understand language without taking in consideration the people and the context of the situation where language takes place.

In order to obtain information from the texts, it is necessary to be aware of the context in which the language exchange takes place. Thompson (2004) summarizes the relation between language and context:

In order to identify meaning choices, we have to look outwards at the context: what, in the kind of society we live in, do we typically need or want to say? What are the contextual factors that make one set of meanings more appropriate or likely to be expressed than another? But at the same time we need to identify the linguistic options...and to explore the meanings that each option expresses...as it were, from the bottom up – from wording to context – and the other from the top down – from context to wording. (p.9)

The way language is realized is so deeply embedded in the context that meaning is sometimes only inherent by shared context clues. To illustrate the significance of these extra-textual cues, Eggins (2004), gives the example of a note she found at her place of work placed in the sink of the tearoom. The note read, “You use it, you wash it!” Even the exclamation mark conveys some meaning, she remarks; no one questions the perfect sense of this note (pp. 85-86). Perhaps, if you were to find this note somewhere else, the meaning could be interpreted in a completely different manner. It is the extra-textual cues found in the context that gives meaning; however, these cues are only applicable assuming there is a shared socio-cultural understanding among the participants. Eggins (2004) argues that among the multiplicity of meanings of a text, context works “as the retrieval source to clear up indeterminacies of meaning” (p.86). The context cues allow the reader to deduct information from unclear or open interpretation texts; such is the

case of specific jargon texts targeted to a set of readers who presumably share this underlying contextual knowledge with the writer.

Identifying the context is the first step in language research; however, SFL goes beyond as a research tool. While SFL is primarily considered a theory, it also lays out the instruments to apply its notions directly to language research. Matthiessen et al. (2010) explain this particularity, “SFL has not been divided into two different disciplinary branches of theoretical SFL and applied SFL. Rather, SFL has always been what Halliday (2010) calls “*applied linguistics*” (p. 37). The main purpose of *applied linguistics* according to Halliday (2010) is to create “a way of engaging with language that is theoretically robust and the same time serviceable – capable of being put to use in addressing a range of problems and tasks” (p.19). That is, the main purpose of SFL is, in fact, the study of every aspect of language while relentlessly keeping its vision on what languages does for a society. The *applied* theory feature of SFL is made feasible by means of several linguistic tools that provide researchers with the techniques and methods to analyze all features of a text. Patpong (2009) summarizes how SFL structures language:

Language is organized as a multidimensional semiotic space according to: (i) the hierarchy of stratification (semantics, lexicogrammar and phonology or graphology); (ii) the metafunctional spectrum of meaning (ideational: experiential, logical, interpersonal and textual); and (iii) the cline of instantiation (the cline between potential and instance). Within each stratum, language is organized locally according to rank (clause, group/phrase, word and morpheme),

axis, (paradigmatic organization represented by system networks and syntagmatic organization represented by function structures) and delicacy (less delicate to more delicate). (p. 196)

This organization is what supplies researchers with information to do a comprehensive analysis of all linguistic features. It allows a “close-up lens” and a “distant but sharply focused view” by means of “stratification, instantiation, metafunctions, and the biaxial (paradigmatic and syntagmatic) matrix, within which any given feature is ordered and from which it derives its value in the system” (Halliday, 2005, p.134).

How exactly is language analyzed through this order of dimensions? First, it is crucial to localize the role that context plays in this “complex stratified semiotic system” Bache (2010, p.2565). Bache says, “the close link between context and language is also reflected directly in the systemic stratificational scheme by having language embedded in context” (p.2566). Hasan (1989) argues that context cannot be studied apart from text and vice versa, “they are related by *realization*: text construes the *context of situation*, at the same time that the *context of situation* is ‘the prime mover in the shaping of the discourse’” (as cited in Lukin, 2013, p. 526). The concept of *realization* is therefore defined as the process of making manifest the options in every level or strata. In other words, “meanings are ‘encoded’ in wordings, and these in turn are ‘recorded’ in some form of expression, typically sounds” (Halliday, 1981, p.14). Bache (2010) elucidates the notion of *realization* as *context* positioned at the top in the hierarchy of stratification:

Context \supset semantics \supset lexicogrammar \supset phonology \supset phonetics

However, he adds, this *realization* of context is much more complex as it is “not a one-to-one relationship between strata but accumulative”. The actual relation looks as follows:

Context \supset (semantics \supset (lexicogrammar \supset (phonology/phonetics))) (p. 2566)

Context is ultimately constructed by the choices made in each rank of the strata from sounds to semantics.

While *stratification* deals directly with the *realization of context*, it is the concept of *instantiation* that deals with the *realization* of the *context of situation* in the broader *cultural context*. The definition of *instantiation* is “the ‘relation between an instance and the system that lies behind it,’ a relation ‘based on memory’ (Halliday, 2003, p. 7), individual and collective” (as cited in Lukin, 2013, p.526). According to Lukin (2013),

Context of situation is an instance of the social and culture systems that lie behind it; thus, in any particular situation, a history of social practice inheres, and what we reify as “society” and “culture” can be seen as the sum of what people do when they are interacting. (p.526)

Martin (2008) explains the concept of *instantiation* as “aggregating the meaning potential of a culture across instances”. He uses the well-known Hallidayan metaphor of weather and climate, “instances of language use are related to the system as a whole in the same way that daily temperature readings are related to average temperatures for that year” (p. 32).

In addition to *realization* and *instantiation*, there are two other concepts that need to be identified before further explaining how language is analyzed through the SFL lens. These are the concepts of *genre* and *register*. These terms are key to understand the

relationship between *context of situation* and *context of culture* as they are realized through the metafunctions. *Genre* is what connects the text to the *context of culture* while *register* is how language is realized in its *context of situation*. Eggins (2004) explains, “texts are coherent to their cultural context, through the concept of genre” while “texts are coherent to their context of situation, through the concept of register” (p. 85). Morley (2000) explains how the concept of *genre* and the *context of culture* are related:

The social and cultural background in which the language is set and the participant’s understanding of the prevailing social meanings and cultural values in systemic functional linguistics it is studied under genre, which is concerned with the classification of types of social behavior within a given cultural environment and, using that framework, with the assignment of the function of any given interaction. (p. 10)

To summarize both concepts and put them into perspective, *register* is “certain recognizable configurations of linguistic resources in certain contexts”, while *genre* is “register plus purpose”. In other words, *genre* “includes the more general idea of what the interacts are doing through the language, and how they organize the language event, typically in recognizable stages, in order to achieve that purpose” (Thompson 2004, pp. 40-43). *Genre* helps to contextualize the texts in their culture but how exactly are the text realized through language can only be understood by looking into the concept of *register*.

Register is defined by Halliday as “what you are speaking at the time, depending on what you are doing and the nature of the activity in which the language is functioning” (Halliday and Hasan, 1989, p. 41). Matthiessen (2015) situates the role of *register* along

the lines of the *cline of instantiation* and the *hierarchy of stratification* (see Figure 2.1).

This map is an effort to fill in the gaps of information to analyze every text in terms of any given situation by mapping where the dimensions of *Instantiation* and *Stratification*

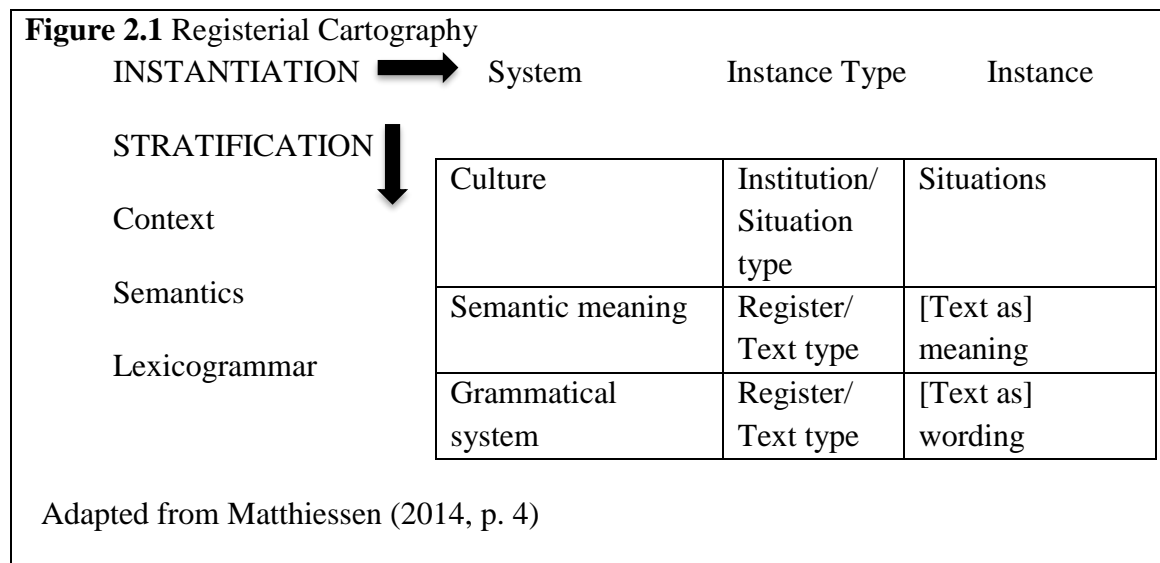
meet in terms of context and situation types. Matthiessen based his Registerial

Cartography in the need to “develop linguistic accounts of the region between system and

instance” and “relate contextual patterns stated in terms of field, tenor and mode to

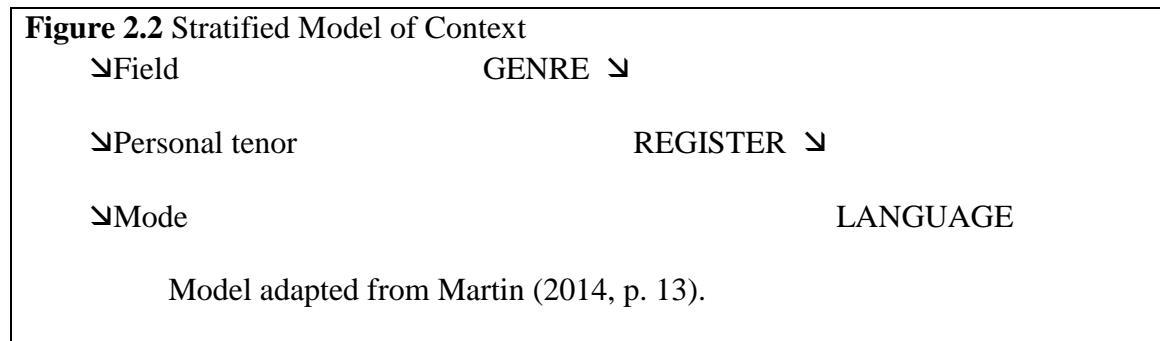
semantic patterns (and then, by another step, to lexicogrammatical patterns (pp.4-5).

That is, this map helps to visualize every space across the dimensions of language.



According to Halliday, there are three aspects inherent to every language explaining how language is constructed by *register*. Eggins (2004) calls them “key dimensions within the register” (p.9). These aspects are *Field*, *Mode*, and *Tenor*. The relationship between these concepts and the *register* within a *context of situation* are best explained in Figure

2.2. To summarize all three aspects: *Field* is “what language is being used to talk about”; while *Mode* is “the role language is playing in the interaction”, and *Tenor* encompasses “the role relationships between the interactants” (p.90). Halliday asserts the universal importance of these three aspects because “they are the three kinds of meanings language is structured to make” (Eggins, 2004, p.110).



Halliday asserts the universal importance of these three aspects because “they are the three kinds of meanings language is structured to make” (Eggins, 2004, p.110). The functionality of applying these three aspects to linguistic research resides in the fact that *register* is a linguistic aspect found in every language. That is why Martin (2016) describes the *Field*, *Tenor*, and *Mode* as “patterns of linguistic patterns” (48). These patterns are universal and each one of them carries different information about the message as will be explained next.

2.2.1 Register: Field, Tenor, and Mode

All three aspects play a different role in the language exchange. To start with *Field*, it refers to what the text is about, or as Halliday describes it, it is “what is

happening...the nature of the social action that is taking place: what is it that the participants are engaged in, in which the language figures as some essential component” (Halliday and Hasan, 1989, p.12). Eggins (2004) explains how *Field* is realized in language through *transitivity* patterns:

Field is realized through patterns of process (verbs), participants (nouns), and circumstances (prepositional phrases of time, manner, places, etc.). These types of grammatical patterns expressing ‘who is doing what to whom when where why and how’, can be collectively described as the transitivity patterns in language.

(p.110)

The *Field* carries the social and cultural information in the specific meaning exchange instance. Matthiessen (2015) refers to *Field* as a social-semiotic process, that is, “a process of interactive behavior or one of exchanging meaning” (p. 6). He identifies eight aspects to this parameter. These categories cover most purposes of human interaction. The following table explains the different functions covered by each process that are present in every language:

Table 2.1 Semiotic Functions Carried by Field

Expounding	Reporting	Recreating	Sharing	Doing	Recommending	Enabling	Exploring
Explaining	Chronicling	Narrating	Experiences	Directing	Promoting	Instructing	Arguing
Categorizing	Surveying	Dramatizing	Values	Coordinating	Advising	Regulating	
	Inventorying						

Note: Table adapted from Matthiessen (2015, p. 9)

Hassan (2014) describes *Field* as the “subject matter”, that is, from the three parameters of context (Field, Tenor, and Mode), *Field* is the one that tells what the texts is about and what is the purpose of the participants. The *Field* correlates to the *Ideational Metafunction*, which will be explained in the next section of this work.

The second parameter of *register* is *Tenor*. The *Tenor* aspect carries the information of the people participating in the communication exchange. Halliday (in Halliday and Hasan, 1989) says *Tenor* refers to,

Who is taking part, to the nature of the participants, their statuses and roles: what kinds of role relations obtain among the participants, including permanent and temporary relationships of one kind or another, both the types of speech role that they are taking on in the dialogue and the whole cluster of socially significant relationships in which they are involved. (p.12)

That is, *Tenor* is defined by the relationships between the participants. “You can with no doubt recognize that the kind of social role you are playing in a situation will have an effect on how you use language. For example, you do not talk to the greengrocer the same way as you talk to your mother” (Eggins, 2004, p. 99). *Tenor* is realized through the patterns of *Mood*. *Mood* is known as “clause structure (declarative, interrogative), the degree of certainty or obligation expressed (modality), the use of tags, vocatives, attitudinal words which are either positively or negatively loaded...expressions of intensification and politeness markers of various kinds” (Eggins, 2004, p. 110). The *Tenor* denotes how the choices of meaning correlate and define the roles of the

communication exchange in the context and culture. It is directly related to the *Interpersonal Metafunction*, which will be explained in the next section.

The third parameter of *register* is *Mode*. *Mode* is defined as “the role language is playing in an interaction” (Martin 1984, as cited in Eggins, 2004, p. 90). Therefore, *Mode* is the means and organization of the language as it is presented in the communication exchange. Halliday (in Halliday and Hasan, 1989) refer to this aspect as,

To what part the language is playing, what it is that the participants are expecting the language to do for them in that situation: the symbolic organization of the text, the status that it has, and its function in the context, including the channel (is it spoken or written or some combination of the two) and also the rhetorical mode, what is being achieved by the text in terms of such categories as persuasive, expository, didactic, and the like. (p.12)

Mode is generally divided into spoken discourse vs. the written text and it is realized through patterns of *Theme* and *Rheme*. Eggins (2004) calls them “textual patterns...patterns of foregrounding and continuity in the organization of the clause” (p.110). *Mode* is what defines the organization of the text and corresponds to the *Textual Metafunction*.

As mentioned before, these three registerial aspects, which outline the *context of situation*, primarily account for the lexico-grammatical patterns of language. However, *context of culture* is realized through semantic patterns. In SFL these patterns are called metafunctions. There are three metafunctions: *Ideational*, *Interpersonal*, and *Textual*, and each one of them is parallel to the register variables. The *Field* corresponds to the

Ideational Metafunction; the *Tenor* corresponds to the *Interpersonal Metafunction*; the *Mode* corresponds to the *Textual Metafunction*.

2.2.2 Metafunctions: Ideational, Interpersonal, and Textual

Comprehensive research about language under SFL is only possible by these three metafunctions. Matthiessen calls them “modes of meaning that are characteristic of a language and a number of other semiotic systems” (in Matthiessen, Teruya, and Lam, 2010, p. 9). Because language is considered a system, every aspect of it can be explained by these functions working together as “linguistic units” (Eggins, 2004, p. 3) There are four concepts of semantics that exist in all languages: *experimental*, *logical*, *interpersonal*, and *textual* (Halliday and Hasan 1989, p.23). Note that the *Ideational Metafunction* is divided into experiential and logical meanings. In Table 2.2, Kim (2009) illustrates the correlation among these metafunctions and how they are realized in grammar and context:

Table 2.2 Realization of Metafunctions

Grammar ←	Semantics	→Context (register)
TRANSITIVITY	Ideational	Field
MOOD	Interpersonal	Tenor
THEME	Textual	Mode

Note: table adapted from Kim (2009, p. 131)

In other words, Kim explains:

Ideational meaning is realized through the TRANSITIVITY system in association with the field of the text; interpersonal meaning is realized through the MOOD system in association with the tenor of the text; and textual meaning is realized through the THEME system in association with the mode of the text. (p.130)

That is, each one of the metafunctions relates to one of the registerial parameters by a specific system. These systems are what allow researchers to get specific grammatical information from the communication exchange.

The *Ideational Metafunction* is directly related to the *Field* registerial aspect. It gives researchers the more detailed information about the communicative exchange as it is the one that,

Provides the resources for the expression of content, including on the one hand the persons, objects, abstractions, processes, qualities, states and relations that constitute the phenomena of experience, and, on the other hand, the abstract logical patterns relatable to experience only indirectly. (Halliday and Webster, 2014, p. 20)

Wang (2010) attributes to this metafunction the purpose “to convey new information, to communicate a content that is unknown to the hearer. It reflects the events and experience in both objective and subjective worlds” (p.255). The *Ideational Metafunction* is separated into the *experiential* and *logical* meaning. The *logical meaning* is defined by Halliday and Webster (2014) as the one that,

Looks at how clauses expand into and become texts as a whole through elaborating (‘equals’), extending (‘is added to’), and enhancing (‘is multiplied

by’). One clause can elaborate on another through exemplification, clarification, or restatement; or a clause can extend the meaning of another by adding some new element, giving and exception, or offering and alternative; or a clause can enhance another through embellishment, or qualification.” (p. 227)

However, the *experiential meaning* is the one being more extensively used for research purposes. The *experiential meaning* represents how we experience the world around, that is, “who (participant 1) does what (process) to whom (participant 2), how, when, and why (circumstances); while logical meaning only refers to the logical relations between the experiences” (Kim, in Angelleli and Jacobson, 2009, p. 129). To explain in more detail, the *experiential metafunction* is the “‘content’ of a message;” it is the type of language that “reflects our view of the world as consisting of ‘goings-on’ (verbs) involving things (nouns) which may have attributes (adjectives) and which go on against background details of place, time, manner, etc. (adverbials)” (Thompson, 2004, pp. 86-87).

Halliday and Webster (2014) describe this metafunction as the potential that we have for putting our experience into words, which means being able to talk about processes and things with, as always, the provision that ‘being able to talk about’ is an informal way of saying ‘having at our command a ‘meaning potential’ whereby we can represent them in terms of systematic contrasts and combinations (p.24). This metafunction is realized in grammar by the *transitivity* system. Halliday and Webster (2014) define *transitivity* as “the representation in language of *processes, participants, and circumstances*” (p.25). There are six *processes of transitivity* (see Table 2.3), which are further divided into *material, mental, verbal, and relational processes*. The *material*

process is the “action clause”; it involves an actor and a goal. *Mental processes* are “a process of consciousness” and they involve a sensor and a phenomenon. The *verbal processes* include the process of verbalization and convey a sayer and a process. The *relational processes* describe the “relation between two entities-between two roles in the structural configuration” and require a carrier and an attribute (Halliday and Webster, 2014, pp. 52-70).

Table 2.3 Transitivity Process

Participant Roles			Process Type
Actor/agent	Goal/affected	Material	Doing, happening, sensing, knowing
Sensor	Phenomenon	Mental	Seeing, feeling
Sayer	Verbiage	Verbal	Saying
Behaver		Behavioral	Behaving, coughing, sleeping
‘There’	Existent	Existential	Existing
Carrier	Attribute	Relational	Being, becoming, having

Table 2.3 adapted from Halliday and Webster (2014, p. 222) explains how these participants and process relate. To summarize the purpose of the *experiential metafunction* and its processes, Thompson (2004) describes the *material processes* as those that “involve physical actions”; the *mental processes* as “something that goes on in the external world and something that goes on in the internal word of the mind”; the *relational processes* as when “a relationship is set up between two concepts”; and the *verbal processes* as when “saying something is a physical action that reflects mental operations” (p. 90-100).

The *Interpersonal Metafunction* allows the analysis of the voice, passive vs. active. It also allows the analysis of the type of clauses used in the text. For example: demonstratives, interrogatives, and imperatives. One of the most important results of analyzing clauses through the *Interpersonal Metafunction* lens is that it exposes the hierarchy in social relations between the actor and the participants. This metafunction elucidates the communicative roles of each one of the participants. After all, the main purpose of communication is to have some kind of influence or effect in other people's ideas, attitude, or behaviors (Gaiser, 2008). Morley (2000) explains that the *Interpersonal Metafunction* could serve in terms of "social integration" for example, every day conversations and greetings are at what he calls the "superficial level"; however, this function could also serve for "instrumental interaction" where it "seeks to influence the behavior of others in order to get things done". There is also "informational interacting" where people "make statements to impart information and ask questions to seek information" and "expressive interaction" where people can "give vent to their emotions". Lastly, there is "personal mediation/modulation" where people express attitudes and/or assessments (pp.12-14). Thompson (2004), highlights the purpose found in this metafunction, "we tell other people things for a purpose: we may want to influence their attitudes or behavior, or to provide information that we know they do not have, or explain our own attitudes or behavior, or to get them to provide us with information, and so on", "giving" and demanding" are the most basic features (p.46). This metafunction connects the choices of the creator of the message with the receptor.

Halliday and Matthiessen (2004) refer to this feature as ‘goods-and-services’ (p.108) because of the exchange of meaning and the purpose of it. Matthiessen, Teruya and Lam (2010) say this exchange is what enacts the different roles and relations within a given community or institution (p.9) In a more recent definition, Halliday and Webster (2014) talk about this metafunction and explain how it is realized in language: “the interpersonal metafunction deals with our use of language to relate to our listeners. When we communicate we deliver more than just a content of information, we also communicate our role vis-à-vis our partners in the exchange” (p. 233). In languages, like English and Spanish, this function is realized through the *Mood*. Halliday and Webster (2014) call the choices in *Mood* “mood-residue structure” where *Mood* “consists of the elements Subject and Finite. *Residue* consists of Predicator, and possible Complement and Adjunct” (p.234). Thompson (2004) proposes to identify the *Mood* of each clause before analyzing a text as indicated in the Table 2.4. The way the sentences are expressed carry information about the relation among participants. The variety in *Mood* will give the researcher enough information to understand the overall intention of the text and how the speech roles, the subject, and the finite will be realized.

Table 2.4 Realization of Mood

Mood	Subject	Finite	Speech Role
Declarative	<i>My heart</i>	<i>did</i>	statement
Interrogative	<i>The duties</i>	<i>Present [start]</i>	question

Note: Examples from Table 4.1 in Thompson (2004, p. 59). Complete clauses –
Sample 1: Maybe my heart did sink.

Sample 2: When will the duties actually start?

The *Textual Metafunction* may not reveal as much linguistic information as the *Interpersonal* and *Ideational Metafunction*, but it is what gives order to the textual information (Eggins 2004, Gaiser 2006). This metafunction is related to the registerial component of *Text* and it is realized through the *Mode*, which is, the *Theme* and *Rheme* of the clause. Some forms of text organization that can be analyzed through this function are thematic structure, ellipsis, conjunctions, repetitions, and lexical chains (Eggins 2004, Gaiser 2006). However, the most important contribution of this metafunction is the organization of the text as it features the notion of coherence and cohesion, which allow the message to be understood. Lukin (2013, citing Halliday and Hasan, 1976) argue that the unity of text is shaped by the textual meaning as it provides the “texture” which reflects the “environment” in which the language exchange is taking place (p.527). Halliday (1971) says that this function “fulfills the requirement that language should be operational relevant, having texture in a real context of situation that distinguishes a living passage from a mere entry in a grammar book or a dictionary” (as cited in Wang, 2010, p.256). This texture is the difference between meaningless uttered words and a narrative. Morley (2002) calls it “narrative coherence” (p.14). The cohesive and coherent components of language are what create texture in a text (Halliday and Webster, 2014, p.235). One of the key terms in SFL is “ArchiteXture” as it refers to the way the text is constructed by its texture. Halliday and Webster define this term as “taking the text as ground and building span by span to each constituent paragraph allows a different perspective on the text as semantic unit” (p.272). By means of *Cohesion* and *Coherence*

the other two metafunctions are intertwined with the *Textual* feature. As Thompson (2004) explains:

Cohesion refers to the linguistic devices by which the speaker can signal the experiential and interpersonal coherence of the text – and is thus a textual phenomenon...Coherence, on the other hand, is in the mind of the writer and reader: it is a mental phenomenon and cannot be identified or quantified in the same way as cohesion. (p. 177)

Kim (2009) describes how the *Textual Metafunction* works in conjunction with the other two metafunctions, “*Textual* meaning organized ideational and interpersonal meanings into a coherent linear whole as a flow of information” (p.130). They follow this order:

Table 2.5 Metafunctions and Theme

Theme			Rheme
Textual	Interpersonal	Experiential	
Well,	certainly,	sanity	is a precarious state
And,	oddly,	he	was right

Note: table and examples from *Multiple Themes* (Thompson, 2004, p.159)

As it was presented in this section, it is through the study of these three metafunctions that is possible to analyze every linguistic exchange embedded in the context of culture and situation. For this research paper, these metafunctions will allow to explain how they are presented in the health context. The next section will explain the need for SFL as a theory in institutions of healthcare.

2.3 SFL in Health Institutions

Communication in the workplace has been the subject of study by the branch of linguistics known as language policy and planning. Bell (1995) developed a theoretical approach called “Political Linguistics” to deal with issues of power, influence, and authority in the workplace. He calls the communicative act in the work place “negotiations”. Bell defines political linguistics as “the use of language and communication to change values, beliefs, attitudes, and behaviors” (p.43); however, he makes clear that any workplace negotiation requires “mutual understanding about the meanings of various forms of verbal and nonverbal expressions,” the lack of shared understanding can lead to “disastrous consequences” (p.51). In the area of health institutions, miscommunications often lead to serious issues when it pertains to communicating decision-making information to linguistic and cultural minorities. Iedema (2007) in the introduction of his book, *The Discourse of Hospital Communication: Tracing Complexities in Contemporary Health Care Organization*, discusses the role of applied linguistics and discourse analysis in the policy making of health organizations. Here, he emphasizes how little research has been done outside the small doctors’ offices and argues that,

Such focus runs the risk of ‘invisibilizing’ the extent to which the doctor’s work and the patient’s treatment trajectory depend on exchanges with others (pathology laboratory scientists, allied health professionals, health administrators and managers, to name but some) in addition to the patient and immediate peers. (p.4)

The effect of communication in healthcare contexts goes beyond what happens inside the institution and the research available concerning the outside aspects of the health/healing process has been a debatable topic in the past years.

Matthiessen (2009) cites the work of Idema in Australia to prove the usefulness of SFL in healthcare. Idema analyzes medical discourses sustained by the concepts of clinical and organizational linguistics. Matthiessen (2012) justifies the use of SFL in healthcare institutions due to its *applied linguistics* feature, term created by Halliday (see Section 2.2). His definition of '*applied linguistics*' is "a kind of linguistics where theory is designed to have the *potential* to be applied to solve problems that arise in communities around the world, involving both reflection and action" (p. 436). A starting point to situate SFL in hospital setting is to look at Matthiessen definition of a hospital. He says, "we can interpret a hospital in contextual terms as a *cultural institution*, more specifically as a *cultural institution* of healthcare". This interpretation allows to position meaning making in healthcare communication in both the hierarchy of stratification and the cline of instantiation (Matthiessen, 2013, p. 444). After all, as Doak, Doak, and Root (1996) say, it is "the experience and customs of another culture" what can create "a change in the focus of a health care instruction" because every culture has a cultural experience filter used to understand and manage health information. As an example, "the organization as well as the sequence of information can change with the culture" also "in many cultures it is logical for the authority figure to give 'orders'. Nobody asks questions. In fact, to ask question because you didn't understand can be perceived as being critical of the authoritative figure" (pp. 68-69).

The focus of SFL in healthcare contexts goes beyond communication in the healthcare institution setting, it allows for researchers to focus on patients and their sociocultural background. Matthiessen (2013) calls healthcare language planning to “aim for the development of autonomous patients” urging for a “relationship-centered healthcare” which “embodies principles such as team work, and shared informed decision making where everybody concerned is involved with the field of care and healing; and it also makes sense from the point of view of patients as *meaners* taking on roles in many meaning groups and being helped by friends and family members” (p. 462). The emphasis of SFL is to view patients and caregivers as an active part of the communication exchange. This patient centered care is primarily achieved by means of written texts. Matthiessen states that the study of texts is of utmost relevance in order to understand how SFL can be applied to healthcare contexts (p. 439).

Matthiessen (2013) explains how language plays two different roles in healthcare; it is a “*medical symptom*” and it is a “*healthcare resource*”. Illnesses are expressed through language while decision-making is achieved through information communicated by language. Considering the SFL metafunctions, Matthiessen says that normally the *Interpersonal Metafunction* has been given more attention in the analysis of healthcare written information. That is the relationship between the professional writers and the readers; however, says Matthiessen “the question of how patients and healthcare professionals construe experiences of health and illness is also central to healthcare”. In regard to the *Field* and the *Ideational Metafunction*, two out of the eight social-semiotic

processes identified by Matthiessen (2013) (see Table 2.1) deal with written texts in the healthcare:

1. Context: Expounding general knowledge about the world.

Process: explaining, categorizing/documenting

Discourse used to: create and disseminate general medical knowledge

Examples: medical journal articles, medical text books, clinical lectures, health handbooks

2. Context: Recommending some course of action

Process: Advising

Discourse used to: advise patients

Examples: medical consultations, medical leaflets

Process: promoting

Discourse used to: promote healthcare services and products

Examples: pharmaceutical advertisements. (p.451)

These written processes link medical professionals to the patients and go back to the concept of negotiation in the work place discussed previously in this chapter. In order for communication to be effective, both parties must understand verbal and cultural meanings. Any misunderstanding in the communication can have adverse results for the patients. Matthiessen (2013) cites McClanahan et al. (2011) who suggest five key strategies to reduce errors in the healthcare context: “improve information access”, “reduce reliance on memory”, “reduce number of hand-offs”, “standardize tasks” and “error-proof processes” (p.458). Two of these key strategies concern this research:

improve information access and reduce reliance on memory. Indeed, SFL is a valuable tool to analyze communication in the healthcare institutions; however, for the purposes of this research there is one more factor to take into consideration: **the communication is being mediated through translated texts**. Doak et al. (1996) warn translators about considering cultural variations when translating documents because what makes sense to someone may not make sense to people from other cultures (p.69). It is of vital importance that translation takes into account the culture and beliefs of the people they are trying to instruct. In the next section, different translation theories that have historically intertwined with SFL will be discussed.

2.4. Translation Theories

Translations of documents have been done since the beginning of the Common Era when it was “crucial for the early dissemination of key cultural and religious texts and concepts” (Munday, 2012, p.13). However, it was until 1972 that translation became recognized as a field of study. James S. Holmes was the first to use the term “Translation Studies,” establishing it as a science (Hatim and Munday, 2004, p.7). Eventually, translation developed into a full interdisciplinary field. Hatim and Munday mapped five main areas crossing with translation: linguistics, philosophy, literary studies, cultural studies, and language engineering. These disciplines divide into multiple research areas (p.9).

Historically, the field of translation has been the subject of many theoretical approaches (see Ghanooni 2012, for a complete and brief review of the history of

translation). For the purpose of this research, the methods that relate into Halliday's theory will be mapped. For many years, the studies of translations focused on whether it was a free or a literal translation; that is, the focus was in the process chosen by the translator. Then, the concept of *equivalence* became important. Munday says equivalence was the first translation technique that became useful as an academic tool (see Jakobson, 1959/2012; Nida, 1964; Nida and Taber, 1969). The concept of equivalence was based on what Munday calls "linguistic universalism", the notion that "although languages may differ in the way they convey meaning, there is a (more or less) shared way of thinking and experiencing the world" (p.59). Nida and Taber (1969) were some of the most prominent advocates for achieving equivalence in translation. Nida has the "four basic requirements of a translation": (1) Making sense; (2) Conveying the spirit and manner of the original; (3) Having a natural and easy form of expression; (4) Producing a similar response" (p.67).

Nida and Taber divided the concept of equivalence into *formal equivalence* and *dynamic equivalence*. Formal equivalence focused on the message while dynamic equivalence focused on the equivalent effect (Leonardi, 2000). Munday cites Jakobson who "points out that 'there is ordinarily no full equivalence between code units'; however, there is the concept of "linguistic universalism" which "considers that, although, languages may differ in the way they convey meaning and in the surface realizations of that meaning, there is a (more or less) shared way of thinking and experiencing the world" (59). Halliday's theory became part of the translations field in 1988 when Peter Newmark used a hierarchical rank scale to identify the units of

translation. Later, John Catford in his book *A Linguistic Theory of Translation* (1965) based translation theories in the work of Firth and Halliday. Catford came up with the term “translation shift” referring to the smallest unit of translation. However, Hariyanto (2002) points out that the definition of Catford fails to consider culture:

He states that translation is the replacement of textual material in one language by equivalent textual material in another language. In this definition, the most important thing is equivalent textual material. Yet, it is still vague in terms of the type of equivalence. Culture is not taken into account. (para. 5)

Munday (2012) says that it was German translator Katharina Reiss in the 1970s who first tried a deeper approach to translations from a functional perspective by “systematizing the assessment of translations” thought three functions: (1) informative function, (2) expressive function, and (3) appellative function (p.111-112). Reiss also took into consideration (1) linguistics components, such as semantic and lexical equivalence, and grammar and style features; and (2) non-linguistic determinants such as situation, subject, time, place (country and culture), receiver, sender, and affective implications (p.114).

Reiss later worked together with Hans J. Vermeer and they co-authored a book resulting in what is now known as *Skopos Theory*. This theory is based in the premise that “the action has to be negotiated and performed and has a purpose as a result,” what Vermeer called “functionally adequate” (p.122). Hatim and Munday (2004) identify the work of Reiss and Vermeer as some of the first works to consider “purpose” in the target text:

A translated piece of software must work perfectly on-screen and enable the user to perform the desired action; advertisements, most particularly, and poetry need

to be translated at the level of the text (or even culture) and not the word if their message is to function in the target culture; and medicines and other food stuffs must carry instructions and warning notices that satisfactorily alert the TT [target text] reader to possible dangers. (p.24)

Nevertheless, in 1977, House considered *Skopos Theory* as “misguided”. House (2006) calls for a “cline” of overt and covert translation rather than opposites where “if functional equivalence is desired but the ST [source text] genre does not exist in the same form in the target culture, the aim should be to produce a version rather than a ‘translation’ (p. 143). Talking about the reliability of SFL in translation, Nguyen (2012) cites Newmark (1991, p. 65) who finds advantageous that SFL merges with translation given that it “sees language primarily as a meaning potential” becoming “a serviceable tool for determining the constituent parts of a source language text and its network of relations with its translation” (Nguyen, 2012, p.5). The most contemporary approaches to translation see translation from a functional product perspective.

In 1992, Baker published *In Other Words*, which was largely based in studying translations at different clause levels. It was Baker (1992), the first to use SFL terminology to talk about translation. She focused on the concept of cohesion and coherence of the text (Munday, 2012, p. 144). Choi (2013) in a review of translation theories concludes that the translation of the text “is only complete when both grammar (clauses) and context (genre/register) are dealt together”. Munday calls the work of Basil Hatim and Ian Mason as the most recent researchers, in 1990 and 1997, to apply SFL to translation incorporating ideational and interpersonal functions. Hatim and Mason, says

Munday, combine “the kind of bottom-up analysis” with “some top-down consideration” concluding that it applies to translation because “language and texts are considered to be realizations of sociocultural messages and power relations” (p. 151). They use translations about the American native narratives done from a Eurocentric perspective as an example of how power relationships through history can bias a translation (p. 151). Hariyanto (2002) summarizes the need to consider context by citing Halliday’s idea that “context precedes text”; he affirms that context of situation and context of culture “is necessary for adequate understanding of the text, which becomes the first requirement for translating. Thus, translating without understanding text is non-sense, and understanding text without understanding its culture is impossible” (para. 29).

While there are still many approaches to translation, the contributions of Systemic Functional Linguistics have been largely acknowledged. Halliday (2010) justifies the use of SFL in translation because of its *applied linguistics* features. “Translation is one art where it is valuable to be able to reflect on what we are doing, and to explore the meaning potential of a language –of two or more languages as they are brought into contact – in an explicit and recoverable way” (p. 19). In the next section a review of work dealing with translation and SFL will be provided.

