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The Impact of Dysphagia on Quality of Life and Stigma in Hispanic New Mexicans

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THE IMPACT OF DYSPHAGIA ON QUALITY OF LIFE AND STIGMA IN HISPANIC NEW MEXICANS

BY

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DEDICATION

This thesis is dedicated to my family, past and present. To every individual who never had the opportunity, or privilege, that I have been given, you never cease to inspire and motivate me, and you will continue to do so for the rest of my life.

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ABSTRACT

INTRODUCTION: Eating is a function of daily life and is the centerpiece of family gatherings, business meetings, and holiday/religious traditions. Dysphagia (difficulty swallowing), can abolish the pleasure of mealtimes, which can negatively impact quality of life (QOL) and result in stigma. These variables may be influenced by cultural perceptions and/or acculturation, which is a measure of the impact that one cultural group has on another. The purpose of this investigation was to: a) identify the relationship between level of acculturation and QOL and stigma for Hispanics, b) measure the relationship between dysphagia severity and QOL and stigma, and c) explore the QOL experiences for Hispanics with dysphagia.

METHODS: This study was divided into two phases. In Phase I, seven participants completed the SWAL-QOL, Neuro-QoL stigma subtest, and the Acculturation Rating Scale for Mexican Americans- II. SWAL-QOL was divided into three clusters; Cluster 1 represented mental health, Cluster 2 encompassed swallow symptoms, and Cluster 3 was fatigue. In Phase II, three individuals from Phase I with varying levels of acculturation, as measured by the ARMSA-II, participated in two semi-structured interviews designed to explore their QOL experiences.

RESULTS: Level of acculturation was weakly correlated with quality of life for Cluster 1 and 3, and moderately correlated with Cluster 2. That is, reporting of swallow symptoms increased as level of acculturation increased. A strong correlation was observed between acculturation level and stigma. Increased dysphagia severity resulted in decreased quality of life for Cluster 2. Oddly, as dysphagia severity increased, reports of fatigue decreased. A weak relationship was observed between dysphagia severity and stigma.

Quality of life experiences as identified from the ethnographic interview in Phase II were classified into *emotional experiences* and *swallow safety.* Emotional experiences included: stigma, distrust, fear, frustration, religion, coping, and impact. Swallow safety was comprised of: symptoms, treatment, triggers, and compensatory strategies.

CONCLUSION: Acculturation did not align well with measures of mental health or fatigue. Yet, there were noted relationships between level of acculturation and symptom reporting, as well as patient perception of stigma. Overall, disease severity correlated with swallow related QOL, but not with levels of perceived stigma.

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Chapter 1

Introduction

Dysphagia, or swallowing difficulty, is a common symptom experienced by individuals with non-degenerative, non-terminal disease, and reportedly occurs in 25-65% of these individuals (Mackay, Morgan, & Bernstein, 1999; Martino et al., 2005; Smith-Hammond et al., 2004; Winstein, 1983). Mealtimes and eating are a function of daily life and are often the centerpiece of family gatherings, business meetings, and holiday or religious traditions. Dysphagia can potentially abolish the pleasure of mealtimes, which in turn, may negatively impact quality of life (QOL) and result in the presence of disease-related stigma. These variables may be further influenced by cultural perceptions. In order to better understand the influence of culture on quality of life and stigma in individuals with disease, we must first define the level of acculturation or cultural reduction due to continuous exposure to other cultures.

For individuals of Hispanic culture, acculturative stress, the psychological impact of adapting to a new culture, is highly predictive of disease-related quality of life and psychological distress (Thoman & Surís, 2004). Participants with breast and gynecological cancer, and those seeking psychological services had the lowest quality of life (Janz et al., 2009; Lim, Yi, & Zebrack, 2008). In fact, those with a lower level of acculturation were less likely to seek psychological intervention (Zhang & Dixon, 2003), and were found to have a smaller social network size and higher depressive symptoms (Lim et al., 2008). A lower level of acculturation and perceived stigma impacts how Hispanic individuals complete a health-related questionnaire. Specifically, individuals with a lower level of acculturation were less likely to report somatic symptoms, such as fear, depression, and sense of failure, but more likely to report positive events and emotions (Nguyen, Clark, & Ruiz, 2007).

This investigation served as a pilot study to explore the relationship between the level of acculturation and swallowing-related quality of life. To the best of our knowledge, this is the first investigation evaluating the impact of dysphagia on quality of life and disease-related stigma for Hispanic individuals with non-terminal, non-degenerative disease. The specific aims of this investigation were to answer the following research questions:

1) What is the relationship between level of acculturation and (a) dysphagia-related quality of life, and (b) disease-related stigma for Hispanics?

   Hypothesis: In Hispanics, if level of acculturation increases, then quality of life will decrease, and stigma will increase.

2) What is the relationship between dysphagia severity and (a) dysphagia-related quality of life, and (b) disease-related stigma for Hispanics?

   Hypothesis: In Hispanics, if dysphagia severity increases, then dysphagia-related quality of life will decrease and stigma will increase.

3) What are the disease-related quality of life experiences for Hispanic individuals with, non-terminal, non-degenerative, disease?

   Hypothesis: In Hispanics, the quality of life experiences will vary as a function of acculturation.

Chapter 2

Literature Review

Culture

There are a plethora of definitions of *culture* and these definitions vary as a function of discipline (Hofstede & McCrae, 2004; Riquelme & Rosas, 2014). Cultural mores bind individuals within a cultural group; however, there is often some degree of variability among individuals within a culture (Hofstede & McCrae, 2004). Although not always observable, culture can influence one's interaction style and interpretations of life events.

Using an iceberg analogy, whereby the visible surface of the iceberg represents only 10% of its mass, Weaver (1993) provided a framework for discussing cultural group identity. He described 3 aspects of culture-- high or surface, folk, and deep culture. The two top levels, surface and folk aspects of culture, are visible to others. Surface aspects of culture include cultural artifacts such as music, art, literature, and clothing (Ford & Moore III, 2004). Folk aspects of culture may include dancing, games, and cooking. The deep aspects of culture are not readily visible to outside viewers and can be defined using parameters such as patterns of thought, child rearing practices, religion, beliefs, interests, morals, motivation to work, and cause of disease (Riquelme, 2004; Triandis, 2000; Hanley, 1999).

Another approach, divides cultural parameters into the implicit and explicit aspects of culture (Hamayan & Damico, 1991). Explicit aspects of culture are those that are observable and include language, religious ceremonial practices, mealtime preferences, and celebrations (Hamayan & Damico, 1991). Implicit aspects of culture are abstract, internal, and must be inferred. These may include the degree to which code switching (switching between first and subsequent languages when communicating) is allowed, expectancies when rearing children, the role of each member involved in the education process (e.g., teacher, student, etc.), and health care (e.g., practitioner-patient relationship etc.), the roles of males versus females in society, and finally, whether one's religious beliefs are monotheistic or polytheistic.

As cultures can vary greatly within a single culture, and/or across other cultures, Hofstede proposed five cultural dimensions (Hofstede & Bond, 1988) to consider how cultures vary. The five cultural dimensions include: determining whether a specific culture emphasizes long or short term orientation, the presence and extent of power distances, uncertainty avoidance, whether masculinity or femininity is emphasized, and whether the culture is individualistic or collectivistic (Hofstede et al., 1991). Hofstede's results have been replicated (Chow, Shields, & Chan, 1991; Shackleton & Ali, 1990), and his proposed five cultural dimensions have been stated to be important when describing culture variation (Triandis, 1982). Further, the terms individualistic and collectivistic have been used to describe the relationship between an individual and others within a culture, and are considered to be the most significant dimension when denoting differences across cultures (Triandis, 1996).

Hispanic culture. Traditional Hispanic culture is considered a collectivistic culture (Gregory & Munch, 1997), while the mainstream United States culture is considered to be individualistic (Caldwell-Harris & Ayçiçegi, 2006). Collectivistic cultures emphasize strong links amongst its members. For those belonging to a collectivistic culture (such as the Hispanic culture), the personal needs of an individual are inferior to the needs of the group. Family needs are emphasized over personal needs or desires, and members are interdependent (Hui & Triandis, 1986; Mills & Clark, 1982). In comparison, individuals belonging to an individualistic culture often see themselves as a single unit, mainly identifying with themselves. Personal needs are considered before that of the group, and self-reliance is highly valued and encouraged (Kashima et al., 1995; Oyserman & Lee, 2008).

Language use varies depending on whether a culture is collectivistic or individualistic. Verbalization of self-reference and self-attributes can vary with this cultural parameter. For example, members belonging to an individualistic culture may state, “I am polite”, while members from a collectivistic culture would share “my family feels that I am polite” (Triandis, 1989).

Collectivistic and individualistic cultures vary in the way that their members respond to various situations. In the mist of conflict, collectivistic cultures are concerned with relationships, while individualistic cultures are concerned with achieving justice (Ohbuchi, Fukushima, & Tedeschi, 1999). Those from collectivistic cultures are rather shy when they enter new groups, where those from individualistic cultures tend to be less reserved (Singelis, Triandis, Bhawuk, & Gelfand, 1995).

Hispanics comprise 17% of the population in the United States, and are the largest growing minority (U.S. Census Bureau, 2010). The population is projected to double by 2050, resulting in Hispanics comprising approximately one third of the United States population (Krogstad, 2014; Passel & Cohn, 2008). The term Hispanic, while often used to describe descendants of Spanish-speaking countries, is not consistently used to identify all individuals of Spanish descent. Some individuals self-refer as Latino/a, or by their country of origin (e.g., Cuban) (Doan & Stephan, 2006; Zavella, 1993).

Historical data suggests that traditional Hispanic culture (those that are less acculturated) is family-centered and collectivistic; family is essentially the most important concept or core value (Ferrari, 2002; Miranda, Frevert, & Kern, 1998; Steidel & Contreras, 2003; Vega, 1990). Compared to non-Hispanics, Hispanics have an elevated level of family integrity or *familism* (Battle, 2012; Ferrari, 2002; Ramirez et al., 2004). Values of familism include living in close proximity to family, and using family for emotional and social support (Gil, Wagner, & Vega, 2000). Familism influences are observed within the family as well as in public settings (Battle, 2012).

The concept of family is universal, yet, the definition of family may be specific to different cultural groups (Keefe, Padilla, & Carlos, 1979; Ng, Phillips, & Lee, 2002). In general, the term family is most associated with the nuclear family, which refers to two parents and their dependent children (Allen et al., 2007; Keefe, 1984). Hispanics are more inclusive when defining family and also include extended, and fictive family members (Sabogal, Marín, Otero-Sabogal, Marín, & Perez-Stable, 1987; Villarreal, Blozis, & Widaman, 2005). Extended family refers to relatives living in close proximity who have considerable contact with the nuclear family (Battle, 2012); fictive family members are those who are not related through blood, or marriage, but rather close friends who assume family-like roles (Johnson, 1999; Mac Rae, 1992). These non-biological based individuals are often referred to as *compadres* or *comadres,* which are translated into co-parents. These compadres/comadres are granted the same family status as biological members (Callister, Beckstrand, & Corbett, 2011). In traditional Hispanic culture, respect and loyalty are extended to, not only nuclear family members, but fictive members as well (Taylor & Willies-Jacobo, 2003).

In summary, a traditional Hispanic individual is concerned with the needs of the family, has great respect for family members, both biological and fictive, and views him/her self from the eyes of the family unit as compared to egocentric. Although these cultural mores bind individuals within the Hispanic culture, there is some degree of variability across Hispanic families and individuals living in the United States. The level of variability may be accounted for by acculturation.

Acculturation. There are various definitions of the term acculturation across the anthropology and psychology domains (Chirkov, 2009). First proposed by Redfield, Linton, and Herskovits (1936), acculturation is multidimensional, and describes the influence of one culture on another. That is, as individuals from various cultural groups intermingle geographically, they are exposed to values and beliefs of other cultures. Acculturation examines the impact that one cultural group has on another when they have continuous contact (Wu & Smith, 2016). More specifically, acculturation describes a process of cultural learning that occur(s) with exposure to a non-native culture (Padilla, 1980). Acculturation measures the social and psychological changes that occur when individuals enter into a new and mixed cultural context. Even more so, acculturation is the result, change, or adaptation in personal values, beliefs, behaviors and way of life as a result of exposure to other cultures (Ryder, Alden, & Paulhus, 2000).

It has been stated that acculturation is a normal part of the immigration experience, and this can have both a positive and negative impact on an individual's health (Satia et al., 2001). For example, cortisol levels, an indicator of physiologic stress, increases with higher levels of acculturation and greater economic hardship (Mendoza, Dmitrieva, Perreira, Hurwich-Reiss, & Watamura, 2017). There is agreement that acculturation is a lengthy process where stress is a major theme due to relocation and interactions with unfamiliar cultural practices and beliefs (Rudmin, 2009). However, the acculturation process has a positive effect on health care use, especially for preventative services for individuals with a higher level of acculturation, that is, a greater level of integration into the mainstream culture (Hu & Covell, 1986; Marks, Garcia, & Solis, 1990).

Swallow Function

The swallow is a sophisticated physiologic event that requires coordination of the brain, various nerves, muscles, and joints. Dysphagia is difficulty swallowing where the source occurs somewhere from the oral cavity to the stomach. Approximately 18 million individuals in the United States are living with dysphagia and many millions more internationally (Robbins et al., 2008).

Dysphagia is also a common problem found with older individuals (Achem & DeVault, 2005). The presence of dysphagia, depending on its severity, can cause dehydration, weight loss, aspiration pneumonia, or airway obstruction. Those with dysphagia have reported coughing or choking when swallowing, difficulty initiating a swallow, food sticking in the throat, drooling, unexplained weight loss, changes in dietary habits, nasal regurgitation, and recurrent pneumonia. Thus, when the above mentioned symptoms are observed due to dysphagia, quality of life is reduced (Ekberg, Hamdy, Woisard, Wuttge–Hannig, & Ortega, 2002; Jennifer & Mikoto, 2000).

Quality of Life

Quality of life can be broken down into three life perspectives--quality of life conditions, satisfaction with life conditions, and a combination of both life conditions and satisfaction (McInerney, Borthwick-Duffy, Widaman, Little, & Eyman, 1995). Health-related quality of life refers to aspects of life directly affected by one’s health, and is a multifaceted phenomenon that encapsulates the effect of disease on a patient’s mental, physical and social wellbeing (Varni, Limbers, & Burwinkle, 2007). Quality of life can be altered by illness type and severity, medical treatment, and level of acculturation can impact how individuals cope with disease (Gillespie, Brodsky, Day, Lee, & Martin-Harris, 2004; Kim, Ashing-Giwa, Singer, & Tejero, 2006; Ståhl et al., 2005).

Relationship between dysphagia and quality of life. The presence of dysphagia can impact an individual’s quality of life (Gustafsson & Tibbling, 1991). Eighty-four percent of individuals with dysphagia feel that eating should be an enjoyable experience. Yet, approximately 41% feel anxious or panicked during mealtime, and avoid eating with others due to their dysphagia (Ekberg et al., 2002). Dysphagia can reduce quality of life due to the increased risk of malnutrition, dehydration, respiratory infections, morbidity and mortality. These factors can result in an increased length of hospitalization, and increased health care costs when needed (Alhashemi, 2010; Krakau et al., 2007; Wieseke, Bantz, Siktberg, & Dillard, 2008). Dysphagia can result in social isolation, as individuals are less willing to engage in social events and leisure activities where food is involved. Further, a feeling of frustration, anger, inadequate self-confidence/esteem leading to a reduction of quality of life has been reported (Ekberg et al., 2002; Gustafsson & Tibbling, 1991; Ward, Bishop, Frisby, & Stevens, 2002). The presence of dysphagia has a negative impact on quality of life. For example, for individuals with dysphagia secondary to Parkinson's disease, head and neck cancer, multiple sclerosis, and oculopharyngeal muscular dystrophy, quality of life was reduced compared to individuals without dysphagia (Leow, Huckabee, Anderson, & Beckert, 2010; Lovell, Wong, Loh, Ngo, & Wilson, 2005; Nguyen et al., 2005; Palmer, Neel, Sprouls, & Morrison, 2010; Poorjavad et al., 2010; Robbins et al., 2005).

Dysphagia severity has been shown to correlate with a reduction of quality of life, as well as an increase in anxiety and depression for those with head and neck cancer, and as dysphagia severity increased, quality of life continued to decrease (Nguyen et al., 2005). To our knowledge, this is the first investigation evaluating the relationship between dysphagia severity and perceived stigma. However, severe depression is strongly related to perceived stigma (Kanter, Rusch, & Brondino, 2008; Pyne et al., 2004; Rusch, Kanter, Manos, & Weeks, 2008; Sirey et al., 2001), and psoriasis patients with a greater severity of disease reported increased experiences of stigmatization (Vardy et al., 2002). As it has been concluded that dysphagia reduces quality of life, it has further been stated that the impact that dysphagia has on quality of life can be influenced by culture.

Dysphagia and Culture

In many cultures, mealtimes are considered to be a social event where sharing often signifies warmth, closeness, and friendship (Nguyen et al., 2005). Culture is the filter through which people view the world, and evaluate aspects of their existence. The extent to which health recommendations and interventions are consistent with the family's cultural values may determine understanding, acceptance, and compliance (Davis-McFarland, 2008). Further, food preferences can act as a signature of cultural identity (Threats, 2007). Thus, food and eating experiences provide opportunities for maintaining cultural practices (O'Doherty & Holm, 1999). Unfortunately, a limited amount of focused data are available on the impact of culture on assessment or treatment outcomes in dysphagia (Riquelme, 2007). However, it has been broadly stated that two individuals with the same dysphagia severity will likely experience different social and cultural participation limitations as a result of their dysphagia (Colodny, 2005).

Impact of Culture on Health-Related Quality of Life

It is crucial to consider the role of sociocultural contexts when evaluating health related quality of life in ethnically and socioeconomically diverse populations (Guillemin, Bombardier, & Beaton, 1993; Kagawa-Singer, Padilla, & Ashing-Giwa, 2010). Health-related quality of life is both participative and multidimensional in nature, and it comprises physical, social, functional, and overall well-being. Culture is fundamental to human existence and is one of the important elements of health-related quality of life (Ashing-Giwa, 2005; Kagawa-Singer et al., 2010). As cultures share similar values and beliefs, it is reasonable to anticipate that when a disease occurs, the impact on quality of life or perception can be similar across individuals that share a cultural belief system. Yet, individuals may differ within the same, or across cultural groups as goals, expectations and standards vary as a function of culture (Ibrahim, Burant, Siminoff, Stoller, & Kwoh, 2002; Kagawa-Singer et al., 2010; Skevington, Lotfy, & O'Connell, 2004).

Health-related quality of life has been show to differ among multiethnic populations (Wang, Li, Liu, Thumboo, & Luo, 2015). Compared to Caucasians, quality of life was more negatively impacted for Asian individuals with cancer (Lord et al., 2013), African Americans with arthritis (Ibrahim et al., 2002), and Hispanics with urinary tract infections (Kupelian et al., 2006). As discussed above, the Hispanic population is increasing; yet, a majority of the quality of life literature focuses on non-Hispanics (Yanez, McGinty, Buitrago, Ramirez, & Penedo, 2016).

Stigma and Disease

Goffman (1963) as cited in (Whetten, Reif, Whetten, & Murphy-McMillan, 2008), described stigma as an individual's possession of a characteristic viewed as non-typical by others, and the result of others being aware of this specific characteristic. Thus, stigma can result in a negative inter and intrapersonal experience as the individual may be perceived as flawed by themselves or others. In the presence of disease-related stigma, individuals experience adverse social judgment, labeling, stereotyping, blame, exclusion, and devaluation (Link & Phelan, 2001; Weiss & Ramakrishna, 2006; Weiss, Ramakrishna, & Somma, 2006). Furthermore, stigma has been linked with a reduced self-image, feelings of shame, and diminished self-worth, where self-worth is reduced even more when stigma is internalized (Berger, Ferrans, & Lashley, 2001; Kato et al., 2016). A co-occurrence of stigma, depression, and psychological distress has been observed (Butt, Paterson, & McGuinness, 2008). Stigma is present for individuals who are living with conditions, diseases, or illnesses and has been associated with a variety of social and behavioral consequences. For example, those living with HIV (Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007), individuals considered to be obese (Puhl & Heuer, 2008), those with diabetes (Della, Ashlock, & Basta, 2016), Parkinson's disease (Ou et al., 2015), and participants with sickle cell disease have all reported a presence of stigma. Individuals may feel the presence of stigma in employment (Giel, Thiel, Teufel, Mayer,

& Zipfel, 2010), health care (Hansson, Näslund, & Rasmussen, 2010), and daily living settings (McClure, Puhl, & Heuer, 2011), resulting in a reduction in health-related quality of life (Quach et al., 2012).

Disease has been reported to influence self-confidence (Butt, 2008), and is often accompanied by negative reactions from others (Guirgis, Nusair, Bu, Yan, & Zekry, 2012). Individuals with sickle cell disorders stated that their stigma was not a result of sickle cell disease. Rather, the presence of stigma resulted from the assumption that social norms and expectations were broken. Specifically, those social norms that deal with education, employment, and parenthood were broken (Ola, Yates, & Dyson, 2016). Stigma was observed in individuals living with diabetes and included encountering negative life experiences, identifying themselves with Type 2 Diabetes, difficulty maintaining balance between patient and social roles, and reconstructing a sense of identity (Kato et al., 2016). In individuals with HIV, stigma serves as a barrier to receiving treatment; those individuals with a higher level of stigma were less likely to seek intervention services (Sangaramoorthy, Jamison, & Dyer, 2017). Individuals with Hepatitis B reported a sense of social stigma, which resulted in feelings of condemnation, embarrassment, and discrimination. They further reported a sense of rejection, isolation, and frustration as a result of their disease (Valizadeh, Zamanzadeh, Bayani, & Zabihi, 2017). The presence of stigma and its resulting effects on patients' feelings towards themselves hinder medical care and may alter measures for diagnosing and treating a given disease, receiving medical services, and preventing disease (Bayer, 2008; Butt, 2008; Guirgis et al., 2012). Minimal evidence was located evaluating the relationship between stigma and dysphagia (Ou et al., 2015). However, the impact of drooling, a consequence of dysphagia, reduces overall quality of life and generates stigma in individuals with Parkinson’s disease. Those who drool had a higher perceived stigma than those who did not drool as measured by the Parkinson disease questionnaire 39 (PDQ-39) (Ou et al., 2015).

Culture and stigma. The perception of disease, illness, stigma and disability are influenced by the specific culture that one belongs to, geographic location, and social environment (Kleinman, Eisenberg, & Good, 2006; Meisenbach, 2010). However, in the field of speech-language pathology, there is a limited research regarding cross-cultural beliefs towards illness as well as disability (Bebout & Arthur, 1992; Chepeha et al., 2009; Salas-Provance, Erickson, & Reed, 2002). Cultural beliefs influence the severity and presence of stigma (Georg Hsu et al., 2008). Between Chinese, African, and Indian cultures, cultural and religious beliefs were unique and varied among one another regarding the perception, attitude towards cleft lip and palate, associated stigma, and treatment (Loh & Ascoli, 2011). For those residing in Nigeria, culture was described as one of the variables that drove the perceived stigma for those with sickle cell disease, due to a supernatural belief system about the reincarnation of ill children orchestrated by supernatural spirits (Nzewi, 2001). Those belonging to the Hispanic culture often have more stigmatizing feelings towards a diagnosis of dementia compared to non-Hispanic individuals. Furthermore, Hispanics perceived elderly individuals with dementia as potentially being irrational, or having bad blood. Thus, the willingness to seek assistance outside of the family network decreased (Henderson & Guitierrez-Mayka, 1992). Further, differences in willingness to seek care may be due to differences in stigma for individuals living with HIV (Rao et al., 2007).

Literature Summary

In summary, cultural values and beliefs can influence interaction style and interpretation of life events such as disease and cause of disease (Colodny, 2005). Although there are various aspects within a cultural group that bind the members together, there is some degree of variability within each group (Wu & Smith, 2016). The phenomenon of acculturation, or the level of integration into the mainstream culture, has been shown to have a positive and negative impact on an individual's health (Satia et al., 2001).

Swallowing is an activity of daily living, and when dysphagia is present, quality of life can be reduced and there could be a risk of increased stigma. Although health-related quality of life has been show to differ among multiethnic populations, there is a limited amount of evidence evaluating the impact of cultural beliefs and practices on dysphagia (Riquelme, 2007). Yet, it has been speculated that culture does impact how those with dysphagia cope (Wang, Li, Liu, Thumboo, & Luo, 2015). Stigma has been reported as a result of disease, and individuals may perceive themselves as flawed (Quach et al., 2012). Additionally, cultural beliefs have been reported to influence the presence of stigma. However, to date there is no current evidence evaluating the relationship between level of acculturation (or level of integration into the mainstream culture), quality of life, and stigma for Hispanics with dysphagia.

The purpose of this investigation was to explore the relationship between the level of acculturation and (a) dysphagia-related quality of life, and (b) disease-related stigma for Hispanics, as well as the relationship between dysphagia severity and (a) dysphagia-related quality of life, and (b) disease-related stigma for Hispanics. Disease-related quality of life experiences for Hispanic individuals with, non-terminal, non-degenerative, disease were also evaluated using qualitative methods.