2.5 SFL in Translation Studies

Munday (2012) has been one of the most prolific writers in translation and SFL. He has acknowledged the importance of applying this theory because of its recognition of choice. He says that:

The reader (and translator or interpreter) approaches the ST in the belief that the writer's choice is meaningful, asking questions such as: Why this wording rather than another? What choices did the writer have at each point: What is the function of the writer's choices" and what form of communication is produced by this choice? (as cited in Webster, 2015, p.143)

Translating implies not only the choices of the producer of the message but also the choices of the translator. A long-time researcher of SFL and translation, Manfredi (2011), in her article "Systemic Functional Linguistics as a tool for translation teaching: toward a meaningful practice" points out that Yallop (1987, p. 347) recognizes that "one of Halliday's many contributions to linguistics is his wish to build bridges between linguistic theory and professional practice" (p.30). She explains how SFL is important for translation because of the possible meanings in both the source and the target language:

In an SFL paradigm, a speaker makes choices from within the total meaning potential of the language...thus, a translator, in order to accomplish his/her delicate task of interpreting and tendering a source text into a meaningful and effective target text need to understand all these meaning, and reproduce them in another language." (Manfredi, 2011, p. 52)

In regard to *register*, Manfredi provides one of the stepping-stones works concerning SFL and translation directed to translation students. She calls House, Bell, Baker, and Steiner as the models that allowed for SFL and the field of translation to come together. SFL not only brings to the field of translation the issue of meaning but also

allows researchers to look at translation from both perspectives, the context of situation and context of culture. Manfredi adds that SFL can help the cultural oriented translations come to an agreement with the linguistic oriented studies “because it is based on a strict link between language and culture, language and context of culture, and the notion of context of culture in translation is fundamental” (Di Bari, 2013, p.136). SFL is vital for translation because as Choi (2013) explains, it entitles the ability to use a theory that truly becomes a tool to understand both grammar and context as it “enables both a top-down (from context to grammar) and a bottom-up (from grammar to context) approach to a text” (p.5).

House’s work “Translation Quality Assessment: A Model” published in 1977 and revised in 1997 has been identified as the first work to deal with SFL and translation; specifically, with the concept of *register*. However, as Kim states (2009) translation is still an “under researched” and “problematic area” (p.123). It is argued that “in order to produce a translation that functions within a specific register (field, tenor, and mode), translators may have to ‘legitimately manipulate’ (House 2006, p. 141) the source text at all these levels using a ‘cultural filter’ and linguistic knowledge of both languages” (p. 131). This manipulation should result in the creation of different meanings. Regardless of grammatical errors, a translation may still be inappropriate, says Kim, if it fails to “recreate the required register”; wording is not as important as a text that “serves its purpose within the context” (p.131-134).

In regard to *genre*, House (2006) in her work “Text and Context in Translation” discusses the important of context and how problematic this concept can be for the field

of translation. One of the issues resides in the fact that “translation is an operation on (pre-existing) written text as opposed to talk as oral, linearly and sequentially unfolding, negotiable discourse. (p. 342). In order to achieve an adequate translation under this view, a re-contextualization is necessary. Grounding her ideas on Malinowski’s view of the *context of situation*, she cites that “translation becomes ‘rather the replacing of linguistic symbols against the cultural background of a society than the rendering of words by their equivalents in another language’” (p. 343). In order to achieve a re-contextualization, it has to meet the following criteria:

- (1) It has to explicitly account for the fact that source and translation texts relate to different context;
- (2) it has to be able to capture, describe and explain changes necessitated in the act of re-contextualization with a suitable metalanguage; and
- (3) it has to explicitly relate features of the source text and features of the translation to one another and to their different contexts. (p.344)

House states that an “overt translation,” which is culture specific, has to be “equivalent at the level of *Language/Text* and *Register* as well as *Genre* (p.347). She mentions the concept of “cultural filter” which is “a means of capturing cognitive and socio-cultural differences in expectation norms and discourse conventions between source and target linguistic-cultural communities” (p. 349).

The three SFL metafunctions are functional tools to understand translation by means of the processes of *transitivity*, which are universal to every language (as cited in Manfredi, 2012, p. 21). Kim and Matthiessen (2015) in the article “Ways to move forward in translation studies: a textual perspective” explain how the metafunctions work

in translation. They explain, “translation involves recreating ideational meanings of the logical kind, ideational meanings of the experiential kind, interpersonal meanings and textual meanings” (p.336). However, they find utterly important to know that “in translating it is important to focus on the recreation of meaning rather than the recreation of wording” (p.343). Kim and Matthiessen propose an innovative approach to translation that would take into consideration the “shift” meaning among the metafunction to reveal “if they prioritize one kind over another as they translate texts from different registers” (336). This recent approach to translation “started to see translation as a process of producing a text within its context, which inevitably involves a constant process of making choices” (337). Recent studies involving this new approach include translations to Norwegian, Chinese, Korean, Portuguese, and Spanish (p. 338). Ma and Wang (2016) mention Kim and Matthiessen, and Wang as some of the most recent research articles to investigate textual metafunction and recognize how SFL would be of great help to translations as it “has rendered a clear identification of personal relationships” (38). However, it is concluded that the research is still limited to identify the benefit for translations as they began to “realize the intended function of the translated text, and to reflect the potential sociocultural meaning” (40).

Halliday wrote a seminal article in regard to SFL and translation: “Pinpointing the Choice: Meaning and the Search for Equivalents in a Translated Text” (2010) where he talks about a new concept in this effort to apply SFL to translation and he describes what Matthiessen et al. (2010) calls “environments”, which “are defined by the dimensions

along which every human language is organized: stratification, rank, instantiation, metafunction, delicacy and axis”. Matthiessen, cited by Halliday, writes that:

Translation equivalence and translation shift are two opposite poles on a line of difference between languages...the wider the environment of translation, the higher the degree of translation equivalence; and the narrower the environment, the higher the degree of translation shift. The ‘widest’ environment is that in which the text is ‘maximally contextualized” –and therefore, by the same token, is likely to be ‘maximally effective” (p.16).

To give an example, Halliday analyses the translation of a Chinese tourist guide using the following methodology to pinpoint the translator choices:

Table 2.6 Pinpointing the Alternative Choices

Example	Point at issue	Stratum	Rank	Metafunction	Possible alternative choices
The scenic spots of central area is taking...	English error	Lexicogrammar (syntax)	Clause	Interpersonal	Correct number concord: Subject + Finite
From the soul of Guilin’s landscape	Unmotivated shift	Lexicogrammar (lexis)	Word (lexical item)	Experiential	From the essence of

Note: Table adapted and Examples taken from Appendix 1, Halliday (2010, p. 21)

This table allows the researcher to determine the different alternatives in meaning as it shows in a dimensional line starting from the point at issues. As mentioned before, there is still much work to be done regarding the SFL theory and its application. Currently Halliday, Matthiessen, and Eggins have been publishing research done in Australia; Manfredi in Italy; Steiner and House in Germany.

2.6 Previous Research in Translation and SFL

As it was stated in the previous section, recent research has emerged trying to prove the helpfulness of applying SFL to the field of translation. Kim has been an avid researcher in both fields to provide a framework for translation students. She has concluded that the meaning-based approach of this theory “can empower students, for their part, to think critically and systematically about the translation options they have and articulate reasons for their choices” (in Coffin, Lillis and O’Halloran, 2010, p. 92). Another insight came from Hu (2010) who concludes that register analysis is of crucial importance to translator because:

Through the analysis of the linguistic feature of the SLT [source language text], its register can be identified and thus the determinations of its context of situation are possible. Second, in the production of the TLT [target language text], the proper words and expressions in the TL [target language] should be chosen so that the corresponding context of situation can be reestablished in the TLT [target language text]. Seeking the equivalence of meaning is in fact seeking the equivalence in situational context (p.324).

However, for a grammatical oriented traditional translator it is not easy to adapt to the ideas of the functional approach (Spence, 2004). In the last decades, there has been a surge in studies using Systemic Functional Linguistics to analyze translated written texts. In the field of translations, Kim has done extensive research using SFL to understand the relations between Korean and English language. In 2003, she did a study at Macquarie University based on SFL text analysis in which she categorized student translation errors into different Modes. Choi (2013) has also been using SFL to analyze bible translations from Korean to English. He concluded from his research that, “grammar (in this study, clause combination systems) and context (genre and or/register) interact to make logical meaning in a translation text in such a way that each affirms the significance of the other”. Therefore, “the analysis of a text is only complete when both grammar and context are dealt with together (Choi, 2013, p. 5). Even though, translation in all areas requires the consideration of context as an inherent part of the process, when it comes to health documents, context and culturally sensitive translation become even more important since the consequences of a bad translation can be life threatening. One of the most compelling debate topics around this issue is the use of human or machine translation. The implication of these two practices will be explained in the next section.

2.7 Human Versus Machine Medical Translation

Medical translation is defined as “the most complex of arts” (Stahl, 1992, p. 265). The effectiveness of both, human and machine translation in the medical field has been a debatable topic. Stahl cites Levy who owns a translator service and recognized that

machines could never replace human translation due to the fact that “the computer just cannot make subtle distinctions” (p. 266). Halliday has been concerned with computational translation in relation to the medical field. Bateman and O’Donnell, (2015) explain the translation project in which Halliday worked with a group founded by the National Science Foundation to put together a thesaurus for machine translation. “Halliday’s work in the translation project also concerned the translation of syntax as opposed to lexical meaning” (p.457). His ideas were also used for natural language in Artificial Intelligence and Computational Linguistics. The eagerness to rely on machine translation language resides in the fact that language is considered a “code” “requiring only the appropriate codebook to be converted into various forms” (Bateman & O’Donnell, 2015, p. 454). Bateman et al., (1999) cite Karkaletsis et al., (1998, p. 324) to define the generation of machine translated text adaptableness as the “same message in more than one language using the grammar, lexical, and morphological rules for the supported languages” (p.609). In regard to the mass production of translation of health documents, Turner et al., (2014) discuss a huge problem with providing culturally appropriate translations: “an important barrier to producing multilingual health materials is the time and costs required for language translation, given that there are an estimated 300 different languages spoken across the United States” (p. 524). In order to alleviate this problem, Turner proposes the use of free machine translations such as Google Translate and Microsoft Translator to translate health materials followed by a human post-edition done by trained native speakers with experience in public health. Due to its

life threatening consequences, numerous articles have been published with a focus on translated health materials available until now.

2.8 Previous Research in Translated Health Texts

Throughout the United States, linguistic minorities in the United States rely on interpreters and translators to obtain their information. In many cases, un-trained medical personnel and ad hoc family members are the only source of information for patients with language barriers. Language barriers and low literacy levels make it very difficult for patients and family to access secondary sources of information. In most cases, patients depend entirely on the information exchanged during the medical encounter to make life-altering decisions about their health. However, it has been documented that many errors occur during this encounter. Flores et al. (2003) has conducted many studies in this area. In one situation, they followed pediatric encounters for seven months in Massachusetts concluding that errors in medical interpretation by hospital interpreters and ad hoc interpreters are dangerously common. Among the errors found, those with “potential clinical consequences” averaged at least 31 per encounter. In South Carolina, Martinez-Gibson, and Gibson (2007) studied access to health care in eight large institutions finding that only one of them provided professional interpretation (p.120). The lack of efficient information in Spanish forces the patients to find their own limited means of interpretation. Another study by Flores (2006) mentions several cases in which minors had been victim of providing his own erroneous interpretation, such as a 12-year-old kid in Boston who erroneously translated his symptoms or that of a mother who lost custody

of her two children due to a misinterpretation after bringing her daughter to the Emergency Room with a fracture (p. 229).

That is because many translations are not well done, and in most cases, they rely on direct translations, which results in inaccuracies. A report by the Latino Health Initiative (2011) characterized these errors as “egregious”. They give several examples such as “efectos secundarios” which in Spanish means “side effects” but it is often translated as “secondary effects”. They also give more common examples as follows:

The literal translation of, “to lie on your back” is “acostarse sobre la espalda” while the intended meaning is correctly stated as “ponerse boca arriba” ...another example is “cold turkey detoxification” this would incorrectly be translated as “desintoxicación pavo frío” if done literally while the correct translation of the intended meaning is “desontixación a palo seco” ... “slurred speech” would be “articular mal” in literal terms, when the correct interpretation is “lenguaje enredado” (language caught in a net or entangled language). (p. 13)

Indeed, research has proven the adverse effects of unprofessional interpretation in the medical encounter; however, written information is a second source of information for patients and families. Written information is particularly important for two reasons: not only it is a way of mass promotion of health information and early detection of serious illnesses, but it is the only way patients can review their health options in a more private manner and share it with those close to them as many times as necessary to make an informed, well-thought, decision. Written information is largely use for health promotion since print materials can be easily distributed to communities through various means.

Several studies have pointed out the role of written information in chronic illness prevention. Paul et al. (2003) concluded that, “printed materials such as pamphlets are widely used as an educational tool in the area of cancer prevention and control” (p.181). In the same manner, Guidry and Walker (1999) concluded, “printed materials have increasingly become the most common method of educating individuals about cancer prevention”. Their results pointed out that “printed cancer education materials (PCEMs) can positively affect the knowledge, attitudes, and practices of individuals; thereby, increasing the likelihood for individuals to adopt cancer prevention practices” (p. 291). In 1997, Mumford published an article in which leaflets made by nurses posed the generalized concern that “the most worrying aspect of the findings is that we do not appear to have progressed much in this field in 40 years” (p.990). It has been clearly stated that written information does help a patient to make informed decisions, as Nathan et al. (2007) in their research using information from Medline and Google Scholar seek to “evaluate whether patients read medication information leaflets...and assess patients’ opinions concerning the understandability and usefulness of these leaflets” (p.777). Their study was done in pharmacies and concluded that two-thirds of patients found written information to be a “useful resource” (p.777). Regardless of the benefits proven to be obtained by written information, the problem continues to be the inaccessibility to the language “health information leaflets are still being produced with high reading levels, despite an increase in their usage” (Mumford, 1997, p.990). Powers, Trinh, and Bosworth (2010) published an article expressing their concern that patients are not able to follow written instructions and bringing up the issue of how much limited literacy affects

health outcomes. However, their study also shed light on another important issue that has often been overlooked, and that is how “physicians are often unaware of patient’s reading abilities” (83).

For patients with low literacy levels, written information, regardless of availability, is not always serviceable. As it was discussed in Section 1.3, the percentage of people in the United States classified as low literacy and/or limited English proficient is critically high. While most laws have focused on making information available, only a few have taken into consideration the usefulness of the information. The US Department of Health and Human Services formed The Steering Committee (1996) to draft what is now known as The Public Law 104-180 which pertains to information about drugs. This law required that by 2006, 95% of patients should be able to receive written “useful” information with their medications. This law applies to all “national organizations representing health care professionals, consumer organizations, voluntary health agencies, the pharmaceutical industry, drug wholesalers, patient drug information database companies, and other relevant parties” who were required to come with a plan to “assess the effectiveness of the current private-sector approaches used to provide oral and written prescription information to consumers”. The law guidelines call for information that is “sufficiently specific and comprehensive as to adequately inform consumers about the use of the product, and in an understandable, legible format that is readily comprehensible and not confusing to consumers expected to use the product” (United States Government Printing Office, 1996, p.1). The fact that the literacy average of the average consumer in the nation was taken into consideration while drafting this law is

significant step. However, Krass et al. (2002) surveyed a consumer panel of 24 individuals to evaluate two newly designed readability evaluation instruments, and even though their sample was too small to generalize results, their results suggested that “existing pharmacy leaflets used in the US fall far short of the criteria set by the 1996 Action Plan” (p.34).

Several studies, from questionnaires to focus groups, have tried to demonstrate the functionality and usefulness of written health information from the consumer point of view, revealing the country’s reading characteristics. Most research papers have been conducted using readability formulas to analyze health related written texts in English; however, their results only lead to form a conclusion on how this continues to be problematic for the United States population in general, and how it increases for linguistic minorities. A readability formula is “a mathematical equitation derived by regression analysis” (Contreras, 1999, p. 21). One of most well-known formulas is the SMOG readability formula “one of the simplest but most valid and reliable readability formulas available” published by McLaughlin in 1969 (Contreras, 1999, p. 21).

D’Alessandro et al. (2001), found concerning results that unfortunately, they say, are “consistent with previous studies”. They agree that the high level of readability found in pediatric text information “has significant implications, as adults are the main group health care providers are educating on how to take care of themselves and their children” (p.809). Luk and Aslani (2011) conducted a research to evaluate written medicine and health information provided to consumers. They concluded that while some formulas like SMOG were “a reasonable tool to use”; and were “popular in health research”, the

formulas were not able to distinguish between the type and the context of the text, therefore, recommending the use of the Suitability Assessment of Materials (SAM) for a better measure (p.392). Before the SAM, most readability formulas did not take context and culture into consideration.

The SAM was developed in 1993 by Doak, Doak, and Root, who after studying all the available readability formulas concluded that they focused on sentence length among other issues but neglected to take context and culture into consideration. SAM added “cultural appropriateness” to their set of measuring items. (See *Teaching Patients with Low Literacy Skills*, chapter 4, for a detailed description of their assessment). However, SAM as well as most others readability skills, applied only to English language. Doak, Doak, and Root mention the Rapid Estimate of Adult Literacy in Medicine REALM and the Wide Range Achievement Test (WRAT) as helpful instruments that should be used by physicians to understand the literacy of their patients (pp.30-34). Some other readability formulas have continued to emerge; however, neither the SAM nor the REALM have been able to provide a comprehensive readability formula for linguistic minorities with low literacy skills.

The National Institute of Health (2016) published the guidelines for written material titled “Clear and Simple: Developing Effective Print Materials for Low Literate Readers,” it has been updated to “Clear and Simple” for “contemporary use” to address this issue for 90 million American adults that have low literacy skills (para.1). The guidelines have five standards:

1. Define the target audience

2. Conduct target audience research
3. Develop a concept for the product
4. Develop content and visuals
5. Pretest and revise draft materials (para. 6)

Nothing is mentioned about translations, however. Even though their bibliography mentions Spanish readability research, they date back to the 1970s. One of the first studies to take Spanish into consideration was done by Contreras (1999), where he applied the SMOG formula to analyze 10 samples of literal –type translations available in English, Spanish and French with different difficulty reading levels. Because of the differences in language clause construction, he came up with a new formula called SOL which aimed to “provide Spanish – speaking and French - speaking health communicators with a readability formula for preparing written materials appropriate to the level of comprehension of specific target audiences” (p.28). He proposes the use of the SOL formula to make written texts accessible to “specific target audiences” (p.28). Unfortunately, no follow up research using the SOL formula is available. Researchers have started to see they need to study readability directed to minorities. H.A. Massett (1996) conducted an analysis “to assess the linguistic appropriateness and cultural sensitivity of the materials in efforts to establish preliminary guidelines for the development of future materials” (p.232). He analyzed the content of 26 national print breast cancer educational materials targeting Hispanic women. He cites the Department of Health and Human Services admitting that they heavily rely on print media to educate about the early detection of this illness; however, the National Coalition of Hispanic

Health and Human Services Organization (COSSMHO, 1990 as cited in Massett, 1996, p.232) points out that “materials written in English should not simply be translated into Spanish. ‘They must be adapted linguistically and culturally to your target population’” (p.232). The results showed that the English-speaking counterparts scored 100% in readability at the high school level. Guidry and Walker (1999) highlight the fact that information needs to be culturally appropriate “because individuals respond to healthcare information in terms of beliefs and values that shape identity and rules of behavior associated with group survival and welfare, healthcare information that does not coincide with an individual’s beliefs or practices can be interpreted as insensitive and maladaptive” (p.291). Gerstle (2010) conducted a study to determine the readability of health education literacy published by health education organizations aimed at “immigrants and native speakers with a fourth-grade level of literacy”. He emphasized the importance of taking context into consideration: “contexts are not simply containers within which actions, practices, and activities occur. Instead, they are dynamic streams of overlapping and integrated discourses, spaces, sociocultural practices, and power relations” (p. 250). Translated texts, as Martin (1992) explains, are “social processes and need to be analyzed as manifestations of the culture they in large measure construct” (as cited in Martinez Lirola, 2006, p. 251).

Some efforts have been done to integrate culturally appropriate written translations in healthcare, Jacobson’s work has opened a new path of guidelines to produce translated information. She says, “If successful communication is to take place, interlocutors must share the same interpretive frame (definition of the situation),

repertoire of contextualization cues, and sociocultural knowledge and expectations (Jacobson, in Angelleli and Jacobson, 2009, p. 5). Jacobson's dissertation (2002), "Translation of the health brochure and impact on the target reader: a contrastive analysis of the structural and pragmatic features of texts translated into Spanish versus texts written originally," is one of the few works that deals with translations of health brochures. She analyzed a set of translated brochures published in the United States and compared it to a set of brochures published in Mexico. She had a subject set of 54 Spanish-speaking adults who went through a pretest and posttest protocol, a recall protocol, and interviews. In her findings, she discusses how health brochures are the second source of information for patients. "Informants demonstrated awareness of the lack of health information available in Spanish" (p.187). They also noted that "the words they use are different from those used by recent Mexican immigrants" (p. 188). Cultural issues were important such as "family, God, and society" (p. 183) and "defining the reader-author relationship" (p.183). Another research focused on the translation of educational written texts was done by Horner et al. (2000) where they focused on asthma-related materials and parents with a 5th grade reading level, who also had English as a second language. They redesigned the documents so that both languages would appear side by side because, they noted, some parents "may be more familiar with some English terms used to describe certain aspects of health or health care" (p.20). They also edited sentences "to use clear, direct statements describing asthma...the use of passive voice was eliminated...[and] a bullet format was used..." (p.20). After these modifications, the reading level was of 6th grade. They also did a field test and made further revision to

reflect regional dialect (p.21). While they highlighted the need of follow-up research to find the outcome of their newly designed brochures, the importance of these type of studies is the recognition of the literacy levels needed to understand medical information.

All these researchers have focused on adding the cultural element to translation; however, accommodations for cultural sensitive material and the high reading levels are still a tangent problem. Some organizations such as The Robert Wood Johnson Foundation have taken the lead to move forward. Through the program *Hablemos Juntos: we speak together*, they developed a plan to translate documents to Spanish. Jacobson has been a keen advocate of providing adequate written information for minorities in the United States. She created the *Ten Principles for Developing Effective Spanish Health Written Materials* (2004) as a guide for the *Hablemos Juntos* program. The *Ten Principles for Developing Effective Spanish Health Written Material* stipulate the following:

1. You must know your target reader.
2. Message development should always be driven by the target reader.
3. Message development should involve a participatory process involving the healthcare provider requesting the materials
4. You must know the writers and health experts developing the texts (the authors). No mystery writers or translators!
5. Messages cannot be created or used in a vacuum.
6. Messages should be grounded in theory.

7. Theoretical foundations for messages should not be limited to health behavior theory, but should also be grounded in communication, learning, social marketing and linguistic theory.
8. Formative evaluation and field testing is essential before a message can be disseminated.
9. Formative evaluation and field-testing should be planned and built-in- early in the development process.
10. The effects of materials on the target reader should be tracked.

Indeed, one of the main concerns in the field of minority health is the question about what are the patients doing with the information provided. This question has been central not only for policy maker advocates but also for medical professionals who are first hand witnesses of the impact that an un-informed patient can have on their own health management. Dixon-Woods (2001) says that written medical information usually follows two discourses: The “patient” education discourse, and the “patient empowerment” discourse. She mentions that the most powerful motivation for using patient education texts “derives from a discursive construction of patients as irrational, passive, forgetful, and incompetent” (p.1419). While the patient empowerment discourse is “to reflect the priorities of patients...to consider patients as active participants in the consultation” (p.1421). She calls for a new discourse that could make “use of a wider range of resources, including sociological resources, could help to bring these two discourses, which already have overlapping concerns, closer together, and could facilitate the development of a rigorous theoretical framework within which to think about patient

information” (p.1428). A new approach that has been used to provide health documents that empower patients involves the use of Systemic Functional Linguistics to analyze the construction of the health discourse as will be detailed in the next section.

2.9 Review of Previous Research Involving SFL and Health Texts

Halliday has dedicated several research papers to the architecture of language that people use to construe their experiences in regard to health. As mentioned earlier, “On the Grammar of Pain” (1998) was his seminal work on the topic. He explains that this paper came as a later version to a previous research in 1991 where he analyzed 20 million expressions of pain. In 1995, he presented a continuous research, this time involving clauses integrating Norman Fairclough’s notion of Critical Discourse Analysis. In this paper, he analyses how pain is “transformed” into meaning as a process, a quality, or a thing. Halliday considered pain as encountered in everyone’s daily life, and he asserts that it is through language that “experience is transformed into meaning”. This gives language power in everyone’s social life which enables the “ability to systematize our everyday encounters with the world: enabling us to talk about the to each other, giving them value, and so helping us to ‘make sense’ of things that we still, for all our cleverness, cannot control” (Halliday, 1998).

SFL concentrates on the analysis of authentic products of social interaction (texts), as they are constructed in the social and cultural context. The most generalized application of systemic linguistics is “to understand the quality of texts: why a text means what it does, and why it is valued as it is” (Halliday, 1994, p. xxix, as cited in Martinez

Lirola, 2006, p. 250). Fryer (2012) conducted a study about written texts in Sweden. He concluded that “the analysis of generic conventions can provide useful insights into the communicative practices of specific discourse communities. This typically involves studying the structural and grammatical features of texts as well as their historical, sociocultural, and ideological significance” (p. 6). According to his findings, he was able to demonstrate the usefulness of SFL to study the generic discursive constructions within a genre or institution (p. 32). Fryer’s findings demonstrated the usefulness of SFL to analyze the rhetorical techniques of a medical research texts, which “should be applicable to genre and text analysis in general, for both research and teaching purposes” (Fryer, 2012, p. 32). In a recent study, Magaña (2016) used SFL tools to analyze the modality resources of psychiatric interviews in Spanish and examined all the cultural values implied during the interaction. Kealley, Smith, and Winsor (2004) conducted a study in Australia where they used Systemic Functional Linguistics to analyze informational pamphlets given to relatives of patients in the Critical Care Unit. The information was written by nurses. The basis of the study relies on patients and relatives being viewed as clients, (which implies that the health system is a service provider) “because such information is perceived to increase the ability of clients to make informed choices” (Ellis-Stoll and Popkess-Vawter, 1998). When clients are seen as clients they become empowered and take control of their illness.

Taking a patient-centered viewpoint several studies have been published using SFL as a framework. Clerehan et al. (2005) results say that, “patient information leaflets are an important adjunct to verbal exchange between doctor and patient. Their value is

dependent upon whether they contain useful information from the viewpoint of the patient and are easily understood” (p. 334). Another study by Clerehan and Buchbinder (2006) focused on 18 sets of leaflets written in Australia and it used SFL as a tool to assess the comprehensibility of the information. Their work was divided into the following sub-sections:

specialization of lexis (lexical choices); author-reader identities and status relations (“author’s assumptions about the relative status of writer and reader in the real world”); visual aspects, headings, and lexical density (quality of texts); mood (“what the writer takes to be matters of “fact”); theme (“what the writer takes to be an appropriate starting point for the purposes of their message”). (p. 44-45)

Following these previous studies, Hirsh et al. (2009) developed an “Evaluative Linguistic Framework (ELF) to assess the quality of written patient information about drug treatment based on systemic functional linguistics where they conducted a thematic analysis” (p. 248). Their conclusion was that:

high quality information leaflets which take into account key variables of context, text structure and the writer-reader relationship should be able to better support patients to take their medication appropriately...Medication information leaflets are an important extension of the care provided by the doctor, and their provision within the consultation may enhance the communicative relationship and lead to better care. An explicit awareness of patient expectations by leaflet writers is likely to lead to improved clarity of patient information leaflets. (p. 254)

A parallel study in a follow-up research focused on people suffering from arthritis was also done (see Clerehan, Hirsh and Buchbinder, 2010). As in the other studies, they found that perception of patients is the most important factor to assess the usefulness of written materials. However, they observed that they did not take into consideration demographic factors, health literacy, and health beliefs (p.125). Finally, Kazemi (2015) did a study about theme markedness among medical texts in Persian and English using SFL. Kazemi (2015) cites Mohammadi (1995), who “emphasized the significance of the theme, its types, and its importance in translation, and believes that recognition of marked or unmarked themes in translation is important because they play different roles and thus convey different meanings” (p. 2416). Kazemi’s purpose was to shed light in the medical genre as the previous research is limited. Based on the evidence provided by previous research and the facts presented in Chapter 1, it is the purpose of this research to open new paths to the field of medical translation by using SFL as the basis. The purpose of using this theory resides in the idea that it takes context and culture into consideration and the meaning potential of every information exchanged, oral or written.

2.10 Hypothesis

Health institutions in the Rio Grande Valley comply with the current government regulations by implementing steps to provide health information written in Spanish. Resources such as translations provided by national organizations such as the American Cancer Society and the Leukemia and Lymphoma Society alongside with translations made by native speakers in the medical field are being used to make sure information is

readily to be distributed. However, this research papers suggests that the availability of written information does not diminish the language barriers obstacles, as these translations are not always accessible and comprehensible to the community. This paper will take on the premise of SFL that in order to have effective communication, language should be studied as it is embedded in the context of situation and context of culture, proposing that written health information would have an effective impact as vehicle of health promotion and decision making if it would be aligned with the community registerial features.

The objective of this research is to answer the following questions:

1. Are pediatric cancer translated booklets and handouts culturally and linguistically appropriate for this community to effectively decrease health disparities? (see Section 1.6)
2. How is it that the oral narrative construction of the illness by caregivers could contribute to the process of culturally sensitive translations?
3. What are the current barriers (or determinants of health) that affect this linguistic minority community to have full access to the dissemination and promotion of health that could result in early diagnosis of pediatric cancer? (see Section 1.8)

The purpose of answering these questions is to elucidate the following hypothetical points:

1. Literal and traditional grammatically-oriented translations made by national organizations rely highly on the assumption that the patient must understand all

medical vocabulary if it is written in Spanish, regardless of the literacy level of the texts. Therefore, translations are rendered useless to low literacy patients who then have to depend in the medical encounter or on trained family members to obtain all the information in regard to the illness.

2. Anonymous translations are not critically evaluated and present a large number of grammatical errors and illegible clauses making the information confusing to the reader. Cultural elements are also not aligned for the target text community.
3. Language planning is not being done appropriately to have a timely and effective communication outside the health institutions setting. The community is not being educated about general symptoms and the socio-demographic or hereditary determinants of illnesses such as pediatric cancer that could empower families resulting in an early diagnosing and greater survival rate.

A systemic functional approach could close the gap between health institution and linguistic minorities and bridge the access to health for parents of children with cancer. The goal of this paper is to present a corpus of translated text analyzed through the lens of SFL as well as a series of community narratives with the aim of contributing to create a 'code' that could eventually be used in machine translation, as is being currently researched in other countries.

Chapter 3

Methodology

3.1 Introduction

This research analyzes translated medical texts provided to Spanish-speaking families in the Rio Grande Valley. These texts are used for two purposes: as means of health promotion and to provide information throughout the stages of diagnosis and treatment of pediatric cancer. This paper also analyzes community narratives and their oral construction of the illness. The purpose is to establish the practicality and viability of the translated texts as instruments for the promotion of health and for the dissemination of supportive information as well as how they are perceived and deemed by the community by laying out patterns of choices of meaning in the communication. This study delivers a detailed look at the constructions made by the translators to “recreate meaning” (Kim and Matthiessen, 2015) following on Matthiessen definition of language as a “medical (or healthcare) resource” (p. 438). In addition, it also uncovers the functional patterns of made by the community. This is especially important in this border area because the limited English proficiency and illiteracy rates, in addition to the high poverty rates, have created a communication barrier between the community and the health system resulting in concerning health disparities (see Section 1.6). The production of effective translations is necessary not only for the field of linguistics but also for healthcare practices that are patient-centered and inclusive to cultural and linguistic minorities. While the governmental requirement of providing information in languages

other than English to patients is, indeed, carried by healthcare institutions through the distribution of written texts in Spanish, this study elucidates whether the target readers are, in fact, not only receiving but using the message conveyed by the translators to make informed decisions about their health. It is the objective of this study to shed light on relevant data that will facilitate the use of meaningful language-in-context input choices to generate human or machine translations that can be an efficient resource for the “community needs” (p. 440).

Using Systemic Functional Linguistics as the theoretical foundation, this project provides a way to minimize the well-documented linguistic obstacles that affect minorities by revising health translations and their utility as the communication form that extends from the medical institution encounter to the community households and sociocultural groups. As explained in Chapter 2, Matthiessen (2015) justifies the use of SFL to enter the healthcare contexts because the tools can be “applicable” to “cultural institutions of healthcare” (p.444). Meanwhile, the focus on the analysis of translations in this research is one “centrally involving the *recreation of meaning* through choices made by the translator in the interpretation of the source text and through *choices* in the generation of the translated text” (Kim and Matthiessen, 2015, pp. 335-336). It is the aim of this research to analyze the linguistic choices used to create meaning by the translated written texts alongside with the choices used by the community to construct their own experiences about the illness. The results provide key linguistic information to negotiate future translations. After all, the goal of SFL is to “build bridges between linguistic theory and professional practice” (Yallop 1987, as cited in Manfredi, 2011, p. 50).

In this section, a detailed description of the data and the process for collection will be explained. Additionally, the process to select participants to conduct interviews and the methods used to analyze the data will be described.

3.2 Data Collection

This research project is based on written data and semi-guided oral narratives. The written data is comprised of two different sets of Spanish-translated texts. The first set of written data consists of a collection of handouts put together in a binder. They are translated by the Texas Children's Hospital and distributed by healthcare facilities upon patient admission. The second set of written data includes booklets translated by national advocate organizations such as the American Cancer Society (ACS) and the Lymphoma and Leukemia Society (LLS); these are distributed to the community by local healthcare facilities. This research also uses narrative discourse data collected by interviews conducted with people from the community. As a final component of this research, medical personnel and community health workers have been interviewed in order to identify their perception about the issue and obtain their insight on the effectiveness of the translated texts.

3.2.1 Written Data

The written texts were collected at the social service office of the Vannie E. Cook Jr. Children's Cancer and Hematology Clinic. Every person that visits the clinic to look for information is initially sent to this office. This office is located just to the side of the

reception desk and it is where all the free text materials are stored. The binder with procedural handouts is only given to patients and families upon admission, but the booklets are available to anyone interested in getting information about pediatric cancer. These booklets are also used as means of health outreach and promotion. Most of the forms provided in this clinic are accessible in English and Spanish; however, there are still a few available only in English.

The first set of written texts is provided to the family upon diagnosis and it consists of several handouts pages put into binders. These binders are not used for health outreach and promotion; they are only provided to families once the child has been admitted to the clinic. They are used as supplemental information to explain general procedures into detail and to help families in the decision-making process. Every family receives two binders. The first binder is provided by the American Cancer Society and its function is to help with the organization of information. It opens with a page explaining what is cancer (only the English version is available); the rest is divided into tabs with forms ready to be filled out in order to keep record of when and what type treatments are being provided (see Appendix D for samples). Another tab is meant to keep track of the follow-up with appointments, and manage the results. The last tab provides directory information to obtain additional resources such as counseling and finances. Even though this binder will not be analyzed through the theoretical tools, it is an important part of the available texts.

The second binder is called *Manual para les padres: Guía para les padres de niños con cáncer* [sic]. On the cover page, it states that it was provided as a donation by

the Nurse Oncology Educational Program funded by the Texas Cancer Council and it was developed at the Cancer Center in the Texas Children's Hospital in Houston, Texas. The name of the English version is *Parent Handbook: A Guide for Parents of Children with Cancer*. This binder provides contact information of the doctors that work at the clinic. It is comprised of 97 black and white pages explaining cancer in general, and several different possible treatments. It also has pages detailing general procedures such as white blood cell counts, catheters, and bone marrow aspiration. The function of these handouts is to help the families make informed decisions about the different treatments available as well as to how to communicate the procedures to the child. In addition, it provides a list of financial and informational resources. At the end, it gives a glossary list of the terminology related to the illness (see Appendix E for samples). The translator or method of translation is anonymous. The following handouts will be used in this research:

1. *¿Quién es quién?* (Who is who?)
2. *¿Qué es el cáncer?* (What is cancer?)
3. *Tratamiento para el Cancer: Cómo se elige el tratamiento para el cáncer de su niño(a)* (Treatment for cancer: how to choose cancer treatment for your son/daughter)
4. *Procedimientos* (procedures)
5. *Conteo Sanguíneo* (Blood Count)
6. *Efectos Secundarios* (Side effects)
7. *Vida familiar* (family life)

They were selected because, as previously discussed in this study, one of the causes for health disparities among Hispanics is their understanding to make decision in regard to treatments for pediatric cancer (see Section 1.6). These handouts also cover procedures that children will undergo regardless of the type of cancer that have been diagnosed. The characteristic shared among all the written selections used in this project is connected by the fact that it shows how the illness is constructed and allows for a future comparison to the oral narratives.

The second set of data collected consists of a series of booklets provided by ACS and LLS. They cover a variety of cancer-related topics such as health promotion, early diagnosis, available treatments, the consequences of living with cancer, the effects it has in the family, and how to talk to children about the diagnosis and the quality of life during the treatment. These booklets are very well presented in a colorful, long-lasting, paperback material. They are easy to carry and distribute since they only range from 29 to 66 pages and measure approximately 8 by 6 inches. Table 3.1 shows some of the titles available at the clinic, which will be used for this research. Even though all booklets had important information about cancer, these titles were chosen for three main reasons: 1) they represent the broad spectrum of available titles, 2) they show how the translators structure the illness narrative and 3) they have specific passages directed to parents and families. A complete list of titles available from LLS and ACS and samples can be found in Appendix F.