Chapter 3

Methods

Participants

This research project was approved by the Institutional Review Board (IRB) at The University of New Mexico. Participants were recruited through distribution of IRB-approved flyers throughout Albuquerque, Santa Fe, and Las Vegas, New Mexico. Inclusion criteria were (a) self-identified Hispanic, (b) presence of stable dysphagia, (c) 6 months status post dysphagia-causing diagnosis, and (d) successful completion of a modified version of the Telephone Interview of Cognitive Status (Appendix A). Seven self-identified Hispanic New Mexicans, over the age of 18, served as participants. Information regarding participant gender and age can be found in Table 1.

Table 1

Age, gender, and etiology of dysphagia for Phase I participants

ID	Gender	Age	Etiology
S01	F	41	Status post stroke
S02	M	64	Undiagnosed muscle weakness
S03	F	71	Status post stroke
S04*	M	49	Cerebral Palsy
S05	F	68	Status post Guillain- Barré syndrome
S06	M	53	Status post traumatic brain injury
S07	M	36	Status post traumatic brain injury

*Participant was unable to complete the required quality of life instruments and is not included in the analysis.

Phase I

Data collection. This pilot study included two phases. In Phase I, all participants completed three questionnaires and one assessment: (a) the SWAL-QOL (McHorney et al., 2000), (b) Neuro-QoL stigma subtest (Gershon et al., 2012), (c) the Acculturation Rating Scale for Mexican-Americans-II (Cuellar et al., 1995), and (d) the Mann Assessment of Swallowing Ability (MASA; Mann, 2002). Following consent, data were collected in the swallowing and voice laboratory at The University of New Mexico Department of Speech and Hearing Sciences. In exchange for their time, all participants received a $5.00 prepaid merchandise card and a free swallow evaluation.

A subset of individuals from Phase I were selected to participate in Phase II, where two semi-structured interviews were completed and will be discussed in greater detail later in the manuscript.

Quality of life and acculturation questionnaires. Participants completed the SWAL-QOL, stigma subtest of the Neuro-QoL, and ARSMA-II questionnaires. All participants were provided the opportunity to 1) read the questionnaire themselves, or 2) have each questionnaire read to them. The SWAL-QOL (Appendix B) is a psychometrically validated and reliable questionnaire that includes 44 items that evaluate the burden, eating, symptoms, food selection, communication, fear, mental health, socialization, and fatigue of those with oral pharyngeal dysphagia (McHorney et al., 2000). The SWAL-QOL was constructed to be reflective of the patient's quality of life experiences, and assesses multidimensional domains to encapsulate dysphagia outcomes (McHorney et al., 2000). The SWAL-QOL utilizes a 5-point rating scale that ranges from a significant problem (1) to no problem or concern (5). Questions per category were totaled and averaged, resulting in one score per subcategory. All subscales of the SWAL-QOL with the exception of fear, obtained the Cronbach's alpha reliability standard of 0.80 for group-level research. Most of the correlations within each subscale were above .70. Internal consistency results ranged from 0.79 to 0.94. Scale-scale correlations range from 0.05 to 0.78. Scales that measured similar constructs correlated more highly with those measuring differing constructors. For example, scales evaluating eating (burden, food selection, and eating) correlated with an average of 0.51 thus displaying convergent validity (McHorney et al., 2002).

The Neuro-QoL (Appendix C) is a comprehensive validated and reliable measure that contains multiple sub-measures addressing dimensions of health-related quality of life universal to patients with chronic neurological disease. It further evaluates concerns common to many or most neurological conditions, and assesses symptoms and concerns specific to certain neurologic disease (Salsman et al., 2013). This facilitates cross disease comparison (Nowinski, Victorson, Cavazos, Gershon, & Cella, 2010). Using a 5-point rating scale, ranging from never (1) to always (5), participants rated negativity during various scenarios regarding their illness and various associated limitations. The stigma portion of the Neuro-QoL consists of 24 items. The stigma portion of the Neuro-QoL was utilized for this project. Internal consistency for the stigma portion of the Neuro-QoL is .91, with an intraclass correlation of .83. Regarding reliability, Cronbach's alpha for test-retest reliability was .91 and the intraclass correlation coefficient was .83 for the stigma portion of the Neuro-QoL (Victorson et al., 2014).

The ARSMA-II (Appendix D) is a bi-dimensional behavioral scale used to measure acculturation and cultural diversity among participants quantitatively.

Specifically, the ARSMA-II measures language use and preference, ethnic identity and classification, cultural heritage and ethnic behaviors, as well as ethnic interaction. A five-point scale is utilized ranging from not at all (1) to almost always (5). Forty-eight items in total are included in the ARSMA-II. The ARSMA-II consists of the Anglo Orientation Subscale (AOS) and the Mexican Orientation Subscale (MOS); both subscales were administered. Although the ARSMA-II is not validated, it is the most frequently used rating scale in acculturation research (Gutierrez, Franco, Powell, Peterson, & Reid, 2009). Throughout the ARSMA-II, the word Mexican is utilized. In the event that participants stated that they would not identify themselves as Mexican, they were asked what box they would check on the U.S. Census. If they stated Hispanic, they were encouraged to mentally replace the word Mexican with Hispanic while completing the ARSMA-II.

Dysphagia severity instrument. The Mann Assessment of Swallowing Ability (MASA; Mann, 2002) was administered to all participants to quantify dysphagia severity. The Mann Assessment of Swallowing Ability (Appendix E), is a validated clinical instrument with 24 items that quantify the level of oropharyngeal dysphagia. Sensitivity (73%), specificity (89%), positive predictive values (92%), negative predictive values (65%) and positive likelihood ratios (6.6) were reported for the identification of dysphagia. Further, sensitivity (93%), specificity (63%), positive predictive values (41%), negative predictive values (97%) and positive likelihood ratios (2.5) were reported regarding the likelihood of aspiration. Upon completion, an overall numerical dysphagia severity score and a quantifiable aspiration risk measure were obtained.

Data analysis. For each of the questionnaires, data were reduced and summarized. The procedures used for each individual questionnaire are noted below. Final scores for each individual were used in the final analysis.

SWAL-QOL. For each participant, data were reduced using the following procedures; a total score for each subsection of the SWAL-QOL was calculated. Data analysis was completed using non-parametric correlations. Individual SWAL-QOL subsets were combined into three clusters by using Spearman's rank order correlation to determine the relationship between SWAL-QOL subtests, as the data were non-parametric. Items were clustered if correlation results were $r \geq 0.70$. Cluster results are displayed in Table 2. The first cluster included the following subscales: burden, eating, food, mental health, and social. Cluster 2 encompassed: symptoms, fear, and communication. Fatigue, which did not statistically cluster with any other measures, served as the third cluster. Broadly, Cluster 1 of the SWAL-QOL evaluates mental and social health, Cluster 2 is associated with physical symptoms, and Cluster 3 assesses fatigue.

Table 2.

SWAL-QOL Cluster 1 and 2 items

SWAL-QOL Cluster 1	
Items	**Correlation**
Burden and Mental Health	.971
Food and Eating	.928
Burden and Eating	.912
Eating and Mental Health	.886
Burden and Social	.702
SWAL-QOL Cluster 2	
Items	**Correlation**
Symptoms and Fear	.899
Symptoms and Communication	.721

Spearman's rank order correlation was then used to determine the relationship between level of acculturation and each respective cluster. There is not a table for Cluster three as the *fatigue* sub-section of the SWAL-QOL was not clustered with any other items.

Neuro-QoL. A Neuro-QoL total score was calculated by summing participant's responses to each question resulting into a total stigma score. An average score was then obtained for each participant.

ARSMA-II. An acculturation rating was calculated following the standard scoring procedures of Cuellar, Arnold and Maldonado (1995). The Anglo Orientation Subscale score (AOS score) was obtained by summing items 2, 4, 7, 9, 10, 13, 15, 16, 19, 23, 25, 27, and 30 on Scale I of the ARSMA-II; the sum of the AOS was divided by 13 to obtain a mean score for the subscale. The Mexican Orientation Subscale score was calculated by summing the following: 1, 3, 5, 6, 8, 11, 12, 14, 17, 18, 20, 21, 22, 24, 26, 28, and 29. The sum of the preceding items was divided by 17 to obtain a mean for the MOS subscale. The MOS mean was subtracted from the AOS mean in order to obtain an acculturation score. This resulted in a score along a continuum from very Mexican oriented to very Anglo oriented (Cuellar, Arnold, & Maldonado, 1995). Acculturation score ranges, descriptions of those scores, and associated acculturation level(s) can be found in Table 3.

Table 3

ARSMA-II score description (Cuellar et al., 1995)

ARSMA-II		
Acculturation Level	**Description**	**ARSMA-II Acculturation Score**
I	Very Mexican Oriented	<-1.33
II	Mexican Oriented to Bicultural	≥-1.33 to ≤-0.7
III	Slightly Anglo Oriented Bicultural	> -.07 and < 1.19
IV	Strongly Anglo Oriented	≥ 1.19 and <2.45
V	Very Assimilated/ Anglicized	>2.45

MASA. Following the procedures of (Mann, 2002), sub-measures were summed resulting in a total score. Scores associated with severity and aspiration risk are summarized in Table 4.

Table 4

MASA aspiration risk and dysphagia severity score description (Mann, 2002)

Aspiration Risk and Dysphagia Severity	
Severity Rating/Aspiration Risk	**MASA Score**
Nil abnormality	≤178-200
Mild	≤168-177
Moderate	≤139-167
Severe	≤138

Phase I correlation analysis. Spearman's rank order correlation was calculated given the non-parametric and ordinal scale data. However, as a result of the small sample size, the data were not assessed for monotonicity (Yue, Pilon, & Cavadias, 2002). The relationship between level of acculturation and, (a) swallowing related quality of life as measured by the SWAL-QOL clusters, and (b) associated stigma as measured by the Neuro-QoL was evaluated. The level of association between dysphagia severity as measured by the MASA and (a) swallowing related quality of life as measured by the SWAL-QOL, and (b) stigma as measured by the stigma portion of the Neuro-QoL was assessed.

When evaluating the relationship between dysphagia severity, the following numerical values were assigned to the severity ratings. Nil severity (0), mild (1), moderate (2), and severe (3).

Phase II

Data collection. A subset of individuals from Phase I were selected to participate in Phase II, (S03, S07, and S05) where two semi-structured interviews were completed upon completion of consent. Participants were selected based on level of acculturation (per ARSMA-II) and dysphagia severity (per MASA). In exchange for their time, each individual participating in Phase II was offered \$10.00 per interview for a total of \$20.00. Participants S03, S05, and S07 were informed that the interview could be conducted in a location of their choosing. A Sony Handyman video camera model number: HDR- CX 220, and the Voice Memos app on an iPhone were used to audio and video-record each interview. Following the structure of Rodriguez and Olswang (2003), five to seven open-ended questions were formulated to help guide the interview and can be found in Appendix F. These questions were based on the participant's response(s) to the SWAL-QOL and the Neuro-QoL. During data collection, further questions were posed based on participants' responses to the predetermined questions. Upon completion of the first interview, participant(s) were asked to return for a follow-up interview within 1 week of the initial interview.

Identified themes across all participants can be found in Figure 5. The interviews were video/audio recorded and transcribed by two trained undergraduate students who were unfamiliar with the research questions, as well as the thesis author.

Data analysis. Transcendental realism, a type of qualitative data analysis was performed using techniques defined by Miles and Huberman (1994). Content categories and themes were identified using a recursive process. During an interview, the interviewer generated a list of frequently occurring topics. These topics served as an initial list of hypothesized themes. The thesis author and two undergraduate students, unfamiliar with the research question, then transcribed each interview. Data transcripts were visually inspected for exemplars of the hypothesized themes by looking for (a) words or phrases related to the themes, and (b) recurring words or phrases. Further, transcripts were dissected into phrase groups and an attempt was made to assign any applicable phrase group into any of the identified themes. This 3-step process occurred after every interview.

When an interview resulted in a novel topic, this topic was added to the list of themes. Previous interviews were then re-reviewed for evidence of that new theme. This recursive process continued until all interviews were completed, transcribed, and reviewed. The result was a final list of categories and themes. This final list of themes was used to re-review the interviews to confirm theme assignment and finalize the frequency of each theme. Phrase length was limited to contain only one theme per phrase. If more themes were identified, the phrase was chunked into smaller segments to isolate the themes. Themes were organized by broad categories and each theme was carefully defined.

The transcribed interviews, identified themes, and definition of each theme were given to a second reviewer for re-coding. The results from the second reviewer were evaluated to note the differences in theme assignment. Differences between the two coders were clustered into three error types which included differences related to (a) limitations or misunderstanding in the theme definition, (b) coding errors such as not identifying a particular exemplar, or (c) disagreement regarding which theme best fit a phrase segment. Coding differences were discussed to obtain, when possible, a consensus. Researcher coding errors included missed or uncoded phrases. These were identified and coded before being evaluated in the code checking process. When coding differences were related to ambiguity in theme definition, the definition was clarified and the phrase(s) were re-coded. Coding differences that were related to disagreement in the theme assignment were used to calculate coding reliability. Check-coding procedures were implemented as a reliability procedure for all interviews (Miles & Huberman, 1994). A percentage of reliability was obtained by dividing the number of agreements between the two raters by the total number of agreements plus the total number of disagreements.