Table 3.1 List of Translated Booklets from LLS and ACS

Booklet Title	Pages	Year of publication	Organization
<i>Aspecto [sic]Emocionales de Niños con Leucemia: La Informacion para los Padres</i> (Emotional Aspects of Childhood Blood Cancers: A Handbook for Parents)	66	2000	LLS
<i>Comprendiendo la Farmacoterapia y Manejando los Efectos Secundarios</i> (Understanding Drug Therapy and Managing Side Effects)	62	2003	LLS
<i>La quimioterapia: en qué consiste, cómo ayuda</i> (Chemotherapy: What it is, how it helps)	24	2006 (online version updated in 2013)	ACS
<i>La radioterapia: en qué consiste, cómo ayuda</i> (Radiation Therapy: What it is, how it helps)	20	2006 (online version updated in 2015)	ACS

As shown in Table 3.1, these booklets are also available online. In fact, the online version has been updated more recently. Furthermore, each booklet, at the back-cover page, directs the reader to look online for more information available in Spanish. However, for this study, the hardcopy version given to patients will be used. Also, as explained in Section 1.7, the poverty rates and the *colonia* settlements in this community mean that they have limited resources including the lack of Internet access in many areas. Is it important to mention that, even in the website, some titles have a notice informing about English only availability. One more issue to consider, is that even if the community were to have access to more information online, the legibility level of these publications is still higher than the average education level of the community (see Section

1.3 and 2.8). Regarding the translator and editors of these texts, they do remain anonymous. In the Leukemia and Lymphoma Society booklets, the translation is attributed to the organization. However, the American Cancer Society website offers the following note at the end of every publication:

Nuestro equipo está compuesto de médicos y enfermeras con postgrados y amplios conocimientos sobre el cáncer, al igual que de periodistas, editores y traductores con amplia experiencia en contenidos médicos.

They state that their team is made of doctors, nurses, journalists, and experienced translators. The name of the translators can be found in the website; however, there is not information about their experience or professional affiliations.

3.2.2 Oral Narratives

To provide a more comprehensive analysis of the issues presented in the written texts, this study takes into consideration the oral discourse of the community, more specifically, the parents or caregivers of children who have accessed the health system and have needed the health services to be provided in Spanish. Their narrative provides the register and the linguistic choices that are meaningful to this community and reveal their insight on the accessibility and effectiveness of the information available to them. Therefore, these interviews serve two purposes: 1) to have a first-hand and valid account of their response to the availability and efficiency of the written materials, and 2) to further the analysis of the word choices that the community uses to construct experiences about pediatric cancer. The speech of the patients has been the subject of research, as

Hydén states, “how patients spoke about their ills, symptoms and problems was regarded at best as a pale reflection of the language of the organs and tissues” (Hydén, 1997, as cited in Matthiessen, 2013, p. 460). Patients now are seen as “meaners” and their health not only revolve around their own organs but it extends to making informed decisions and involving friends and family members in the healing process (p. 462). According to Hyden (1997) the narrative “is able to represent and reflect illness experiences in daily life...this makes it possible to study the patient’s illness experience and illness world as a social reality apart from the conception and definition of illness as formulated by biomedicine” (p.52).

The participants and the instrument used to obtain these data are explained in the following section.

3.2.3 Interviews

Interviews were conducted with 20 residents of this area. They all had children (ranging from newborn to 18 years old) and they have received health information about pediatric cancer as means of health promotion or have received the information because their child has been hospitalized within the last 5 years. Interviews were open not only to parents of children with cancer, but also to every parent that was exposed to a prolonged time in a hospital setting. The rationale behind this decision was based on the fact that one of the objectives of the research is to find out if parents and caregivers know about cancer before the possibility of facing the illness; that is, if there is enough information about cancer as means of health promotion that could potentially result in an early

diagnosis. To initiate contact with parents a public announcement of the project was made at places where it was projected to find volunteers such as local churches, and community centers. Parents were not approached at any hospital or doctor's offices because of the emotional conditions of these places and the vulnerability it presents on patients and families. To motivate participation, the public was made aware of the project and the anticipated benefits for the general community. Once a participant was located, they read and sign the Consent Form in order to set up a time for the interview. It is explained in the Consent Form that their participation is voluntary and their recordings will not include names or any other immediate identifiable information (see Appendix G). In case they mentioned names of institutions or medical personal during their narrative, they were assured it was to be kept confidential and substituted by a different name in the transcriptions. It was anticipated that the interview would last for about 10 to 15 minutes. While the gender or age of the parent was not taken into consideration, only parents that have accompanied the child and have received information directly were selected. Because of the children's age, it was expected for parents to range between the ages of 18 to 40 years old.

The process of the interview started with the following two prescreening questions:

1. Do you speak, understand, and read English? If the answer was yes, the person was not a candidate to participate in this research. If the answer was no, continue to the next question.

(¿Usted habla, entiende y lee en inglés? Si la respuesta es sí, usted no es candidato para esta investigación Si la respuesta es no, continúe a la siguiente pregunta)

2. Do you have a child (younger than 18 years old) that has been to the hospital within the last 5 years? If not, the person was not a candidate to participate in this research If yes, the person was asked to continue to the research questionnaire.

(¿Tiene un hijo o hija (menor de 18 años de edad) que haya estado en el hospital en los últimos 5 años? Si la respuesta es no, usted no es candidato para esta investigación. Si la respuesta es sí, se le invita a continuar con el cuestionario)

After these pre-screening questions, candidates were directed to answer the study questionnaire. The first set of questions is aimed to determine their sociocultural and linguistic backgrounds. It includes the following questions:

1. What is your city/county of residence?

(¿En qué ciudad o condado vive?)

2. What is your or your family's country of origin?

(¿De qué país es originario usted (o su familia)?)

3. How many years have you lived in the United States?

(¿Cuánto tiempo lleva viviendo en los Estados Unidos?)

4. What language do you speak at home all/most of the time?

(¿Qué idioma se habla en su casa todo el tiempo o la mayor parte del tiempo?)

5. If you are employed, what language do you speak at work?
(*Si trabaja, ¿qué idioma habla en su trabajo?*)
6. What was your last completed grade of school?
(*¿Hasta qué año fue a la escuela?*)
7. On a scale of 1 through 5, how well will you say your English ability is to speak/read/write/and understand? (refer to Table 3.2)
(*En escala del 1 al 5, ¿qué tan bien considera que habla/escribe/entiende/lee inglés?*)

Table 3.2 Participants Self-evaluation of English Proficiency

	Nothing (<i>nada</i>) 1	Fair (<i>poco</i>) 2	Average (<i>promedio</i>) 3	Good (<i>bueno</i>) 4	Excellent (<i>excelente</i>) 5
Speak (<i>hablar</i>)					
Read (<i>leer</i>)					
Write (<i>escribir</i>)					
Understand (<i>entender</i>)					

This part of the interview took about 2-3 minutes to complete and it helped to rule out participants who were English proficient and had access to information in both languages.

The second part of the interview consisted of a set of guided questions aimed to gather information about their overall experience with written information. These questions lasted from 5 to 7 minutes. They were all recorded and transcribed. These following questions were used as a guide to elicit a response:

1. When your child was admitted to the hospital, can you explain the process you went through before getting information about your child health?
(Su hijo/a estuvo en el hospital, ¿me puede explicar cómo obtuvo información sobre la enfermedad de su hijo/a?)
2. Did they speak Spanish to you in all the medical institutions you visited?
(¿Le hablaron español en todas las clínicas/hospitales que visitó?)
3. Talking about health, in general, what have been your main sources of information about your children illnesses?
(Hablando de la salud en general, ¿cuál es la principal manera en la que obtiene información sobre las enfermedades que haya tenido su hijo (por ejemplo, en internet, en la clínica, la televisión, folletos, etc.)?)
4. Did you have written information about this illness before your child was diagnosed? If not, would it have helped you to seek for an early diagnosis?
(¿Tuvo usted información sobre la enfermedad de su hijo antes de que lo diagnosticaran? Si no, ¿cree usted que le hubiera ayudado a detectarlo antes?)
5. After diagnosis, has the written information been useful to you and your family in the decision-making process?
(Después de que estuvo en el hospital, ¿ha usado usted información por escrito que le haya ayudado a tomar decisiones?)
6. Do you have any recommendations for other parents who do not speak English?
(¿Tiene alguna recomendación para otros padres que no hablan inglés?)

This part of the interview allows the project to interpret how important the role of written information is for early diagnosis and how much it can help to make informed decisions. The results are analyzed quantitative and qualitatively and presented by percentages to explain the community perception in regards to the role of written health information.

The last part of the questionnaire is semi-guided and it allows this research to find out information about the effectiveness of health promotion in regards to childhood cancer. It also provides this study with the linguistic features that are characteristic of this community to create meaning and linguistically construct illness. The purpose of these questions was to elicit a narrative about pediatric cancer and obtain a comprehensive sample of the shared linguistic words choices of the community to talk about the illness. This part is composed of the following questions:

1. As a child caregiver, do you have information about childhood cancer and early diagnosis?

(Como padre de familia, ¿tiene usted información sobre el cáncer infantil y cómo se podría detectar a tiempo?)

2. What is cancer?

(¿Qué es el cáncer?)

3. Do you know what could be some of the early symptoms?

(¿Sabe usted cuales son algunos síntomas que pueden ayudar a detectarlo a tiempo?)

4. Do you know what are some of the available treatments and procedures?

(¿Conoce usted algunos de los procedimientos o tratamientos para el cáncer?)

5. Without mentioning names, who are the people you rely upon to make health decisions about your child?

(Sin mencionar nombres, ¿quiénes son las personas que le ayudarían a tomar decisiones sobre la salud de su hijo/a)

In addition to parents, this study also interviewed the social worker of the clinic with the only purpose of getting a panoramic view of the medical staff opinion and their recommendations on the effectiveness of the written materials available. The following three open-ended questions were directed to the social worker as well as community health workers:

1. What supplemental written material do you consider relevant for patients?
2. Have you read the written material provided by the clinic? What is your opinion?
3. Do you have any recommendations for future translations?

There are four Pediatric Oncologist currently working at this clinic and they are of Hispanic origin; however, it is worth noting that none of them were born or raised in this border area. The medical director is from Costa Rica, while the other two oncologists are from Mexico City and Puerto Rico respectively. The social worker is the person in charge to provide patients with the written materials. Even though, they speak Spanish as native speakers, one point to take into consideration is that their cultural experiences differ from the Rio Grande Valley culture and they use a different dialect and register of Spanish. Therefore, the social worker point of view was important to show a comprehensive view of how patients still need the written texts to complement the information in Spanish that they get in the clinic. Community Health Workers were

contacted during an announcement made in the local chapter of the organization LUPE (La Unión del Pueblo Entero), an activist organization that provides, among other services, health services to *colonias* around the Rio Grande Valley. Their answers to the questionnaire are also important to further the analysis into the community perspective of written information.

After all the data collection, this research presents three different sets of data:

- 1) The local and nationally translated written data analyzed through the SFL lenses elucidating the choices made by translators to recreate meaning in the context of pediatric cancer.
- 2) The interview narratives, which show the perception of the patients and their self-reported knowledge of the illness, as well as register used for the construction of pediatric cancer.
- 3) The semi-guided interviews with medical personnel and health providers provide a quantitative analysis of the institutional perception of availability and effectiveness of the dissemination of written information for early diagnosis and coping with cancer.

A detailed explanation about how each one of these data sets is analyzed is presented in the next section.

3.3 Analysis of the Data

The data is comprised of Spanish-translated written texts and transcriptions of oral narratives. It gives a thorough perspective of the linguistic choices made by the translators in comparison to the Spanish language use of the community; that is, the

register variations for health-related information in this particular context and culture.

The analysis of both the written and the oral discourses allow seeing the bottom up perspective (wording to context) and the top-down perspective (from context to wording).

As Thompson (2004) says,

In order to identify meaning choices, we have to look outwards at the context: what, in the kind of society we live in, do we typically need or want to say? What are the contextual factors that make one set of meanings more appropriate or likely to be expressed than another? But at the same time, we need to identify the linguistic options (i.e. the lexical and structural possibilities that the language system offers for use), and to explore the meanings that each option expresses.”

(P.9)

The results of this research consider context as the factor that delineates the word choices, but also takes into account the possible alternatives in wording by studying the choices from multiple perspectives.

The starting point to conduct an analysis using SFL is to identify the registerial parameters of *Tenor*, *Field*, and *Mode* (see Section 2.1.1). They are identified as follows:

Table 3.3 Tenor, Field, and Mode

Tenor	Field	Mode
Translators; Community members	Pediatric cancer	Booklets and handouts provided by National Organizations and the Texas Children’s Hospital Oral Narratives

Once this information has been identified, the study then presents a detailed analysis of the written translated texts based on the three metafunctions: *Ideational*, *Interpersonal*, and *Textual* (see Section 2.2.2) within the *context of situation* and the *context of culture*. Each one of the metafunctions gives different information that reveal the choices of the translators to create meaning. The functional structure of the written discourse is analyzed following the components of each one of the metafunctions.

Table 3.4 Metafunctions and Structure of Clauses

Component	System of choices	Structure
Ideational	Transitivity	Participants, processes, circumstances
Interpersonal	Mood	Indicative vs. Imperative
Textual	Theme	Texture

The manner that *Transitivity*, *Mood* and *Theme* are structured to study clauses in any text are best explained in the following table adapted from Thompson (2004):

Table 3.5 Structure of Clauses in Each Metafunction

Type of structure:	Did	Jim	take	her calculator?
Experiential		Actor	Process	Goal
Interpersonal	Finite	Subject	Predicator	Complement
Textual	Theme		Rheme	

Note: (Table adapted from Figure 3.7 in Thompson, 2004, p.34)

In the following section, it is explained into further detail how each one of the metafunctions is realized and studied with the data collected.

3.3.1 Interpersonal Metafunction

In SFL, the *interpersonal metafunction* corresponds with the role of the *tenor*. This metafunction deals with the interaction of participants in the communication event. It is ultimately shaped by the roles that are placed and/or negotiated by the context in society. To analyze the *interpersonal metafunction*, the *Mood* of the clause was identified by dividing the clause into two parts: Subject and Finite (predicate and complement). While this research is in Spanish, Lavid et al. (2010) note that despite some differences, English and Spanish share basic similarities due to cultural and linguistic influence. The difference, says Lavid, is that Spanish adds a formal and informal option. According to Thompson (2004), the clauses generally serve four functions as: statement, question, offer, and command (p.47). However, what Halliday and Matthiessen (2004) deem more important is what they call the “good-and-services,” the giving or demanding information (pp.107-108). In other words, the *Mood* of the clause is what positions the translator in reference to the readers. If the speech role is made of commands rather than offers, it may position the translator in a higher place where the validity information is not expected, although possible, to be questioned. Halliday and Matthiessen added a new component to the interpretation of the reader responses and identified a “discretionary alternative” which is an alternative to the expected response. For example, this table explains some of the response exchanges:

Table 3.6 Discretionary Alternatives

	Initiation	Expected Response	Discretionary Alternative
Give goods-and-services	Offer <i>Do you want to get married?</i>	Acceptance <i>Absolutely</i>	Rejection <i>Certainly not!</i>
Give information	Statement <i>I am getting married</i>	Acknowledgment <i>Wonderful news!</i>	Contradiction <i>Over my dead body</i>

Note: Table adapted from Thompson (2004, p.79) and examples from Halliday (1994) as cited in Thornbury and Slade (2007, p.118)

The analysis of this research shows the type of clauses proposed by the translated texts, which because its description of the illness and the procedures, as well as advice given to the caregiver, implies an immediate expected response. By using the *interpersonal metafunction*, this work plans to elucidate the interaction between the translated texts and the expected role of the reader as an active agent in early detection of the illness, as well as in the management of the health and healing processes. In other words, this part of the analysis allows positioning the tenor and identifying who is at the center of the health information exchange.

3.3.2 Ideational Metafunction

The second step of this study is to analyze the data based on the *ideational metafunction*, which corresponds to the *Field* and it is divided into the *experiential* and *logical* meaning. For the purpose of this research, only the *experiential metafunction* will

be used (see Section 2.2.2). The *Field* or subject of the activity in this case is pediatric cancer. Matthiessen (2013) says that even though the *interpersonal* resources have been given more attention in the analysis of health texts, there are patterns within the *experiential* function that could help respond to the question of “how patients and healthcare professionals construe experiences of health” (p. 440). The *experiential* function analyzes the *transitivity processes*. There are eight different types of processes (see Section 2.1.1) Table 3.7 shows all these processes and example of clause analysis. The purpose of this analysis is to elucidate what type of interactions are being done in the translated information and compare the processes in the English and the Spanish version. This comparison will show the equivalency among both texts.

Table 3.7 Transitivity Processes and Examples

Process	Participant	Roles
Material	Actor/Agent <i>La puerta</i>	Goal <i>se abrió</i>
Mental	Senser <i>Tú</i>	Phenomenon <i>no te preocupes</i>
Verbal	Sayer <i>El amo que llevo dentro</i>	Verbiage <i>está hablando</i>
Behavioral	Behaver <i>A las cinco se pone oscuro</i>	
Existential	“There” <i>Había</i>	Existent <i>dos personas</i>
	Carrier <i>El jabalí</i>	Attribute <i>es un animal feroz</i>
Relational	Identifier <i>Ésta</i>	Identified <i>es las más grande</i>
	Possessor <i>Yo</i>	Possessed <i>tengo unos amigos</i>

Note: Table adapted from Halliday and Webster (2014, p. 222). Examples from Lavid et al., (2010).

These eight processes not only will define how the illness is build but they will also show how the construction may be similar in both languages. However, the meaning conveyed to the reader may differ.

3.3.3 Textual Metafunction

The third step is to analyze the *textual metafunction* that corresponds to the *Mode*. Halliday states in his article *On the Grammar of Pain* (1998) how the position of the clause in a text carries meaning:

In English (as many other language, though not all), there is a particular meaning associated with first position in the clause. Whatever element is put in initial position is being construed by the speaker as theme of the message...Now, if I say my head aches, or my head's aching, the first element in that clause is my head; I have construed a message in which my head is presented as the Theme. But this is not the way the situation presents itself to me. Where I start from, what I feel to be the setting of this unpleasant experience, is not my head, it is me – myself, as a whole. So, the grammatical Theme of the clause ought to be “me.” (p. 309)

Halliday cites examples such as “I have a headache” where “ache” is the process and the participant is not the person but the head. He says there could be other constructions such as “my head's aching” or “my head aches”. To interpret how the written and the oral discourse are organized this study classifies the *theme* and the *rheme* of the clauses to identify repetitions, which are called “lexical repetitions” (Thompson, 2004, p. 141).

Repetitions in the *theme* serve to indicate, “what the speaker thinks is a viable/useful/important starting point” (p.165). This allows our results to locate the words that the translator deem more important to convey the message among the medical vocabulary while the narrative will allow to indicate the most common motifs that the community uses to communicate when talking about pediatric cancer. Halliday and Webster (2014) propose to create a word cloud, which is a computational representation of the most frequent words in a text, to “reveal most prominent motifs” in their research (p. 368-380). These repetitions allow this study to elucidate the value given to context-carrying words in both languages.

The textual analysis helps in determining the “Texture and ArchiteXture” of the data (Halliday and Webster, 2014, p. 378). They state that the *theme* is the “point of departure” of the message and it “may be related to textual, interpersonal or ideational meaning, or even a combination of meanings” (p. 235). This step allows to further the understanding the choices made by the translators and how through their voluntary or involuntary choices they construe the meaning; it also allows the results to show what lexical and semantic choices are more recurrent in the written and oral data.

3.4 Organization of Data

Based on previous SFL research projects (Halliday and Webster 2014; Thompson, 2004, Lavid et al., 2010) this study first divides the written data and the oral narratives. First, it starts with the locally translated written handout by presenting a panoramic analysis of the significance of the differences among the Spanish and the English version.

Then it provides the results of the *interpersonal metafunction* analysis, which elucidates the roles of the addresser and the perception of the addressee. The second step shows the results of the *ideational metafunction* analysis, which by means of the *transitivity processes* show how the communication about the illness is experienced. The third step provides the results of the *textual metafunction* analysis by using word clouds, which will shed light in the themes, motifs, and repetitions providing a complete visualization of the linguistic choices that appear more meaningful for both the translators and the community. The SFL analysis using the three metafunctions of language exposing patterns in the translated texts allows the identification of potential miscommunication in healthcare. In fact, this study can demonstrate why the existing information is disconnected with the intended audience.

The next part of the results provides the analysis of the nationally translated booklets. Since both, Spanish and English version, follow the equivalence principle of translation; it is important to establish the readability level in the English versions. The readability was determined by using the common calculation scales such as the Flesch Reading Ease, The Funning Fog Scale, The Flesh-Kincaid, The Coleman-Liau Index, and the SMOG index. As seen in Section 2.8, these scales are commonly used to measure readability of text and the results are based on computer calculations measuring sentences lengths and syllables. Even though, the Spanish readability calculators available up to date have not proven to be helpful, the English results allow to put into perspective the readability level at which these booklets are originally written. Once these levels have been established, the booklets are analyzed by what Halliday calls “Pinpointing choice”

(Section 2.5, Table 2.6). This particular SFL tool permits the identification of clauses that could potentially have a better alternative positioned along the three metafunctions as delineated by the *context of situation* and the *context of culture*. Lastly, for the written analysis, word clouds are used again to define repetitions and motifs in the translated texts.

The last part of the study provides a demographic chart of the subjects that participated in the study, followed by the analysis of the transcribed narratives in regard of their perception of written texts and the usefulness and availability of Spanish written information. The construction of the illness by the community was analyzed and contrasted to the construction of the illness as previously presented by the translated texts. The narratives provided by medical personnel and community health workers aid to corroborate the questions raised by the study about the functionality of the available translations and the need for culturally adapted translations.

As a conclusion, this study opens the path to future human and machine translations that are appropriate for the community in the health care context. Matthiessen (2013) proposes as the use of the *Stratification -Instantiation Matrix* to apply systemic functional linguistics in health care contexts (see Figure 2.1). This instantiation matrix is explained by Matthiessen as helpful for language in healthcare because it explains the processes across all instances and the strata as they are mapped and situated in context as the departure point (p. 442). By analyzing how text is constructed, written and orally, in both dimensions, this research is able to address what Matthiessen calls an “instance of healthcare as contextual concern” (p.444). Taking healthcare as a contextual

institution allows for the translation of healthcare information to be considered as part of the language engineering tools designed as part of the SFL theory. Halliday (2005) expands in this topic in his article “Computing with Meaning” where he proposes that the application of *instantiation*, *stratification*, and *realization* to language research can expand on the concept of “intelligent computing” which refers to the use of natural language as language of the computer. To summarize this section in terms of SFL, the cline of instantiation goes from the context of culture, to cultural institutions (in this case, healthcare institutions), to the context of situation, (diagnoses, treatment, information) to the realization of the situation in the form of *register* (Matthiessen and Halliday, 2004).

This study provides the necessary results so that future researchers can appropriate use linguistic choices for functional translation making the information accessible and effective for linguistic minorities. The results can expand to other border regions as well since ultimate goal of effective written materials is to “reduce reliance on memory” (McClanahan et al, 2001, cited in Matthiessen, 2013) and empower patients in their decision-making process. The use of Spanish should not be limited to the medical encounter where the doctor or another untrained interpreter (medical personnel, staff, family, etc.) provides the translation. The community must have the resources to continue learning about the illness at home and revise this information as often as needed and share it with the family to make decisions that are well-documented, valid, reliable, relatable, and culturally appropriate.

Chapter 4

Results and Analysis

4.1 Introduction

This chapter is divided in two main sections followed by a discussion of results. The first section presents the results of the written data; that is, the translated documents. The second section details the results of the oral narratives about the illness provided by the community. Each part converges to unfold the answer to the three questions and hypothetical points discussed in this research. These points are validated through the lenses of the Systemic Functional Linguistics (SFL) tools as applied to the written and oral narratives. The culture and the context where this communication exchange is taking place, as explained in the previous chapters, is fundamental for the development of this analysis. Within these conditions, the Tenor, Field, and Mode can be positioned as follows:

Tenor - Translators/Caregivers and families of children with cancer

Field - Pediatric cancer

Mode - Translated handouts and booklets/oral narratives

These three registerial parameters will be kept in consideration throughout this chapter as they are realized throughout the linguistic exchange. Because of the hierarchical situation of the translator as the *Tenor*, it is expected that it will be positioned as a voice of expertise giving information about the illness to caregivers of children with cancer, while the all the processes happening in the *Field* and *Mode* should reflect the linguistic characteristics of the target community. The written communication exchange is

disseminated in a socio-demographic area with high levels of poverty and illiteracy where the majority of the people speak Spanish at home (see Chapter 1). After the analysis of both, the written and oral narratives, the results are discussed amid the current national debate about the accessibility and functionality of written language services as they are being used for the promotion and distribution of health materials by federal founded institutions of healthcare. The discussion of the results takes on these issues from the perspective of the translator as well as from the community. The ultimate goal of this chapter is to interpret, through the SFL metafunctions, the choices of meaning used by translators and community to construct their experience with the illness.

4.2 Written Data

As explained in Chapter 3, for the purpose of this research two different sets of written data were used. The first set is composed of local, in-house, ad-hoc type of translations distributed by the clinic with information provided by the Texas Children's Hospital and the Baylor College of Medicine. The purpose of these translations is to provide more personalized information to parents who have a kid that has being diagnosed with cancer and that will indeed go through most of the treatments and experiences described in these handouts. The second set is comprised of booklets translated by large national non-profit organizations focused on pediatric cancer such as The American Cancer Society (ACS) and the Leukemia and Lymphoma Society (LLS). These two different sets of information are the main source of written information used for health promotion and dissemination. Caregivers obtain these handouts and booklets

as educational resources that provide information about their child illness outside the medical encounter. The importance of the information provided to families reside in the fact that it is expected to provide a reliable second source of information, aside from the oral exchanges received at the time of the visit in the medical office. This is the information they can take home and share with other family members in order to reach a thorough understanding of the illness and make informed decisions. The two sets of written data are analyzed in their translated Spanish version, the Target Text (TT), and then compared to the original English version, the Source Text (ST). At the forefront of the discussion is the target community (TC); that is, the readers, their sociocultural background, and health literacy skills.

TT – Target Text (Spanish translation)

ST – Source Text (English original version)

TC – Target Community (The Spanish-speaking community in South Texas)

The SFL analysis allows the study of all linguistic elements present in the TT and the ST as they are embedded in situation of context and the situation of culture within the parameters established by the linguistic features of the TC. The SFL tools provided a panoramic but closely focused view of all linguistic characteristics of the text, from the lexicogrammatical aspects to the broader semantic level exposing if, and how, translators negotiate meaning through a cultural filter as necessary by the socio-ecological situation of the target community. After all, the effectiveness and functionality of translation, in the medical field, relies in mutual understanding. The only way that communication can

develop into the empowerment of the target readers as active agents in the healing process is contingent upon agreement of meanings in and out of the medical encounter. As mentioned in Section 1.7, people from this border community because of language and legal barriers often face the issue of invisibility in the healthcare setting (Martinez, 2008, p.360). The written information provided should be a bridge of continuous quality information so that the patients and their culture remain visible even when they are not in the healthcare institution.

This section starts with the results of the local translation followed by the national translations. The reason to begin with the local translation is because that is the same order in which caregivers receive them when visiting the clinic. The local information, put together in binders, is the first link between the clinic and the patient. Parents are encouraged to use it on constantly as the diagnosis and treatment progresses. The information is anticipated to be tailored to this community. On the other hand, the nationally-distributed booklets are the second source of information received, and while they are expected to be used and understood by the community, their target readers are Spanish-speakers nationwide before and after a diagnosis has being made.

4.2.1 Written Data: Local Translation

Before reviewing the results of the SFL analysis, this section starts from the premise that both, the ST and the TT, are considered equivalent in terms of the information given. As soon as the child is admitted into the clinic, parents are given the choice to get the informational binder in English or Spanish. The binders are used as

parallel texts meant to provide the equal information regardless of the spoken language.

Not only the title of the binders is the same, but also all extra textual context cues lead to this same understanding.

Title in English - Parent Handbook: A Guide for Parents of Children with Cancer

Title in Spanish - Manual para padres: Guía para los [sic] padres de niños con cáncer

The two versions are kept side by side; they are both in the same type and color of binder.

The type of font and illustration used on the cover page are almost identical. However, a quick glance through the pages reveals noticeable differences among the texts. The differences range from minor grammatical errors, which could be an oversight when typing and editing, to some more concerning issues such as missing information in the TT. This leads back to the work of Jacobson and the Robert Wood Johnson Foundation (see Section 2.8), which states that in order to develop effective health written translations field-testing should be conducted to guarantee its reliability as tools of health communication. Another requirement cited by Jacobson (2004) that is not seen in this translation is to avoid the anonymity of the translators. In the Spanish binder, there is no information as to who is responsible for the translation; it only states that it was the result of a donation by the oncology-nursing program and the Texas Cancer Council. The original version comes from the Baylor College of Medicine and it consists of information adapted from the Children's Oncology group.

The fact that there could be errors, spelling mistakes, and/or omission of information, may not reveal as much as information as the SFL analysis in terms of the

choices made by translators to recreate the meaning. However, it is the pervasiveness of these deviations from the original text that have become a constant in translated health communication what ultimately validates one of the theoretical points of this study. The second hypothetical point in this study (see Section 2.10) predicted that the number of errors in translation due to poor editing and lack of cultural awareness make the information confusing to the potential readers in this community. This diminishes all efforts to empower the patient. It has been established that ad-hoc, in-house translations, serve to provide readily available information in compliance with the law exist. However, if the translator's choices are not rooted in an interdisciplinary theory and the message is not filtered in terms of cultural sensitivity for the target community, the information may be well intentioned, but utterly imprecise and unfamiliar. The most important question that prompts this research is to shed light on the presumption that the provision of translations is solely driven by the need to comply with governmental mandates requiring the delivery of the service and this delivery of services is not purposefully planned and crafted as an instrument of patient education, information, and empowerment. The next section highlights a list of deviations from the original English version, which taken into the context of culture, harm the intended outcome of the Spanish translation.

4.2.1.1 Local Translation: Deviations from Original Text

These Spanish and English binders carry the most basic, yet the most comprehensive and immediate information parents and/or caregivers receive upon

admission to the clinic. To contextualize the situation, they are the first written information obtained amid the emotional turmoil of the life-threatening news they recently received. The primary intent of putting together these binders is to serve as the first guide to complement the verbal information received at the office and to be a guide to walk parents through decisions and procedures. They also provide advice and important resources and contact information. Parents take this information home to share with families and everyone who participates in the decision-making process or the people who at some point will be in contact with the child. Everyone around the child's life needs to be aware of information such as when and who to call in case in emergency and what behaviors are or are not normal during the treatments. While most of this information is covered by the medical staff, the health system is a fast paced and highly overwhelming environment; therefore, some parts of the information may be misunderstood or unintentionally disregarded by parents during the medical encounter. Moreover, not every family member is physically present during the visit. The child may face an emergency while he or she is under the care of someone else; therefore, it is highly important to be able to understand and share information. The access to written information at home could make a difference in the lifestyle of the child diagnosed with cancer and could result in an early intervention when something is going wrong; thus, potentially saving a life.

There are two concepts that have to be brought into the discussion to entirely address the impact that an inaccurate or incomplete translation may have in this particular community and the ability of its population to make the best use of the written

information. These two concepts are (a) the literacy level, and (b) the cultural implications of dealing with an illness under the ecological conditions that are characteristic to this demographic area (see Sections 1.3 and 1.4). The translation issues that are presented and discussed in this section stood up during the data review because when juxtaposed against the context and the culture, they undoubtedly hindered the accessibility to information for a population that has been recognized to struggle with readability and accessibility to the health system. The following are examples of the issues found in the binders that affect, in distinctive ways, the accessibility, and reliability of the information. The first difference found in these two, apparent equal binders, comes as soon as the binder is opened. The first page of the ST is not the same start page as the TT.

Table 4.1 Differences Between ST and TT: Omission of Information 1

Text	Example
ST	Starts with a welcome letter directed to the family signed by the Medical Director of the Clinic (see Appendix H for the letter).
TT	The first page is the Table of Contents.
Problem	Letter is omitted

This letter reassures the family that the clinic has “highly trained” staff promising the “finest” care for their child. Spanish speakers do not get this welcome letter nor the assurance that their child will receive the best care possible. This, by no means says that the child will not receive care, but it makes them dependable to an oral assurance

provided only when they are in person at the doctors' office or the clinic. This type of omission of information contributes to the issue of *invisibility* of the reader once the visit to the clinic is over. Confronted with the uncertainty that a chronic illness, such as cancer, brings to a community who traditionally struggles to build trust in the health system, parents of children with cancer would have definitely appreciated the empathy and sense of security that this kind of warm welcome letter usually provides.

The second page of the binder is another example of how Spanish speakers have to rely on oral information. The page is titled *Important Information to Know* or "Información importante a saber," in Spanish. It provides a space for patients to fill out the type of cancer diagnosed, the name of the doctor, the nurse, and the social worker assigned to their case. It also provides information about when to call for emergencies.

Table 4.2 Differences Between ST and TT: Omission of Information 2

Text	Example
ST	Phone numbers to schedule a visit, to talk to a nurse during clinic hours, and to contact the pediatric oncologist on call at any time are provided.
TT	There are no phone numbers provided to contact the clinic for emergencies.
Problem	Omission of information

The TT in Table 4.2 has a blank space to fill out the information. This means, parents have to depend on someone else to obtain the phone numbers so they can write them and keep them in this page. Once again, Spanish speakers have to rely on information given

to them at the time of their appointment in order to get information that is a given in the ST. Spanish speakers are unnecessarily denied from the advantage of just opening the first page of binder and have the directory information readily to be used as needed. While this is not an error of translation per se, it talks about how the information given is incomplete and requires a certain degree of dependency on oral information.

The binders are divided in sections as shown in the *Table of Contents*. However, one version seems to be easier to access because the headings are further divided into subheadings. The following table shows the *Table of Contents* in both languages side by side.

Table 4.3 Table of Contents in the TT and ST Version

Contenido	Table of Contents
Carta del Centro	Who's who
Quién es quién	The treatment team
	Doctors
	Nurses
	Support services
	Other healthcare providers
	Your role on the team
¿Qué es el cáncer?	What is cancer
	Cause of cancer
Tratamiento para el cáncer	Cancer treatment
	Types of cancer treatment
	What are clinical trials
	Central catheters
Procedimientos	Procedures
	Having a bone marrow test
	Having a lumbar puncture (spinal tap)
	Sedation for tests and procedures
	Blood count
Conteo Sanguíneo	Side effects
Efectos Secundarios	Immunizations
Inmunizaciones	Family life
Vida Familiar	

	Talking with your child about cancer and treatment
	Helping your child cope
	Caring for the whole family
	Impact of the child's cancer on a marriage
	Impact of cancer on siblings
	Impact of cancer on grandparents
	Disciplining your child with cancer
	Dealing with advice from friends and family
	Keeping records
	Planning ahead
	Parent-to-parent
De padres a padres	School
Escuela	Going back to school
	Off treatment
	The long-term survivor program at Vannie E. Cook Jr. Children's Cancer Center
Recursos	Resources
	Websites
Palabras para aprender	Words to know
	Emergency Preparedness
Mapa/Calendario	

Note: In the TT, the welcome letter is mentioned in the index as “carta del centro;” however, it is not found in the binder.

In terms of readability and access, the *Table of Contents* in the ST gives a way to quickly find the information under each heading inside binder. Spanish speakers, on the other hand, have to go through each handout under each section in order to find out what each heading includes. While these differences do not affect the meaning of the actual content written in each of the handouts, it makes it noticeable that the TT does not have the same quality of information as its counterpart. Moreover, the *Table of Contents* reveals other

notorious differences between these versions. That is the omission of sections that talk about services provided by the clinic.

Table 4.4 Differences Between ST and TT: Omission of Information 3

Text	Example
ST	Provides information about off-treatment programs provided at the clinic to support survivors and their families.
TT	This version does not have a section for the clinic’s long-term survivors program.
Problem	Omission of information

Health disparities research has proven that Hispanic children have a lower quality of life and experience more health complications after cancer than other ethnic groups in the United States (see Section 1.6). Hispanic children have a lower survival rate due, in part, to lack of follow-up care yet the information about where to find support after the illness has been controlled is not found in this binder. Milam et al. (2015) state that Hispanic children have a lower rate of follow-up care and list some of the main reasons for not pursuing long-term care the lack of insurance, not having a primary family physician, and geographical limitations. All these barriers to follow-up care are characteristic of the TC (see Section 1.7); therefore, the information about a local program that provides support to families after the illness is vital for the Hispanic community. The next issue found in the *Table of Contents* also deals with omitting information that is relevant to the particular situation of this community. In this case, the

section about what to do in case of natural disasters is not found in the TT. Because of the demographic and the socio-ecological living conditions that distinguish this community, there is a high probability that they will go through a natural disaster emergency during the process of the illness.

Table 4.5 Differences Between ST and TT: Omission of Information 4

Text	Example
ST	It provides a section that explains what to do when faced with natural disasters such as hurricanes, terrorism, tropical storms, heavy rains, and floods.
TT	This version does not have a section for Emergency Preparedness.
Problem	Omission of information

The exclusion of this document leaves the Spanish speaking families unprepared with the most basic tips to confront these situations. The proximity to the Gulf of Mexico and the unsafe conditions of *colonias* (see Section 1.7) mean that there is a large percentage of the population vulnerable to hurricanes and flooding.

The *Emergency Preparedness* section in the ST covers the following topics:

- Preparing for an Emergency Natural Disaster
- Preparing for an Emergency with a Child who has Special Medical Needs (Natural Disasters Supplement)
- Emergency Information Form for Children with Special Needs*
- Emergency Information Form Instructions

- Emergency and Disaster Planning for Children with Special Health Care Needs
- Types of Disasters
- Internet Resources for Families
- Are you prepared?
- Preparation and Planning Tips
- Disaster Supply Kit
 - Water
 - Food
 - If you must leave home...
 - Supplies for babies and children
 - Supplies for people with special needs
 - First aid and general medical supplies
 - Clothing and bedding
 - Entertainment
 - Documents and other important items
 - Tools and emergency supplies
 - Cleaning supplies
 - Supplies for families with service animals
- If Disaster Strikes...
- Tips to Help Families Support their Children

Emergency preparedness has information that is life altering for everyone dealing with cancer treatments and/or side effects at home. "Patients with cancer are exposed to an enormous risk when natural disasters occur; the logistics of the treatment as well as communication with the medical staff is interrupted" (Ullman, 2011). Additionally, family members may not be together during evacuation to provide support. Natural

disasters make an excruciating circumstance for people dealing with cancer specially if the living conditions are not optimal.

All this missing information was found even before revising the actual content of the pages inside the binder. Just by looking at *Table of Contents* (Table 4.3) there is already a significant amount of missing information that while, it may not be directly related to the actual translation strategies, it is a harmful omission of information. This has a profound impact in the value given to the provision of information and the perception of equality from the readers' perspective. The lack of information in minority languages reflects a problem that has been going on throughout the country; hence, the creation of the laws and regulations discussed in Section 1.2 and the continuous efforts of health agencies to provide adequate information. Although the situation has been addressed by governmental agencies, there is still research to be done in regards to the actual implementation of linguistic strategies that can elevate the quality of translated information. These deviations from the original source let researchers infer the extent to which linguistic and cultural strategies are being implemented by translators to create functional texts.

The first section of the binder gives information about who is part of the support staff and what kinds of services they provide throughout the illness. The ST includes the following subheadings:

- Clinical Support Assistants
- Social Workers
- Child Life Specialist
- Dietitians/Nutritionist

- Psychologist
- Financial Counselors and Business Services
- Clergy and Hospital Chaplains
- Home Care Nurses
- Volunteers

The translation of each subheading is mostly word-by-word following the equivalence principle (see Section 2.4); however, it is again the omission of important information what permeates the course of information. There are two main deviations from the original text found in this section. In the ST, the information under clergy and hospital chaplain reads as follows:

Clergy and hospital chaplains are people who are trained to offer spiritual care, support, and prayer according to each patient of family's individual needs.

While the TT version is minimized to:

El clero y los capellanes del Hospital [sic] proporcionan apoyo y alivio espiritual.

Faith and religion play a major role in the Hispanic culture, especially when confronted with life-threatening illnesses. Therefore, it is remarkable that the translation, which should be culturally sensitive, pays little attention to the section about the availability of clergy and chaplains as needed to each family's religious beliefs. Wiener et al. (2013) talk about the role religion plays in the decision-making process in pediatric cancer. Their article states that, "cultural practices and spiritual beliefs are the foundations on which many lives are based...this is especially vital during the vulnerable period of end-

of-life during childhood” (p. 2). The concept of life and death are deeply entrenched with religion in the Hispanic culture; in some instances, the clergy not only provides comfort to the families, they even guide families with decision-making. The second issue found in this same section is the fact that the section about *volunteers* is not found in the TT.

The ST explains the following about the availability volunteers:

Volunteers: provide non-medical activities for children in the Cancer Clinic while they wait for/or receive treatments. Volunteers play with the children, organize activities, and also provide special events. In the Hospital, volunteers help to staff the playroom, deliver a coffee cart, deliver toys to rooms if needed, and organize fun activities through day and evening hours. (p.6)

There is no indication as to why the information about volunteers is omitted from the Spanish version. The section about home cares nurses is also missing in the Spanish version.

In a similar manner, the next section titled *Other Healthcare Providers* is also missing information about some health professionals. The ST has the following subheadings:

- Pharmacists
- Physical Therapists
- Radiation Technologist
- Respiratory Care Therapists
- Translators
- Hospital School Teachers

The sections about *Translators* and *Hospital School Teachers* are missing in the TT. It is particularly interesting that the section about translators is missing while the ST goes on to provide a phone number to contact translation services in the hospital and the clinic. The importance of missing the *Hospital School Teachers* information goes back to the issue of considering the target community. The information about the existence of services to help kids with school while they are at the hospital is crucial for a community that already struggles with low education rates (see Table 1.1).

Moving forward in the binder, the differences between both versions become more concerning as information that is crucial to make informed decisions is not found in the TT version. The most important decision families have to make is to decide on the type of treatment that will be given to their child. This is one of the main issues discussed under the concept of *Health Literacy* (see Section 1.3). In order to make decisions and take control over the treatment; families need to have a complete understanding of the illness. The decision should be made by the patient and his/her family guided by medical professionals. If the decision is solely based on the information provided by one physician, these patients become only spectators in the healing process instead of active participants. Under the section *Cancer Treatment*, the ST has the following subsections:

- Types of cancer treatment
 - Chemotherapy
 - Radiation therapy
 - Surgery
 - Bone marrow transplantation

- Biotherapy
- What are clinical trials?
 - Types of clinical trials
 - Phase I
 - Phase II
 - Importance of clinical trials
 - Benefits and risks of clinical trials
 - Does my child have to be in a clinical trial?
 - Children's oncology Group (COG)
 - How are trials reviewed
 - Randomization
 - Roadmaps
 - Informed consent

The TT starts this section with a handout titled “Tratamiento para el cancer” and it goes on to explain the process for clinical trials. After the brief, single page explanation, the section is divided into the next subsections:

- Tipos de tratamiento para el cáncer (*types of cancer treatment*)
 - Cirugía (*surgery*)
 - Quimioterapia (*chemotherapy*)
 - Terapia de radiación (*radiation therapy*)
 - Cuántos tratamientos de radioterapias se aplican (*how many radiation treatments are done*)
 - Efectos secundarios de la terapia de radiación (*side effects of radiation treatments*)
 - Cosas que debes recordar (*things to remember*)

- Trasplante de médula ósea (*bone marrow transplant*)

As it can be seen from the subheadings, there is a significant difference on the amount of information provided. According to Aristizabal (2015), pediatric oncologist and lead researcher in the area of Hispanics in pediatric cancer (see Section 1.6), clinical trials are one of the most controversial issues for this community. The lack of accessible information about the nature of the trials causes families to think that their sick child will be exposed to a treatment that has not been proven successful. To quote Aristizabal, there is a tendency to think that their child will be used as a “guinea pig” to determine if the treatment is successful. The TT starts with clinical trials and the information it gives is vague as its best. It tells parents that there are two treatments available, the standard, and the clinical trial, which, if accepted, will be chosen “al azar” (random). With no other information, it seems like the child will be giving a random treatment in hope to find a good alternative option. The information directs parents to look for another handout titled “Pruebas clínicas” (clinical trials) in order to find more information. This handout; however, is not found in the binder leaving caregivers with incomplete, ambiguous information. The following excerpt is how the TT explains parents the process of selection to participate in a clinical trial.

Algunos protocolos tienen como meta determinar qué tratamiento es más efectivo para tratar un tipo de cáncer en particular. Por ejemplo, en un protocolo con dos planes de tratamiento, llamados ‘brazos’ del tratamiento, un tratamiento es la terapia estándar actual para un tipo específico de cáncer. En el otro brazo, llamado el brazo de investigación, se prueba nuevamente una terapia nueva

después de que estudios anteriores sugieran que es efectiva y segura. Para saber cual de los dos tratamientos es el más efectivo, se seleccionan los pacientes al azar por computadora para uno de los dos brazos de tratamiento. (p.10)

This paragraph makes parents, with the little written information provided, the only agent responsible to decide if their child should or should not participate in the random treatment. It is assumed that more information about the trials would be discussed by the doctor at the office. However, this is the information they get to take home to review and share with other family member. This is one of the central issues of the concept of health literacy as the responsibility is solely put into the parent. Parents are asked to make a decision based on the oral information they may, or may not, receive at the doctor's office and if received, they may or may not have understood it entirely. Parents are expected to find information on their own, if any, to make a decision about the life of their child. However, most families living under the poverty level have no internet access and/or the reading ability to find this information.

On the contrary, the ST is extremely different. The information is found under the question "does my child have to be on a clinical trial?" First, the subheading is a question. This rhetorical device incorporates the readers as active agents with the possibility of two choices. The section reads as follows:

To help you make a decision, you may want to get a second opinion. A doctor who is not a part of your current health care team will look at your child's history, laboratory findings, and exam. The doctor will give you his/her opinion about your child's treatment plan. Some insurance companies require a second

opinion before starting treatment. Your doctor may refer you to another expert doctor. The National Cancer Institute has a toll-free number (1-800-4Cancer) and a web site (www.cancer.gov) to find cancer centers and doctors all over the country. You may choose not to enter your child on a clinical trial. You may also choose to remove your child from a trial at any time. Your choice will not affect how the health care team feels about you or your child. Your child will still receive the best possible care. If you decide not to enroll in a clinical trial, your child will receive what is known as standard treatment. Standard treatment is the best know therapy at the time. (p.12)

There is a significant difference between telling caregivers they have to make a decision than to tell them their decision will be based on a second option while reassuring them that they can remove their child from trial at any time if they feel it is not the optimal care. Comprehensive knowledge about the illness and participation in clinical trials has been identified as one of the reasons behind the lower survival rate for Hispanic children (Aristizabal et al., 2015). Less kids die of cancer, in part, thanks to participation in clinical trials; however, according to studies conducted by the Children's Oncology Group and the Pediatric Brain Cancer Consortium, "Hispanic children remained the most underrepresented in ethnic groups overall" (Nooka et al, 2016, p. 3210). The proposed solution for this problem is to educate the community about their participation.

Community Health Workers have started to work with minorities in trying to inform them about the benefits of clinical trials. In general, according to data by National Institute of Health, in their sponsored clinical trials only 1% focused on minorities.

Across the nation, Hispanic participation rate in clinical trials ranges from 3% to 4% (Arevalo et al., 2016). When it comes to clinical trials, the lack of information makes families from ethnic minorities “feel more anxiety and less control over their decision-making” (Aristizabal et al., 2015b, p.1342).

The English version of the document goes on to explain how both, standard and trial treatments, compare:

In most studies we do not know which treatment is better until all the children on the study have completed treatment and have been followed for several years. However, if one of the treatment arms is found to be better than the others while the trial is in progress, the trial is stopped and all children are given the treatment with the best results. If for any reason the treatment plan is found to both be the best for your child, the plan will be changed. If a clinical trial is not currently open when your child is diagnosed, your child will receive the best standard treatment. (p.13)

This information ensures parents of the continued monitoring that go on when entering a clinical trial; Spanish-speaking parents however, do not have this information to read, process, share with family, and make a decision. The *Informed Consent* section in the English version reads as follows:

After your doctor reviews the treatment plan with you, you will be asked to file your permission for your child to start treatment. This is called giving parental permission or informed consent. You will be asked to sign a form that describes the plan. This form lists the risks and benefits of the treatment and what other

treatments may be available. When you sign the form, you are saying that you understand what the doctor has explained to you and you agree to start the treatment. If your child is old enough to understand, he or she will be asked to agree with the treatment plan as well. When a minor (a child less than 18 years old) agrees with the plan, the child is giving assent. Members of your health care team will help explain the treatment to your child in words that he/she can understand. Informed consent is a process that does not stop after you sign the form or start treatment. Every day in the hospital or at each clinic visit, your doctor or nurse will talk with you about the plan of care. This is your chance to ask questions and decide whether or not you agree with the plan. (p.14)

There are a few things to highlight from this passage. First, it acknowledges the fact that there should be shared responsibility to make sure families and patients have complete understanding of the treatments available. It explains how the doctor will review the plan with families until a decision is made. It also offers help to explain the treatment to the child in “words he/she can understand”. This is a huge step towards the goals of health literacy; however, it is only provided in the English version. The TT only slightly mentions the consent form:

Se le pedirá que acceda a que su niño(a) participe en el estudio antes de que realice la selección al azar. Su consentimiento implica que usted aceptará el tratamiento con cualquiera de los planes de tratamiento. Para mayor información consulte el panfleto de pruebas clínicas. (p.10)

It was mentioned before that the TT asks readers to read another handout for information but that page is not available. This is the only information provided. The most significant difference is that there is no mention of shared responsibility in the Spanish passage, it says that [families] will be asked to agree before participating in the random process; then, it adds that their consent means they agree to undergo treatment with either of the treatment plans [standard or trial]. In any part, it says that it will be reviewed with them before giving consent and that even after consent its progress will be continuously reviewed and assessed. Again, this by no means says that it won't be reviewed; however, it demonstrates the persistent reliability in receiving oral information at the time of the visit. Research has found that some reasons for parents to not enter a trial are barriers such as "limited knowledge about cancer clinical trials, lack of trust in entities leading trials, and an inability to include family members in the decision-making process at the time of clinical trials"; however, the issue remains largely "unaddressed" (Cupertino et al. 2015, p.1). Another reason why the information about this review process is so crucial for Hispanic families is what Aristizabal et al. (2015b) identify as "passivity" which they define as a "Hispanic cultural tradition" where "the presence of an authoritative figure, such as a physician, is associated with asking fewer questions even when there is need for clarification of very difficult concepts and information" (p.1342).

Following this same issue of omitting information, the next section in the binder is titled *Procedures* and it has the most common procedures that most children with cancer will undergo regardless of the type of cancer. For example, the first procedure explained is *Central Catheters*. Catheters are used for various reasons, from

administering chemotherapy and other medication, to take blood samples and to give nutrition in some cases. The information is also provided in Spanish; nevertheless, it is not as complete as the English version. Some of the sections are left out. In the ST, parents are warned about the risk of infection. This passage explains what to do in case of a complication with items that can be found in the household:

If you see any redness, swelling, pus, shaking, or chills after flushing, or your child complains of pain, call your doctor right away. Always wash your hands before touching the line or dressing. If you see a break or leak in the line, clamp the line right away. Use a shoelace, rubber band, paper clip or clamp to tie off the line between the break and your child. You must call AND take your child to the hospital right away to have the line fixed. If you are flushing the line and you feel resistance (fluid hard to push in), do not force it to make sure the line is not twisted or kinked and try again. If you still feel resistance, call your nurse or doctor. (p.15)

The TT lacks this information, yet the risk of infection is one of the most common complications of catheters (Cecinati, 2012). Medical research has proven that:

Catheter-associated bloodstream infections (CABSI) are frequent complications encountered with cancer treatment. CABSI may become life-threatening and can contribute to treatment-related morbidity and mortality for children with malignancy. Infections associated with the use of intravascular devices represent 10–20% of all nosocomial infections. (Celebi et al., 2013, p.187).

For this community in specific, the living conditions play an important role in keeping a catheter free from infections, since it is important to keep in mind that there is large percentage of the community living in *colonias* and these settlements are “one of the worst breeding grounds for disease in America” because of their lack of public services and healthcare facilities (Atkinson, 2001, para. 4). Nevertheless, the most basic written information about infections and the first aid steps in case of an emergency are not given to them.

The next section in the binder explains about the bone marrow aspiration and lumbar puncture. There is one section under this heading that is particularly important because it applies to most procedures the children will undergo, this is *Preparing for Painful Procedures*. The TT is titled “Cómo preparase para procedimientos dolorosos”. In this section, it will be seen again how the ST integrates the reader and the medical staff as part of the process while the TT does not highlight the shared responsibility.

Preparing you and your child for painful or uncomfortable procedures involves education and the introduction of methods to decrease stress and discomfort. Your child's experience during the first procedure may determine how well he or she tolerates future ones. In addition to treatment goals, we try very hard to cause as little pain for your child as possible. For invasive procedures your child's preparation begins with age appropriate information. The child life specialist may be involved in the teaching process, which may involve real and play medical equipment, pictures, dolls, and information sheets. We encourage parents to participate in this preparation. The child life specialist will also teach

your child coping techniques, which may include allowing him or her to pick out music or distraction items (like pictures or dolls) for the treatment room, practicing deep breathing and muscle relaxation before the procedure, and discussing ideas for guided imagery or storytelling that may be done during the procedure. The child life specialist may be present during procedures to help create a calming environment and provide positive reinforcement. (pp. 17-18)

Contrary to this version, in the TT, there is no mention about the help of the child life specialist nor does it not encourage parents to participate. It seems like it is the full responsibility to caregiver and even the child to carry the techniques recommended:

La preparación de usted y de su niño(a) para procedimientos incómodos o dolorosos implica educación y la presentación de métodos para disminuir la tensión y la molestia. La experiencia vivida por su niño(a) durante el primer procedimiento puede determinar qué tan bien va a tolerar los procedimientos subsecuentes. Además de las metas de tratamiento, nos esforzamos en provocar el menor dolor posible a su niño(a). Algunas buenas técnicas de adaptación incluyen: permitirle que elija música o artículos para distraerse (como son libros, dibujos o muñecos) en la sala de tratamiento, practicar respiración profunda y relajación muscular antes del procedimiento, y hablar sobre ideas para imaginación guiada o cuentos que puedan realizar durante el procedimiento.
(p.16)

In this version, there is no help from staff to “provide a positive reinforcement”. While the proposed techniques to help the child cope with the procedure are the same in both

versions, caregivers in the TT play a larger role in being able to provide this environment for their child.

The next section is about *Blood Count* and it covers information about blood cells, anemia, platelets and bleeding, white blood cells, and infection. In the ST, under information about what to do in case of bleeding parents are urged to call the clinic if the following situations occur:

- Complains of frequent headaches
- Complains of blurred vision
- Receives a sharp blow to the head
- Has bleeding that does not stop after pressure is applied for 10 minutes
- Is coughing or spitting up blood
- Has bloody or pink-tinged urine
- Has dark or bloody bowel movements
- Has bleeding from the rectum or gums
- Has bleeding into the white part of the eyes

In the TT, only the following situations are translated:

- Si el sangrado continúa por más de 10 minutos o si presenta mucho sangrado
- Si su niño(a) presenta dolor de cabeza severo repórtelo a su doctor o enfermera de la clínica porque puede ser señal de sangrado dentro de la cabeza

The missing information is so important it could be life threatening. The ability to identify internal bleeding is vital as “excessive bleeding, or hemorrhage, can be dangerous and affect the brain or major body functions” (Dana-Farber/Boston Children’s Hospital, 2017, para.3). Having this information in written form is important as the person who may have received this information orally during the clinic visit, may not be with the child at all times.

The next section that is not included in the TT is titled *Cancer Myths*. It covers and explains the following subheadings:

- Cancer is no one’s fault
- Cancer is NOT contagious
- Cancer causes hair to fall out
- Cancer in children is the same as cancer in adults

It is interesting that the TT has no section to inform about myths. If culture was taken into consideration for the translation, this section should have been necessary. According to the National Cancer Institute (2012b), “Hispanics are more likely than whites to maintain some erroneous beliefs about cancer” (para.1). This article explains that while it is true that cancer is no one’s fault and it is not contagious, there is some truth to the fact that “recent Hispanic immigrants may have a greater risk of some cancers caused by infectious agents if there was a higher prevalence of related infections in their country of origin” (para.4). Moreover, it states, some types of cancer can also be caused by some hereditary genes; therefore, it is important to discuss any history of cancer with the doctors (NCI, 2012b).

The last section that is missing from the TT explains about how to deal with the illness as a whole family. The TT briefly covers the following topics:

- Vida familiar
- Hermanos y hermanas
- Cómo manejar los consejos de amigos y parientes
- Cómo llevar registros
- Planear con anticipación

The ST, on the other hand, has all the following information:

- Helping your child cope
- Caring for the whole family
- Coping with your feelings
 - Fear
 - Anger
 - Guilt
 - Depression
- Coping with your child's illness
- Impact of the child's cancer on a marriage
 - Respecting coping styles
 - Maintaining communication
 - Accepting changing roles
 - Parents working together

- Suggestions for divorced parents
- Impact of cancer in siblings
 - How to help siblings
- Impact of cancer on grandparents
- Disciplining your child with cancer
- Dealing with advice from friends
- Keeping records
- Planning ahead

Again, the difference between the information provided is largely significant.

The examples given in this section do not carry information in regards of the linguistic quality of the translations, which will be discussed in the next section.

However, there is much to be discussed by what is left unsaid as it shows the value given to the translated documents and its role in the healing process. The message given by this set of data is that the information was put together to comply with the current laws and regulations in regards to the provision of providing services in languages other than English, and maybe it was done in good faith. However, it lacks the cultural sensitivity and it is not deeply rooted in knowledge about the target community that is necessary to create effective and functional translations. Once the patient leaves the clinic, there is disengagement in the flow of information. Parents cannot go home and share valuable information with their close social circle because the information provided is incomplete and confusing. McClanahan et al. (2015) warns about the reliance on memory as one of the main issues of health access disparities (see Section 2.3). There is the possibility that

all the information contained in these binders is also discussed thoroughly by doctors and/or other medical staff; however, families need to rely on their memory in order to take this information home and share with others. The fact that families have to depend on oral interpreters or information shared, while also receiving overwhelming emotional news about their ill child, puts families at a more vulnerable position than their counterparts who have access to more outside reliable information. It is important to keep in mind that the purpose of this information is to be able to be functional in the social context where it is being distributed. All errors, whether they are grammatical or of omission, contribute to the overall structure of the text and therefore to the meaning. Knowledge about the illness and the ability to take control of the information empowers people, what families know about their child's illness treatment matters, but what they do not know threatens their experience living and surviving the illness. In summary, equal attention should be given to the availability of translations as to the final product through social accountability.

4.2.1.2 Local Translation: Interpersonal Metafunction

The *Interpersonal Metafunction* carries information about the relationship between the translator and the reader. Even though in this binder the translator is anonymous, a review of the relationship between translator and reader gives information about the role of the choices the translator makes to act as mediator between the information provided by experts in the field of pediatric cancer and the reader as caregivers and active agents in the healing process. The data is coming from an

anonymous source; therefore, it is not established if the translation is made entirely by a human or if it is based on information coming from a machine translator. Some of the grammatical errors found could very well be classified as a human typing mistake; however, there are errors that do not correspond to natural language. It is highly possible that this translation was done by ad hoc translators basing the information off a machine translator. The previous chapter, it was established the dangers of relying on a machine translation without proper editing to produce written information that is utmost human, relational, and ideological.

An analysis of the type of sentences used in both the English and the Spanish version showed that most of the sentences are declarative or imperative. The pages in the binder serve two main purposes, which are two of the socio-semiotic process that Matthiessen identifies as *Expounding*, which is discourse used to "create and disseminate general medical knowledge," and *Enabling*, which is discourse used to "instruct healthcare practitioners (in training) or patients in medical procedures" (Matthiessen, 2013, p.451). This study will not thoroughly analyze the type of sentences in these pages because, due to the type of information, it is expected that the *Mood* is mostly comprised of descriptions and commands. However, the discussion focuses on the strategies that the translator as the *Tenor* makes to negotiate culture. One of the questions that this section intends to answer is who is at the center of the communication exchange and what is the hierarchical position of all parties involved, that is, the source text, the translator, and the target reader. In the examples provided it will be shown that there is no clear definition as to who is at the center of the translation due to the fact the voice keeps shifting its

person from "we" to "them" in regards to the experts providing the information. In some sentences, the translator becomes part of the professional medical staff as in the following passage:

Si usted decide que no quiere participar en el proceso de selección al azar, su niño(a) recibirá la terapia estándar actual utilizada para tratar la enfermedad. Nosotros apoyaremos su decisión, ya sea a favor o en contra de la participación de su niño(a), dándole al niño el mejor tratamiento disponible. (p.10)

Table 4.6 Tenor: Translator as Mediator 1

Mood	Subject	Finite
Declarative/indicative	si usted	decide
Declarative/indicative	nosotros	apoyaremos

In this paragraph, there is a direct negotiation with the reader asking him/her to decide whether to participate (or not) in the random selection of clinical trials. Then, the center goes back to the translator as part of the staff that will support any decision the patient makes. In other passages, the translator goes from being part of the conversation to a third person. This makes the translation confusing because the reader loses track of who is giving the information. For example:

Podremos hacer cirugía para retirar el tumor o un pedazo pequeño del mismo, para decidir qué tipo de células cancerosas están presentes...es importante preparar a su niño(a) para la cirugía. Es posible que él o ella no quiera o no

necesite saber todo lo que usted sabe. Los doctores y las enfermeras le explicarán a usted lo qué va a pasar. (p.11)

Table 4.7 Tenor: Translator as Mediator 2

Mood	Subject	Finite
Declarative/indicative	Podremos (1 st . person plural)	hacer cirugía
Declarative/indicative	Los doctores y las enfermeras (3 rd . person plural)	le explicarán

In the previous passage, the translator starts as the voice of the surgeon who can conduct a surgery with his team to remove the tumor. However, a couple of sentences down, the translators shifts the voice to tell the reader that doctors and nurses will explain everything. That is, there is an unmotivated shift from first person to third person.

This shifting of the tenor voice continues throughout the binder. In the section about *sedation*, the translator gives the following information:

*Todos tenemos maneras diferentes de manejar las situaciones llenas de tensión. Queremos ayudar a su niño(a) en estos procedimientos dolorosas [sic] de manera que **podamos** cubrir sus necesidades. Aunque es posible que **le recomendemos** un método en particular, **usted** es quien tiene la última palabra. (p.17)*

Table 4.8 Tenor: Translator as Mediator 3

Mood	Subject	Finite
Declarative/statement	todos	tenemos
Declarative/statement	[nosotros]	queremos
Declarative/statement	[nosotros]	podamos cubrir
Declarative/statement	[nosotros]	le recomendamos
Declarative/statement	usted	es

In this passage, there is an exchange of communication between the translator as part of the staff and the caregiver receiving information while being expected to give a response. The translator starts by making himself/herself part of the community. The choice of word *todos* (all of us) gives the impression that the translator understands the stress of the situation. The voice then goes on to offer help and recommendations and finishes the paragraph by shifting the conversation to the reader in expectation of a response.

This type of passages positions the translator very closely to the procedures and the situations that are going on. There is a sense of empathy and understanding. This closeness to the reader and the use of the pronoun "we" instead of "them" reassures the reader about the reliability of the information. Nevertheless, as seen in the previous passages, there is a constant shifting in the voice, which makes the source of the information confusing to the reader. When the translator becomes part of the information, it is assertive, positioning the voice as one of expertise in the field. The use of declarative clauses to give information and elicit a response, after giving the facts, brings the information close to the caregivers with the confidence that the information is from a good source. This works well from a cultural standpoint because it gives readers a

personal feeling and reassurance of the reliability. The voice is trustworthy, and because building trust in the health system is crucial for the Hispanic community, the use of “we” is a good translation strategy. Nevertheless, this is not consistent throughout the document. There is not a conscious effort to bring closeness to the reader; the use of “we” is not the result of a cultural negotiation, it is only the product of the choice of word based in the English source text.

As expected, because of the type of information given, there is also a great use of imperative sentences. These sentences are used to command the reader to perform some procedures on their child. Notice that there is no use of “we” while giving commands. The translator role is only to command, not to share responsibilities and empathy. In sections where procedures are explained, there is strict use of the third person to just tell caregivers what they have to do to correctly carry out the procedure.

The next example comes from a handout that teaches parents how to apply the EMLA cream, which is an anesthetic cream that parents can apply to the skin of their child before he or she goes through a painful procedure such as and intravenous injection, spinal tap, access to catheters, or any other skin invasive procedure. This cream has to be applied hours before the treatment; therefore, caregivers need to apply it before visiting the clinic for the treatment. It reads as follows:

*S1. **Pregúntele** al médico a o la enfermera cuándo se va realizar el procedimiento*

*S2. **Prepare** la piel de su hijo al menos 1 hora antes del comienzo del procedimiento.*

- S3. **Limpie** la piel donde se va a introducir la aguja.*
- S4. **Utilice** agua y jabón para limpiar la piel.*
- S5. El médico o la enfermera le mostrarán qué área de la piel **debe** limpiar.*
- S6. **Asegúrese** de que la piel esté limpia y seca antes de aplicar el medicamento*
- S7. **Coloque** el medicamento en una capa espesa o en un copo en el lugar en donde se va a colocar la aguja*
- S8. **Lea** las instrucciones que vienen con el medicamento o*
- S9. **Pregúntele** al médico o a la enfermera para averiguar qué cantidad de medicamento debe utilizar.*
- S10. **Deje** al [sic] medicamento en un copo.*
- S11. **No frote** el medicamento contra la piel.*
- S12. **Busque** el apósito transparente que viene con el paquete del medicamento*
- S13. **Quite** la pieza central recortada del apósito*
- S14. **Pele** el forro de papel del apósito*
- S15. **Cubra** el medicamento con el apósito. (n.p)*

All these sentences are imperative and they either omit the subject pronoun or use pronominal clitics to refer to the caregiver. In Sentences 1, 5, and 9, it can be seen that the translator becomes again a third, outside person that is not involved in the process. It commands the reader to ask the doctor or the nurse, that is, the experts, about the time of the procedure as well as the area, and the amount of cream that needs to be applied. In this case, the translator is only an expert in the technique of applying the cream as he/she commands the instruction, but does take any part in the process.

While this may not be too problematic for the reader because commands are generally easy sentences to follow and the imperative voices gives a sense of unquestionably knowledge about the topic, it is the choice of words what makes passages like this one inaccessible to the reader. Aside from the oral narratives that will be discussed later in this chapter, community members were informally asked to recognize some of the words, as they are uncommon in this region. There was not a single person that could recognize the words: "apósito" and "copo," in the health-related context. As a result, the translators' choice of words to denote expertise on the topic, as realized using imperative clauses guiding caregivers to perform a new procedure, is diminished in terms of functionality. This lack of understanding happens when the choices made by the translator to give information does not match the register of the community. The information does, indeed, exist and it is correct, but it is not accessible because the choice of words is not culturally adjusted.

In Sentence 14, the word *pele* appears as a translation for *peel*. If the verb *to peel* is translated to Spanish in a computer translator such as the popular Google Translate™, it only gives the answer: *pelar*. A more comprehensive online translator such as the one provided by the website *SpanishDict* gives the searcher more meanings for the verb *to peel* and it goes a step further giving examples of how it is used in different contexts. There are two different results under *peel* as a "transitive verb". The first meaning is translated as *pelar* which means to remove "outer covering" such as a *peeling an orange*. The second meaning is *quitar*, which means to remove a "thin covering" such as *peeling a sticker*. A trained translator would have known that while *pelar* is a correct translation

for the verb *to peel* it is not the right translation for this command. The verb *quitar* would be a better choice or even the verb *remover* which means, “to remove” in English. If an exhaustive editing process is not done by a trained translator, the quality of information and the respect geared towards the translator as an expert voice will be tainted by the errors of this type.

Another example of the errors due to lack of editing is the following sentence taken from a passage where catheters are explained:

*Un TIVAS (también llamado "port-a-cath" o "infuse a port") es un sistema de acceso a la vena totalmente implantado. El médico inserta este catéter en una vena mientras el niño está en la sala de operaciones. Le quedará una protuberancia debajo de la piel. Esta es la vía de acceso. No **poeda** ninguna parte del catéter **visiole** fuera del cuerpo [sic]. (n.p)*

The last sentence in this passage is almost unreadable which diminishes the authority of the voice of the translator. It should say "No **queda** ninguna parte del catéter **visible** fuera del cuerpo". Once again, the TT shows poor editing and the lack of effort to present the reader with accessible information.

In summary, while the use of declarative and imperative sentences in the translator's voice strive to create a trustworthy negotiation of information, the constant shifting of personal pronouns, and the choice of words that are not adjusted to the community variety, reduces the translation to confusing at its best, useless at its worse. The inclination of translators to follow the principle of equivalence in the voice in order to build rapport with the readers is unsuccessful when there is not a purposeful effort to

maintain the same voice throughout the document; in addition, the numerous errors of translation make the final product not good enough to be of full benefit for caregivers.

4.2.1.3 Local Translation: Ideational Metafunction

As stated in Chapter 2, the main socio-semiotic functions found in this translation are to explain and to educate caregivers about the different procedures their child will undergo while in treatment. The purpose of the *Ideational Metafunction*, as an analytical tool, is to review what aspects of the translation help to construct the narrative in the *Field* of pediatric cancer. The purpose of this section is to analyze *who* are the actors, *what* are the processes, and *how* the lexical choices help construct an experience that, ideally, should be rooted in the cultural background. The way the translators choose words from the meaning potential reveals the attitude and the expected response from the readers. Through the *transitivity process* (see Table 2.3), the translator constructs the experience and presents it to readers while negotiating between the two languages and cultures. To review the *transitivity processes*, this section focuses on the information that is found under the section in the binder titled *From Parents-to-Parents* or “De padres a padres” in the TT version, (see Table 4.3) where experienced parents give advice about their own experiences to parents who are new to the illness. These examples shed light into the real experiences of living the illness and how their construction of the experiences is negotiated in the translation.

The choice of words can change how something is perceived by the reader. For example, the next passage warns the reader about the first reactions they will experience when their kid is diagnosed with cancer:

*Since the time of **your child's diagnosis**, your lives have not been the same. **The diagnosis of cancer brings changes** to your life and the lives of the whole family. Every family is different. Each family has ways **to cope** with stressful experiences. Many families have **told us** about feeling fear, anger, depression, and guilt. All these feelings are **common human emotions**. **You are not alone**. Talking with family and friends, a member of the health care team, or another parent of a child who has cancer may be **helpful**. By **sharing these feelings** you may find it **easier** to cope with the changes you are experiencing. (p.50)*

This is the equivalent in the TT:

*El diagnóstico de su niño (a) cambiará de muchas maneras a su familia. La **tensión** de vivir con un niño que **sufre** de una enfermedad crónica es tanto **emocional como práctica**. Usted **se preocupa** por la salud de su niño(a), por su trabajo, su seguro de gastos médicos y la capacidad de poder pagar el costoso tratamiento. Usted **se preocupa** por los procedimientos dolorosos que tiene que **sufrir** su niño(a) y también por tener que faltar al trabajo. **La tensión** que usted **siente** es normal. Permítase usted mismo un poco de tiempo para ajustarse a estos cambios. Todas las familias y los amigos responden de manera diferente en las **crisis** - cada quien maneja **el problema** de manera diferente. Mantenga abierta la comunicación durante estos tiempos de **tensión**. (p.51)*

The TT of this paragraph seems to focus on the negative feelings. It repeats the fact that the child "suffers" from the illness and "suffers" painful procedures while the ST only says the "diagnosis" brings changes. The TT highlights how the parent "worries" and "stresses" about the child's health, about the insurance, about the cost of treatment, about the procedures, and about missing work, while the ST reassures the parent he/she is "not alone". It encourages them to find help and share feelings in order to make it "easier". The way the message is constructed in the TT puts the action in the *tension* and the *worrying* while the wording in the ST is more varied, reassuring the reader that all the feelings are normal and there are ways to make it easier on them.

The next section is comprised of a series of pieces of advice given by parents to parents. The section covers several topics. This particular section in the binders is meant to create connections among parents. It is included with the intention for parents to learn from other people that have experienced the same situation. The strategy of creating a community with a shared bond could be highly effective for parents to know that they are not alone and there is people that know what it is to live through the illness the best way possible; however, it is unsettling that they give advice to Spanish speakers from a community that does not share the same cultural heritage. The TT version is based on the ST and there is no adjustment to show cultural understanding among the parents giving the advice and the parents receiving the advice. While going through the illness of a child could make parents from any cultural background connect, as it will be shown in the examples, there are cultural differences that will ultimately define the functionality in the delivery of the message. Both, the English and the Spanish version are included in the

following examples. The ST is presented first, then the TT, followed by the different processes that each clause presents. While the processes are the same in both languages, the actual information has different meanings. Parents and/or caregivers go through the same processes; however, the way that information is translated changes the meaning conveyed to the reader.

Table 4.9 Ideational Metafunction: Parental Advice 1

Text	Example
ST	When our child's cancer was first diagnosed, we felt like the only ones in the world with this type of problem. We didn't know what to do or what to expect.
TT	Cuando diagnosticaron el cáncer de nuestro niño(a), sentimos que éramos los únicos en todo el mundo que tenían este tipo de problema. No sabíamos qué hacer o qué esperar.
<u>Processes</u>	
Mental	(nosotros) sentimos - que éramos los únicos
Mental	(nosotros) no - sabíamos - qué hacer

Table 4.10 Ideational Metafunction: Parental Advice 2

Text	Example
ST	In addition to fear was grief: grief over the loss of my "old" way of life. The old life consisted of only imagined fears, fears that, when you had them , were considered paranoia. After the diagnosis, I longed for the days of only imagined fears. I thought that I would never stop wishing for those days. I never stop wishing for things to be better, but that intense grieving did fade away.

TT Además del temor, **sentía** dolor por la pérdida [*sic*] de nuestra vida "anterior". La vida anterior consistía únicamente de temores imaginarios. Temores que cuando **los sentía** se consideraban como paranoia. Después del diagnóstico **extrañaba** los días en que mis temores eran únicamente imaginarios. **Llegué a pensar** que nunca **dejaría de desear** aquellos días. Nunca he **dejado de desear** que las cosas mejoren, pero ese dolor tan intenso si [*sic*] se disipó.

Processes

Mental	(yo) - sentía - dolor
Mental	temores que cuando - los sentía - se consideraban como paranoia
Mental	Después del diagnóstico - extrañaba - los días
Mental	(yo) - llegué a pensar - que nunca
Mental	(yo) - dejaría de desear - aquellos días
Mental	(yo) nunca - he dejado de desear - que las cosas mejoren

As it can be seen from these two examples, most of the experiences described by parents are mental processes, both in the TT and the ST. The only exception is the first sentence in Table 4.10 where the ST starts in third person talking about grief being there, while the ST starts with the parents feeling the grief. However, the construction of the illness in these examples relies, in great part, in the understanding of their feelings and cognitive processes. It is of equal concern for parents to understand the illness from a practical standpoint, the "happenings," as it is to understand what is going on in their minds and how it affects the family emotionally. The translator must, therefore, understand how to explain procedures in a cultural sensitive way, and to have a complete understanding of the way that the Hispanic community deal with emotions. Sahler et al. (2005) have shown that mothers that only speak Spanish are more likely to go under traumatic stress and "are more likely to experience their child's situation as severe and life-threatening even when reassured otherwise" (p. 273). While all parents go through the same mental process of anxiety and fear, it is important to understand that Spanish speaker caregivers

have some particular cultural issues such as the gender roles, family participation, religion, and an additional sense of fear caused by the partial understanding of the situation due to linguistic barriers, going on and those mental processes are not being addressed.