The frequency of each theme was identified for each respective participant and evaluated as a function of acculturation. Conclusions were drawn by noting regularities, and patterns; the above tactics were implemented in order to test and confirm themes, as well as safeguard against self-delusion (Miles & Huberman, 1994). Hypotheses were generated regarding each theme as a function of acculturation or a specific cultural trait.

Chapter 4

Results

Quality of Life

For quality of life, the 11 SWAL-QOL categories were divided into 3 clusters. The average scores for each participant are summarized in Tables 5, 6, and 7 for Clusters 1-3, respectively. The SWAL-QOL utilizes a five point rating scale, where a score of one denotes a severe impact on quality of life, and a score of 5 signifies no impact on quality of life. Participant S04 is not included in this analysis because he could not complete the SWAL-QOL questionnaire.

Table 5

SWAL-QOL Cluster 1 results

SWAL-QOL Cluster 1						
ID	**Burden**	**Eating**	**Food Selection**	**Mental Health**	**Social**	**Average**
S01	3.50	2.80	3.00	2.60	4.60	3.24
S02	4.00	4.60	5.00	4.80	5.00	4.68
S03	3.00	4.00	4.00	3.00	2.60	3.32
S05	2.00	2.50	3.50	1.80	2.60	2.48
S06	3.00	1.75	1.50	2.40	3.40	2.41
S07	4.00	4.25	5.00	4.00	4.80	4.41

Table 6

SWAL-QOL cluster 2 results

SWAL-QOL Cluster 2				
ID	**Symptoms**	**Communication**	**Fear**	**Average**
S01	3.64	1.00	3.75	2.80
S02	3.64	3.00	4.75	3.80
S03	3.43	5.00	2.00	3.48
S05	3.14	3.50	2.75	3.13
S06	2.14	2.50	2.25	2.30
S07	1.71	1.50	2.25	1.82

Table 7

SWAL-QOL Cluster 3 results

SWAL-QOL Cluster 3	
ID	**Fatigue**
S01	3.45
S02	3.00
S03	3.40
S05	2.20
S06	3.40
S07	1.40

Stigma

The total and average scores of the stigma subtest of the Neuro-QoL for each participant are summarized in Table 8. The presence of stigma ranged from 24 to 65, with the greater numbers representing an increased presence of stigma. Participant S04 is not included in this analysis because he could not complete the stigma subtest of the Neuro-QoL questionnaire.

Table 8

Neuro-QoL stigma results

Neuro-QoL		
ID	**Raw Score**	**Average**
S01	65	2.71
S02	24	1.00
S03	55	2.29
S05	62	2.58
S06	26	1.08
S07	45	1.88

Level of Acculturation

The Anglo Orientation Subscale (AOS) score, the Mexican Orientation Subscale (MOS) score, and the calculated acculturation as measured by the ARSMA-II, are summarized in Table 9 for each participant. Across the 7 participants, acculturation ranged from -5.04 (Level I very Mexican oriented) to 1.91 (Level IV strongly Anglo oriented).

Table 9

ARSMA-II results

ARSMA-II				
ID	**AOS**	**MOS**	**Acculturation Rating**	**Description**
S01	4.38	2.47	1.91	Strongly Anglo Oriented
S02	4.31	4.35	-0.04	Slightly Anglo Oriented Bicultural
S03	1.08	6.12	-5.04	Very Mexican Oriented
S04	1.38	4.29	-2.91	Very Mexican Oriented
S05	4.31	2.71	1.60	Strongly Anglo Oriented
S06	3.84	3.64	0.20	Slightly Anglo Oriented Bicultural
S07	4.08	2.94	1.14	Slightly Anglo Oriented Bicultural

MASA

The MASA, dysphagia severity rating, aspiration risk, and total score for each participant, are summarized in Table 10. All individuals tested positive for dysphagia. Across the 7 participants, dysphagia ranged from mild to severe. A greater total score on the MASA denotes decreased dysphagia severity.

Table 10

MASA results

		MASA	
ID	**Total Score**	**Dysphagia Severity**	**Aspiration Risk**
S01	152	Moderate	Mild
S02	173	Mild	Nil
S03	151	Moderate	Mild
S04	119	Severe	Severe
S05	177	Mild	Nil
S06	161	Moderate	Mild
S07	157	Moderate	Mild

Relationship Between Acculturation and Quality of Life

The relationship between level of acculturation and the three SWAL-QOL clusters are depicted in Figure 1. This figure is arranged in the order of level of acculturation where participant S03 had the lowest level of acculturation (-5.04; Level I very Mexican oriented per ARSMA-II) and participant S01 had the highest level of acculturation (1.91; Level IV strongly Anglo oriented per ARSMA-II).

Cluster 1. Cluster 1 includes burden, eating, food, mental health, and social measures. Spearman's rank order correlation between level of acculturation and quality of life for Cluster 1 of the SWAL-QOL was r = -0.371 (1 tailed, n=6, p=0.23).

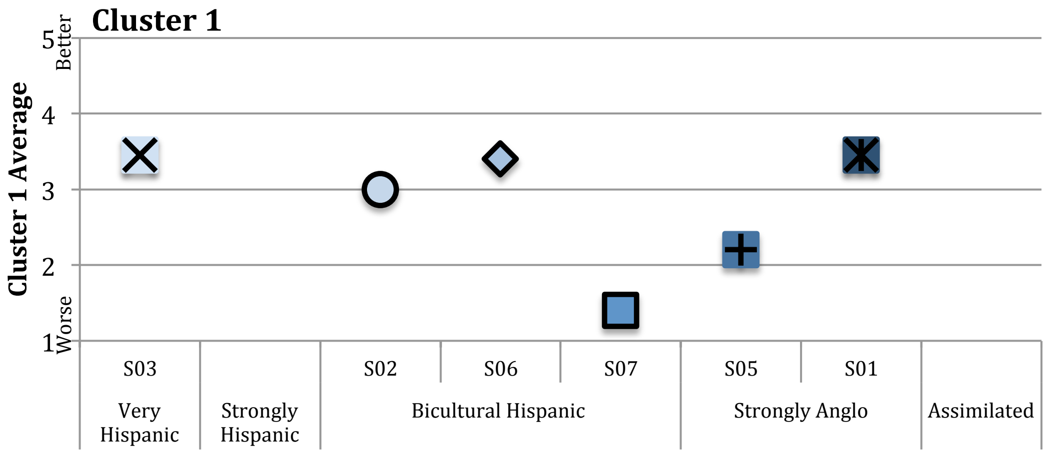
Cluster 2. Cluster 2 includes symptoms, fear, and communication measures. Spearman's rank order correlation between level of acculturation and quality of life from Cluster 2 of the SWAL-QOL was r = -0.486 (1 tailed, n=6, p=0.33).

Cluster 3. Cluster 3 includes fatigue. Spearman's rank order correlation between acculturation level and quality of life from Cluster 3 of the SWAL-QOL was r= -0.174 (1 tailed, n=6, p=0.37).

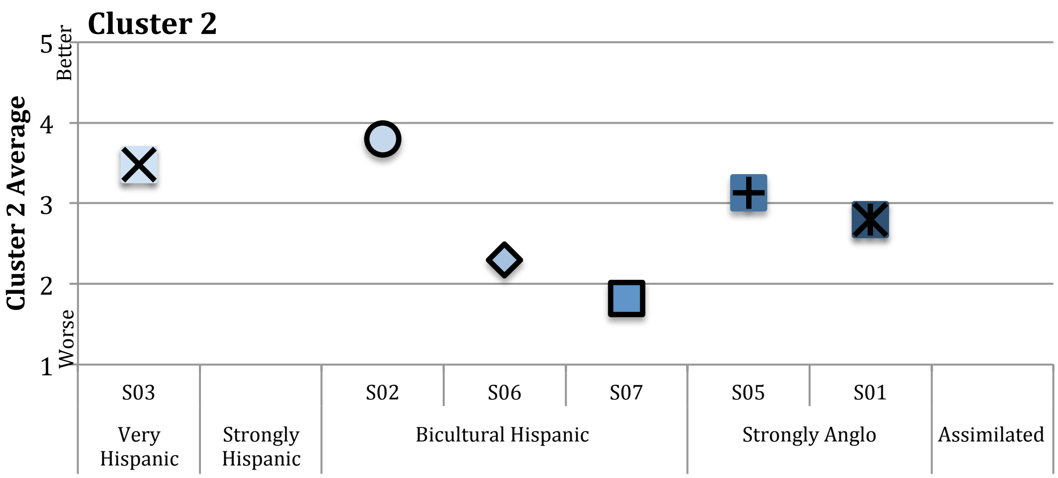
Figure 1

Relationship between level of acculturation as measured by the ARSMA-II and quality of life as measure by the SWAL-QOL which is clustered into 3 groups where (a) Cluster 1 contains mental and social health, (b) Cluster 2 is associated with physical symptoms, and (c) Cluster 3 assesses fatigue.

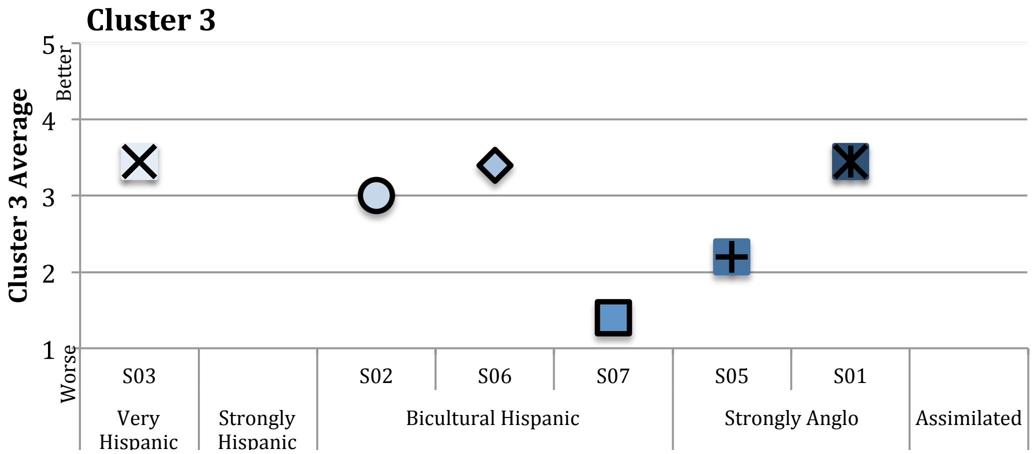
(a)



(b)



(c)

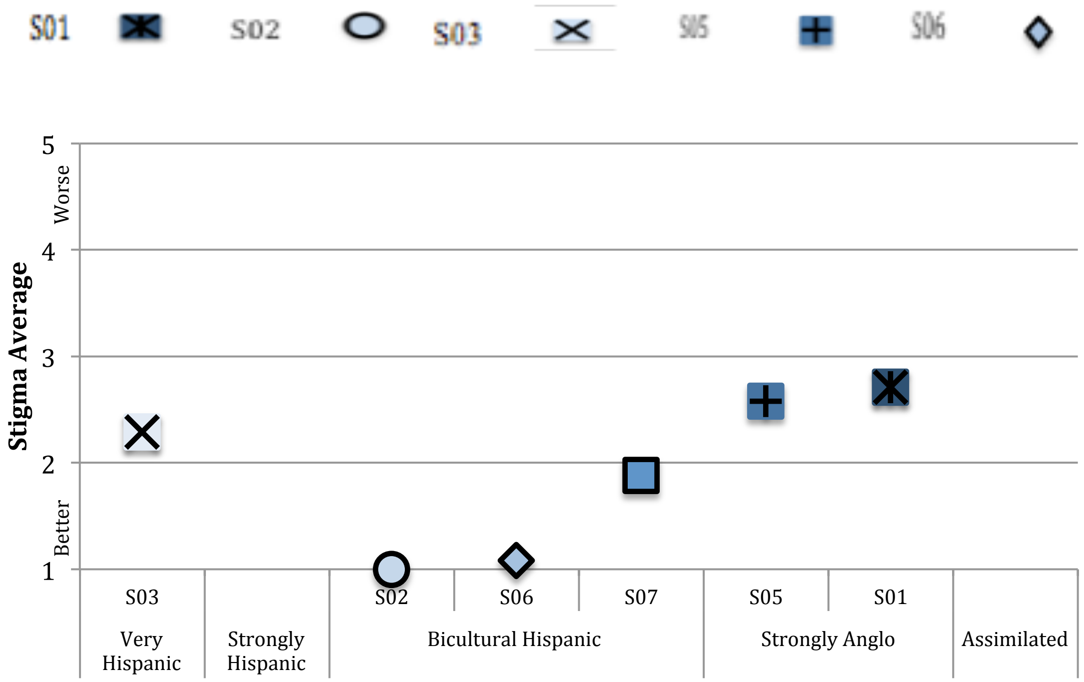


Relationship Between Acculturation and Stigma

The relationship between level of acculturation and stigma as measured by the stigma subtest of the Neuro-QoL is depicted in Figure 2. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04; Level I very Mexican oriented) and S01 had the highest level of acculturation (1.91; Level IV strongly Anglo oriented). Spearman’s rank order correlation between level of acculturation and stigma from the Neuro-QoL was r = .657 (1 tailed, n=6, p=0.78).