Table 4.11 Ideational Metafunction: Parental Advice 3

Text	Example
ST	It is helpful to us to keep on top of what is going on with our child. We find it important to be aware of our child's protocol, medications, and procedures.
TT	Es muy importante para nosotros saber qué es lo que está pasando con nuestro niño. Nos hemos dado cuenta que es importante estar al tanto del protocolo de nuestro hijo, de sus medicinas y de los procedimientos.

Processes

Mental	...nosotros - saber - qué es lo que está pasando
Mental	Nos - hemos dado cuenta - que es importante estar al tanto

Table 4.12 Ideational Metafunction: Parental Advice 4

Text	Example
ST	I kept notes of everything that was going on. It kept my mind straight.
TT	Yo hice notas de todo lo que sucedía. Me ayudó a mantener la sanidad mental.

Processes

Material	Yo - hice - notas
Material	me - ayudó – a mantener la sanidad mental

Table 4.13 Ideational Metafunction: Parental Advice 5

Text	Example
ST	My child was old enough (5) to understand that he was very sick. I told him everything he wanted to know . For me, the best way is to be very honest and tell him the truth.
TT	Yo utilicé el libro de colorear que prepara el Instituto Nacional del Cáncer para darle la noticia a mi niño. Mi niño estaba lo suficientemente grande (5) como para comprender que se encontraba muy enfermo. Yo le dije todo lo que deseaba saber . Para mí, lo mejor es ser muy sinceros y decirle la verdad.

Processes

Material	Yo - utilicé - el libro de colorear
Relational	Mi niño - estaba - suficientemente grande
Verbal	Yo - (le) dije - todo
Mental	Todo lo que - deseaba saber
Relational	lo mejor - es - ser sinceros

The Parental Advices 3, 4, and 5 show a variety of processes. However, more material and verbal processes are used which implies the things that have to be done by the parents. That is, these parental advises involve some type of action. What is very interesting about the "doings" advised by experienced parents is that they require some level of literacy from the parents. Parental Advice 3 (Table 4.11) highlights the

importance of knowing everything there is to know about the illness and treatment. Meanwhile, Parental Advice 4 (Table 4.12) capitulates on the importance of taking notes. This could actually be a helpful tip for Spanish speaking parents since they rely, on most part, on the oral information received at the time of the visit; however, it requires parents to have note-taking skills. In a similar manner, Parental Advice 5 (Table 4.13) could be very helpful to parents to talk about the illness with their child using a coloring book provided by a national organization. Notice that the TT does not mention the need to use a coloring book to help the child understand the illness. Since the coloring book is supported by a National Organization, it is safe to assume that parents look for an expert point of view to help them explain the illness to the child; nevertheless, as it will be discussed in the next section, national booklets in their translated version are not 100% accessible and culturally adapted. While the processes presented in this section are shared by all parents going through a cancer diagnoses, for Spanish speaking families verbal processes such as *asking* for questions and *requesting* a trained interpreter should be included. Also, verbal processes for in the TT should address how much information is *shared* with the children and who shares the information as it varies according to culture. For instance, “for Mexican and Hispanic children with cancer, extended family systems were and essential part of the coping process...The degree and nature of care the family provides is affected by a variety of cultural differences including boundaries, roles, and dynamics” (Goldstein, 2016, p.124-135). While it can be agreed that Mental, Material, and Verbal processes are prominent in this type of communication, and there is a set of processes shared by parents when faced with a chronically ill child, regardless of

their cultural background, the carrying out of the processes is deeply embedded in cultural practices.

The next set of pieces of Parental Advices are very important, not as much in terms of the processes as the previous ones, but in regards as to how the construction of the message does not integrate culture.

Table 4.14 Ideational Metafunction: Parental Advice 6

Text	Example
ST	As a single parent I found it useful to get in touch with other single parents
TT	Como padre soltero me ha sido de ayuda estar en contacto con otros padres solteros

This message translates "single parent" as "single father". The action asks single parents to get in touch with other parents in order to find support from others in the same situation; however, it does not take into consideration gender usage in Spanish. It is culturally highly unusual to find a single father in charge of the kids at the hospital. Traditionally, taking care of sick children is a female role. There could very well be several single fathers out there, but using the word "padre" excludes all the single mothers taking care of their children. A better translation would be to use gender-defining words such as "padre soltero" (single dad) and "madre soltera" (single mom) to include both genders. The lack of appropriate gender use denotes the lack of cultural understanding of the editor. While *parent* does indeed mean "padre" there is no revision

to adjust the meaning in the ST, which in the TT is easily understood that it refers to any single parent.

Table 4.15 Ideational Metafunction: Parental Advice 7

Text	Example
ST	When our son's (age 3) cancer was first diagnosed, he had a hard time getting adjusted to the IV pole . We told our son that he had to wait for his " wagon " to catch up with him. To this day, whenever he sees an IV pole, he thinks it is a wagon.
TT	Cuando diagnosticaron con cáncer a nuestro hijo de 3 años de edad, le costó mucho adaptarse al poste para intravenosas . Se echaba a correr olvidándose que estaba conectado al poste. Le pusimos nombre al poste. Le dijimos a nuestro hijo que tenía que esperar a que su " vagón " lo alcanzara. Hasta el día de hoy, cada vez que ve un poste para intravenosas piensa que es un vagón.

In this example, the parents make a comparison between a wagon and the IV pole so that the child would not be scared of it. The pole is attributed the characteristics of a toy to give it a friendly value. However, the wagon works for those kids who are acquainted with the culture of the United States. Since 1927, the wagon is an icon toy in the country (Scott, 2010, p.257). Every child either has one or has seen pictures of one in popular children's stories or movies. On the other hand, "el vagón" is not part of the Hispanic culture. In Spanish, it does not refer to a toy but it refers to an actual railroad car.

Another issue in this passage is the translation of the IV pole as "poste para intravenosas" which is a literal translation from "pole" that does not exist in Spanish. The actual name

used in Hispanic countries is "portasueros". This example does not carry the same meaning for Hispanic children, as they do not have the very popular reference of children playing with a wagon.

Table 4.16 Ideational Metafunction: Parental Advice 8

Text	Example
ST	We picked one staff person who never did " ouchies " to be friend. This was important in the beginning and helped build trust with the professionals.
TT	Escogimos como amiga a una persona del personal que nunca le hiciera " cocos ". Al principio esto fue muy importante y ayudó a que se creara confianza hacia los profesionistas.

In this example, the action is to find a medical professional that has never realized a painful procedure to the child in order to build trust. However, the child-friendly word used in English is "ouchies" which is translated to Spanish as "cocos". "Cocos" does not exist in the colloquial language of Hispanics as something causing pain. It is sometimes used in Spanish in reference to the head, which is a completely different meaning. In the target community, the word "ouchies" cannot be translated. The phrase would have to be translated as a staff person who never caused pain or who never made the child cry.

The *Ideational Metafunction* helps to reveal the choices made by the translator to negotiate the attitudes, beliefs, and situations that go on in the source text. While most of the transitivity processes seem to be translated to Spanish in the same manner at the lexical level, what complicates the negotiation is at the semantic level. That is, what is

relevant and helpful in the content of the text for one culture may not be as meaningful for the target community if it is not based on cultural practices. The experiences may be quite similar across ethnic groups in regard to coping with the recent news and adjusting to the new lifestyle; however, the personal processes that caregivers go through are thoroughly filtered by their cultural experiences.

4.2.1.4 Local Translation: Textual Metafunction

A review of the *Textual Metafunction* allows understanding the structure of the text, what Halliday calls the *ArquiteXture* of language (see Section 3.3.3). The *Textual Metafunction* divides the clause into *Theme* and *Rheme*. This process of the translation reveals how the text is constructed and which part of text is given more importance. How a clause starts engages the reader and it can construct either an ideal or a vague message, because it reflects the way the translator organizes the ideas. However, due to the fact that most clauses in these binders use the passive voice, or are imperative, the translator used equivalence translation in most places. Therefore, the *Themes* in both versions are practically the same. Table 4.17 shows three examples of the parallel construction used in most sentences.

Table 4.17 Textual Metafunction: Examples of Theme Similarities

	Text	Theme	Rheme
ST	a)	This section	Reflects the feedback from other parents
TT	a)	Esta sección	Refleja la información que hemos recibido de otros padres
ST	b)	Remember	You are not alone

TT	b)	Recuerden,	No están solos
ST	c)	You	Are probably going through a multitude of emotions
TT	c)	Usted	Probablemente está sintiendo una multitud de emociones

As seen in these examples, the construction of *Theme* and *Rheme* is parallel in most cases because of the principle of equivalence used by most translators and the similarity of sentence construction in both languages. In terms of cohesion and conjunctions used, the differences were not significant as shown in Tables 4.18 and 4.19.

Table 4.18 Textual Metafunction: Conjunction Similarities 1

Text	Example
ST	The child life specialist will also teach your child coping techniques, which may include allowing him or her to pick out music or distraction items (like pictures or dolls) for the treatment room, practicing deep breathing and muscle relaxation before the procedure, and discussing ideas for guided imagery or storytelling that may be done during the procedure.
TT	Algunas buenas técnicas de adaptación incluyen: permitirle que elija música o artículos para distraerse (como son libros, dibujos o muñecos) en la sala de tratamiento, practicar respiración profunda y relajación muscular antes del procedimiento, y hablar sobre ideas para imaginación guiada o cuentos que se puedan realizar durante el procedimiento.

Table 4.19 Textual Metafunction: Conjunction Similarities 2

Text	Example
ST	Some chemotherapeutic drugs, such as etoposide (VP-16), L-Asparaginase, other medications, and blood or blood procedures, may cause an allergic reaction if your child is sensitive to them.
TT	Alguno medicamentos [sic] quimioterapéuticos, tales como el etoposide (VP-16), l tenoposide (VM-26) [sic], L-Asparaginase, otras medicinas, y la sangre o los productos sanguíneos pueden causar reacciones alérgicas si su niño(a) es sensible a hacia ellas.

The length of the sentences and the use of conjugations is the same in both versions.

However, the literacy level of the target community must be taken into account when translating sentences. The use of long sentences is not recommended for a community that struggles with literacy. Hence, the importance of the *Textual Metafunction*; an analysis of the structure of the sentences, that is, the length, cohesion, and conjunctions can allow translators to modify their choices to make the TT appropriate for the intended readers. The second example (Table 4.19) is not only long and confusing due to the amount of conjunctions and prepositions, but it also presents several errors. First there is no number agreement in the words “alguno medicamentos.” There is an “l” by itself instead of “el”, also the name of the medication “tenoposide” is wrong; the name of the medicine is “teniposide”. Lastly, there is a double preposition “a hacia ellas” where only one of them should be used.

Another way to approach the *Textual Metafunction* in the health context is the one suggested by Halliday and Webster (2014) where they propose the use of a word cloud to

reveal the most common motifs in the narrative (see Section 3.3.3). The motif and repetitions help reveal what are the lexical items that help construct the textual representation of the experience. These clouds will reveal the words that are consistently used to represent the illness by the translation.

The following word cloud compares the motif and repetition in the English and Spanish text responding to the question: What is cancer? The results will be further analyzed later in this chapter when the motif resulting from the community oral narratives responding to this same question are also compared. Figure 4.1 and Figure 4.2 display the different words used more predominantly in both languages.

Figure 4.1 Word Cloud in English: What is cancer?

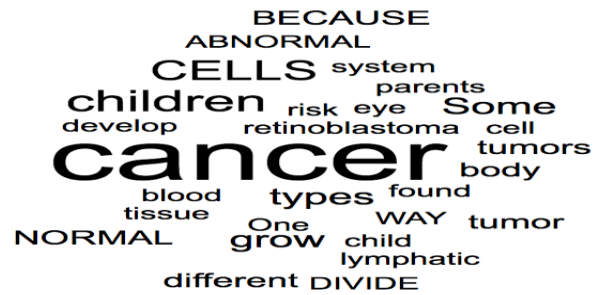
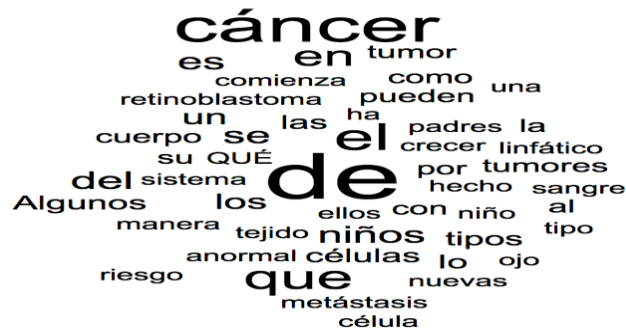


Figure 4.2 Word Cloud in Spanish: What is cancer?



The most prominent features in the English response to what is cancer are nouns and verbs such as: *cancer, children, cells, abnormal, grown*, and *divide*. In Spanish, on the other hand, the most commonly used words apart from the expected two words, *cancer* and *niños*, are prepositions and articles such as *de, que, el, en, del*, and *algunos*. In terms of texture, the English version carries more words containing information than the Spanish version.

4.2.2 Summary of Results for Local Translation

The results shown by the three metafunctions contribute to understand how meaning is embedded through the choices made to construct the translation. The strategies used to create translated text have a deep impact in the way the information is received and perceived by the community. These binders are the extension of information from the Clinic to the household. Following on Matthiessen (2013) definition of the hospital as a cultural institution of healthcare, it is vital that the translators also adapt to this definition and the translations become an extension of culture in healthcare. The creation of effective translations must be a purposeful and intentional part of the linguistic planning in health institutions. In the next section, the second form of written information will be analyzed. This next written set of data comes from booklets that are distributed nationally; therefore, the results are expected to apply to the Hispanic community as whole rather than the Rio Grande Valley.

4.2.3 Written Data: Nationally Translated Booklets

These booklets are distributed nationally; therefore, it was expected for them to have fewer errors because of a better edition process. However, the readability levels of these texts are too high for the target community. A measure of the English readability through several scales gave the following results:

Flesch Reading Ease score 58.4 - Fairly difficult to read

Gunning Fog Scale: 11.6 - Hard to read

Flesch-Kincaid Grade Level: 9.2 - Ninth grade level

The Coleman-Liau Index: 11 - Eleventh grade

The SMOG index 8.6 - Ninth grade

These results show that to understand these texts at least a high school education is required. This is not always the case for the community of this area (see Section 1.7). The Spanish version was not analyzed through a readability calculator due to the fact that there are some readability formulas for Spanish; however, they are not easily accessible and they have been deemed by some researchers as unreliable (see Section 3.4). For the most part, these translations follow a word-by-word approach using the same type of sentences; therefore, it is safe to say that the readability in Spanish would be at a very similar level.

The translator is also anonymous in these booklets. The selections discussed in this section contain relevant information for the caregivers. They are meant to give advice and expect a response from the reader. These selections were chosen because the

information is directed to parents and it covers a variety of topics that apply to everyone regardless of the type of cancer diagnosed to their child.

4.2.3.1 The Leukemia and Lymphoma Society Booklets: Pinpointing Choice

After a careful review of the books translated by The Leukemia and Lymphoma Society (LLS), instead of dividing this section into the three metafunctions and discuss them separately, it was found that more relevant information was revealed by following Halliday's model of pinpointing the alternative choices (see Section 2.5). These results give a broader and more comprehensive perspective about the strategies made by the translator to create meaning and how the reader can perceive this information. In Halliday's pinpointing model, he divides the information in four columns. The first section is the "point at issue" which gives "an informal characterization of the instance that is being highlighted". The second section deals with the strata in which the issue is found, next is the rank and the metafunction. The last section, which will be the highlight of these results, is the "possible alternative choice". According to Halliday, the analysis of this last section "suggest how an alternative choice might be made which would improve the effectiveness of the translation" (p.17).

The first booklet is translated by LLS and it is titled *Emotional Aspects of Childhood Blood Cancers: A Handbook for Parents*. The title in Spanish is *Aspecto Emocionales [sic] de Niños con Leucemia: La informacion [sic] para los padres*. As the English title says, these booklets cover all the aspects in regard to the feelings that families and the children go through during the illness. For the purpose of this analysis, both the English and the Spanish versions are included. The next examples show both

versions, the point at issue, the metafunction realized through the sentences, and the possible alternative choices. In addition, there is a brief discussion of how these choices impact the overall construction of the message in regards of the context of culture.

Table 4.20 Pinpointing the Choice: Example 1

Text	Examples
ST	Common reactions include confusion, denial, fear, anxiety , guilt, grief, and sadness.
TT	Las reacciones más comunes son la confusión, negación, miedo, ira , culpa y tristeza.
<u>Point at issue</u>	Choice of equivalent
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Select a more appropriate equivalent. For example: <i>ansiedad</i> .
<u>Notes</u>	In Spanish, the word ira suggests a feeling of intense anger, even wrath.

Table 4.21 Pinpointing the Choice: Example 2

Text	Examples
ST	In addition, your sense of security and your belief in God , or in the meaning of life, may be shaken .
TT	Además, puede sacudir su esperanza y amenazar su fé en la vida.
<u>Point at issue</u>	Omission and choice of equivalent.
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Add a more equivalent for <i>your belief in God</i> . e.g. <i>fé en Dios</i> . The equivalent of <i>sense of security</i> is not <i>esperanza</i> . The word amenazar (to threaten) does not appear in the ST.

<u>Notes</u>	Religious beliefs are omitted which is unexpected because making decisions based on religious beliefs is deeply embedded in the Hispanic culture. Also, the word <i>threaten</i> suggests a bigger change than just a <i>shake</i> in their emotions.
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Table 4.22 Pinpointing the Choice: Example 3

Text	Examples
ST	Whatever feelings you experience, as individuals and as parents, are valid reactions to your specific situation.
TT	Not available
<u>Point at issue</u>	Omission of information
<u>Metafunction</u>	Interpersonal
<u>Alternative</u>	Add the sentence
<u>Notes</u>	The missing information is an important reassurance to parents about their feelings. This sentence is meant to provide support and understanding.

Table 4.23 Pinpointing the Choice: Example 4

Text	Examples
ST	Physicians and other treatment team members understand this and you can ask them to repeat information as your questions arise.
TT	Los médicos comprenden esta confusión inicial y por lo general están dispuestos a repetir la explicación cuantas veces sea necesario.
<u>Point at issue</u>	Unmotivated change in structure
<u>Metafunction</u>	Textual
<u>Alternative</u>	Delete the connecting clause: <i>por lo general</i>
<u>Notes</u>	Saying that medical professionals, <i>in general</i> , are willing to repeat information is not as reaffirming as the TT.

Table 4.24 Pinpointing the Choice: Example 5

Text	Examples
ST	Denial about the accuracy of the diagnosis for too long is detrimental to the future well-being of your child and the entire family.
TT	Cuando la negación se prolonga resulta perjudicial para la futura felicidad de su hijo y de toda la familia.
<u>Point at issue</u>	Choice of equivalent word
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Use a more equivalent word to translate <i>well-being</i> . For example: <i>bienestar</i>
<u>Notes</u>	<i>Well-being</i> is a more comprehensive and inclusive word than <i>happiness</i> , which is the word used in TT.

Table 4.25 Pinpointing the Choice: Example 6

Text	Examples
ST	Before beginning treatment, some parents seek a second opinion or want to get additional information about the credentials of treating physicians of the medical center. Consultations should be scheduled in a timely manner. Physicians are generally willing to help arrange this.
TT	Not available
<u>Point at issue</u>	Omission of information
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Add the information to the TT
<u>Notes</u>	Information about the opportunity to request a second opinion is important for Hispanics as it builds trust. In the local translated document the option to find a second opinion was also omitted from the TT.

Table 4.26 Pinpointing the Choice: Example 7

Text	Examples
ST	Hope provides strength and helps us to maintain the will to live.
TT	La esperanza da fuerzas para conservar el deseo de vivir.
<u>Point at issue</u>	Shift of voice
<u>Metafunction</u>	Interpersonal
<u>Alternative</u>	Use the first person
<u>Notes</u>	The use of first person brings the translation closer to the reader. There is no apparent reason to use the third person in the TT.

Table 4.27 Pinpointing the Choice: Example 8

Text	Examples
ST	Don't be surprised if you feel very angry at times .
TT	No se sorprendan si sienten enojo, mucho enojo .
<u>Point at issue</u>	Unnecessary word. Omission of words
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Delete the word enojo the second time. Add the translation for at times which could be: <i>algunas veces</i>
<u>Notes</u>	The feeling of being angry is a negative feeling. There is no need to include it twice. It is only mentioned once in the ST. The ST goes further to lessen the feeling by saying it is only felt at times while the TT stresses the feeling by repeating the word.

Table 4.28 Pinpointing the Choice: Example 9

Text	Examples
ST	Emotions may be misdirected toward family members, co-workers or even complete strangers.

TT	Los cónyuges y los demás hijos pueden convertirse en <i>chivos expiatorios</i> de los sentimientos no resueltos.
<u>Point at issue</u>	Awkward choice of word
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Use a word that is more equivalent or rephrase the whole statement.
<u>Notes</u>	The word <i>chivo expiatorio</i> in Spanish is used when there is someone is falsely accused of a wrongdoing. It is not used for misdirected emotions.

Table 4.29 Pinpointing the Choice: Example 10

Text	Examples
ST	You may feel responsible for causing your child's illness. You may blame yourself for not paying more attention to your child's symptoms.
TT	Se sienten responsables de causar la enfermedad de su hijo.
<u>Point at issue</u>	Omission of second sentence that completes the thought.
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Add the missing sentence
<u>Notes</u>	The missing sentence shifts the feeling of guilt from causing the illness to a more specific action of causing it by not paying attention to the symptoms.

Table 4.30 Pinpointing the Choice: Example 11

Text	Examples
ST	As hard as it is to accept, you may never know what caused your child to have cancer.

TT	Deben aceptar que sea lo que sea que hizo que su hijo tuviera cáncer seguirá siendo un misterio .
<u>Point at issue</u>	Choice of word
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Delete or replace the word misterio .
<u>Notes</u>	The definition of the word misterio means something that exceeds the capacity of the human reasoning. The fact that is hard to pinpoint why the child became ill does not mean there the cause is beyond all understanding.

Table 4.31 Pinpointing the Choice: Example 12

Text	Examples
ST	It is important to be aware of how premature grief can affect your child. It can make a child feel worried or neglected , of feel the need to somehow protect his or her parents from sadness.
TT	Demasiada congoja demasiado pronto puede hacer que el niño se sienta abandonado .
<u>Point at issue</u>	Choice of word. Missing clause.
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Use a better word such as preocupado or descuidado . Add the complimentary clause about how kids feel the need to protect parents.
<u>Notes</u>	The grief in the original version makes the child feel worried or neglected . In the TT version, the meaning was changed to the child feeling abandoned which is a very different feeling. Also, the information about how the child may hide feeling to protect the parents from feeling grief is unnecessarily omitted.

Table 4.32 Pinpointing the Choice: Example 13

Text	Examples
ST	Often with the help of their pastors, ministers, or rabbis, parents realize these emotions are not helpful. They try to make the most of their child's life and the time they have together.
TT	Not available
<u>Point at issue</u>	Omission
<u>Metafunction</u>	Interpersonal
<u>Alternative</u>	Add the information
<u>Notes</u>	The information about religion and spirituality is constantly omitted from the Spanish texts (See Section 4.2.1.1 and Table 4.21)

Table 4.33 Pinpointing the Choice: Example 14

Text	Examples
ST	Many untapped energies and skills lie dormant until you really need them.
TT	Muchas energías y capacidades no utilizadas yacen latentes hasta que uno las necesita.
<u>Point at issue</u>	Awkward choice of words
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Use a better word. For example: <i>permanecen inactivas (stay inactive)</i> .
<u>Notes</u>	The word <i>yacen latentes</i> is not common for the register of this area.

Table 4.34 Pinpointing the Choice: Example 15

Text	Examples
ST	There are immediate medical, family, and financial decisions to make.
TT	Primero, hay ciertas decisiones médicas inmediatas que se deberán tomar.
<u>Point at issue</u>	Incomplete information
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Add the missing information
<u>Notes</u>	The TT is missing the family and the financial decision which are also very important in the decision-making process.

Table 4.35 Pinpointing the Choice: Example 16

Text	Examples
ST	If you have been referred to a large medical institution for complete diagnosis and treatment, you may have to cope with a very sick child in a new hospital, with a new physician, perhaps in an unfamiliar city or town.
TT	Si el niño ha sido derivado a una institución médica de envergadura para recibir diagnóstico y tratamientos completos, puede que tengan que hacer frente a la realidad de un niño enfermo en un hospital nuevo y con un médico nuevo.
<u>Point at issue</u>	Choice of unusual words/wrong words
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Use of commonly used words. For example, <i>referred</i> should be <i>referido</i> or <i>enviado</i> . A <i>large medical institution</i> could be <i>un hospital más grande</i> .

<u>Notes</u>	To be <i>referred</i> is translated as <i>derivado</i> , which means a <i>derivate</i> , that is, something that comes from something else. The word <i>envergadura</i> is highly unusual in the community register.
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Table 4.36 Pinpointing the Choice: Example 17

Text	Examples
ST	You need to explain the nature of the illness to your child and find ways to comfort him or her. In addition, you need to help your child to cooperate with medical treatment.
TT	Deben decidir rápidamente cómo explicarle la naturaleza de la enfermedad al niño. Con sensibilidad y candor , deben hallar la manera de disipar los miedos de su hijo y asegurarse su cooperación en cuanto al tratamiento médico.
<u>Point at issue</u>	Unnecessary phrase
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Delete the extra phrase
<u>Notes</u>	The connecting phrase <i>con sensibilidad y candor</i> (<i>with sensibility and candor</i>) uses words that are unfamiliar in the community register. They are not needed to convey the meaning and create confusion. The ST does not have them; it uses more direct verbs such as: <i>you need to help</i> and <i>you need to explain</i> .

Table 4.37 Pinpointing the Choice: Example 18

Text	Examples
ST	When parents are having problems with their marriage or are separated or divorced, they need to find a way to set aside conflicts and cooperate in caring for their child.

TT	Not available
<u>Point at issue</u>	Omission
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Add the information and adjust it culturally
<u>Notes</u>	This sentence refers to parents who are separated or divorced. The information in the TT should also include involuntary separation, as it is common in the Hispanics families to have one parent leaving for migrant work or living in Mexico for legal or work-related reasons.

Table 4.38 Pinpointing the Choice: Example 19

Text	Examples
ST	This is also an important time to carefully consider the pros and cons of introducing other significant changes into your family's life.
TT	Los padres con frecuencia hallan que es mejor evitar hacer muchos cambios en su vida
<u>Point at issue</u>	Choice of words
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Use a more equivalent translation
<u>Notes</u>	The ST gives the reader an option to consider <i>pros</i> and <i>cons</i> before making a significant change in their lives. The TT recommends <i>to avoid</i> these changes.

Table 4.39 Pinpointing the Choice: Example 20

Text	Examples
ST	Nine months after Laura, age nine, was diagnosed, her mother Marge , who was divorced at the time of Laura's diagnosis, remarried. Initially, Marge's new husband was supportive, but as Laura's illness

	progressed, he began drinking and leaving home for long periods at a time.
TT	Nueve meses después de que Laura fue diagnosticada, la Sra. W. quien estaba divorciada al momento del diagnóstico, contrajo nuevamente matrimonio. Al principio, el Sr. W. ofreció su apoyo, pero a medida que fue avanzando la enfermedad, comenzó a beber, a salir con mujeres y a ausentarse de la casa por largos periodos.
<u>Point at issue</u>	Omission/extra details
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Add the full name of the person. Avoid the extra information
<u>Notes</u>	The name of the mother is replaced by a letter in the TT. This makes the information less personal. While it may be a strategy to avoid using a non-Hispanic name, the name of child is kept. Also, there is no reason to add an extra detail in the TT to a situation where the husband leaves with other women when the ST only tells he would leave for long periods of time.

Table 4.40 Pinpointing the Choice: Example 21

Text	Examples
TT	To overcompensate for the illness by showering your child with gifts or by abandoning all previous forms of discipline is confusing to a child.
ST	Sobrecompensar por la enfermedad calmando al niño de regalos o abandonando toda forma previa de disciplina confunde al niño.
<u>Point at issue</u>	Error in translated word
<u>Metafunction</u>	Ideational
<u>Alternative</u>	The correct translation for showering with gifts should be <i>colmado de regalos</i> .

<u>Notes</u>	The word showering is translated as <i>calmando</i> , which means <i>calming down</i> .
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Table 4.41 Pinpointing the Choice: Example 22

Text	Examples
ST	Raul lived with his parents and two brothers, ages 4 and 2. His mother believed her sick child needed all her attention. She showered him with gifts, kept him home from school, took him on special outings without her husband or other sons... Raul's father disliked coming home.
TT	Raúl vivía con sus padres y sus dos hermanos de 4 y 2 años. La Sra. W. creía que su hijo enfermo necesitaba toda la atención. Ella lo calmaba con regalos, lo hacía faltar a la escuela, lo llevaba en paseos especiales sin su esposo ni sus otros niños... Al Sr. S. le disgustaba llegar a la casa.
<u>Point at issue</u>	Omission and wrong equivalent word
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Add the full name and change the translation of the word showering.
<u>Notes</u>	These two points are recurring throughout the document. For some unknown reason the names of the parents are omitted from the TT. Using the name actual brings the reader closer because it is a real person behind the story. Also, the word <i>showering</i> is translated as <i>calmaba</i> again instead of <i>colmaba</i> .

Table 4.42 Pinpointing the Choice: Example 23

Text	Examples
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ST	If this describes your family, for your child's welfare, it is most important for you to seek professional help.
TT	Es vital que estas familias procuren asistencia psicológica o ayuda profesional.
<u>Point at issue</u>	Use of third person
<u>Metafunction</u>	Interpersonal
<u>Alternative</u>	Use of first person
<u>Notes</u>	The use of the plural first person in the ST creates a sense of closeness and understanding with the reader.

Table 4.43 Pinpointing the Choice: Example 24

Text	Examples
ST	It is harder, in some ways , to talk to younger children about these issues.
TT	Es mucho más difícil, de muchas maneras , hablar a los niños pequeños sobre su diagnóstico, tratamiento y pronóstico.
<u>Point at issue</u>	Sentence structure
<u>Metafunction</u>	Textual
<u>Alternative</u>	Use an equivalent word for the clause in some ways . The translation <i>de muchas maneras</i> means <i>in a lot of ways</i> .
<u>Notes</u>	The translation should be made as simple as possible to make it accessible for people with low literacy. Readers should not have to think about what the translator meant to say.

Table 4.44 Pinpointing the Choice: Example 25

Text	Examples
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ST	Honest information, presented in simple, age-appropriate terms supports their ability to trust you. It encourages your child or adolescent to ask questions about what is happening to them. This gives you the opportunity to be aware of and address their perceptions about what is happening and why. It helps decrease some of your child's fears.
TT	La honestidad presentada en términos simples y apropiados para la edad y el desarrollo del niño refuerza la capacidad del niño de confiar y lo alienta a que pregunte sobre lo que le está pasando. Esto les da a los padres la oportunidad de conocer y atender a las percepciones y malinterpretaciones del niño sobre lo qué está sucediendo y sobre el porqué, y por ende reducen los miedos innecesarios del niño.
<u>Point at issue</u>	Sentence structure
<u>Metafunction</u>	Textual
<u>Alternative</u>	Make shorter sentences and avoid more conjunctions than necessary.
<u>Notes</u>	Long sentences unnecessarily elevate the readability level of the text.

Table 4.45 Pinpointing the Choice: Example 26

Text	Examples
ST	When the diagnosis and seriousness of the illness have not been shared honestly with a child, the child generally does not reveal his or her fears about death , or other fantasies that are not addressed openly may lead to a loss of hope, optimism, and good quality of life .
TT	Cuando el diagnóstico y la gravedad de la enfermedad no se han compartido honestamente con el niño en términos apropiados por su edad, ese niño generalmente no revelará abiertamente que se ha dado cuenta de la potencial fatalidad de la enfermedad, de sus miedos u

otras fantasías sobre lo que está sucediendo. Los miedos y preocupaciones reales de un niño, así como los miedos y las fantasías irreales, que no son atendidos abiertamente tienden a hacer que se pierda la esperanza y el optimismo tan cruciales para **la supervivencia**.

<u>Point at issue</u>	Wordiness and wrong word equivalence
<u>Metafunction</u>	Ideational
<u>Alternative</u>	<i>Seriousness of the illness</i> in not <i>potencial fatalidad (potential fatality)</i> . <i>Quality of life</i> is not the same meaning as <i>supervivencia (survival)</i> .
<u>Notes</u>	The use of the wrong equivalent words makes the sentences more difficult to understand.

Table 4.46 Pinpointing the Choice: Example 27

Text	Examples
ST	Kevin, age 15, recalls, "I knew I was really sick when dad bought me a dirt bike . I had wanted one for several years and dad had said, Absolutely not! Then, two days after I came home from the hospital, there was the bike. That made me feel terrible."
TT	Kevin, de 15 años, recuerda: "Me di cuenta de que estaba realmente enfermo cuando mi papá me compró una bicicleta campera . Yo había querido una por años y mi padre siempre se había opuesto rotundamente. Entonces, dos días después de regresar a casa del hospital, se apareció con la bicicleta. Santo Dios, que mal me hizo sentir."
<u>Point at issue</u>	Equivalent word
<u>Metafunction</u>	Ideational

<u>Alternative</u>	Use a better word to translate <i>dirt bike</i> . The term <i>bicicleta campera</i> does not exist in Spanish. A more correct word would be <i>bicicleta todo terreno</i> .
<u>Notes</u>	The constant use of wrong words makes the situation not easy to follow. The reader is more aware of the fact that the information they are reading is a translation and may contains more errors. Reduces the chance of trusting all the information presented.

Table 4.47 Pinpointing the Choice: Example 28

Text	Examples
ST	Bill graduated in the top 20 percent of his class and was accepted at his first-choice college .
TT	Bill se graduó entre los primeros 20 de su clase y fue aceptado en una universidad importante .
<u>Point at issue</u>	Equivalence/misleading information.
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Use the right word, which is <i>20 por ciento (twenty percent)</i> . The <i>first-choice college</i> is not <i>una universidad importante (an important university)</i> .
<u>Notes</u>	The error in this sentence gives the wrong information about graduating in the top 20 students vs. the top 20% of the graduating class. Also, the ST talks about the kid getting into his first choice of college while the TT only mentions being accepted into an important university.

Table 4.48 Pinpointing the Choice: Example 29

Text	Examples
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ST	People often describe treatment as a “safety net,” a “ security blanket ” or an “ umbrella ”. Like many families, you may come to feel that treatment - as grueling as it is - offers a kind of magical protection to your child.
TT	Las personas con frecuencia describen el tratamiento como una “red” o “ manta de seguridad ” o un “ parasol ”. Como muchas familias, puede que lleguen a considerar que el tratamiento - a pesar de lo agotador que es - ofrece cierta protección mágica sobre su hijo.
<u>Point at issue</u>	Wrong equivalent word
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Use a more appropriate word. <i>Security blanket</i> is not <i>manta de seguridad</i> . <i>Umbrella</i> does mean <i>parasol</i> , but it is a very uncommon translation for the word.
<u>Notes</u>	The translation for <i>security blanket</i> is a literal translation for an expression that is not used Spanish while the translation for <i>umbrella</i> is also not a common word used in Spanish.

Table 4.49 Pinpointing the Choice: Example 30

Text	Examples
ST	Most treatment teams have members who are trained to help parents prepare for these discussions; ministers, priest, or rabbis can also help.
TT	Not available
<u>Point at issue</u>	Omission
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Add the information

<u>Notes</u>	The information about religion and spiritual well-being is constantly omitted in the TT (See Table 4.32). Issues of religion and faith are very important for Hispanics.
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Table 4.50 Pinpointing the Choice: Example 31

Text	Examples
ST	Death has a social significance .
TT	La muerte tiene significación social .
<u>Point at issue</u>	Wrong translation
<u>Metafunction</u>	Ideational
<u>Alternatives</u>	Use a better translation that is not literal. For example: <i>impacto social</i> (<i>social impact</i>).
<u>Notes</u>	This is another example of literal translation that does not mean anything in Spanish.

The second booklet is also provided by the Leukemia and Lymphoma Society and it is a handbook meant to provide information about the different medications used in chemotherapy and how to deal with side effects. The title in Spanish is *Comprendiendo la Farmacoterapia y Manejando los Efectos Secundarios*. The title in English is *Understanding Drug Therapy and Managing Side Effects*. The relevance of a good translation in this booklet is the fact that because of insurance issues or lack of transportation, Hispanics have a tendency to self-medicate. It is vital that parents and caregivers understand the side effects of each medication so that they can recognize any symptoms appropriately and in a timely manner. Continuing with Halliday's concept of pinpointing the choice, these are the examples found in this book:

Table 4.51 Pinpointing the Choice: Example 32

Text	Examples
ST	If skin changes are noticed, it is important to alert your healthcare provider promptly. Treatment for these side effects can make you more comfortable and may prevent infection and other serious problems from developing.
TT	Es importante avisarle al médico si se notan cambios en la piel.
<u>Point at issue</u>	Incomplete information
<u>Metafunction</u>	Textual
<u>Alternative</u>	Add the information
<u>Notes</u>	There is important information missing that can result in the patient being aware of the side effects of the treatment and act upon them.

Table 4.52 Pinpointing the Choice: Example 33

Text	Examples
ST	The function of marrow is to produce blood cells and send them out into the blood to circulate throughout the body .
TT	La función de la medula ósea es producir células sanguíneas y enviarlas por el torrente sanguíneo para que circulen por todo el organismo .
<u>Point at issue</u>	Choice of words
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Use words that are common and equivalent in terms of easiness. For example: <i>producir las células sanguíneas que circulan por el cuerpo</i> .