Figure 2

Relationship between level of acculturation and stigma.



Relationship Between Dysphagia Severity and Quality of Life

The relationship between level of dysphagia severity and the three SWAL-QOL clusters are depicted in Figure 3. Along the horizontal axis, participants are ordered by dysphagia severity; S03 had the most severe dysphagia, and S05 had the least severe dysphagia.

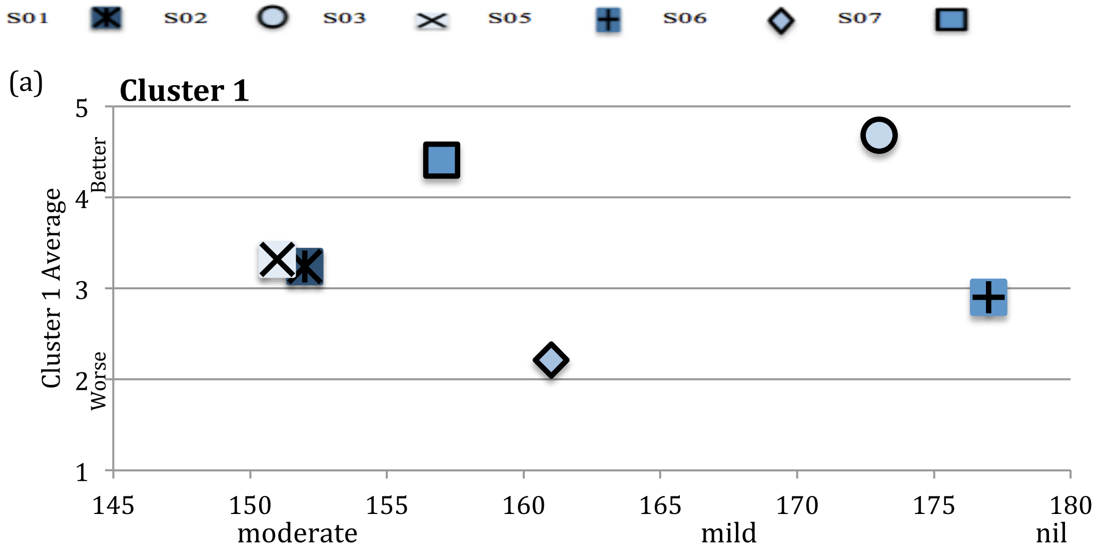
Cluster 1. Spearman's rank order correlation between level of dysphagia severity and quality of life as measured by Cluster 1 of the SWAL-QOL was r = -.068 (1 tailed, n=6, p=0.90).

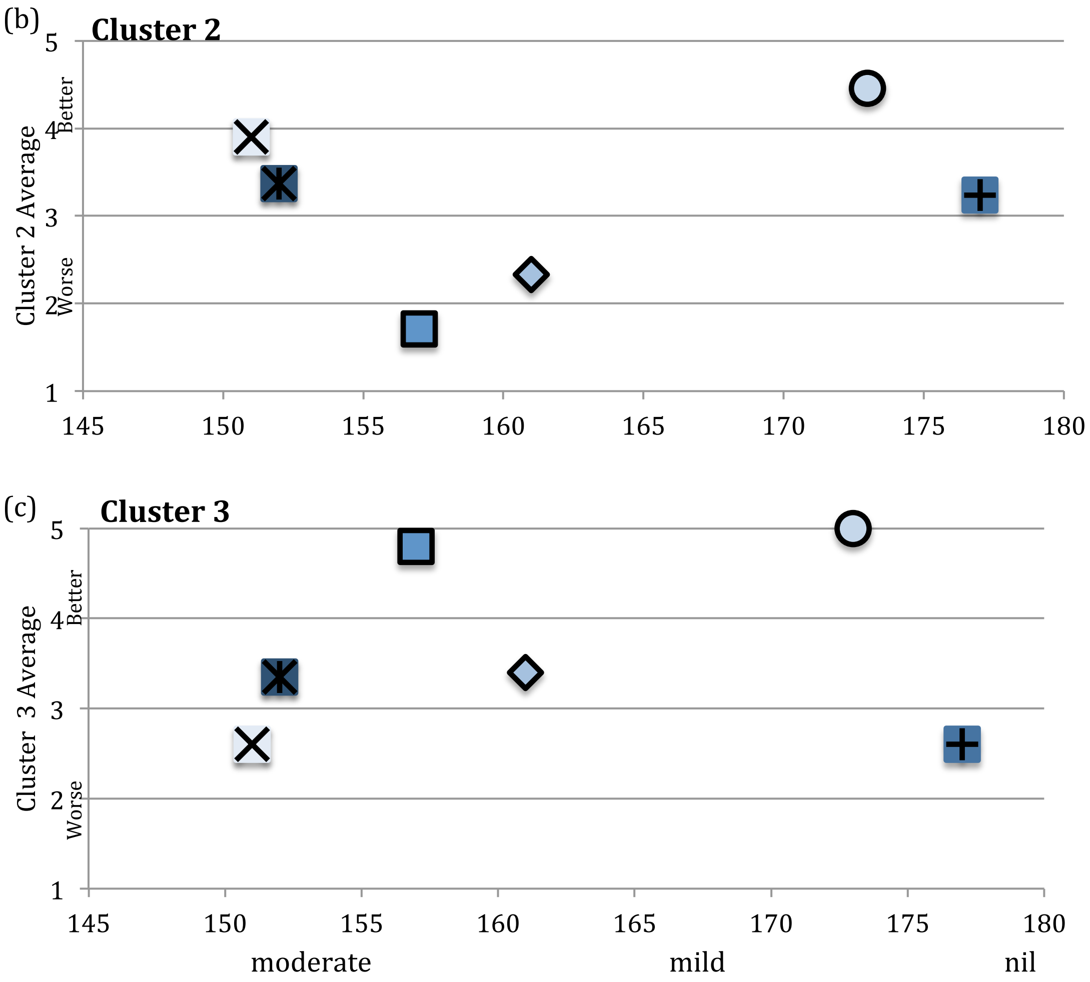
Cluster 2. Spearman's rank order correlation between level of dysphagia severity and quality of life, as measured by Cluster 2 of the SWAL-QOL, was r = -0.541 (1 tailed, n=6, p=0.27).

Cluster 3. Spearman's rank order correlation between level of dysphagia severity and quality of life, as measured by Cluster 3 of the SWAL-QOL, was r = .446 (1 tailed, n=6, p=0.38).

Figure 3

Relationship between dysphagia severity as measured by the MASA and quality of life as measure by the SWAL-QOL . Data are divided where Cluster 1 includes mental and social health, Cluster 2 is associated with physical symptoms, and Cluster 3 assesses fatigue.



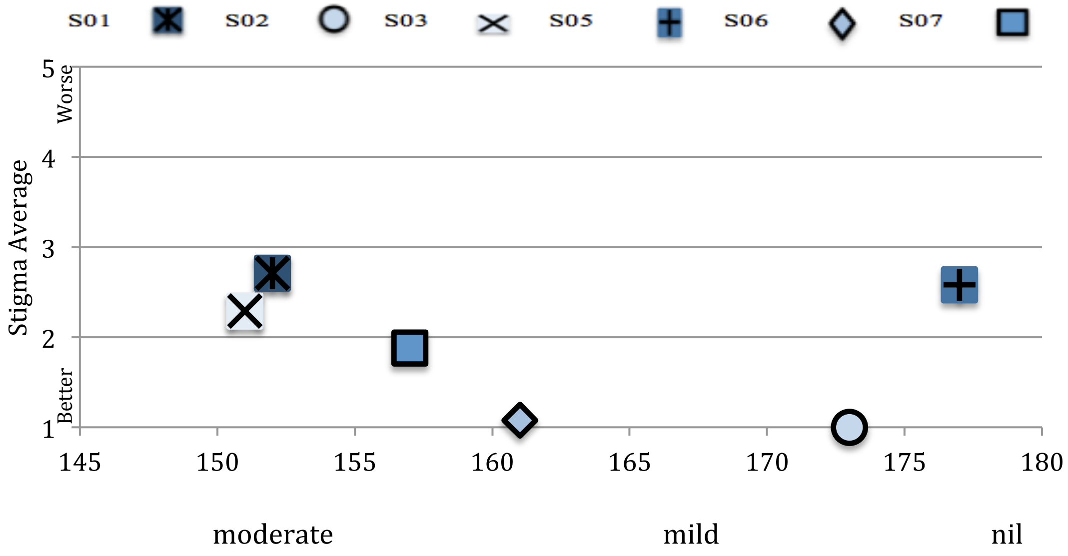


Relationship Between Dysphagia Severity and Stigma

The relationship between level of dysphagia severity and stigma as measured by the stigma portion of the Neuro-QoL is depicted in Figure 4. Along the horizontal axis, participants are ordered based on level of dysphagia severity, where S05 had the least severe dysphagia, and S03 had the most severe dysphagia. Spearman's rank order correlation between level of dysphagia and stigma, was r=0.067 (1 tailed, n=6, p=. 90).

Figure 4

Relationship between dysphagia severity and stigma



Phase II

The quality of life experiences for those selected to participate in the semi-structured interviews were classified into two broad categories: *emotional experiences* and *swallow-safety*. Emotional experience themes included stigma, distrust, fear, frustration, religion, acceptance, and impact. Swallow-safety themes included: treatment, symptoms, compensatory strategies, and triggers. The total runtime for each interview and definition of themes are listed in Table 11 and 12. Check-coding results can be found in Table 13, and a summary of the themes recorded can be found in Figure 5.

Table 11

Interview runtime summary

ID	Interview 1 Runtime	Interview 2 Runtime
S03	42 min. 40 sec.	15 min. 9 sec.
S05	57 min. 30 sec.	43 min. 10 sec.
S07	38 min. 26 sec.	30 min. 30 sec.

Table 12

Definition of themes

Theme	Definition
Stigma	A sensation of embarrassment and/or feeling of disgrace or difference, or not fitting in.
Distrust	Any negative thoughts or feelings about medical professions.
Fear	Any experience(s) where participants felt hesitant or afraid.
Frustration	A feeling of sadness, tension or frustration with life events, or with medical or swallow deficits.
Religion	Information about God, religion, or spirituality.
Acceptance	Acceptance or coping with the situation. Includes both statements of hope and surrender.
Treatment	Treatment or help-seeking behaviors.
Symptoms	Any medical or swallow related symptoms including pain any kind.
Compensatory Strategies	Attempted measures used to improve difficulty swallowing or changes made to the way one swallows or the diet one follows.
Triggers	Events, activities or situations that result in a sing or symptom of dysphagia
Impact	The swallow disorder or medical status results in a change in activities or participation separate from compensatory strategies.