<u>Notes</u>	The use of words that are uncommon may makes it harder to understand. ST uses simple words. For example, <i>into the blood</i> is translated as <i>torrente sanguíneo (blood stream)</i> and <i>body</i> is translated as <i>organismo (organism)</i> .
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Table 4.53 Pinpointing the Choice: Example 34

Text	Examples
ST	Developing blood cells remain in the marrow until they are mature enough to perform these vital functions and then are released into the circulation .
TT	Las células sanguíneas en desarrollo permanecen en la medula ósea hasta que maduran lo suficiente como para llevar a cabo esas funciones esenciales; entonces se les libera al torrente sanguíneo .
<u>Point at issue</u>	Choice of words
<u>Metafunction</u>	Ideational
<u>Alternative</u>	Use a more similar and common word such as <i>circulación</i> .
<u>Notes</u>	Using medical terms such as <i>blood stream</i> instead of the more common <i>blood circulation</i> used in the ST makes the TT difficult to understand by the reader.

Table 4.54 Pinpointing the Choice: Example 35

Text	Examples
TT	Water coming through the spout represents new cells being delivered from the marrow to the circulating blood.
ST	El agua que sale del grifo representa a las células nuevas que se están agregando a la sangre circulante, procedentes de la medula ósea.
<u>Point at issue</u>	Choice of words

<u>Metafunction</u>	Ideational
<u>Alternative</u>	Use a more familiar word. For example: <i>canal (water stream)</i> .
<u>Notes</u>	<i>Grifo</i> is a correct translation, however, it is not the word of choice by the variety of Spanish spoken by the majority of Hispanics in the country.

In addition to these errors in translation, there is one page in the ST that is missing in the TT and it has very helpful information. The page is titled *Sample Questions to Ask Your Healthcare Provider*. This page is divided into the following subheadings:

- About your treatment
- Taking medication at home
- About side effects
- About contacting medical staff
- Tips for keeping track of information from your healthcare provider

It guides patients about the questions to ask. For example:

- Why do I need this treatment?
- What are the benefits/risks associated with this treatment?
- Are there any other possible treatment methods for my type of cancer?
- Do I have a choice about which days or times of day to schedule my treatment?
- Will I be able to go to work (go to school) while I'm undergoing treatment?
- What if I miss a dose?
- How should I store it?

- When are side effects likely to occur?
- How do I contact a health professional after hours?

These crucial questions may be forgotten to be asked by patients at the time of the medical visit because of the emotional state; however, the translation did not consider necessary to add this page in the Spanish version. The analysis of these booklets allows for a clear understanding about how a careful and intentional choice of words to use can dramatically change the outcome of the translation. The translator's choices affect meaning across all metafunctions and the intended result is not the same in both languages.

4.2.3.2 American Cancer Society Booklets: Motifs and Repetitions

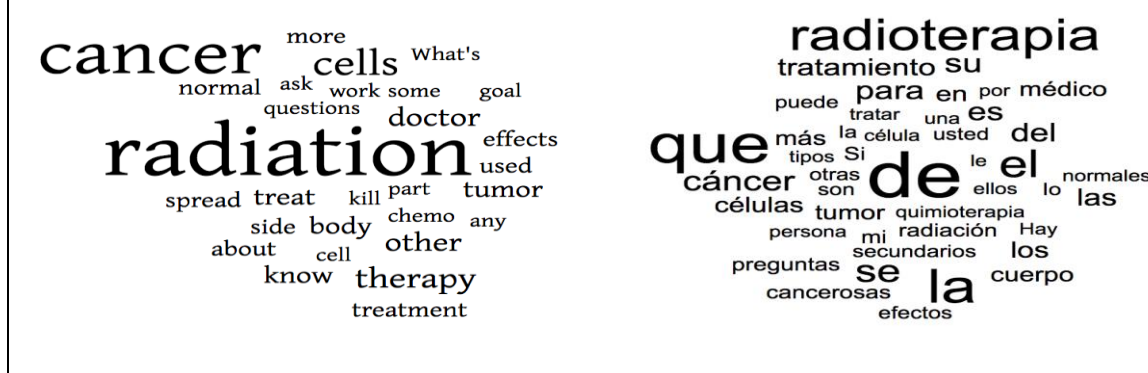
The booklets translated by the American Cancer Society (ACS) follow the LLS approach of an equivalent word-by-word translation. The translator is not completely anonymous for this organization. The name of the translators can be found on the website; however, it does not say anything about their credentials or experience as medical translators. Also, it does not say if they do the complete translation or if they edit translations based on a machine translator. Since both versions were almost identical in terms of the *Interpersonal* and *Ideational Metafunction*, a *Textual Metafunction* analysis was conducted in order to understand the way text are constructed. Two booklets were used for this section and they were selected because their information is helpful to parents and caregivers regardless of the type of cancer diagnosed to their child. The titles of the books are *Chemotherapy* and *Radiation*. In Spanish, the titles are

Quimioterapia y Radioterapia. The word cloud strategy was used to identify the motifs and repetitions used to convey the message. These clouds are based on the following three sections:

- What is chemotherapy - ¿Qué es la Quimioterapia?
- What does chemo do? - ¿Cuál es la finalidad de la quimioterapia?
- Will chemo be my only cancer treatment? - ¿Es la quimioterapia el único tratamiento para el cáncer?

Notice that the tiles suggest closeness to the reader in the English version and it is more familiar to the way people actually talk. The second and third titles use the shortened version of Chemotherapy, which is “Chemo”. This use of the shortened version is highly popular to refer to the treatment. In Spanish, there is also a shortened version that people use when talking, which is *quimio*. This would be the equivalent term; however, it is not translated. In addition, the third title adds the possessive “**my** only cancer treatment”. It recognized the fact that the treatment is individually tailored. The Spanish version uses a very impersonal and general question. The motifs and word repetitions revealed by the word clouds are as follow:

Figure 4.4 Side by Side Word Cloud Repetitions in the Book *Radiotherapy*.



Same as in the previous booklet, the texture of the English text is mainly composed of meaning-carrying words. For example: *Cancer, Radiation, Cells, Doctor, Therapy, Tumor, Body*, and *Effects*. The Spanish version, other than the expected *Radioterapia, Cáncer* and *Tratamiento*, is constructed by connecting words such as: *De, Que, El, La, Se, Para, Su, Es*, and *En*. The clauses in the original text have more content-carrying words; this helps to make the readability level more accessible to the inexperienced reader. This is particularly important when medical terms are used, sentences that are simple and straightforward help the reader to focus on the content.

4.2.4 Summary of Results for National Booklets

The results of the analysis about the booklets distributed by national non-profit organizations further reveals the variability on the quality of translations. While they dedicate a good part of their budget to make sure these booklets reach the households of people who need this information, they are still not very useful. Indeed, there are recent efforts to make these translations as good as possible. Some institutions, such as the

ACS, have made public the name of the people hired as translators, which is a laudable effort to reduce the anonymity of the translator; however, because there is not a wide spread continuous use of a functional theory grounded in language and culture that is also evaluated by community perception, all efforts to provide services have not being optimized. The prevalence of errors and the constant use of words that are not as functional as the equivalent English version defeat the purpose of the availability of information. In the next section, the community's responses to a semi-guided interview about their experiences with linguistic services in the healthcare setting will shed light on the current status of the perception of available services and the essential needs in order to attempt for a better flow of communication in the near future.

4.3 Healthcare Narratives from the Rio Grande Valley

In order to obtain bottom-up results about the functionality and public perception of translated written information, people from the community were interviewed in order to find about their experiences when, because of a child illness, they needed access to health services in Spanish. In addition, because one of the main issues in cancer diagnosis is detecting the illness at the earliest stage possible, it was the aim to find out how much do parents know about the illness and the process of diagnosis and treatment. The interviews were conducted across all three counties that comprise the Rio Grande Valley. It is expected that their narratives will contextualize the results found in the previous sections.

Before presenting the community responses, it is necessary to briefly review the community profile (see Section 1.7). The Hispanic community in the United States is the largest minority group with over 50 million people currently living in the country. Approximately 90% of the people living in the Rio Grande Valley identify as Hispanics and the majority of them speak as the first, and in many cases, the only language. When talking about the health care setting, people are aware that because of the language barrier they have a more difficult time accessing the healthcare; however, their cultural values compels a great respect for medical professionals. The respect for the system, sometimes, impedes them from fighting for their right to obtain information and to seek for a shared responsibility in achieving health literacy. It is a common belief that if a mistake in communication happens in a healthcare institution, it was the people's fault for not learning the main language of the country.

However, language is not the only barrier faced by this community. Another common characteristic that prevents them to ask for help is the fact that they want to remain invisible as much as possible because of legal residency issues. This was also a problem to carry out the interviews. In several cases, people were very hesitant to participate because they were scared to give some compromising information to a researcher. Their legal status scares them so much than when faced with an illness, going to a large healthcare institution is the very last resource. These issues are permeated in the culture and they are incomprehensible for those who are not familiar with the situation. Even people living in the mainstream cities have a hard time understanding what it means to live at the margins.

The interviews were done in different places; churches, a community center, and most of the interviews, were conducted thanks to the organization LUPE (*La Unión del Pueblo Entero*). As soon as this organization was approached with the project, the person in charge of community outreach showed her enthusiasm about the project. She voiced her concern about the access to linguistic services for the people living in *colonias* who only speak Spanish. She proposed two upcoming community meetings as the best place to recruit subjects for this study. These meetings, done in two different cities in Hidalgo county, were hosted at an ad-hoc clinic supported by LUPE and the Methodists Healthcare Ministries of South Texas. They used a mobile clinic to settle far away from the mainstream community, deep in the heart of popular *colonias* where people could go to get basic health services. Some services were provided free, while they also offer financial aid for other, more expensive, procedures.

The first response from potential subject to be recruited for this study was always hesitation. The people in charge of the community event were well aware of the possibility of this situation. They readily offered to help explain the purpose of the interview to the community because of the lack of trust on unfamiliar people. When they saw a new person in their safe place, without previous notice, it created an environment of uncertainty and scrutinizing. After a thorough explanation of the purpose of the study and the potential benefits, the community was more eager to participate, although still scared of saying things that could uncover their legal status. In some cases, the outreach specialist from LUPE, before-hand, identified and approached a potential subject who then would agree to participate in this study. She would then convey us the information

of the potential interviewee. However, when the person was personally approached to carry out the interview, they pretended to not be the person being looked for and denied their name. It was until after they inquired the purpose of the study and received a comprehensive explanation and reassurance of anonymity that they acknowledged to be the person previously approached by the outreach coordinator. After knowing that the only purpose of the interview was to obtain a narrative of their experience, their mood changed and they were very willing to participate. In all the places visited, several persons felt disheartened because they did not meet the requirements to be considered a subject. They were eager to share their story if that meant the possibility of seeing a change in the information received by the health system.

It was a general impression that people are well aware that the services they receive are always tainted by the language barrier; however, they face the system with a sense of helplessness and guilt for not knowing the language. People believe that their children would have a better healthcare if only they knew English. They know they can ask for linguistic services and they recognize when translations and interpreters are provided for them; nevertheless, the general consensus is that they will never attain the comprehensive access they wish to have to all the information pertaining their illness. The language and cultural barriers are always present hindering their abilities to obtain optimal healthcare. The interpreter and the translations, especially when there are errors in the communication, make patients lose confidence in the system. Some patients still feel the services are provided to them regardless of them not speaking English and they should be thankful for what they receive despite of the quality. After all, what can a

person, who does not know the main language of the country and who lives in the shadows of the law, do in order to become part of a health system that is large, complicated, expensive, and impersonal?

The following table breaks down the demographic information collected during the first part of the interview (see Appendix I for the complete questionnaire). These responses shed light on the educational situation of each individual and their self-described abilities to speak, write, understand, and read in English. In addition, it provides information on the years the participants have been living in the United States and their country of origin. Every person interviewed answered the pre-screening questions before the interview (See the pre-screening questions in Appendix J). These subjects have been living in the United States for several years. The most recent resident has been living in the country for 5 years, while some of them have been residing over 20 years. In regard to the education, the subjects who had more than high school education obtained it in Mexico. However, the majority of the people have less than a high school degree. This is especially important because of literacy skills that are needed to effectively navigate the health system. All these subjects spent time at the hospital accompanying a child diagnosed with a chronic illness and were exposed to receive health promotion information about pediatric cancer.

Table 4.55 Demographic and Linguistic Information of Subjects.

# of subject	County	Origin	Years in the US	Lang. Spoken at Home	Highest Year in School	Speaks English	Writes English	Understands English	Reads English
1	Starr	Mex	18	Span	10th	No	No	Little	No
2	Starr	Mex	10-15	Span	9th	No	No	No	No
3	Starr	Mex	30	Span	4th	No	No	No	No
4	Hidalgo	Mex	24	Span	6th	No	No	No	No
5	Starr	Mex	18	Spa	10th	Avg.	Avg.	Avg.	Avg.
6	Starr	Mex	16	Spa	6th	No	No	No	No
7	Hidalgo	Mex	23	Span	College	Good	No	Good	Good
8	Hidalgo	Mex	18	Span	6th	No	No	No	No
9	Starr	Mex	20	Span	8th	No	No	No	No
10	Hidalgo	Mex	20	Span	Drop HS	No	No	Avg.	No
11	Starr	Mex	5	Span	9th	No	No	No	Avg.
12	Hidalgo	Mex	17	Span	12th	No	No	Avg.	Avg.
13	Hidalgo	Mex	30	Span	College	Avg.	Avg.	Avg.	Avg.
14	Hidalgo	Mex	16	Span	8th	No	No	No	No
15	Hidalgo	Mex	17	Span	8th	No	No	No	No
16	Hidalgo	Mex	25	Span	8th	Avg.	No	Good	Avg.
17	Cameron	Mex	10	Span	Technical	No	No	Avg.	No
18	Hidalgo	Mex	17	Span	College	Avg.	Avg.	Good	Good
19	Starr	Mex	20	Span	9th	No	No	No	No
20	Hidalgo	Mex	7	Span	College	No	No	Avg.	No

Note: Numbers in the first column will be used to identify subject with the narratives

The subjects were asked to rate themselves in a scale from 1 to 5 to describe their ability to speak, write, understand, and read English. Some of them chose the scale for average or good; however, in the narrative, most of them talk about how, even when they are not completely unfamiliar with the language, their skills are not enough to recognize different accents, and more importantly, to recognize medical terms.

Table 4.56 Summary of Semi-Guided Questionnaire

Number of subject	Q9	Q11	Q12	Q14	Q16
S1	Yes	No	Yes	No	Yes
S2	Yes	No	Yes	No	Not sure
S3	No	Yes	No	No	No
S4	No	No	Yes	Yes	No
S5	Yes	Yes	Yes	Yes	Yes
S6	Yes	No	No	No	No
S7	Yes	No	Yes	No	Yes
S8	Yes	No	Yes	No	No
S9	Yes	No	No	No	No
S10	Translator	No	Yes	No	No
S11	Yes	No	Yes	No	No
S12	Translator	No	Yes	No	No
S13	Yes	No	No	No	Yes
S14	Yes	No	No	No	Yes
S15	Translator	No	Yes	No	No
S16	Translator	No	No	No	No
S17	Translator	Yes	No	No	No
S18	Yes	No	Yes	Yes	Yes
S19	Yes	No	No	No	No
S20	Translator	No	No	Yes	Yes

Table 4.56 shows statistics of some of the questions asked in the second and third part of the interview. This table shows those questions that can be quantified into positive (yes) or negative (no) responses, and expressions of doubt (not sure). Question 9 (Q9) summarizes if they received services in Spanish when they had to visit the hospital.

Question 11 (Q11) represents answers to the question if they had access to information

about their child's illness before the diagnosis. Question 12 (Q12) comprises responses about the usefulness of written information. Question 14 (Q14) asks if they have information about childhood cancer that could potentially help them seek an early diagnosis. Question 16 (Q16) tells the responses when asked if they know some of the symptoms for childhood cancer. Some people gave a very direct yes or no answer for these questions, in some other cases; the answer was given as part of a narrative. Narratives are also discussed in this section; but, this table allows creating percentages as a complement to interpret the narratives and the results.

More than half of the people interviewed said, in Question 9 (Table 4.56), that they received services in Spanish (60%) and only 30% said they were provided with a translator. However, this translator was not always a professional trained person. As it will be explained in the next part of the results, the interpreters are often family members or nurses who are not trained to translate medical terms. The fact that most people admitted to have received services in Spanish was expected because healthcare centers have bilingual personnel that can provide oral assistance in Spanish. The functionality of the linguistic services provided is uncertain because most people can speak the language but have not been appropriately training. In addition, even in the cases where quality translations were provided, the problem presented by this study is the reliance on oral information that will be lately shared with other family members at home. One of the subjects that understands some English shared a story about a nurse serving as translator and the errors in the communication she was able to witness:

Q9-S7: *Yo entiendo el inglés bien...entonces yo sabía que lo qué le había dicho el doctor en inglés, me lo hablaba la enfermera, pero ya no era lo mismo, como el juego del teléfono descompuesto. Y me pasó una vez, que oí que el doctor le había dicho a la enferma sabes qué, le dio una alergia [al niño] no le pongas esa [medicina] cámbiasela y la enfermera comoquiera, no sé si no obedeció al doctor o no le entendió, pero yo oí que el doctor le hablo en inglés a ella, aunque creo que la muchacha hablaba español, pero hablaron en inglés los dos, y ella le puso a mi hijo la medicina que le hacía daño y se llenó de rash, le dio una reacción mala, y entró el doctor y le dijo oyes pues si te dije que le pusieras otra...creo que ya a veces es como hasta las enfermeras no entienden el idioma.. y me dio risa.*

In this situation, the parent was able to understand when the doctor told the nurse to use a different medication because the child had an allergic reaction; however, the nurse still used the medication and the child developed a skin rash. The mother thought that maybe even the nurses do not understand English very well. It would not be surprising that some nurses also struggle with the language, taking into consideration that the majority of the people in the region speak Spanish most of the time. Also, knowledge of conversational English does not mean people can accurately translate and understand medical language. The reaction of the mother was to laugh at the situation because this particular error only caused a skin rash; however, it talks about the issue that most of the time medical professionals are being asked to serve as translators or interpreters when their own ability in the language is uncertain.

The parents who participated of the study went to the hospital with their children for different health reasons; therefore, the purpose of Question 10 (see Appendix I) was to find out what is the general source of information about their children's prior illnesses. The majority of the participants responded that they searched online or they rely on the information received at the doctors' office. The following are the responses of the subjects that use the Internet for information:

Q10-S1: *Mucho fue en el internet, también periódico, y es que te digan así también.*

Q10-S5: *Internet.*

Q10-S13: *En internet.*

Q10-S14: *Internet pone los síntomas.*

Q10-S17: *Internet.*

Q10-S18: *Por medio del internet.*

Even though 30% of the subjects searches online for information about the illness, the Internet has its own dangers. The information that could be considered reliable online has the same problems as the written information. The translation is not the best in most cases and the level of readability is often too high. Still, people understand that not everything found online can be trusted. This creates a conflict because the information found in reliable sources could be used to obtain knowledge and serve as a guide to ask questions and participate in community groups. Nevertheless, because of the amount of misleading information found online, some people prefer to dismiss it completely and

rely only on the oral information received at the doctor's office as it is explained by these following subjects.

Q10-S2: *Ahí con la doctora, no me gusta por internet miya, es puras mentiras.*

Q10-S4: *Trato de no buscar por internet porque haces más grave el problema, más grave emocionalmente de lo que es, entonces primero que nada me dirijo a sus pediatras, ya después de ahí, de lo que me diga el pediatra, ahora sí me voy con una base más a buscar qué es lo que es el padecimiento.*

Another group of subjects admitted that they did not had any previous information about the illness. They relied on the information received at the healthcare institution. This goes back to the issue of reliance on oral information and memory discussed in Chapter 2 (see Section 2.3).

Q10-S3: *Mi esposo estuvo conmigo y él sí sabe inglés, nada más que eso, lo que nos decían los doctores.*

Q10-S9: *Pues ahí con los doctores, ellos te dan información.*

Q10-S10: *Fue por el doctor primario, que viene siendo la pediatra.*

Q10-S11: *Me lo dan en los dos idiomas, cuando voy a la clínica me dan hojas, información.*

Q10-S19: *En la clínica.*

Q10-S20: *Directamente de los doctores.*

In regard to the written information, they admitted that they received documents at the hospital but they are not very useful. The following examples show what people had to say about written information:

Q10-S6: *Casi todo viene en inglés, entonces ya te explican hasta que llegas al hospital.*

Q10-S8: *Folletos que agarro en las clínicas.*

Q10-S12: *A veces en programas en español, y cuando es en el hospital casi la mayoría te las dan en inglés, hay veces que pides en español, pero comoquiera te dan en inglés, escrita en folletos.*

Q10-S16: *En folletos, en agencias como estas de salud [LUPE].*

The responses of two of them did mention the importance of the job done by community health works and agencies.

Q10-S7: *El outreach [formado de padres hispanos] sí se preocupa de por lo menos encontrarte la información.*

Q10-S15: *Agarro más información por medio de las promotoras de salud, como ellas andan afuera de la comunidad entonces tienen más la información en español, en el idioma que uno habla, pues ya nos dan esa información y pues ya la obtengo de ellas.*

These community organizations and centers have the possibly to disseminate information about illness to every corner of the region. They have the training to build trust and get to know what people need. They provide affordable healthcare services, which provide a perfect meeting place to get information out to the community. However, if the field of medical translation does not allocate resources to the production of culturally appropriate translation as recommended by the current interdisciplinary research, the efforts of these

centers are not as productive as they could be. People do get texts with information, but their level of serviceability ultimately depends on the translation strategies used.

These results led to scrutinize the answers to Question 11 of the semi-guided interview (see Table 4.56). This question asked if they had knowledge about the particular illness before the hospital visit and how it would have helped them to be informed prior to the hospitalization. The purpose behind this question was to know how well information is being used in the community for health promotion, and to know how informed are parents about the different illness that can affect a child. The end-point of this question was to elucidate the fact that parents rely on information given after the diagnosis, once they meet with the doctor; this is based on the premise that health promotion about common children's illness has not fully reached the rural areas that are farther away from the mainstream communities. Eighty five percent of our interviewees accepted they had not heard anything about the illness before they were faced with it. The following subjects went on to explain how to have information before a diagnosis could have made a difference in their experience.

Q11-S1: *Sí me hubiera gustado, si se fuera [sic] podido antes, porque yo tuve otra niña después.*

Q11-S4: *Sí, porque hubiera evitado tanto medicamento que se le suministró sin saber qué era. En la edad de 8 a 12 años, estuvieron con muchos medicamentos que le subieron mucho de peso, y luego le quitaban el hambre y luego cosas así. Entonces, le hubiera evitado eso.*

Q11-S7: *Porque a lo mejor hubiera estado más preparada en lo que es las cirugías o qué esperar, que le hubiera evitado todo ese trauma. Como yo no sabía nada dejaba que le hicieran de todo...si yo hubiera sabido más inglés, y me hubiera informado y le hubiera entendido todo lo que él pasó en 5 años cuando él nació, a lo mejor su vida hubiera sido diferente.*

Q11-S9: *Pues sí, cuando le encontraron el tumor ya era muy avanzado.*

Q11-S12: *Si pides información antes, pues sí. A veces hasta que vas ahí es cuando te dan información y a veces no quedas bien convencida de cuál es la enfermedad.*

Q11-S14: *Sí me hubiera ayudado, como fue así de emergencia no sabía qué tenía, no tenía información.*

Q11-S15: *Sí porque yo no sabía ni qué era y de los doctores me fui informando un poquito.*

Q11-S16: *Es que cuando voy nada más te dicen qué tienen, pero no te explican cómo es que la agarró [la enfermedad], como que hace falta que expliquen un poquito mejor.*

The consensus among these subjects is that by the time they are faced with an illness it is too late to start learning about the illness. As an example, **Q11-S12** states that the general feeling is that the oral information they received from the doctor seems like it is not thorough. **Q11-S14** and **Q11-S5** present the concern that when they are faced with an emergency, everything is so fast paced in the healthcare system that it is too late to gather all the information they need in order to make decision. That is why the availability of

health promotion materials that are readily available to everyone in the community regardless of the language they speak is crucial.

Question 12 (Table 4.56) aims to see if they had information after going to the clinic and how useful they found it as an aid in the decision-making process. The answers show that 55% found information to be useful to make decisions. People understand the importance of written information but they are accustomed to rely more on the oral information so they still do not consider that it can make a significant difference and affect their decisions. The importance of using written information to make a decision is the fact that this is the information they can take home to read at their own pace and share with family members.

Q12-S1: *Ya que tienes a la primera [hija], te estás informando para el segundo embarazo.*

Q12-S2: *Sí, folletos que te dan en el hospital.*

Q12-S4: *Sí, en libros en la librería, empiezo a leer más.*

Q12-S5: *Algunos folletos.*

Q12-S8: *Solo folletos.*

Q12-S9: *Pues ya no vimos nada porque ya era muy tarde y mi niño falleció.*

Q12-S10: *Sí, en el hospital se encargaron de darme lo que es el diagnóstico en español y las instrucciones que íbamos a seguir en casa, en español.*

Q12-S14: *No, no le entiendo.*

Q12-S15: *Sí, por medio de las promotoras que me han dado en papel y de ahí he tomado [información] cómo tenerle limpio el área, cómo lavar su ropa, qué cosas puede usar, qué animales no pueden estar, entonces sí me ha ayudado.*

Q12-S16: *Cuando a mi hija le iban a hacer eso [cirugía] dijeron que había riesgos, me dijeron firmele aquí, pero estaba en inglés, así que nada más me dijeron que era por si a su hija la anestesian y si duele la anestesia, pero no era en español.*

Q12-S20: *Tanto como a tomar decisiones se me hace que no, sí he visto información, pero tanto como para tomar decisiones no, porque la información que he visto es nada más para tener más información sobre la enfermedad.*

As it can be seen by these answers, people do receive information at the hospital; hence the importance of taking culture and literacy into consideration when translating. People want to be informed about the illness. For example, **Q12-S15** says, some people rely on information provided by health workers; caregivers want to know exactly what to do when they get home.

When asked about who helped them make decisions (see Question 18 in Appendix I) the vast majority, 80% of them, had family members to rely upon in order to decide about their child's treatments:

Q18-S1: *Mi esposo.*

Q18-S2: *La familia.*

Q18-S3: *Mi esposo.*

Q18-S4: *Solo yo, su doctor y yo.*

Q18-S5: *Mi esposo.*

Q18-S6: *Mi esposo.*

Q18-S7: *Nada más yo, a veces mi hermana...tengo mi grupo de oración.*

Q18-S8: *Mi esposo y doctores.*

Q18-S9: *Mi esposo y tengo una niña ya de 19 años que también me ayuda.*

Q18-S10: *Mi esposo, mi hija, en sí, lo que es la familia en general.*

Q18-S11: *Mi esposo.*

Q18-S12: *Yo, nada más.*

Q18-S13: *El doctor familiar, y algunas veces los doctores especialistas.*

Q18-S14: *Mi familia, cuñada, hermana.*

Q18-S15: *El doctor de cabecera.*

Q18-S16: *Mi esposo, también mi hija.*

Q18-S17: *Mi esposo falleció, él tomaba las decisiones conmigo, así que ahora solo las tomo yo y a veces mis hijos también me aconsejan.*

Q18-S18: *Mi esposo y hermanas.*

Q18-S19: *Mi esposo.*

Q18-S20: *Mi esposo y mi mamá.*

This is why it is so important to have accessible information for everyone. It is not characteristic of the Hispanic culture for one person to make decisions about health alone; the family is always involved. Without effective written information, only those who are physically present receive the oral information at the office and the family has to make decisions based on the memory reliance of the person that was present when the

diagnosis and/or procedures are explained. Once the family leaves the healthcare institution, more than likely, as proved by the results, they will share the information with family members in order to make health related decisions; however, the advice received from these family members is based on the information they heard from whomever was present at the doctor's visit. The information they received is filtered by the receiver and therefore not as reliable and complete as if they had first-hand access to dependable and functional written information.

Question 14 (Table 4.56) was directly related to the field of pediatric cancer. It was discussed in Section 1.6 that one of the reasons for the disparities in this area was that the diagnosis came at a later, more advanced state. This is, in part, because parents are not aware of some of the symptoms. In these responses 80% of the parents admitted to not having enough information about cancer that could result in an early diagnosis if they were in that situation.

When asked in a more direct question about how much information they had about pediatric cancer, their answers also revealed very limited information.

Q14-S1: *No, o sea nomás lo que hasta ahorita he sabido, conforme van creciendo uno les va poniendo inyecciones sobre el cáncer.*

Q14-S5: *El único cáncer infantil que más o menos tengo información es la leucemia. Sé que cuando empiezan a cambiar sus actividades y empiezan a tener menos energía y ánimo. Lo que tengo entendido es que la leucemia empieza por falta de glóbulos rojos y la anemia, y después se va complicando, va faltando los*

glóbulos rojos. Entonces sé que la falta de apetito y los cambios de humor, todo eso son síntomas.

Q14-S7: *No, porque lo único que he experimentado, y fue muy rápido, porque el cáncer es una enfermedad que ahorita estás bien y mañana no, la única experiencia es mi padre que tuvo cáncer del estómago, y él estuvo vivo por 5 meses. Le pegó bien fuerte, o sea que ya estaba avanzado. Me hubiera gustado tener más información, pero sinceramente hasta ahorita no tengo información, sí tengo información básica, pero hasta ahí. Pero sería bueno.*

Q14-S9: *Pues nada más lo que nos decían de nuestro niño ahí en el hospital, de su tumor.*

Q14-S10: *Sí, he escuchado, no sé mucho, sí sé que da a los niños, jóvenes y adultos, y sí sé que hasta ahorita van avanzados en cuanto a la cura, pero es todo lo que sé.*

Q14-S15: *No nada de información, sé poquito de lo que escucho en la televisión o platico con gente que ha pasado por eso.*

Q14-S20: *Un poquito, he visto los síntomas en internet, como cuando empiezan: la pérdida de peso repentina, sin motivo aparente, fiebres, que los niños se ven como débiles, creo que también empieza con manchitas en la piel, pérdida del apetito creo también.*

The other subjects who denied having information answered with a **no**. What is remarkable about these narratives is the fact that most information comes in oral form, either from a family or friend who went through the illness or via the Internet and

television. It is concerning that answers, such as the one given in example **Q14-S1**, reveal that some information they believe to know is erroneous. Once again, none of the people interviewed admitted to receive any type of written information (except the one read online); this means that either the information is not reaching their households or if it is, then it is not meaningful or accessible enough for them to remember what they read.

The symptoms of childhood cancer, when presented, can be very general, almost as if it was a common ill-feeling any child can experience at some point in their lives. However, it has been explained that when a combination of these symptoms is exhibited, parents are urged to take their child for a checkup. The results to this question (Question 16) showed that 80% said they had no information about the symptoms, 5% percent were not sure, and 35% had some idea about how to recognize at least some of them. The following are some of the answers for the subjects that knew about the symptoms:

Q16-S1: *Yo pienso que la gente se empieza a sentir mareada, se siente mal, realmente no sé los síntomas, no se falta de sangre, falta apetito, miras cambios de una persona alegre a mas apagado.*

Q16-S2: *No sé, a veces ni síntomas da.*

Q16-S5: *Lo que he oído y visto por un conocido que falleció, sé que era que le empezó a salir moretones y que en realidad era leucemia.*

Q16-S7: *Muchas veces depende de dónde te afecte. Por ejemplo, si es en el pecho es que tengas una bolita o calentura, o si es en el estómago, como mi papá dejó de comer, que se sentía lleno, y ya era [cáncer]. Cuando terminó se veía como una señora embarazada. O si es en la garganta, empiezas con molestias. De parte*

de mi papá, sus hermanas que eran como 6, murieron de cáncer, entonces me platicó que lo más importante es cuando dejas de comer, ellas dejaron de comer, aunque según los doctores no es lo más importante, porque hay otras cosas que puedes notar. Pero mis tías una murió de cáncer en la matriz, cáncer en el pecho, cáncer en el estómago, todas dejaron de comer y el dolor que pueden sentir. Algunos no sienten dolor, pero tienen secreciones anormales y pues nada más, no conozco mucho del cáncer.

Q16-S13: *Cansancio, temperatura, debilidad, fiebre.*

Q16-S14: *Como a veces oigo en la tele, que, si te sientes como cansado, con sueño, puede ser. Porque así le pasó a mi amiga, a su mamá, pero no se checó, y ya se dio cuenta cuando estaba avanzado, en etapa 4. Y era los síntomas que tenía ella, con mucho cansancio.*

Q16-S18: *Baja de peso, falta de apetito, dependiendo el lugar del cáncer, son diferentes síntomas.*

Q16-S20: *Fiebre, pérdida de peso repentina, decaimiento que ves en los niños.*

As it can be seen in these responses, some of the interviewees had a vague idea of the symptoms; nevertheless, this knowledge came from things they heard or people they know that had a child with cancer. None of them cite a qualified and reliable source for this information.

Question 17 asks about the interviewees' knowledge of available treatments to cure cancer. Almost half of the answers (45%) were affirmative; yet, a review of the

narratives reveals again, they have only **heard** about chemotherapy and radiation and in some cases the information was misleading:

Q17-S7: *El único que conozco yo que es inmediato antes de que pegue más fuere es la quimioterapia, que muchas personas piensan que te van a meter aparatos y así y no, la quimioterapia es el uso de medicamentos y también aparatos de radiación. ¿Cuántos tipos hay? no sé. Sería interesante [saber] porque mi hermana y yo estamos de que ¡ay no nos vaya a dar cáncer!*

Q17-S9: *Pues la verdad no sé porque, como le dije, a mi niño ya era muy tarde y no le hicieron nada.*

Q17-S10: *Sé que hay muchas alternativas porque ha avanzado la medicina, sé que hay radiación, quimioterapia y otros métodos, pero los desconozco.*

Q17-S12: *Pues yo lo único que sé que con quimioterapia o el medicamento que dicen que cuando está al principio con medicamento pueden tratar de curar y detener. Y la otra es la quimioterapia.*

Q17-S13: *La quimioterapia, y también algunos tratamientos naturales.*

Q17-S14: *Nada más que con quimioterapias.*

Q17-S15: *Sé que hacen las quimioterapias, yo creo que todo depende de qué tipo de cáncer sea, sé que hay el medicamento, es lo que dicen.*

Q17-S17: *Sí sé que se trata por medio de quimioterapias y radiaciones. En algunos casos se puede hacer una cirugía para extraer un tumor o un órgano invadido sin que se pase a cualquier otro lugar.*

Q17-S20: *Nada más de los médicos, es radiación y quimioterapia.*

In the same manner as with the symptoms, the interviewees answered positively to the question claiming they knew about the available treatments, but in the narrative, they assert that the information they have is only what they have heard from other people. None of them mention to have *read* information about it. In example **Q17-S12** it is believed that if it is diagnosed at an early stage, it can be cured with medicine. Examples **Q17-S12** and **Q17-S15** attribute their information to “*lo que dicen*”, that is, to what people say. Again, their knowledge is based on what they believe they have heard from other people. Other subjects do know that the most common treatments are chemotherapy and radiation but they do not have any other information about it other than the name.

Subjects were also asked to describe what is cancer using their own words (See Question 15 in Appendix I). This question had two purposes. The first objective was to find out what was their general perception of knowledge about cancer. The second reason behind this question was to find the recurrent motif found in the texture of the oral narrative; that is, what are the linguistic choices that people use to construct their experiences about the illness. They responded as follow:

Q15-S1: *Es una enfermedad que muchas veces tiene cura y muchas veces no, que es algo que no quisiera uno ni pasar por ahí.*

Q15-S2: *Una enfermedad que te va acabando lentamente.*

Q15-S3: *Una enfermedad malísima y que te puedes morir.*

Q15-S4: *No tengo ni la menor idea.*

Q15-S5: *Es la enfermedad de moda. Lo difícil es que muchas veces no se sienten los síntomas hasta cuando ya está muy avanzado.*

Q15-S6: *No tengo idea, que casi es la muerte.*

Q15-S7: *Una mal deformación de las células que afectan a las otras que están bien y se va creando. Donde se quede pegado esa mala célula, ahí va a estar contagiando a las demás y se va haciendo más grande y más grande. Depende del tipo de cáncer.*

Q15-S8: *No sé nada.*

Q15-S9: *Pues es una enfermedad muy grave que lleva a la muerte y a veces ni te das cuenta hasta ya después.*

Q15-S10: *No tengo mucha idea, desconozco lo que es todo el concepto del cáncer.*

Q15-S11: *Una enfermedad silenciosa que ya cuando te das cuenta ya estás todo podrido.*

Q15-S12: *Nada más lo que oímos, es una enfermedad que va como invadiendo algún órgano y es que va afectado, [lleva] a una muerte. Siempre que escuchas cáncer es lo que dices, es la muerte, es lo que viene del cáncer. Pero a ciencia cierta, no sabemos cómo prevenir, estar checándose para prevenir, que ni nos sabemos cuidar y no nos vamos a checar.*

Q15-S13: *Son células que están dañadas en nuestro cuerpo y que se reproducen.*

Q15-S14: *nomás sé que es una enfermedad muy fea...hay muchos diferentes cáncer [sic], es lo que no le entiendo, nada más sé que es muy fuerte.*

Q15-S15: *Es una enfermedad que si se detecta a tiempo se puede curar, pero si no, sabemos que la mayoría de las personas fallecen por no tener el suficiente cuidado médico o no tener los recursos para ir al doctor.*

Q15-S16: *Escuché que son las células madres que son las que se deterioran o algo, es lo único que sé, que son las células que cambian de color, pero como es silencioso, es bien difícil de detectar.*

Q15-S17: *El cáncer es una enfermedad muy grave.*

Q15-S18: *Es una enfermedad hasta ahorita no curable.*

Q15-S19: *Solo sé que es una enfermedad que no es fácil de curar.*

Q15-S20: *Es como algo que le está haciendo falta al cuerpo para defenderse, como para ser autoinmune a lo que provoca el cáncer.*

From this information, it is understood that people have heard a lot of information about cancer but, again, not even one of the subjects cites a reliable source. All the interviewees have some information about cancer, they all know or have heard about the illness, but they all present different ideas about it. Most of the narratives refer to cancer leading to death (Examples **Q15-S2**, **Q15-S3**, **Q15-S6**, **Q15-S9**, **Q15-S12** and **Q15-S18**). While some of the information is based on facts, for example, they mentioned that cancer is a disorder of cells that affects the good cells and it keeps growing (Example **Q15-S7** and **Q15-S13**). Other participants, however, have misleading information such as the person that knows that cells change colors (Example **Q15-S16**). Several answers described cancer as a “silent killer” (Examples **Q15-S2**, **Q15-S9**, **Q15-S11**). This belief, while it holds some truth, it is also misleading because people think that there is nothing they

can do in order to get an early diagnosis. Also, it shows that people are not aware of the hereditary or ecological factors that sometimes come into play in cancer. Another issue that is highlighted in these answers is the fear of death. While some answers describe it as almost a death sentences, some of them do think that there is no cure (Examples **Q15-12** and **Q15-S18**) and, if diagnosed with cancer, you will most likely die. There is a large number of children who survive cancer, it is the lack of early diagnoses and follow up care what cause death in most cases.

The last set of data gathered from the interview is composed of the recommendations the participants would give to other parents who also struggle with language barriers (Question 13). In the narratives, the need to provide other parents with information written in Spanish is evident.

Q13-S1: *Estaría bien que hicieran pláticas en español de todo lo que pasa, lo que no sabíamos teníamos que estar informados por la televisión y [sic] internet, pero que sean más cosas en español.*

People are aware they are missing out on information that could be very helpful and while they know they can obtain information from some sources, there is a need for reliable information tailored to their specific culture and their needs. Some of them have admitted the fact that they rely on oral information and have found ways to depend less on memory. They are also aware of the need to figure out ways on their own to get reliable information:

Q13-S7: *Que digan pueden traer a una persona que me explique qué medicina le van a poner a mi hijo y que en primer lugar no deben dejar que una persona le*

sufra...me recomendaron que pusiera todo en una libretita...que investiguen de la enfermedad de sus hijos y también pedir segundas opiniones, no de cualquier persona, de doctores, a veces las personas te pueden ayudar, pero si no saben mucho es mejor tomar decisiones de personas que sepan.

Q13-S5: *La mayor información, lo que más se puede sacar es por el internet, puedes encontrar los síntomas, la calidad del hospital y todo lo que necesitas saber.*

Q13-S13: *Pues podemos aprender [inglés] y también informarnos por internet.*

Examples **Q13-S5** and **Q13-S13** show that there is a need for information but they believe the Internet is where they can find information. In the other hand, some of them trust that the information they get during the medical encounter is enough:

Q13-S2: *Todo está bien, no batallas ahí para que te hablen español y te expliquen las cosas.*

Q13-S10: *Siempre hay un apoyo, cuando no entiende el idioma uno al 100 por ciento, siempre proporciona el hospital. Hay medios para poder conseguir la ayuda en la traducción.*

This belief is that they only need someone that can help them translate and all will be fine. This ideology is sometimes based on the feeling of guilt that people have assimilated after they live in the country for years and are not able to learn the language. As reflected by these responses, the general feeling is that Spanish-speakers are usually thankful to get the information in their language. They do not see the oral assistance as a right, but rather as a resource, regardless of how broken it could be, it is perceived as

helpful because that is all they know. In the next examples, it can be seen how they feel guilty for not knowing the language:

Q13-S15: *Seguir aprendiendo de poquito en poquito, pero a veces también por la edad ya es difícil que aprendan el inglés, pero siempre preguntarle a la persona que crees que te va a dar información correcta. Hay veces que le podemos preguntar al vecino o a la amiga y hay veces que no es la información correcta.*

Q13-S16: *Tenemos que aprender inglés precisamente por estas barreras que a veces tenemos. Yo pos ahorita estoy tratando de aprender más inglés también. Y yo sé que para algunas personas es más difícil porque ya están grandes de edad, pero les estoy recomendando que traten de estudiar o que le digan que les expliquen bien, así al doctor, si no entiende.*

However, learning the language well enough to have a conversation does not mean that they can fully function in the health system. They need to be able to understand medical terminology and the different English accents used by medical professionals:

Q13-S20: *Que siempre pidan traductor, porque muchas veces, por ejemplo, en mi caso que los doctores ven que como medio entiendo, medio hablo, se quieren quedar así de que “nombre, usted puede” y me quedo con muchas dudas porque ellos empiezan a hablar en términos médicos que muy apenas los entendería en español, imagínate en inglés, entonces que siempre pidan el apoyo de un traductor.*

Q13-S7: *Hablaban inglés y ahí eran mis hijos los que me estaban traduciendo porque unos son filipinos y hablan el inglés diferente porque a los americanos*

como que hablan más despacio y sí les puedo entender, pero con los filipinos era un sonido diferente y pues no les podíamos entender. El doctor nada más me explicaba lo elemental, de que “está bien su hijo”, pero nada más así, no bien.

In these examples, it is shown how the interviewees recognize the dangers of translating medical information when they have not been properly trained. In example **Q13-S20**, the medical personnel tell the person that because she knows a little English she does not need any linguistic help. The subject quotes the expression “*nombre, usted puede*” told by the medical staff to note that in the fast-paced health system, they seem to think that what she knows will be enough to understand the information. However, as the subject recognizes, the fact that someone can have a conversation in English does not mean that the person will be able to understand, translate, and make decisions based on medical terminology. The subject even goes on to say that the medical language will be hard to understand even in Spanish, her native language. This puts into perspective just how dangerous it is to rely on untrained personnel or family members to translate medical terms with which they are not familiar in their native language.

The responses also indicated that waiting to take a child to the hospital is a threatening action for a timely diagnosis. The waiting time and the self-medication are severe problems for people who are scared of the system and would rather avoid it until there is no other available option.

Q13-S8: *Lleven a los niños a los chequeos porque así ya sabes que tienen porque muchas veces que les duele el estómago, la cabeza y nada más les das para el dolor. Pues no. Es de que los lleses a checarlos para saber qué es lo que tienen.*

Q13-S9: *Que los chequen a tiempo, que un dolor de cabeza puede ser algo peor y hay que estarse checando.*

Q13-S17: *Que no ignoren signos que parecen ser inofensivos porque podría ser algo más grave.*

The response from example **Q13-S8** pointed to the issue that to some parents self-medicating is always the first option. In this community, this is a particularly important issue because there are several reasons why parents rely on self-medication. First, there is a strong sense of the use of cultural remedies that have been passed down through generations. Second, there is high percentage of the population that does not have medical insurance. Third, the legal status of some parents makes them afraid to look for medical help since they are afraid their child might be separated from them. All these reasons are characteristic of this community (see Section 1.7).

One of the parents interviewed had recently lost a child to cancer and in their recommendation, they warned about the lack of information and going to the hospital when the cancer is already in a later stage:

Q13-S9: *Ya no vimos nada [de información escrita] ya era muy tarde y mi niño falleció. Cuando le encontraron el tumor ya era muy avanzado. Nos dijeron que lo lleváramos a un hospital en Corpus Christi. Ahí le hicieron cirugía y como un mes después nos dijeron que teníamos que regresar a ver los resultados y fue cuando dijeron que su cáncer era una de los más agresivos y que no se podía hacer nada.*

This last remark is indeed heartbreaking and leads to ask a rhetorical question: Would have the availability of written information for health promotion made a difference for this family? Maybe, maybe not. Kids still die of cancer all the time. It is a pervasive illness, the second leading cause of death after accidents. What is undeniable is the fact that disparities do exist in regards to diagnoses and survival in different ethnic groups. It is also a fact that linguistic and translation theories have been proven helpful to the field of medical translation. In spite of all the research done until now, the answer to this question will not be found until research, practice, and theory work together towards a common goal. The goal is not to provide linguistic services. Services do indeed exist. The goal is to keep in mind that human beings are at the center of all health services regardless of the language they speak and being empowered to make decision about their health is a human right.

4.3.1 Textual Metafunction: Motifs and Repetitions in the Narratives

In order to finalize the comparison of motifs and repetitions used to describe cancer that were discussed using the written data in Section 4.2.3.2, the narratives were also analyzed to discover the words that the community use to answer the question “What is cancer?”. The most common context-carrying words found in these narratives used to describe what is cancer are the following:

- Cáncer
- Enfermedad
- Células
- Muerte

In the translated written information, the context carrying words that were mostly used to describe what was cancer were (See Figure 4.1 and Figure 4.2):

- Sistema
- Tumor
- Cáncer
- Metástasis
- Cuerpo
- Células

The choices of words that people use to describe the illness are more limited. It was unexpected that they did not use words such as *tumor* or *cuerpo* because these are the most common words used in booklets and flyers. The word *enfermedad* does not appear in the written text but it is widely used by the subjects. Also, the word *células* was used more frequently in the oral narratives. This is due to the fact that these words are easier to understand, in comparison to words such as *sistema* and *metástasis* used by the written texts. A community that is characterized for low literacy levels will prefer less complex words to communicate a message. The next section will shed light on why the people prefer simpler words to communicate.

4.3.2 Medical Staff and Community Health Workers Narratives

Most of the narratives point to the fact that information about health and health promotion is passed via oral form. People learn about illness through what they hear from the doctors, the medical staff, or from experiences learned through family, friends, and neighbors. Some subjects mentioned the importance of the community health workers as

vehicles of information in the rural neighborhoods. Therefore, their perspective about the need of effective translation in Spanish was inquired. The perspective of the community health workers (CHW) is important because as they walk through the neighborhoods and get first-hand accounts from the community, they know what they need in order to have better experiences in the health system.

The first community health worker interviewed made reference to the need to know what services are offered at each institution. She mentioned that all flyers should have a section where resources for the community are present as, often, people from the colonias will not go to a clinic because they lack health insurance and they do not have the money to pay; however, they do not know about the resources that are available to them.

CHW1-1: *Pues creo que lo más importante es como la información de los servicios que dan porque muchas veces la gente no sabe los servicios que ponen en inglés, les dan los folletos en inglés y sería bueno que tuvieran información en español también...yo noto mucho eso, que no te dan la suficiente información en español del lugar y los servicios y si tienen algún tipo de beneficios y servicios para la gente que puedan servirles más, económicos, porque hay veces que hay gente que no tiene seguro médico.*

In regard to the language being used to translate, she mentioned the fact that it is a common practice to use computer translators to make the information available in the language without proper editing.

CHW1-2: *pues yo creo que no nada más los traduzcan con [pause] porque yo entiendo que muchos los traducen nomás con Google y así. Y muchas veces google no te da el suficiente [sic] información sobre las palabras, a veces pone palabras diferentes...a veces ponen palabras que no, la gente muchas veces no conoce, y se quedan, así como que, “¿y eso qué es?” Son palabras muy formales y es mejor que tengan palabras más sencillas, que más se conocen en el área yo creo que depende mucho del área.*

This perspective confirms the need of having a translation that is specific for the language of every region. The community has a very specific linguistic variety; therefore, the translations done by an automatic translator are not effective because people cannot understand them. The CHW 2 goes further into detail about the need to have translations that are understood by the people in this area. She talks about her own struggles trying to translate documents for the mobile clinic they provide to the colonias

CWH 2-1: *Entonces al poner los requisitos, o sea son personas que son de las colonias, son personas que muchos no saben leer, muchos no saben escribir, no saben el inglés, y no saben las formas, o sea, nosotros queríamos nada más llevarles el servicio y nos daban formas que tienen que llenar, el ‘intake’ y esas, son las formas de consentimiento. Y todo en inglés, y el inglés avanzado, o sea, ¿pos qué? ¿cómo traducimos esta palabra? Si nomás viene una nurse practitioner en el bus. Como PA, we can translate that, you know, because she is an assistant, pero nurse practitioner, it took us a while to be able to translate that, and I don’t even think it’s a formal [word]. I don’t know that in Mexico they have*

that. ¿Si tienen nurse practioner? Like, no creo que hay eso, son enfermeras o asistente de doctor o así, o sea porque cuando estábamos buscando y pos I don't think there is nurse practitioners, ese título. So, entonces nosotros para da la palabra rápido dijimos, "okay, tenemos servicios gratis, chequeos gratis...y consultas con una doctora" She is not an actual doctor, but they'll get it...les explicamos que no es una doctora, doctora porque tampoco no podemos decir que tenemos una doctora y no es, pero así es como la gente entiende.

This short narrative gives a panoramic view of the struggles to translate when the people are not properly trained and are not familiar with the community. The CHWs are able to deliver the message because they have figured out ways to interact with the people in order to help them understand about the services. The interviewee mentioned that decided to translate the nurse practitioner title as “doctora” at first because that would convey the message that this person would be able to write prescriptions for them. If they had used the word “enfermera” instead, the community might have not responded to the advertisement of the services as it can be seen by the rhetorical question she presented in her narrative:

CHW2-2: *La gente escucha 'doctora', entonces puede recetar medicina. Sí, sí puede recetar medicina.*

Talking about the same advertisement of services, she went on to mention issues with translations with words as “screenings”. According to the CHW, they prefer to use the word “chequeo” because it is the word that the community recognizes and associates the intended meaning.

CHW2-3: *'Chequeo' is not an actual word, so acá nos dicen 'screening', right?, so okay, son como exámenes básicos, maybe, or examen, pero exámenes, y aquí la gente [dice] ¿Cómo? ¿examen?, pos no, a veces hasta se asusta la gente o así. Entonces pos 'chequeo', la gente entiende eso. Entonces, we have to have our flyers, we know that it's something that is not correct in Spanish, but it is efficient to get the word out. So, 'chequeos gratis y consultas con una doctora', right.*

This narrative is a good example of the alternative choices that translators need to make in order to convey the meaning to the target community. These community health workers have developed strategies to use the language based on their experiences with people. They know how to choose words that will carry the intended meaning; otherwise, the message will not be clear and functional for the purpose of delivering health care services.

In addition to these narratives, the social worker from the cancer clinic was also interviewed. Her perspective is important because she is the person in charge to deliver the binders and booklets with information to the patients when they visit the clinic. She was well aware of the issues found in the written translation and the need for this information to be available as a supplemental aid to what patients are being informed at the time of the visit.

SW1-1: *I think that certain knowledge or advice as to what to do after cancer, or the process of going through the cancer treatment should be given to the patients. Mainly because there is not always a translator around, so when the doctors explain, they don't always know or understand what they are saying so, they end*

up just confused and obviously, if they are the patient, they deserve to know what is happening.

She mentions two of the issues that have been widely discussed by this study. They reliance on the oral information given by the doctor at the time they meet in the office and the right of the patients to be empowered in order to make decisions over their health.

In regard to the written material distributed at the Clinic she stated:

SW1-2: *The material is very basic; the translations aren't given very accurately. So, I think they need to put more effort towards that. They are very basic and to the point. So, I think patients should receive supplemental information besides that.*

That is, the Spanish translations currently available are only transmitting some of the most basic information. This is not enough to clarify any confusion or concerns the patients may still have after the medical encounter.

SW1-3: *Whenever they make translations, they should definitely be putting more effort as to who will translate them and not use like Google Translate because they use Google Translate and it's not understandable, the computers don't do it correctly, so patients end up confused and can be misinformed through that.*

This closing remark is even more concerning as she recognized not only the importance of an appropriate translation to serve as a complement and extension of information, but she highlighted the fact that a bad translation can misinform the patient. In the managing of a life-threatening illness, the flow of information is vital. The danger of a patient or caregiver who is misinformed can severely impair the decision-making process and have

a great impact in the overall outcome of the illness. In summary, the lack of culturally designed translations breaks the bridge between the information and the services available. There are services available to people who lack medical insurance at a low cost or no cost, they do have the opportunity to take their children for timely medical checkups that can potentially result in an early diagnosis; however, the lack of information prevents people from using these services. Once there is a diagnosis of childhood cancer, there are several options for participation in clinical trials and other available treatments, but as the Social Worker, pointed out, the current available translations do not serve the purpose of informing people. As mention in Section 1.8, this Clinic provides services regardless of insurance or legal status, nevertheless, Hispanics children are still being not being diagnosed at an early state. The medical field seem to be doing its part in coming up with new treatments, the research and linguistic services branches of the medical field still have a long way to go in order to reach these communities.

4. 4 Summary of Findings and Discussion

The intent of this study was to present an inclusive perspective on the status of medical written translation in the field of pediatric cancer. The research approach was delineated to display a multifocal approach of the functionality of translations to promote and disseminate health information in a linguistic minority community where the path of accessibility to the health system is constantly obstructed by linguistic and cultural barriers. The use of Systemic Functional Linguistics set side by side with translation

practices and the public's perception about the effectiveness of the information allowed to recognize different issues camouflaged by the readily availability of linguistics services. Through the analysis of the Interpersonal, Ideational, and Textual Metafunctions, different problems in the translation were adverted, but most importantly, the SFL tools shed light on the potential practicality of its use as an alternative method to generate translations contextualized to all cultures and ideologies, and utterly functional in the efforts to eliminate health disparities. The underlying idea in these results is that every choice of words, as revealed in every stratum and instance of the text, ultimately affects how people perceive themselves represented in the system, and as active agents in the healing process. Therefore, the undeniable need to approach translations from an interdisciplinary approach in order to break the patterns of errors in communication that permeate linguistic services in the health system. In the next and last chapter, a summary of the results will be presented as well as the answers to the questions posed at the beginning of the study and how the findings support or reject the formulated hypotheses.

Chapter 5

Conclusion

5.1 Summary of Results

In this chapter, we will present an overview of the main results of the study, followed by some implications for the fields of linguistics and medical translation, and a brief discussion about the future of SFL and Machine Translation in healthcare contexts. The last part of the chapter will include some limitations of the present study and suggestions for future research.

This study started with three questions and three hypotheses that pretended to answer each one of the questions (see Section 2.10). The first question read as follows:

1. Are pediatric cancer translated booklets and handouts culturally and linguistically appropriate for this community to effectively decrease health disparities?

This question referred to the fact that, according to research, written information was not culturally and linguistically adjusted for the target reader. As it was shown in the results (see Tables 4.20 to 4.54), the pinpointing choice analysis allowed this study to present the multiple adjustments that could be made in order to adapt a translation to the target community. Our hypothesis was that literal and traditional grammatically-oriented translations rely in the assumption that patients would understand the message just because it was written in Spanish. The fact that they are translating to Spanish does not mean the message is being delivered and understood by the reader who then has to rely

on the oral information exchanged at the time of the medical encounter. The narrative results for Question 13 (see Section 4.3) show how people have internalized the need to use oral help during the medical visit. They are thankful for whoever can help them translate because they believe it is their fault for not knowing the language. Moreover, the oral narratives do not refer to information they **read**. Quite the contrary; there are multiple references where they claim knowing about pediatric cancer because of information they **heard**. There is also a mixed sense of gratitude because the health system provides translations but also unease because they understand the language barrier prevents them from getting the full spectrum of information.

The second question this study aimed to answer was:

2. How is it that the oral narrative construction of the illness by caregivers could contribute to the process of culturally sensitive translations?

The hypothetical answer was that the anonymity of the translator allowed for a process of editing that was not done thoroughly making information confusing. As it was presented in Section 4.2.1.1 for the locally translated binders, not only there are numerous typing errors, but the omission of information and the choice of words definitely hinder the communicative process. It was confirmed by the Community Health Workers narrative (see CHW2-1 and CHW 2-2 and CHW2-3 in Section 4.3.2) that there are some choices in words that have to be intentionally made in order to convey the appropriate meaning. A translation without a functional edition tailored to the linguistic variety of the community will not be efficient in the dissemination of information.

The third question sought to find the barriers that the community faces to have an unhindered access to the health system.

3. What are the current barriers (or determinants of health) that affect this linguistic minority community to have full access to the dissemination and promotion of health that could result in early diagnosis of pediatric cancer?

The hypothesis behind this question was that language planning was not being done appropriately and timely; therefore, it was not taking into consideration all the determinants of health that characterize the region (see Section 1.4). The only intention of the written translations is to comply with the rules and regulations that request the provision of language services in minority languages and there is not enough follow up research to understand the tangible effectiveness of these translations. The medical staff, as explained by the Clinic's Social Worker (See SW in section 4.3.2), know that translations are made by computer translators and the message is confusing for the reader. The community is not being educated about general symptoms and the socio-demographic or hereditary determinants of illnesses such as pediatric cancer that could empower families resulting in an early diagnosing and greater survival rate.

The linguistic barriers are inevitable; this country has always been characterized as a country of immigrants. Border regions will not cease to receive people that cannot speak English and the health system will always be challenged by communication errors. The solution to eliminate disparities does not reside only on what people can do; neither does it reside only on what the system can do. The solution to the disparities caused by language and culture barriers require a type of practice that goes from the top to the

bottom and from the bottom to the top. The policies and the planning cannot be effective unless they are deeply based on a comprehensive understanding of the community. The community will not act to full effect in taking care of their health until they can completely understand and be part of the health system. The negotiator is the translator. How can the translator be equipped to address the challenge? By employing what Halliday and Matthiessen call “applied” theory and practice. In the next section, it will be explained how SFL is a valuable tool to analyze the results and how it can shed light to the future design of a computerized program based on SFL to create accurate and culturally-sensitive translations.

5.2 Results for The Interpersonal Metafunction

The Interpersonal Metafunction is realized by the Tenor. That is, the construction of the communicative message by means of the Mood. The importance of this realization in the translation resides in the fact that it positions the voice of the translator in a hierarchy of power in regards to the reader. In the field of medicine, brochures are meant to provide information about aspects of the illness requiring a response from the reader. The scope of readers’ responses goes from making decisions about available treatments, to be able to follow instructions on techniques to perform procedures at home. The information used for this study contained resources to live through and after the illness. Therefore, the translator was not seen as separate entity whose role is to simply accommodate the information into the target language in a way that conveys the message from the original writer; the translator is a mediator who negotiates issues of language

and culture among the context of the situation. The environment, the history, the politics, the mobility, the geography, and the urgency of the information, are all entities that need to be negotiated in order to construct a functional translation.

The interpersonal analysis of the data revealed, as it was expected, a predominant use of declarative and imperative sentences. The general information is given through declarative sentences, while the instructions to perform procedures are given using the imperative mood. However, results showed a constant shift of the voice. The translator randomly shifted from the third person to the first person. While the use of the third voice is conventionally used to imply respect and expertise on the topic, the first person is used to become part of the situation and play an empathetic role with the reader. That is, the translator breaks the impersonal rule and addresses the reader directly, in some situations assuming the role of a medical professional. The use of the third and first person, if used purposefully, can be beneficial to disseminate the information; however, there is no clear pattern as to when they are used. It shifts randomly, from one person to the other, demonstrating the lack of an intentional strategy to produce the expected response in the reader. This is problematic for issues of trust, which characterize the target community. In a culture with a strong oral tradition where health and remedies are transmitted through generations and where most of the information about an illness is *heard from* rather than *read*, the translator as a negotiator needs to have a clear position of his or her role in the exchange to achieve the first principle of health communication: mutual understanding.

The Interpersonal Metafunction analysis is crucial because people need to know that there is a credible source at the other side of the message. As shown by the results of the oral narrative, most people rely on the information received by the doctor at the time of the visit. However, the number of people using the Internet to find information about their health is increasing. This is, in part, because the Internet allows them to feel in control about their health. In the Internet, they can ask all the questions that sometimes they feel intimidated to ask personally. There is a general sense of guilt for not learning the new language that hinders their communication skills with the medical professionals. The Internet gives them the opportunity to look for information at their own pace and in their own language. Tonsaker et al. (2014) explain this phenomenon:

Patients now have the ability to find answers for additional or forgotten questions, as well as the opportunity to explore sensitive or embarrassing questions in the comfort and privacy of their own homes. Furthermore, through emerging patient-centered websites, blogs, and support communities, patients can share their personal health and illness experiences; they can offer special insights and reflections from the lived experiences of their specific health conditions, which physicians might not be able to provide. This type of information might help patients to become better informed about their illness, and also reduce feelings of loneliness and isolation. (p.407)

The use of the Internet offers a solution, partial at least, to reduce the invisibility of Spanish speakers outside the medical encounter because they can find the information in their own language, at home, and read as much as they need to be informed. However, as

it is in English and every other language, the Internet is not a reliable source of health information. While there are credible sources, for some people this creates a problem since “many users either lack the basic skills to conduct effective searches, or the resources to purchase a computer and engage in Internet search activities” (Lin et al., 2015, p. 217). In addition to the doctor, the next reliable source of information available to these communities is through the *Promotoras de salud* or Community Health Workers (CHW). Because CHWs belong to the same community they serve and they understand first-hand all the issues that are implicated when confronted with a health issue, they are a trusted source of information. Landers and Stover (2011) describe the work of the CHW and define them as,

providers in bridging the gap between clinicians or public health “professionals” and those in greatest need of health services, a group that often includes individuals within communities that are hardest hit by poverty, racism, immigration status, and language barriers, factors that are commonly correlated with poor health status and outcomes. [They] represent the intersection between risk and resilience, between institution and community, and between research and practice. (p .2198)

Individuals recognize and use information received orally from medical professionals because they are considered experts on the field. They also accept what is said by CHW because of the relationship of trust and respect they build within their own community. The fact of the matter is that reliability on oral information as a source of health promotion and dissemination is because people unquestionably trust the voice at the other

side of the communication exchange. Even on the Internet, they believe that information is coming from a voice of expertise. The translators with the shifts of voice and the constant errors do not portray this sense of trust. The Interpersonal Metafunction tool can shed light on how the written translation can become an effective extension of information if the tenor aligns to make the reader the center of the information. That is, when there is an intentional use the person and the type of sentences used by the translator to foster a relationship with the reader of mutual trust and understanding.

5.3 Ideational Metafunction Results

The Ideational Metafunction results in this study exemplified how the exchange of information was permeated by choices of meaning where the culture was not represented. While the use of parental recommendations intended to create a sense of community, there cannot be a sense of shared community experiences using cultural factors and idiomatic phrases that only apply to the source text culture. While the transitivity processes may be similar in both cultures because of the use of equivalence, the imagery used to represent the ideology behind the mental, material, and relational process are not aligned for the target culture. The process of managing life with a sick child can be translated because parents go through the same experiences. In regard to mental processes, both cultures experience the same feelings and emotions. However, how they deal with these feelings is different, as issues such as *familism* and religion have to be taken into consideration. In regards to material processes, they go through the same “doings” and “happenings” while dealing with the illness, the treatment, the side effects and the periods of hospitalization, and so on, but the images and concepts used to

represent the lifestyle are different in both cultures. The verbal processes are also very similar since parents have to figure out a way to talk to their children and other family members about the illness; however, the way people talk is deeply permeated by culture. Even among speakers of the same language, there are issues of formality and closeness when addressing children and adults that need to be taken into consideration when negotiating translation.

The living situation of parents also presents an issue since some situations that apply often to people to this community were not addressed. For example, there were several instances where information was given about how to deal with a sick child when the parents were divorced or remarried. However, for Hispanic living in the United States there are more issues can cause a parent being away from a child besides a divorce or separation and that are rather common. Parents are often separated by legal residency status. It is not an isolated case to find a single parent dealing with a sick child while the other parent cannot legally enter the country. In some cases, they even send the child to live with relatives in the United States so that he or she can have access to a better healthcare and both parents stay on the other side of the border. There are also parents who have to leave the child only under the care of only one parent because they are migrant workers and they have to report to their job in order to help the family financially. These situations are very consistent in this region and they need to be represented when negotiating the translation.

When explaining all endeavors of the illness, parents and children have to be represented without falling into stereotypes. For example, the drawings and the toys used

as imagery could be negotiated to represent kids from other cultures, this will not change the meaning of the message but will integrate the real experiences of children. All the drawings used in the translations had English text. Adding images that represent the Hispanic children's experiences will not change the content of the information. It does not make it a new text; it makes an inclusive text. Every single choice made by the translator can include or exclude culture. The extent that parents and children can see themselves represented in all the dealings of the information, the more it will reduce the issue of invisibility and will contribute to the translations being a trusted resource.

5.4 Textual Metafunction Results

The Textual Metafunction analysis of the data portrayed the source text as constructed by meaning carrying words. The repetitions and motifs found were directly related to the topic being described. On the other hand, the repetitions and motifs found in the Spanish text revealed the use of connecting words as the only prevalent motif. This can be interpreted in two ways. First, Spanish sentences tend to be unnecessarily longer. The translator deviated from the shorter clauses used in English just because the variety of connectors in the Spanish language allow for a longer sentence. However, longer sentences and lexical density contribute to an elevated text in regard to literacy. Second, the fact that most repeated words in the Source Text lead to the point at issue suggest a more focused reading while the Target Text may not be constantly reinforcing the same concepts, that is, the translator may be using a variety of choices to refer to the

same issue. If the textual metafunction is defined as the *architecture* of the text, the word clouds allow for a panned view of the foundations upon which meaning is constructed.

5.5 Implications for the Fields of Linguistics and Medical Translation

The Systemic Functional Linguistics analysis shows how language can be negotiated at every point across the cline of instantiation and every stratification level. Translation is an interdisciplinary discipline; therefore, it is through concepts of SFL (such as socio semiotics, genre, and register) that the potential of translation as intrinsically related to culture and society can be approached. The translation field has been incorporating SFL since the work of Jakobson (12012), Baker (1992), Nida (1964, 1975), Catford (1965), Snell-Hornby (1988) Hatim and Mason (1990), Steiner and Yalop (2001) Munday (2012), Manfredi (2014). The convergence of linguistics and translation is explained by Nida (1975):

The linguistic orientation in translating has been especially enlarged by work in sociolinguistics, in which the emphasis is not on language as a structure but on the role of language as used by speakers and writers. Sociolinguistics has called attention to the function of levels and registers in language, linguistic dialects, the roles of power and solidarity in language usage and in the systematic character of what some linguists in the past have treated as mere accidental variation. (p.113)

The use of Systemic Functional Linguistics as a theory and as an analytical tool provides valuable contributions to translation because as Nida says:

The most pervasive and crucial contribution to an understanding of translation is to be found in sociosemiotics, the discipline that treats all the systems of signs used by human societies. The great advantage of semiotics over other approaches to interlingual communication is that it deals with all types of codes and signs. No holistic approach to translating can exclude semiotics as a fundamental discipline in encoding and decoding signs. (p. 113)

This understanding of how valuable the SFL could be for the field of translations leads to ask how SFL can contribute to the future of medical translation. The role of register and the roles of power are salient features in medical translation; therefore, the need to approach health communication and ultimately health translation from the SFL point of view. The question is how can the field of sociolinguistics and translation effectively merge to positively influence the field of medical translation to show significant improvement in the areas of promotion and dissemination of written health information.

The medical field involves cross-cultural communication; hence, the effective application of a theory that goes beyond the grammatical formation of text but that contextualizes the translation. The mass translation of brochures and booklets about every illness is costly. Many organizations resort to the use available online translators. However, research has proven that the use of translators such as Google Translate, although, the software continuously strive to improve the production of its results, in terms of context, they fail as the main source of translation. Navarro and Barnes (1996), Lin et al. (2015), and Leite et al. (2016) have all conducted research in regard to medical translation using an online translation. Their results showing the errors produced by

these translators were conclusive. Behnam et al. (2014) summarize the use of machine translation as “a modern and commercial approach to interlingual translation, has placed translators at the fingertips of the people who need quick and low-cost translations, but at the expense of appropriateness of the output (p.714).” Nonetheless, the magnitude and the diversity of health information that needs to be translated and disseminated to different languages, makes the use of an online translator the most viable resource for translation in healthcare. However, the quality of translation the could be achieved by a machine translator relies on professionals coming together and merging expertise to come up with a valid way to merge the fields of healthcare, translation, sociolinguistics and computational linguistics based on theoretical approach that could be replicated across the country.

Some translation theories, such as *Skopos Theory* (Vermeer 1978), have been proposed as an answer to the need of cultural medical translation; however, it requires almost a re-writing of the information which is also costly for healthcare institutions. SLF provides a better alternative because it is “guided creation of meaning” (Halliday 1992, p.15) and although there is more research to be done in order to prove its viability in a computational system used for healthcare, the future looks promising.

5. 6 The Future of SFL and Machine Translation in Healthcare Contexts

Before discussing the future of SFL in medical translation, it is important to map the advances of SFL and computer language. Halliday visualized the use of SFL for translation analysis and production since the early 1960s. O'Donnell and Bateman

(2005) make a historical recount of the history of SFL and translation after Halliday.

This review gives a perspective to future researchers about the work that has been done and what new advances in computer and language mean for the future of SFL based input on sentence generation and potentially the generation of culturally sensitive translation.

The first attempt to create a parse for linguistic computational analysis was done by Parker-Rhodes in 1962. Then, the work of language and computers was continued by Winograd in the field of artificial intelligence in the 1970s. During the 1980s, McCord (1980) created the *IBM WebSphere Translation Server*, which is “one of the best translation systems available today” (p.5). In the next decade, O’Donoghue (1991), Weerashinghe and Fawcett (1993), and O’Donnell (1989) continued working on the creation of a parser to analyze language. It was Webster (1994), who finally created a system called *Functional Grammar Processor*, which was able to analyze sentences in terms of Transitivity, Mood, and Theme. By the late 1990s and early 2000s, researchers were able to create online platforms with the ability to realize computational analysis of sentences using SFL tools; Matthiessen and We (1990) created the *SysFam*, while O’Halloran and Judd (2003) created the *Systemic*. As the language engineering became more sophisticated so did the programs thanks to the creation of new of coders, parsers, graphers and the integration of Natural Language Generation projects such as of KPLM and Penman. O’Donnell created the *Wag System* (1996) which was a huge step forward because this downloadable software not only allow the analysis of language but also has the tools needed for sentence generation. This feature allows the use of the software for the guided production of functional texts:

The WAG system was subsequently employed in a number of generation projects, such as the ILEX project at Edinburgh which relies on systemically-driven generation for the dynamic construction of webpages concerning museum exhibits, and supported the development of compatible computational grammars for further languages, most particularly Greek. There have also been moves towards extending generation to include multimodal presentations. (P.16)

As these new platforms generate the interest of linguist researchers, the more they will be able to advance in the production of sentence generation until they reach the potential to generate translated sentences that are culturally sensitive. O'Donnell and Bateman (2005) explain:

The more that linguists are exposed to these kinds of tools, the more we can expect usefully tailored functionalities to be provided. But the first step here will be a willingness and curiosity on the part of linguists to see what the computational tools that are being explored can offer. (p.25)

The fact that SFL considers language as made out of systems and instances facilitates the use of parsers and other computer tools to analyze language. SFL is largely characterized as an interdisciplinary feature because it can be applied to all types of texts; therefore, the creation of an SFL based medical translator is a feasible project.

The use of machine translation for healthcare could be a helpful resource because its theoretical foundation encompasses “the sociological, semiotic, generic, registerial, discursal, and lexicogrammatical levels by adopting a top-down process” (Ma and Wang, 2016, p.36). Matthiessen (2014) justifies viewing of translation from the SFL

standpoint because it is a “recreation of meaning in context through choice” (p.40).

Therefore, a computer translation system will be able “to make more systematic micro-level choices in their translation, to realize the intended function of the translated texts, and to reflect the potential sociocultural meaning” (p. 40). Matthiessen (2012) describes the importance of continuing to implement technological advances and SFL:

The work in “computational SFL” (e.g. O’Donnell & Bateman, 2005) is less well-known than activities in more exposed areas such as education and healthcare; but it is actually of vital importance to the general project of “applicable linguistics” not only because of computational applications but also, and perhaps more importantly, because the computational work has ensured a degree of explicitness that is often lacking in “discourse analysis” and it has produced computational tools that have extended the analytical power of SFL discourse analysts considerably. (p.438)

He goes on to explain how the use of SFL in technology has contributed in different fields for the benefit of society. He mentions the project *Scamseek* by Jon Patrick at Sydney University were “he and his team were able to develop a system that could detect potential electronic scams (delivered by email or available on the web)” (p. 438).

The failed attempts to use online translators for medical written information, established that machine translators until now have not been able to make subtle distinction to accommodate the humanity factor and the culture, unless taught how to do so based on theory. The advances of computational linguistics and SFL computational analyses has proven that a theory as SFL can break the boundaries of disciplines and be

adapt to analyze and generate text for any field. Everything points out that in the near future an SFL translator can be used to generate medical translations making sensitive choices across registers and cultures.

5. 7 Limitations and Recommendations

The use of SFL in fields such as second language acquisition and healthcare is relatively recent with the majority of the research being done in Sydney and Hong Kong. The use of SFL and healthcare is mostly being done by Slade and Matthiessen in Hong Kong. Current research positions SFL as one of the most interdisciplinary and permeable linguistic theories; however, there is much work to be done in this area. In the United States, there are several courses being taught at the university level in SFL. Some of the courses, and SFL-related research, are currently being conducted by Mariana Achugar in Carnegie Mellon, Beverly Cox at Purdue, Cecilia Colombi at UC Davis, Zhihui Fang at the University of Florida and Mary Schleppergrell at the University of Michigan, among other few courses in other universities. Yet, all of these courses; focus on the use of SFL for educational purposes; for example: second language acquisition, academic writing, and language education. For a theory that has been around since the 1960s, it has not been fully applied in a broader spectrum of disciplines in this country. This study was based on research done outside the United States where similar situations of multiple languages and culture occur. There is critical need for more SFL research to be done in the area of minority languages in healthcare in the country. The United States is characterized by a multiplicity of languages and cultures. The resourcefulness of SFL has

to be brought to light and studied in order to merge with the technological advances and create projects that could benefit society. After all, SFL was conceived under the idea of social accountability.