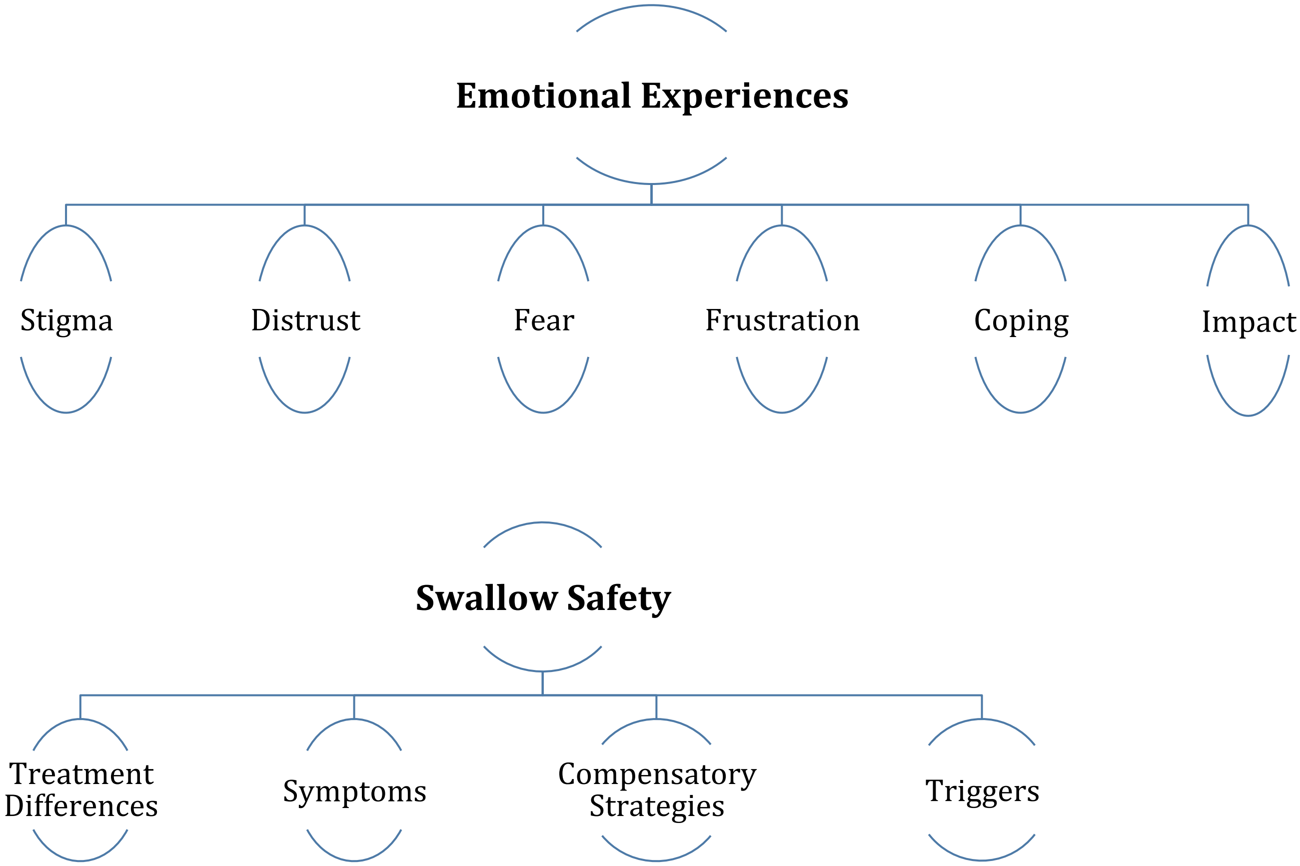
Table 13

Check coding results

Participant	Percent Reliability
S03	100%
S05	98%
S07	100%

Figure 5

Theme summary for emotional experiences and swallow safety



Emotional Experiences

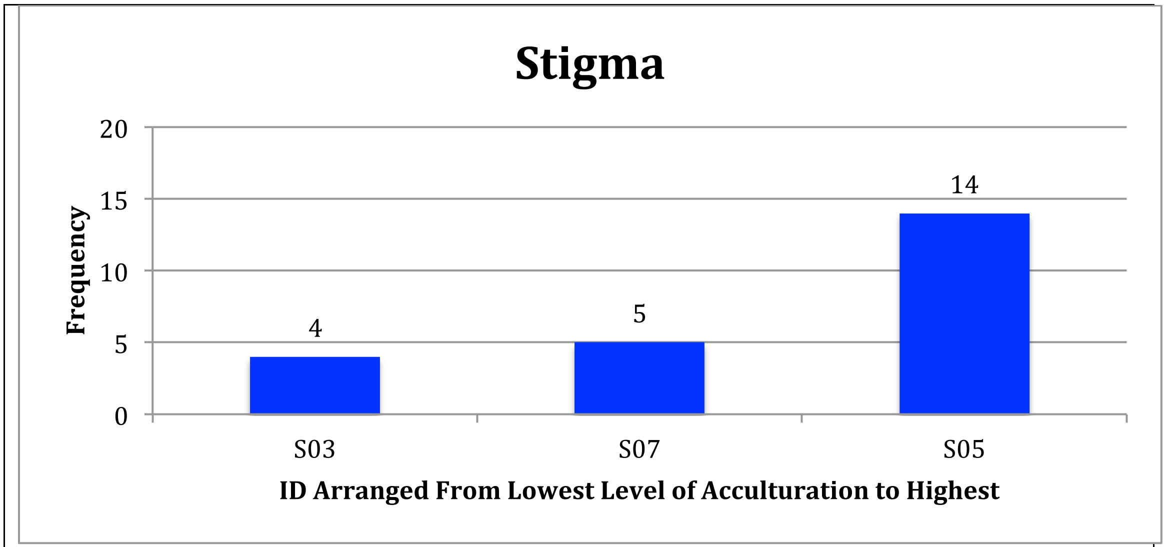
Stigma. All three participants described stigma related to physical changes as a result of dysphagia. Frequency of stigma-related comments ranged from 4 to 14. For S03 stigma comments were related to observations that would be or were made by others.

A summary of the frequency of stigma statements across both interviews can be found in Figure 6 for each participant. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04) and S05 had the highest level of acculturation (1.60) for those participating in Phase II.

For example, when describing treatment received, S03 (Very Mexican Oriented) stated, "I feel embarrassed." For S07 and S05, stigma comments were related to feelings of embarrassment related to swallow symptoms. S07 (slightly Anglo oriented/bicultural) described a sensation of embarrassment by sharing the following statement regarding a recent event in which he was choking, "My friends look at me, you know, all embarrassed…it's just a little bit embarrassing to just sit there and choke all of a sudden like just out of the blue, and loud too." When discussing a new friend, S05 (strongly Anglo oriented) elaborated, "There's a new gentleman that I've met. He wants to take me out to dinner. If and when I decide to go, I'm not going to tell him anything about this" (referring to difficulty swallowing).

Figure 6

Summary of stigma statements for Interview I and II for all Phase II participants



Definition: A sensation of embarrassment and/or feeling of disgrace or difference, not fitting in.

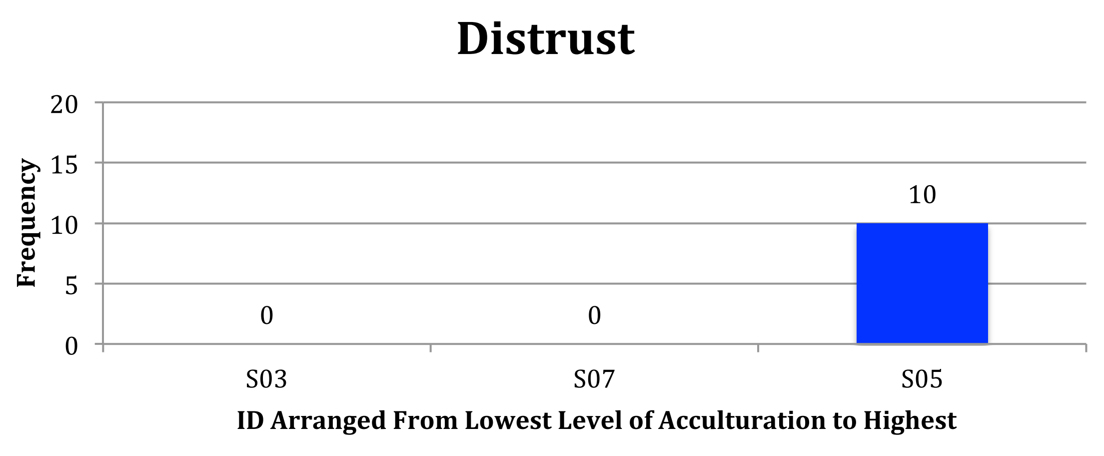
ID	S03	S07	S05
Exemplars	I feel embarrassed because I don't want to choke.	Spitting up stuff all over the place is just not cool.	I don't feel comfortable eating and talking all the time.
	I looked awful.	It is just a little bit embarrassing to just sit here and choke all of a sudden.	I'm not going to tell him anything about this.
	I always have to use a napkin and make sure the food doesn't fall out of my mouth because it's embarrassing.	Based on the embarrassment (when asked why he doesn't eat/drink in public).	It's not something I discuss with other people. I'm not going to.
		My friends look at me all embarrassed.	(I don't go out to eat), because then I would have to let everyone know what was wrong.

Distrust. The theme of distrust of medical personnel was observed for one participant on 10 occasions. A summary of the frequency of distrust statements across both interviews can be found in Figure 7. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04) and S05 had the highest level of acculturation (1.60) for those participating in Phase II.

S05 (strongly Anglo oriented) shared personal experiences with neurologists. To investigate whether there was a sensation of distrust, S05 was asked to provide information regarding how she feels about neurologists. To which she stated, “Well, I’m not overly impressed.” To clarify, S05 was asked to provide an example. She further explained that neurologists generally have a “Total lack of paying any attention.”

Figure 7

Summary of distrust statements for Interview I and II for all Phase II participants



Definition: Any negative thoughts or feelings about medical professionals.			
ID	S03	S07	S05

Figure 7 (cont.)

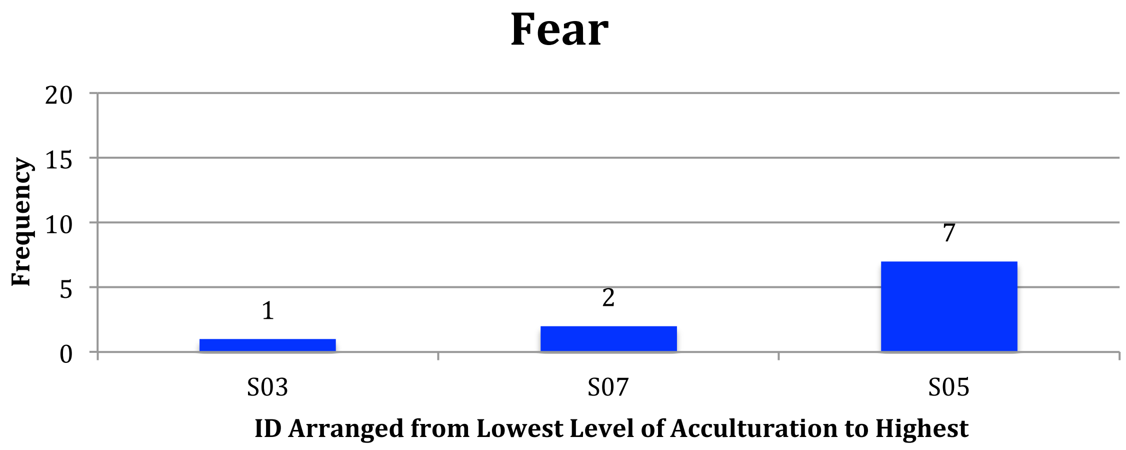
Exemplars	Theme was not observed.	Theme was not observed.	I’m not overly impressed with a single doctor I have ever found in this town.
			Well I’m not overly impressed (speaking of physicians).
			Pretty bad about talking to me (speaking of physicians).

Fear. The theme of fear was observed for all three participants, and theme frequency ranged from 1 to 7. A summary of the frequency of fear statements across both interviews can be found in Figure 8. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04) and S05 had the highest level of acculturation (1.60) for those participating in Phase II.

S03 (very Mexican oriented) described fear related to the physical changes that occurred after her stroke. She stated, “The therapy helped me a lot. I felt like my mouth was twisted towards my ear. I looked awful, and I was terrified that I would stay looking like that for the rest of my life.” S07 (slightly Anglo oriented/bicultural) only spoke of fear when choking. When describing difficulty swallowing, S05 (strongly Anglo oriented) used the word *strangling*. When asked to provide more information about this, she stated, “It’s just not something that you’re expecting, it’s not something that I can prepare or be unprepared for. It’s happened about six or eight times in the last six or eight years, or maybe a little more often than not. It’s not a daily occurrence, but it’s a very scary thing.”

Figure 8

Summary of fear statements for Interview I and II for all Phase II participants

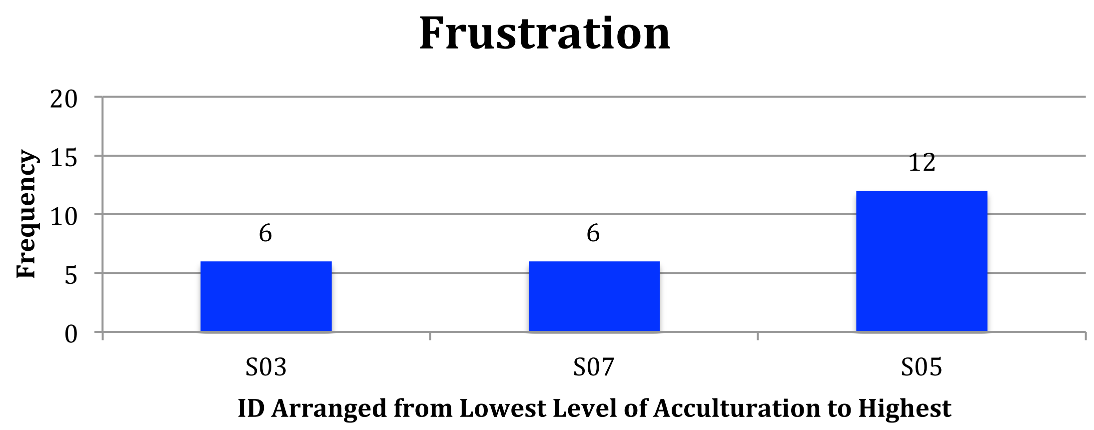


Definition: Any experience(s) where participants felt hesitant or afraid.

ID	S03	S07	S05
Exemplars	I looked awful, and I was terrified that I would stay looking like that for the rest of my life.	I just choke and then I start freaking out looking for something to drink.	The scariest part is it has gone into my throat and the breathing.
		I kind of start to panic.	The scariest things are at night.
			It is scary a lot of times during the day, but especially at night.

Figure 9

Summary of frustration statements for Interview I and II for all participants



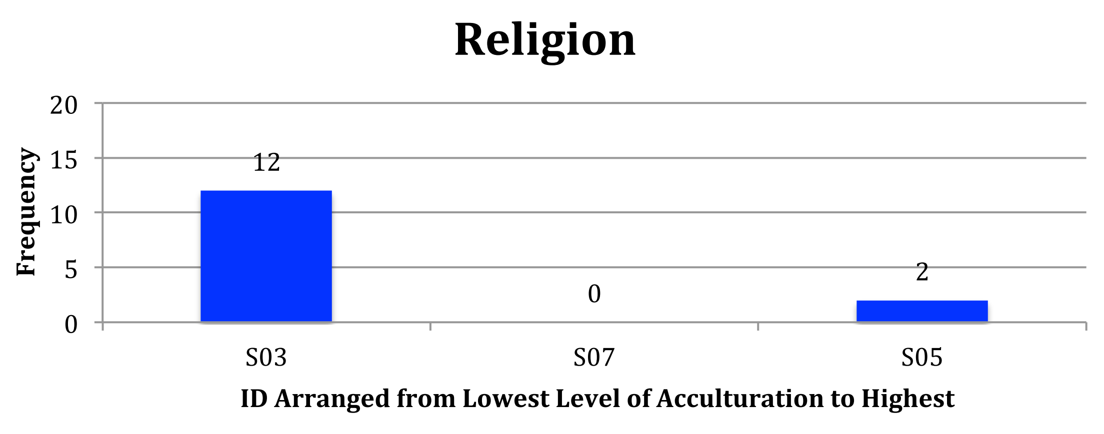
Definition: A feeling of sadness, tension, or frustration with life events, medical, or swallow deficits.			
ID	S03	S07	S05
Exemplars	I get frustrated and anxious because I know that there are other things that need to get done around the house.	It makes me angry	All the symptoms of Guillain-Barré are all the time.
	I feel impatient like I am losing time.	It is just very upsetting.	All three times they wanted to just put me on the thing, hook me up to all the things that shock me.
	I feel pressured because I have to get my meal done.	I don’t like spitting stuff up.	I’m up three, four, five times a night, I don’t get any sleep.
	I was sad (when discussing facial paralysis).	When I choke… then I’m upset.	It never goes away (speaking of pain).
			I don’t have any control. That’s what bothers me the most about it.

Frustration. The theme of frustration was observed for all three participants. The frequency of frustration for all participants ranged from 6 to 12. A summary of the frequency of frustration statements across both interviews can be found in Figure 9. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04) and S05 had the highest level of acculturation (1.60) for those participating in Phase II.

When asked to describe how the time needed to complete a meal impacts daily activities, S03 (very Mexican oriented) stated, “I get frustrated and anxious because I know that there are other things that need to get done around the house. I can’t rush and I have to be there for however long it takes.” Participant S07 (slightly Anglo oriented/bicultural) shared, “It makes me angry. It is just very upsetting.” When asked to describe eating patterns prior to Guillain-Barré Syndrome, S05 (strongly Anglo oriented) shared details about Guillain-Barré Syndrome as well. She elaborated, “All the symptoms of Guillain-Barré are there all the time. So I tend to blame this (referring to swallowing) on Guillain-Barré too. I don’t know if it’s that or not, but I have no other explanation for it.”

Figure 10

Summary of religion statements for Interview I and II for all Phase II participants



Definition: Information about God, religion, or spirituality.			
ID	S03	S07	S05
Exemplars	I'm going to turn 72 in January God willing.	Theme was not observed.	God forbid to marry someone.
	God gives me strength.		Say thank you God missed the bullet at that time.
	I was baptized, and I am Catholic thanks be to God for everything.		
	To me, my faith is the most important thing in my life.		
	Thanks be to God.		

Religion. The theme of religion was observed for two participants, and frequency ranged from 2 to 12. A summary of the frequency of statements regarding religion across both interviews can be found in Figure 10. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04) and S05 had the highest level of acculturation (1.60) for those participating in Phase II.

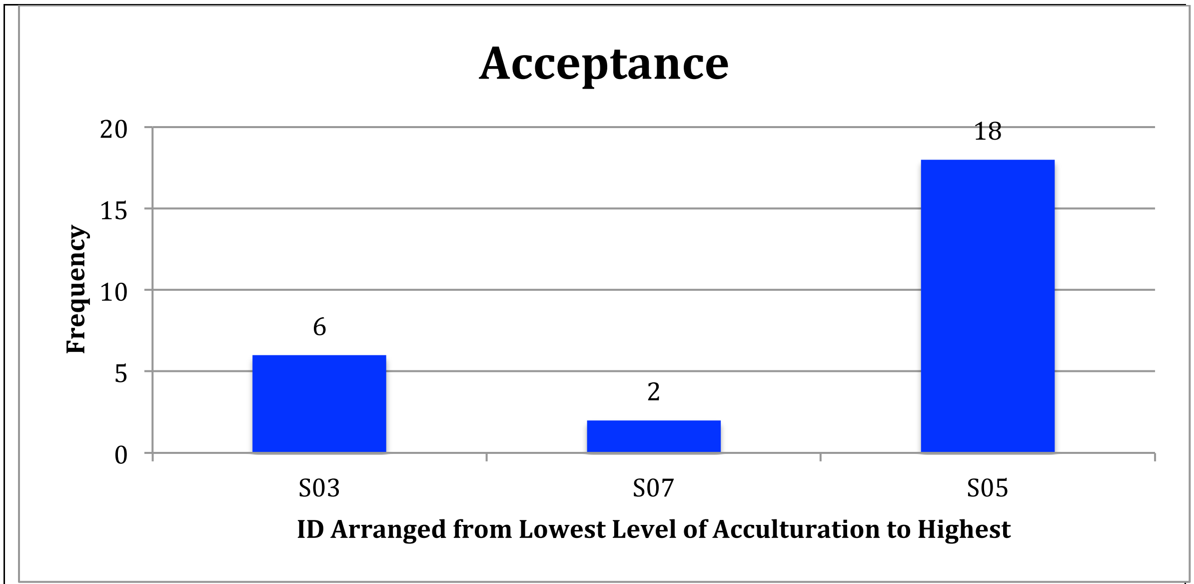
Although two participants made reference to a deity, these references were qualitatively different. When asked to describe any problems she had while eating breakfast, S03 (very Mexican oriented) stated, “No problems, thanks be to God.” When asked how she felt God had supported her, or helped her throughout the process of having difficulty swallowing, S03 shared, “ I was baptized, and I am Catholic.” She continued, “Thanks be to God for everything. God is good. To me my faith is the most important thing in my life.” S05 (Strongly Anglo oriented) used a deity to express an explicative (God forbid) and only once made reference to being thankful for spiritual support, although, it appeared to have a level of light-hearted sarcasm (“Thank you God. Missed the bullet that time”.). This was not observed for S03 who spoke of religion with reverence and respect.

Acceptance. The theme of acceptance was observed for all three participants in Phase II. Frequency of acceptance ranged from 2 to 18. A summary of the frequency of statements regarding coping across both interviews can be found in Figure 11. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04) and S05 had the highest level of acculturation (1.60) for those participating in Phase II.

S03 was asked to provide a specific event when she felt embarrassed in public because of her difficulty swallowing. She provided an example and further specified, “My dad had problems with this, and my aunts had trouble with this too. It might be hereditary, if it is hereditary, it’s my lot.” S07 (slightly Anglo oriented/bicultural) spoke of acceptance in a general sense. He shared, “that’s just the way it goes.” When explaining the presence of fear during a recent choking event, S05 (strongly Anglo oriented) provided information regarding acceptance. She stated, “Yeah, survived that one. Might not take another bite or drink of what just caused it, or eat what I just ate. But basically, if it doesn’t stop my life, it doesn’t stop my life.”

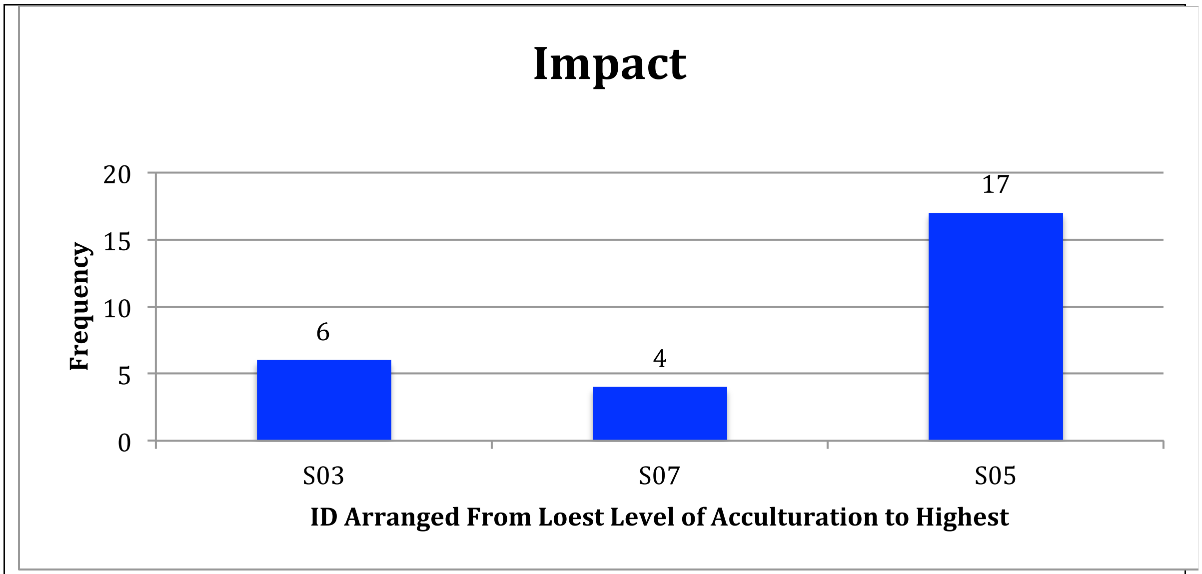
Figure 11

Summary of acceptance statements for Interview I and II for all Phase II participants



Definition: Acceptance or coping with the situation. Includes both statements of hope and surrender.			
ID	S03	S07	S05
Exemplars	If it is hereditary, it is my lot.	That’s just the way it goes.	If it doesn’t stop my life, it doesn’t stop my life.
	I’m not exactly where I need to be, but this is pretty good.		All I can do is keep on keeping on.
			You get used to it being there.
			If it hasn’t killed me yet, it hasn’t killed me yet.

Figure 12
Summary of impact statements for Interview I and II for all Phase II participants



Definition: The swallow disorder or medical status results in a change in activities or participation separate from compensatory strategies.

ID	S03	S07	S05
Exemplars	It takes me more than 30 minutes to eat.	I'm just not normal anymore.	My health has deteriorated a lot.
	I can't rush (when eating); I have to be there for however long it takes.	Everything is different.	I don't accept dinner dates.
	Even if I want to eat fast, I can't	I just don't go out as often.	I will go (out to eat) if it is necessary, but I don't encourage it.
	My mouth was twisted towards my ear.	I used to love those cheese and peanut butter crackers (doesn't eat them as much).	I never needed a doctor.
			I always used to sleep flat on my face, now I have to sleep sitting up a bit

Impact. The impact of dysphagia on quality of life was observed for all three participants. The frequency of impact related statements ranged from 4 to 17. A summary of the frequency of statements regarding impact across both interviews can be found in Figure 12. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04) and S05 had the highest level of acculturation (1.60) for those participating in Phase II.

Participant S03 (very Mexican oriented) spoke of changes in the amount of time that is needed to complete a meal, which further changes her daily activities. S07 (slightly Anglo oriented/bicultural) shared details about not "going out as much." Further, S05 (strongly Anglo oriented) shared information how she no longer participates in certain social and physical activities.