While this research was limited to the field of pediatric cancer, several generalizations can be made for future research. Medical information cannot be translated the same way that a literary work is translated where the center of the translation is the intention and the context of the writer. In medical information, the center of the translation, and the context, is the reader. The target reader has to play an active role in the process. The translation of medical information requires an immediate response from the reader because the appropriate perception of the message is life concerning. The extent of healthcare institutions and their need to provide services for linguistic minorities is far-reaching, every health institution in every city, every town across the country is constantly faced with the need to provide services for all minorities; the task seems almost impossible. However, a unified awareness of the need to provide services based on theoretical tools can start a movement. There is an urgent need for computational linguistics SFL-based projects that can open a path for future translations. SFL shows how language choices are made across the stratification and instantiation matrixes, it is only a matter of creating a corpus of narratives that is large enough to provide a comprehensive list of the choices that are characteristic and meaningful to a particular community. The best corpus for medical translation comes from discourse analysis. For the purpose of this research, a limited number of people were interviewed, but it was proven that linguistic minorities are aware of the barriers they face in the health

system and they are eager to help make a change so that future generations do not have to deal with the same problem. After a review of the results, it is the ultimate recommendation to use oral narratives as corpus to create an SFL based online translator that can negotiate choices and produce written texts that are contextualized to the target community. After reviewing the research currently being done in other countries, it can be assumed that such a project is achievable and potentially beneficial to create effective, budget-wise, translations that can disseminate information and reduce errors in translation that affect peoples' health outcomes.

Another limitation of this research was to present the point of view of more medical professionals and community health workers about the blunt omission of information in the written texts and how much it affects their communication with patients. It would be helpful to conduct a full study about their experiences about how much the use (or not) of written information affects their communication during the medical encounter. Some of the omissions presented in this study included recommendations about what questions to ask during the doctor's visit, it will be beneficial to study how much the lack of information hinders the questions that are being asked by people who did not receive such supportive information. Both, the community health workers and the medical staff have daily interactions with the community, they understand both languages and they are able to identify what words are understood by the community and what words will leave them confused and/or misinformed.

For future research, it is recommended to create a larger corpus of narratives since it could be the inception of the corpus used to create an SFL based translation software.

Also, it is necessary to analyze the information that is being posted in website by the same organizations that publish and distribute the booklets since most people are using the internet for information and they should be considered trusted sites.

5.8 Concluding Remarks

The improvement of translations that empower individuals is a fundamental right for the people. They are not guilty for not learning a language; people are bound by the ecological system where they exist. Even though there is extensive research that proves the negative effects of errors of translations and interpretation in health disparities, the experts have not been able to come with a sustainable solution. The issue is still largely unaddressed. Healthcare institutions conform to the requirement of providing translations but seem to turn a blind eye on the effectiveness of translations.

Despite the high illiteracy levels that characterize this community, people want to be informed, people want to read. Keep in mind that some people are considered illiterate because of their ability in the English language, but they can be literate in their native language, plus, as Zacardoolas' health literacy definition implied (see Chapter 1), there is a wide range of abilities that define health literacy. Effective written information is necessary even for people that do not read, because as shown by the narrative, there is an oral tradition to pass information about health. People will read something and tell their friends and neighbors; therefore, providing reliable written information will change the health outlook of the entire community regardless of literacy levels.

When faced with chronic illness, such as cancer, families go through an overwhelming time, written information should be able to ease their fears and allow them to take control of their illness. Written texts should be direct and relatable information that can reduce the reliance on memory and facilitate the sharing the information with everyone in their social circle. It is imperative to end the concept of invisibility outside the medical encounter and the isolation felt by families living at the margins of the systems. Health information and communication lead to empowerment; errors diminish power and restrict individuals. In a multicultural, multilingual country afflicted by linguistic and cultural barriers and walls, SFL offers a possibility of a theory that knows no boundaries and can create a top-down and bottom-up process of translation that rightfully positions the patient at the center of their health management.

Appendix A

The National CLAS Standards are intended to advance health equity, improve quality, and help eliminate health care disparities by establishing a blueprint for health and health care organizations to:

Principal Standard

1. Provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs.

Governance, Leadership and Workforce

2. Advance and sustain organizational governance and leadership that promotes CLAS and health equity through policy, practices, and allocated resources.
3. Recruit, promote, and support a culturally and linguistically diverse governance, leadership, and workforce that are responsive to the population in the service area.
4. Educate and train governance, leadership, and workforce in culturally and linguistically appropriate policies and practices on an ongoing basis.

Communication and Language Assistance

5. Offer language assistance to individuals who have limited English proficiency and/or other communication needs, at no cost to them, to facilitate timely access to all health care and services.
6. Inform all individuals of the availability of language assistance services clearly and in their preferred language, verbally and in writing.
7. Ensure the competence of individuals providing language assistance, recognizing that the use of untrained individuals and/or minors as interpreters should be avoided.
8. Provide easy-to-understand print and multimedia materials and signage in the languages commonly used by the populations in the service area.

Engagement, Continuous Improvement, and Accountability

9. Establish culturally and linguistically appropriate goals, policies, and management accountability, and infuse them throughout the organization's planning and operations.
10. Conduct ongoing assessments of the organization's CLAS-related activities and integrate CLAS-related measures into measurement and continuous quality improvement activities.
11. Collect and maintain accurate and reliable demographic data to monitor and evaluate the impact of CLAS on health equity and outcomes and to inform service delivery.
12. Conduct regular assessments of community health assets and needs and use the results to plan and implement services that respond to the cultural and linguistic diversity of populations in the service area.
13. Partner with the community to design, implement, and evaluate policies, practices, and services to ensure cultural and linguistic appropriateness.
14. Create conflict and grievance resolution processes that are culturally and linguistically appropriate to identify, prevent, and resolve conflicts or complaints.
15. Communicate the organization's progress in implementing and sustaining CLAS to all stakeholders, constituents, and the general public.

Appendix B

The 10 Elements of the Language Access Plan (HHH, 2013)

ELEMENT 1: Assessment: Needs and Capacity

ELEMENT 2: Oral Language Assistance Services

ELEMENT 3: Written Translations

ELEMENT 4: Policies and Procedures

ELEMENT 5: Notification of the Availability of Language Assistance at no Costs

ELEMENT 6: Staff Training

ELEMENT 7: Assessment: Access and Quality

ELEMENT 8: Stakeholder Consultation (New Element)

ELEMENT 9: Digital Information (New Element)

ELEMENT 10: Grant Assurance and Compliance (New Element)

<https://www.hhs.gov/sites/default/files/open/pres-actions/2013-hhs-language-access-plan.pdf>

Appendix C

1985: Heckler Report

The Secretary's Task Force releases its Report on Black and Minority Health , also known as the ***Heckler Report***. It served to mobilize the U.S. Department of Health and Human Services' (HHS) efforts to eliminate health and health care disparities.

1986: Office of Minority Health

Congress creates the Office of Minority Health (OMH) within HHS in response to the *Heckler Report*. OMH is dedicated to improving the health of racial and ethnic minority populations through the development of health policies and programs that will help eliminate disparities.

1987: Resource Center

The HHS Office of Minority Health launches its Resource Center, the nation's largest repository of information on health disparities issues.

1990: Americans With Disabilities Act

Congress passes the Americans with Disabilities Act (ADA). The ADA is a wide-ranging civil rights law that prohibits, under certain circumstances, discrimination based on disability.

Regional, State, and Territory Advancements

OMH appointed Regional Minority Health Consultants (RMHCs) to work in the 10 HHS Regional Offices to help build networks of consumers and professionals working on minority health issues.

State and territorial offices of minority health were created.

1995: Center for Linguistic and Cultural Competence in Health Care

The HHS Office of Minority Health establishes Center for Linguistic and Cultural Competence in Health Care (CLCCHC). Its mission is to collaborate with federal agencies and other public and private entities to enhance the ability of the health care system to effectively deliver linguistically appropriate and culturally competent health care to limited English-speaking populations.

2000: Healthy People 2010

HHS releases Healthy People 2010, which details a comprehensive, nationwide health promotion and disease prevention agenda, including the elimination of health disparities as a goal.

National CLAS Standards

The HHS Office of Minority Health releases the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care to improve health care quality and advance health equity.

Minority Health and Health Disparities Research and Education Act

Congress passes the Minority Health and Health Disparities Research and Education Act . This Act supports biomedical and behavioral research on minority health and health disparities, medical training for minorities and others, and the study and collection of data regarding minorities and other populations.

Executive Order 13166

President Clinton issues Executive Order 13166 regarding improving access to services (provided by Federal agencies or their grantees) for individuals with limited English proficiency (LEP). The Executive Order requires Federal agencies to examine the services they provide, identify any need for services to those with LEP, and develop and implement a system to provide those services so those with LEP can have meaningful access to them.

National Center on Minority Health and Health Disparities

The Minority Health and Health Disparities Research and Education Act establishes the National Center on Minority Health and Health Disparities (NCMHD) at the National Institutes of Health (NIH). Now an Institute, the National Institute on Minority Health and Health Disparities' mission is to lead scientific research to improve minority health and reduce health disparities.

LEP Guidance

The HHS Office for Civil Rights issues the first LEP Guidance for working with individuals with limited English proficiency.

2003: First National Healthcare Disparities Report

The HHS Agency for Healthcare Research and Quality releases the first *National Healthcare Disparities Report*. This annual report, now part of the National Healthcare Quality and Disparities Report, measures trends in effectiveness of care, patient safety, timeliness of care, patient centeredness, and efficiency of care.

Unequal Treatment

The Institute of Medicine publishes *Unequal Treatment*, which found that a large and consistent body of research underscores the existence of disparities.

Second LEP Guidance

The HHS Office for Civil Rights issues second LEP Guidance for working with individuals with limited English proficiency.

2004: Think Cultural Health

The HHS Office of Minority Health launches Think Cultural Health, a website featuring information, continuing education opportunities, resources, and more for health and health care professionals to learn about culturally and linguistically appropriate services, or CLAS. Think Cultural Health is dedicated to advancing health equity at every point of contact and promoting culturally and linguistically appropriate services.

In the Nation's Compelling Interest

The Institute of Medicine publishes *In the Nation's Compelling Interest*, which considers the benefits of greater racial and ethnic diversity, and identifies institutional and policy-level mechanisms to garner broad support among health professions leaders, community members, and other key stakeholders to implement these strategies.

Setting the Agenda for Research on Cultural Competence in Health Care

The HHS Office of Minority Health and the HHS Agency for Healthcare Research and Quality collaboratively released *Setting the Agenda for Research on Cultural Competence in Health Care*.

2007: National Partnership for Action to End Health Disparities

The HHS Office of Minority Health leads the creation of the National Partnership for Action to End Health Disparities to mobilize a nationwide, comprehensive, community-driven, and sustained approach to combating health disparities and to move the nation toward achieving health equity.

2008: Medicare Improvements for Patients and Providers Act of 2008

Congress passes the Medicare Improvements for Patients and Providers Act of 2008. MIPPA requires that the Office of Inspector General conduct a study examining Medicare and provider and plan compliance with OCR's Guidance.

2009: Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement
The Institute of Medicine releases Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement Report Released , which underscores the importance of REAL data collection to identify, examine, and ultimately address health disparities.

2010: Reauthorization of the HHS Office of Minority Health
The HHS Office of Minority Health is reauthorized with the passing of the Affordable Care Act.

Section 1557 of the Affordable Care Act

Section 1557 of the Affordable Care Act extends Federal civil rights laws prohibiting discrimination on the basis of race, color, national origin, gender, disability or age to any health program or activity receiving Federal funds; any program or activity administered by an executive agency; or any entity established under Title I of the Act.

Section 10334 of the Affordable Care Act

Section 10334 of the Affordable Care Act establishes that the HHS Office of Minority Health will be transferred to the Office of the Secretary. In addition, the National Center on Minority Health and Health Disparities will be re-designated as the "National Institute on Minority Health and Health Disparities." Six individual Offices of Minority Health will also be established within the Department of Health and Human Services.

Healthy People 2020

HHS releases Healthy People 2020 with an expanded health disparities goal to achieve health equity, eliminate disparities, and improve the health of all groups.

National CLAS Standards Enhancement Initiative

The HHS Office of Minority Health launches enhancement initiative for the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care.

Oral Health Initiative

HHS announces its Oral Health Initiative, which seeks to improve the nation's oral health by realigning existing resources and creating new activities. The key message of the initiative is that "Oral Health is Integral to Overall Health."

As part of this initiative, the Office of Minority Health releases an e-learning program for oral health professionals, the Cultural Competency Program for Oral Health Professionals.

2011: Strategic Plans to Reduce Health Disparities

The HHS Office of Minority Health leads two strategic plans to reduce health disparities: the HHS Action Plan to Reduce Racial and Ethnic Health Disparities and the National Stakeholder Strategy for Achieving Health Equity.

Executive Order 13166

The Attorney General issues announcement regarding the Federal Government's renewed commitment to language access obligations under Executive Order 13166.

HHS Promotores de Salud Initiative

HHS launches its Promotores de Salud Initiative, guided by a federal work group representing HHS agencies and coordinated by the HHS Office of Minority Health.

As part of this initiative, the Office of Minority Health releases an e-learning program for promotores de salud, Promoviendo Decisiones Saludables y Cambios en la Comunidad.

Implementation Guidance on Data Collection Standards

HHS issues Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status, pursuant to Section 4302 of the Affordable Care Act.

2013: National CLAS Standards

The HHS Office of Minority Health releases the enhanced National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (the National CLAS Standards).

The *Standards* establish a blueprint for health and health care organizations to implement and provide culturally and linguistically appropriate services. The *Standards* are intended to advance health equity, improve quality, and help eliminate health disparities.

2014: National CLAS Standards

The HHS Office of Minority Health launches its National CLAS Standards Implementation Initiative.

2016: Nondiscrimination in Health Programs and Activities

This final rule implements Section 1557 of the Affordable Care Act. Section 1557 prohibits discrimination on the basis of race, color, national origin, sex, age, or disability in certain health programs and activities. The final rule clarifies and codifies existing nondiscrimination requirements and sets forth new standards to implement Section 1557. The HHS Office for Civil Rights also issued a summary of the final rule.

Appendix D

Observará que el folleto adjunto con información sobre cáncer es la versión en inglés, debido a que la versión en español de este documento no está disponible. En caso de que no pueda leer la información en inglés, sugerimos solicite la ayuda de algún familiar o amigo que sí pueda hacerlo por usted.

Si tiene alguna pregunta, la Sociedad Americana del Cáncer esta aquí para ayudar. Contamos con información, ayuda día a día y apoyo emocional disponible a través de nuestro personal hispanoparlante. Puede llamarnos al 1-800-227-2345, o visitarnos en Internet en cancer.org/español.



Sociedad Americana
del Cáncer™

Diagnóstico

Tipo de tratamiento	Fecha	Médico, enfermera, trabajador social	Información de contacto	Notas

Diagnóstico

Tipo de tratamiento	Fecha	Médico, enfermera, trabajador social	Información de contacto	Notas



1.800.227.2345
cancer.org/español

Appendix E

<p>PALABRAS PARA APRENDER</p> <p>Queremos que usted participe. Por lo tanto es importante para nosotros que usted entienda qué es lo que está sucediendo con su niño(a) y qué es lo que estamos haciendo. Durante el tratamiento de su niño(a) es posible que usted escuche muchas palabras nuevas. A continuación encontrará una lista de algunas de las palabras que es muy probable que usted escuche.</p> <p>"Attending" o Médico principal Es un médico que ha terminado toda su capacitación en un área de especialización, y que supervisa la atención de pacientes de los "fellows", enfermeras especializadas, residentes e internos. El médico principal es el principal responsable de la atención de un grupo determinado de pacientes (normalmente por área de especialización).</p> <p>ADN (ácido deoxirribonucleico) Material básico de la vida. El ADN es un químico largo, tipo cadena, que se encuentra en el núcleo de toda célula. Los segmentos de la cadena son el código genético que guía el desarrollo de cada célula.</p> <p>Afebril Sin fiebre, temperatura normal.</p> <p>Agudo Que se desarrolla rápidamente, súbito. Agudo es lo opuesto a crónico.</p> <p>Aislamiento Proteger a su niño(a) de los microbios de otras personas. Aislamiento estricto quiere decir que todas las visitas deben usar batas, máscaras y guantes. Normalmente los niños del piso de oncología no son aislamiento estricto. Para mayor información consulte el capítulo sobre Conteo Sanguíneo.</p> <p>Alopecia Pérdida del cabello; calvicie.</p> <p>Anafilaxis Una reacción alérgica que va desde ser ligera (urticaria) hasta severa (shock).</p> <p>ANC (conteo neutrófilo absoluto) Número de neutrófilos que se encuentra en una cantidad específica de sangre.</p> <p>Anemia Un número anormalmente bajo de glóbulos rojos en la sangre; menos hemoglobina de lo normal. La hemoglobina es la parte de los glóbulos rojos que acarrea oxígeno a todo el cuerpo.</p> <p>Anestesia Medicinas que evitan que una persona sienta dolor. La anestesia local adormece parte del cuerpo. La anestesia general duerme al cuerpo entero.</p> <p>Anestesia general Un medicamento o una combinación de medicamentos que duerme al paciente para evitar dolor durante una operación o algún otro procedimiento.</p> <p>Anestésico local Medicina aplicada por inyección en una parte del cuerpo para evitar el dolor en el área, sin dormir al</p>	<p>Anorexia paciente (ejemplos: lidocaina y procaina). Pérdida del apetito.</p> <p>Antibiótico Medicina que puede destruir bacteria. Los antibióticos se utilizan para tratar infecciones bacteriales.</p> <p>Anti-eméticos Medicinas para disminuir o detener la náusea y el vómito.</p> <p>Antígenos Substancias químicas que el cuerpo puede reconocer como extrañas y por lo tanto puede estimular una respuesta inmune.</p> <p>Aspiración de médula ósea Toma de una muestra de médula ósea. Consulte la hoja informativa "La prueba de médula ósea" para mayor información.</p> <p>Ataxia Pérdida de coordinación muscular. Una persona con ataxia tiende a tropezarse.</p> <p>Audiograma Prueba de la audición.</p> <p>Bacteriemia Infección de la sangre. Sepsis.</p> <p>Bacteria Tipo de organismo vivo demasiado pequeño como para ser visto sin microscopio. La mayoría de las bacterias son inofensivas, a menos que la resistencia del organismo se vea disminuida, como en el caso de la neutropenia, en cuyo caso el organismo puede ocasionar infección.</p> <p>Bario Substancia utilizada para ciertas pruebas intestinales de diagnóstico. Puede verse dentro del cuerpo con rayos-x.</p> <p>Bazo Órgano del cuerpo que filtra la sangre. El bazo se encuentra junto al estómago.</p> <p>Benigno, tumor No canceroso. Un tumor benigno no invade los tejidos adyacentes y no se disemina a otras partes del cuerpo.</p> <p>Bilis Líquido verde-amarillento fabricado por el hígado a partir de los glóbulos rojos desechados. En el intestino, la bilis ayuda a digerir las grasas.</p> <p>Biopsia Muestra pequeña de tejido que se toma del cuerpo y se examina bajo microscopio.</p> <p>Biopsia de médula ósea Procedimiento durante el cual se toma un pedazo de hueso y de médula ósea, normalmente de la cadera.</p> <p>Blastocito Una forma primitiva o inmadura de célula sanguínea.</p> <p>Cáncer Término general para enfermedades en las cuales existe crecimiento incontrolable y anormal de células. También conocido como <i>neoplasma maligno</i>.</p> <p>Carcinoma Cáncer de las glándulas o células epiteliales del cuerpo (las que recubren los tejidos corporales).</p> <p>Cardiaco Referente al corazón.</p> <p>CAT scan o tomografía Tomografía computarizada; tipo especial de rayos-x.</p>
<p>Catéter Tubo hueco (de hule, plástico, vidrio o metal) que se inserta en una vena o arteria principal para poder administrar medicinas o quimioterapia.</p> <p>Catéter venoso central Tubo pequeño flexible que se inserta en un vaso sanguíneo importante, normalmente en la zona del pecho. Consulte la hoja informativa <i>Catéteres intravenosos</i> para mayor información.</p> <p>Células Unidad estructural básica de toda materia viviente.</p> <p>Celulitis Inflamación (infección) de la piel y del tejido subcutáneo.</p> <p>centiGray Unidad de medida de radiación.</p> <p>COG (Grupo Oncológico Infantil) Es un grupo de investigadores en todo el país que comparten información y resultados de investigación. Para mayor información consulte el capítulo sobre <i>Tratamiento para el Cáncer</i>.</p> <p>Consentimiento (forma) Descripción escrita de un tratamiento y de las medicinas que van a utilizarse. Los padres o tutores del niño deben comprender y estar de acuerdo con el tratamiento antes de administrarse. El firmar la forma de consentimiento indica que han dado su permiso.</p> <p>Consentimiento informado Permiso otorgado por una persona antes de una cirugía u otro tipo de tratamiento. El paciente, sus padres o tutores deben comprender los riesgos y los beneficios del tratamiento, y aceptar legalmente dichos riesgos.</p> <p>Consolidación (A veces llamada intensificación). Es la segunda fase de la quimioterapia, después de la inducción, en la cual el niño recibe la quimioterapia más intensa.</p> <p>Consulta Proceso formal de obtener la opinión de un especialista.</p> <p>Contagioso(a) Que puede pasar de una persona a otra. Una enfermedad contagiosa puede contraerse de alguien que la tiene.</p> <p>Conteo sanguíneo Número de glóbulos rojos, glóbulos blancos y plaquetas que se encuentran en una cantidad específica de sangre. Normalmente se le llama conteo sanguíneo completo o CBC. Consulte el capítulo sobre Conteo Sanguíneo para mayor información.</p> <p>Conteo sanguíneo completo (CBC) Prueba sanguínea que se efectúa para medir los componentes de la sangre (glóbulos rojos, glóbulos blancos y plaquetas). Esta prueba es útil para diagnosticar ciertos problemas de salud y para seguir los resultados del tratamiento.</p>	<p>Conteo sanguíneo blanco (WBC): se refiere al número total de glóbulos blancos por milímetro cúbico de sangre periférica.</p> <p>Diferencial (diff): el porcentaje de diferentes tipos de glóbulos blancos que constituyen el WBC.</p> <p>Conteo de plaquetas: número de plaquetas presentes por milímetro cúbico de sangre periférica.</p> <p>Hemoglobina: la cantidad de hemoglobina presente en la sangre periférica se mide como porcentaje de hemoglobina por gramo de sangre.</p> <p>Hematocrito: volumen empaquetado de glóbulos rojos que puede separarse del plasma (porción líquida de la sangre). Se mide como porcentaje de glóbulos rojos por gramo de plasma.</p> <p>Conteo de reticulocitos (retic): porcentaje de glóbulos rojos inmaduros presentes en la sangre periférica.</p> <p>Evento repentino que puede incluir sacudidas de los brazos, las piernas o el cuerpo, y torcer los labios u ojos.</p> <p>Crónico Continuo o de larga duración. Crónico es lo opuesto a Agudo.</p> <p>Cultivo Manera de identificar un microbio que está causando infección. Requiere que se coloque una muestra de tejido, fluido, u otro material corporal, en un recipiente especial para ver si crece algún microbio. A menudo puede tomar varios días. Si crece algún microbio en particular en la muestra, es posible que también esté creciendo dentro del cuerpo y sea lo que ocasiona el problema. Saber de qué microbio se trata permite que el doctor recete el antibiótico más efectivo.</p> <p>Cumbre y fondo Muestra de sangre que se toma para revisar los niveles del medicamento para asegurarse que la dosis del medicamento sea terapéutica. El fondo se saca justo antes de que toque tomar el medicamento, y la cumbre se toma después de haber tomado la dosis.</p> <p>Deshidratación Pérdida de demasiada agua y demasiados minerales del cuerpo.</p> <p>Determinación de etapa – staging Determinar el nivel (etapa) de la enfermedad (tumores sólidos, enfermedad de Hodgkin). Normalmente requiere de pruebas de laboratorio y biopsias, y en ocasiones de cirugía o exámenes de diagnóstico.</p> <p>Diagnóstico Proceso por el cual se identifica una enfermedad.</p> <p>Disfunción Funcionamiento anormal, doloroso o difícil de alguna parte, órgano o glándula del cuerpo.</p>

Appendix F

Titles available in Spanish by the Leukemia and Lymphoma Society:

TITLE 1 – Comprendiendo la Farmacoterapia y Manejando los Efectos Secundarios

TITLE 2 – Aspecto Emocionales de Niños con Leucemia: La informacion Para Los Padres. *[sic]*

TITLE 3 – La Leucemia

TITLE 4 – Los linfomas: Guía para pacientes y las personas que los cuidan.

TITLE 5 – Cómo enfrentarse a la leucemia y el linfoma en los niños.

TITLE 6 – Leucemia linfocítica aguda: Guía para pacientes y las personas que los cuidan.

Titles available in Spanish by the American Cancer Society:

TITLE 1 – La quimioterapia: en qué consiste, cómo ayuda.

TITLE 2 – La radioterapia: en qué consiste, cómo ayuda.


Titles available in Spanish by the National Cancer Institute:

TITLE 1 – Consejos de alimentación: Antes, durante y después del tratamiento del cáncer.

Appendix G


<div data-bbox="477 380 659 457"><p>UNIVERSITY of HOUSTON A CARNEGIE-DESIGNATED TIER ONE PUBLIC RESEARCH UNIVERSITY</p></div> <div data-bbox="383 476 756 491"><p>Consentimiento personal para participar en esta investigación</p></div> <div data-bbox="345 495 794 533"><p>Título del trabajo de investigación: CONSTRUYENDO SIGNIFICADOS: UN REPASO DE LA LINGÜÍSTICA SISTEMICA FUNCIONAL DE LA TRADUCCIÓN DE TEXTOS MÉDICOS Y LAS NARRATIVAS DE LA COMUNIDAD.</p></div> <div data-bbox="345 558 466 571"><p>Investigadora: Ana Villarreal</p></div> <div data-bbox="345 577 587 592"><p>Supervisora de la disertación doctoral: Dr. Marta Fairclough</p></div> <div data-bbox="345 598 664 615"><p>¿Por qué se me invitó a tomar parte en este estudio?</p></div> <div data-bbox="345 617 781 642"><p>Usted a sido invitado(a) a participar en este estudio porque tiene experiencia al cuidado de niños que han pasado por el sistema de salud.</p></div> <div data-bbox="345 651 573 665"><p>¿Qué debo saber sobre este estudio?</p></div> <div data-bbox="363 665 774 758"><ul style="list-style-type: none">• Alguien le va a explicar este trabajo de investigación• La decisión de participar es suya• Usted puede decidir no participar• Usted puede aceptar y después cambiar de opinión• Su decisión no será tomada en su contra• Usted puede preguntar todo lo que quiera antes de tomar una decisión, así como durante el proceso de la investigación</div> <div data-bbox="345 764 591 781"><p>¿Por qué se está haciendo este estudio?</p></div> <div data-bbox="345 781 789 844"><p>El propósito de esta investigación es analizar la manera en la que las personas hablan sobre la enfermedad y compararla con la manera que se usa en los documentos traducidos. Nuestro objetivo es ayudar a la creación de documentos traducidos que sean de beneficio para las personas que viven en esta área. Queremos que todas las personas que no hablan inglés tengan acceso a la información escrita.</p></div> <div data-bbox="345 850 500 867"><p>¿Cuánto dura el estudio?</p></div> <div data-bbox="345 867 751 894"><p>Esperamos que esta investigación tome alrededor de 20 minutos. Si usted desea considerar su participación, podemos hacer una cita para después.</p></div> <div data-bbox="345 900 628 917"><p>¿Cuántas personas participarán en el estudio?</p></div> <div data-bbox="345 917 573 932"><p>Esperamos entrevistar a 20 personas en este estudio.</p></div> <div data-bbox="297 995 389 1026"><p>STUDY00000295 UH IRB Approved 4/26/2017 - 4/25/2018</p></div> <div data-bbox="539 984 596 999"><p>Page 1 of 4</p></div>	<div data-bbox="902 388 1222 403"><p>Consent to Take Part in a Human Research Study</p></div> <div data-bbox="902 407 1325 422"><p>¿Qué pasa si digo que sí quiero participar en esta investigación?</p></div> <div data-bbox="902 422 1359 449"><p>Se le harán unas preguntas sobre su experiencia con el sistema de salud. También se le pedirá que describa la enfermedad utilizando sus propias palabras.</p></div> <div data-bbox="902 474 1378 499"><p>Este trabajo de investigación incluye el siguientes componente donde planeamos grabar su voz. Usted como participante:</p></div> <div data-bbox="935 508 1365 564"><ul style="list-style-type: none"><input type="checkbox"/> Está de acuerdo en ser grabada durante el estudio.<input type="checkbox"/> Está de acuerdo en que el audio sea usado para publicaciones/presentaciones.<input type="checkbox"/> No está de acuerdo en que el audio sea usado para publicaciones/presentaciones.<input type="checkbox"/> No está de acuerdo en que se grabe su voz para este estudio.</div> <div data-bbox="902 571 1354 588"><p>Si usted no está de acuerdo en que su voz sea grabada, ¿nos permite tomar notas de su narrativa?</p></div> <div data-bbox="902 596 1230 611"><p>¿Qué pasa si no quiero participar en este estudio?</p></div> <div data-bbox="902 611 1382 638"><p>Usted puede decidir no participar en este estudio y no se tomará en su contra. Escoger no participar no conlleva ningún tipo de pérdida de beneficios que de otra manera se le otorgarían.</p></div> <div data-bbox="902 646 1252 663"><p>¿Qué pasa si digo que sí, y luego cambio de parecer?</p></div> <div data-bbox="902 661 1310 678"><p>Usted puede dejar de participar en cualquier momento sin que sea tomado en su contra.</p></div> <div data-bbox="902 678 1351 707"><p>Si usted decide abandonar la investigación, contacte a la investigadora para que pueda borrar su grabación.</p></div> <div data-bbox="902 707 1382 737"><p>Si usted deja de participar en la investigación, los datos que ya se hayan tomado serán removidos de la investigación.</p></div> <div data-bbox="902 745 1321 762"><p>¿Hay alguna manera en este que este estudio me puede afectar?</p></div> <div data-bbox="902 760 1377 789"><p>No prevenimos ningún tipo de riesgo con esta investigación. Si usted decide participar y siente que hay algún riesgo relacionado con el estudio por favor informe a la investigadora.</p></div> <div data-bbox="902 798 1192 814"><p>¿Ganaré algo por participar en este estudio?</p></div> <div data-bbox="902 812 1278 827"><p>No hay ningún beneficio personal o compensación por participar en este estudio.</p></div> <div data-bbox="902 850 1195 867"><p>¿Me ayudará a mi participar en este estudio?</p></div> <div data-bbox="902 867 1362 894"><p>No le prometemos ningún beneficio directo por participar. Sin embargo, los beneficios incluyen la creación de mejores traducciones de materiales de salud.</p></div> <div data-bbox="902 894 1382 924"><p>Aunque no hay beneficios aparentes para usted personalmente, este estudio puede beneficiar a otros al ayudar a un diagnóstico temprano.</p></div> <div data-bbox="902 949 1297 966"><p>¿Qué pasará con la información grabada durante el estudio?</p></div> <div data-bbox="902 974 1326 991"><p>Su participación es confidencial y no hay nada que relacione la grabación con su identidad.</p></div> <div data-bbox="847 1014 948 1045"><p>STUDY00000295 UH IRB Approved 4/26/2017 - 4/25/2018</p></div> <div data-bbox="1109 1003 1170 1018"><p>Page 2 of 4</p></div>																
<div data-bbox="345 1123 631 1138"><p>Consent to Take Part in a Human Research Study</p></div> <div data-bbox="345 1140 768 1178"><p>Podemos publicar los resultados de esta investigación. Sin embargo, a menos que sea especificado en este documento, su nombre y cualquier otra información que lo (la) pueda identificar será tratada de manera confidencial.</p></div> <div data-bbox="345 1201 677 1218"><p>¿Puedo ser removido del estudio sin mi consentimiento?</p></div> <div data-bbox="345 1218 764 1255"><p>La persona a cargo de este estudio o la supervisión pueden removerle de este estudio sin su consentimiento. Algunos posibles razones serían que su narrativa no contribuya a la investigación de ninguna forma.</p></div> <div data-bbox="345 1276 501 1293"><p>¿Con quién puedo hablar?</p></div> <div data-bbox="345 1293 747 1333"><p>Si usted tiene preguntas, dudas o quejas o piensa que este estudio le ha causado daño, usted debe contactar al equipo de investigación al correo electrónico avillarreal2@uh.edu o mfairclough@uh.edu. También puede llamar al número 713-743-3007.</p></div> <div data-bbox="345 1352 774 1390"><p>Esta investigación ha sido revisada y aprobada por el Consejo de Revisión Institucional (IRB, siglas en inglés) de la Universidad de Houston. Usted también puede contactarlos al (713) 743-9204 o spib@central.uh.edu.</p></div> <div data-bbox="363 1392 719 1459"><ul style="list-style-type: none">• Sus preguntas, dudas, o quejas no son respondidas por el equipo de investigación.• Usted no puede contactar al equipo de investigación.• Usted desea hablar con alguien que no sea del equipo de investigación.• Usted tiene preguntas sobre sus derechos como participante.• Usted quiere darnos información sobre esta investigación.</div> <div data-bbox="297 1728 389 1759"><p>STUDY00000295 UH IRB Approved 4/26/2017 - 4/25/2018</p></div> <div data-bbox="532 1717 586 1732"><p>Page 3 of 4</p></div>	<div data-bbox="894 1123 1183 1138"><p>Consent to Take Part in a Human Research Study</p></div> <div data-bbox="1073 1140 1149 1155"><p>Firma de adulto</p></div> <div data-bbox="894 1163 1183 1180"><p>Su firma confirma que usted acepta participar en esta investigación.</p></div> <div data-bbox="894 1197 1326 1323"><table border="0"><tr><td>_____</td><td>_____</td></tr><tr><td>Firma del participante</td><td>Fecha</td></tr><tr><td>_____</td><td>_____</td></tr><tr><td>Nombre del participante</td><td></td></tr><tr><td>_____</td><td>_____</td></tr><tr><td>Firma de la persona que obtuvo su consentimiento</td><td>Fecha</td></tr><tr><td>_____</td><td>_____</td></tr><tr><td>Nombre de la persona que obtuvo su consentimiento</td><td></td></tr></table></div> <div data-bbox="847 1734 938 1768"><p>STUDY00000295 UH IRB Approved 4/26/2017 - 4/25/2018</p></div> <div data-bbox="1081 1726 1136 1740"><p>Page 4 of 4</p></div>	_____	_____	Firma del participante	Fecha	_____	_____	Nombre del participante		_____	_____	Firma de la persona que obtuvo su consentimiento	Fecha	_____	_____	Nombre de la persona que obtuvo su consentimiento	
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Nombre de la persona que obtuvo su consentimiento																	

Appendix H



The Vannie E. Cook Jr.
**CHILDREN'S CANCER AND
HEMATOLOGY CLINIC**

1111 Expressway 83, McAllen, TX 78503 (956) 661-9840 fax (956) 661-9841



Texas Children's Hospital
BCM
Baylor College of Medicine
Department of Pediatrics
Section of Hematology/Oncology

Dear Family Members:

The staff at the Vannie E. Cook Jr. Children's Cancer & Hematology Clinic recognizes that this is a difficult time for you. This parent handbook is designed to answer questions that you may have now, or may arise throughout your child's treatment. In addition, the medical staff and your social worker are available at any time to provide you with information to assist you with making informed decisions about your child's care.

Our caregivers are the finest in their fields. They are all highly trained and have specialized expertise in the care of children with cancer and blood disorders. This means that your child benefits from the combined talents and expertise of senior physicians, nurse practitioners, nurses and social workers. Patients are seen by the same caregivers to provide continuity, familiarity, and trust.

Please keep this handbook handy and refer to it when questions arise. Be assured that staff members are also available 24 hours a day to answer questions or for any emergencies. I encourage you to visit our website at www.txch.org for more information about our doctors, clinical trials, and treatment programs.

Vannie E. Cook Jr. Children's Cancer & Hematology Clinic is committed to providing the finest possible patient care and education in the areas of pediatric and adolescent cancer and blood disorders. While receiving treatment at our Clinic, your child will have access to the best care available, and his or her well-being will always be our number one priority.

Sincerely,

Juan Carlos Bernini, M.D.
Medical Director, Vannie E. Cook Jr. Children's Cancer & Hematology Clinic

Appendix I

Spanish Questionnaire

Primera parte:

1. ¿En qué ciudad/condado vive?
2. ¿De qué país es originario usted o su familia?
3. ¿Cuánto tiempo lleva viviendo en los Estados Unidos?
4. ¿Qué idioma se habla en la casa todo el tiempo/la mayor parte?
5. ¿Si trabaja, qué idioma habla en su trabajo?
6. ¿Hasta qué año fue a la escuela?
7. En escala del 1 al 5 ¿qué tan bien habla usted el inglés?
¿Escribe?
¿Entiende?
¿Lee?

1	2	3	4	5
Nada	poco	promedio	bueno	excelente

Segunda parte:

8. Su hijo/a estuvo en el hospital ¿Me puede explicar cómo obtuvo información sobre la enfermedad de su hijo/a?
9. ¿Le hablaron español en todas las clínicas/hospitales que visitó?
10. Hablando de la salud en general, ¿Cuál es la principal manera en la que obtiene información sobre las enfermedades que haya tenido su hijo?
11. ¿Tenía usted información sobre la enfermedad de su hijo antes de que lo diagnosticaran? Si no, ¿cree usted que le hubiera ayudado a detectarlo antes?
12. ¿Después del diagnóstico, la información escrita ha sido útil a usted y su familia para tomar decisiones?
13. ¿Tiene alguna recomendación para otros padres que no hablan inglés?

Tercera parte:

14. . Como madre/padre de familia ¿Tiene usted información sobre el cáncer infantil y cómo detectarlo a tiempo?

Me puede explicar en sus propias palabras las siguientes preguntas:

15. ¿Qué es el cáncer?
16. ¿Cuáles son algunos síntomas que pueden ayudar a detectarlo a tiempo?
17. ¿Cuáles son algunos de los procedimientos/tratamientos?
18. Sin mencionar nombres, ¿Quiénes son las personas que le ayudarían a tomar decisiones?

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