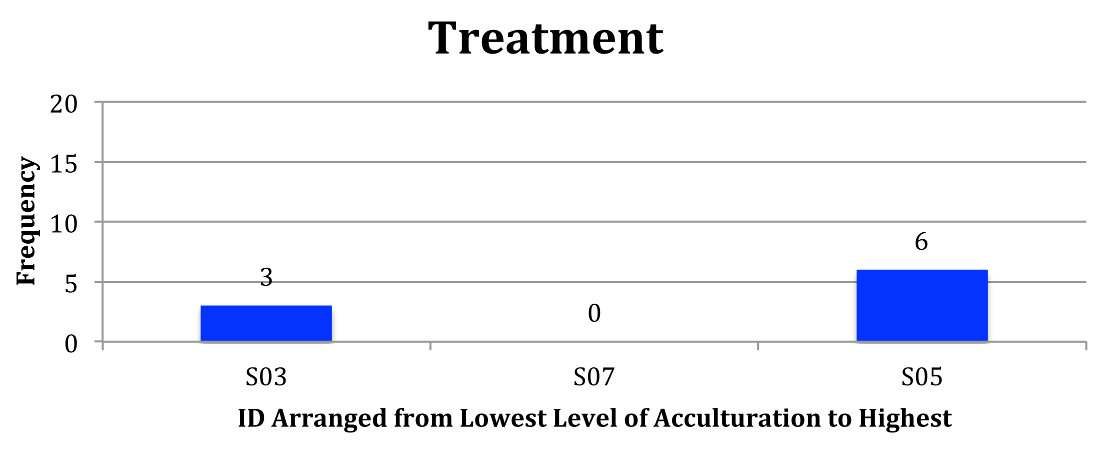
Swallow Safety

Treatment. For two participants, comments about treatment were observed. Frequency of treatment related comments ranged from 3 to 6. A summary of the frequency of statements regarding treatment across both interviews can be found in Figure 13. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04) and S05 had the highest level of acculturation (1.60) for those participating in Phase II.

When asked to describe any treatment or assistance that may have been sought, S03 (very Mexican oriented) said, "The therapy helped me a lot, I felt like my mouth was twisted towards my ear." She further specified, "I would go everyday. I would drive 30 minutes from home, and they would do electric stimulation every day for 3 months." S05 (strongly Anglo oriented/bicultural) shared details about her variability of doctor appointments ranging from cardiology, to primary care, as well as an allergist. She elaborated, " I'm going back to see this last doctor… that I've uh… he's actually an allergist."

Figure 13

Summary of treatment statements for Interview I and II for all Phase II participants

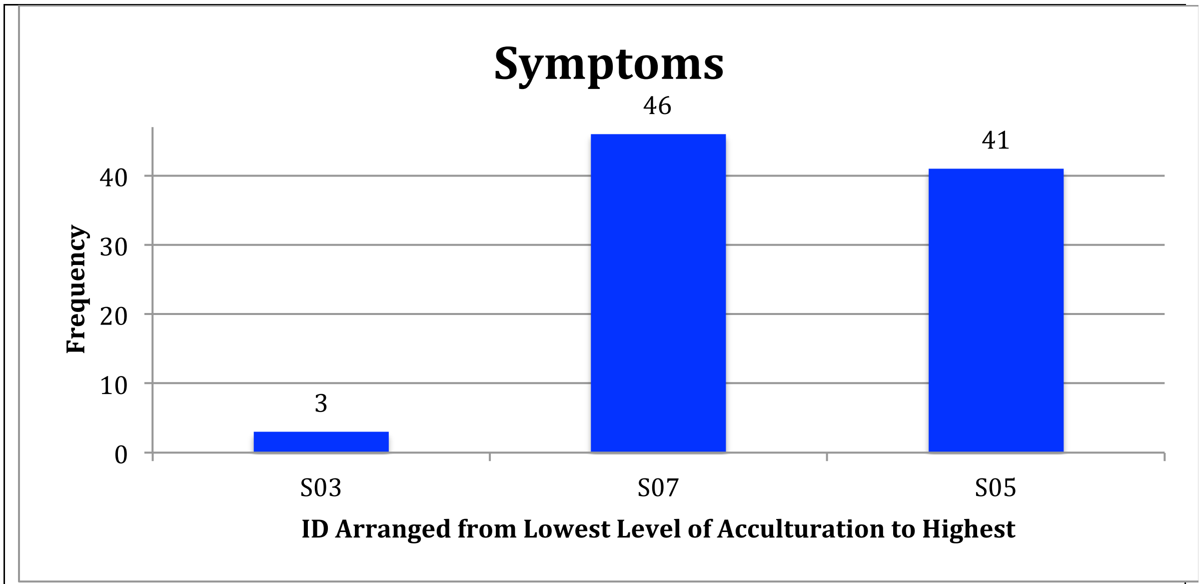


Definition: Treatment or help-seeking behaviors.			
ID	S03	S07	S05
Exemplars	I was in therapy for three months.	Theme was not observed.	My cardiologist, Dr. B.
	The therapy helped me a lot.		I go to a doctor.
			I can't find a doctor in this town (treatment seeking).

Symptoms. For two of the three participants in Phase II, the theme of symptoms was observed. Frequency of pain related comments ranged from 3 to 46. A summary of the frequency of statements regarding pain across both interviews can be found in Figure 14. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04) and S05 had the highest level of acculturation (1.60) for those participating in Phase II.

Figure 14

Summary of symptom statements for Interview I and II for all Phase II participants



Definition: Any medical or swallow related symptoms including pain of any kind.			
ID	S03	S07	S05
Exemplars	I also had trouble chewing.	It'll get stuck up here, and I'll choke on food real bad.	My throat, its… it hurts right now. It hurts.
	I sometimes choke.	They get stuck right here in my throat.	My chest pain.
	My mouth was twisted towards my ear.	I have a lot of pain and stuff.	It always feels like there's a thickness, a growth in there that is stopping me from swallowing and from talking and from breathing.
	It feels like I am choking or drowning.		And I'm spitting out everything.
			It is hard to eat.

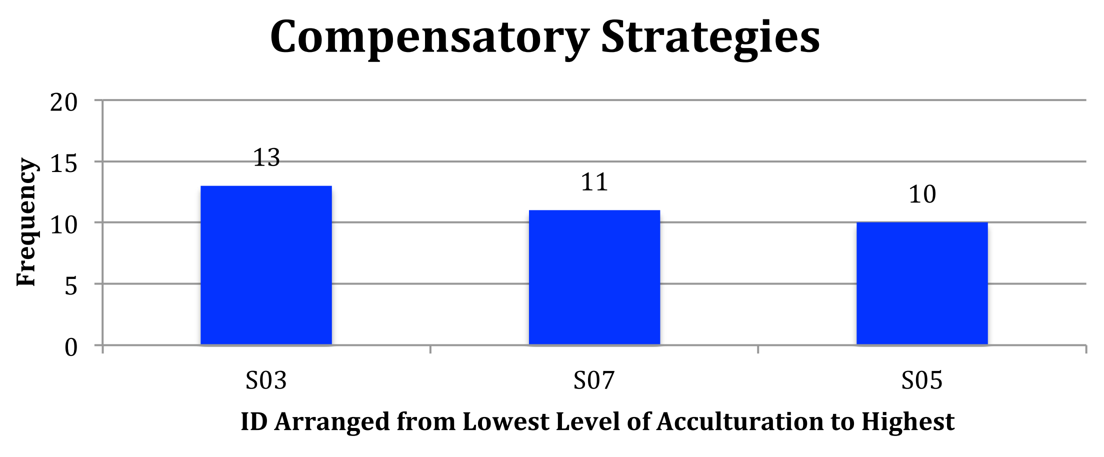
Participant S05 (slightly Anglo oriented/bicultural) shared details regarding chest pain as well as throat pain. When asked to describe this pain, she explained, "My throat hurts right now. My throat just feels…it just has a dull scratchy ache to it. I… it's just, there it is like a big lump, it is like… it's uncomfortable. Sometimes it hurts more, sometimes it is just more uncomfortable." Participant S07 (strongly Anglo oriented) spoke of general pain, as well as pain associated with events that he described as choking. He explained, "It's real uncomfortable, like a pain almost." He further specified, "When it goes into the airway, and I choke bad, that one really hurts."

Compensatory strategies. The use of compensatory strategies was described by two of the three individuals who participated in Phase II. Frequency of compensatory strategy related statements ranged from 10 to 13. A summary of the frequency of statements regarding compensatory strategies across both interviews can be found in Figure 14. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04) and S05 had the highest level of acculturation (1.60) for those participating in Phase II.

S03 (very Mexican oriented) spoke of the use of compensatory measures in order to prevent food falling from her mouth while eating, as well as difficulty swallowing. When asked to describe a typical mealtime, S03 shared, "It takes me more than 30 minutes to eat. I have to feed my son. We sit down and eat together, and I have to take my time when chewing." Further, when discussing mealtimes that occur in public, S03 explained, "When I'm out I need to have a paper towel, that's my tool. That's the first thing I need when we're out. I need a napkin." Participant S07 (slightly Anglo oriented/bicultural) spoke about preventative measures; on one occasion, he stated, "I can look at a piece of meat and say no, that's not going to work. It's going to be tough and rubbery; I'm not going to be able to chew it and swallow it easily. I have to be picky with certain things." He provided additional details regarding compensatory measures that are utilized while he is choking. He stated that he can't breathe, and "I have to push it down with something else. Something to drink." Participant S05 (strongly Anglo oriented), discussed compensatory strategies while eating, as well as preventative measures before consuming liquids (not drinking from a water fountain). She stated, "I have to slow down" (while eating).

Figure 15

Summary of compensatory strategy statements for Interview I and II for all Phase II participants



Definition: Attempted measures used to improve difficulty swallowing or changes made to the way one swallow or the diet one follows.

ID	S03	S07	S05
Exemplars	I have to be prepared before I swallow.	I have to drink something to help push it down.	I have to slow down.
	I have to take my time when chewing.	Either it's going to come up, or I need to make it go down somehow.	I have to be really careful with what I eat.

Figure 15 (cont.)

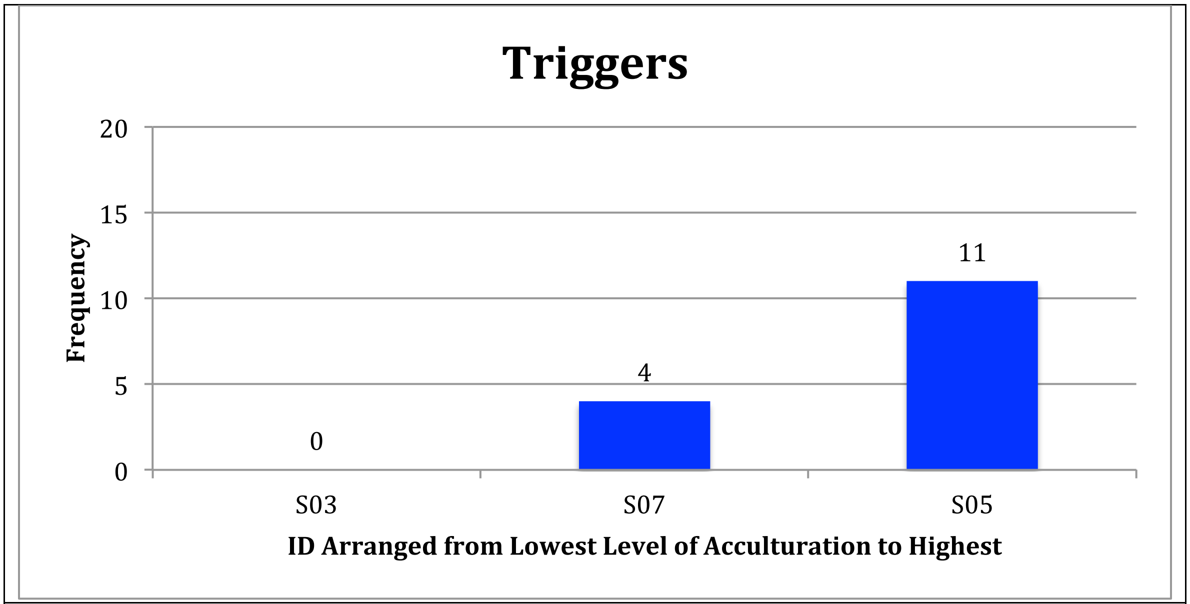
	When I’m eating, I always have to use a napkin and make sure the food doesn’t fall out of my mouth.	I have to be picky with certain things. (speaking of foods).	
	I just have to be careful and cautious when I’m eating.		
	The napkin is my tool.		

Triggers. The identification of triggers that make swallowing difficult were identified by two of the three individuals who participated in Phase II. Frequency of trigger-related statements ranged from 0 to11. A summary of the frequency of statements regarding triggers across both interviews can be found in Figure 15. The figure is arranged in the order of level of acculturation, where S03 had the lowest level of acculturation (-5.04) and S05 had the highest level of acculturation (1.60) for those participating in Phase II.

Participant S07 (slightly Anglo oriented/bicultural) spoke of triggers in regards to specific foods. He shared, “For some reason, I choke on potatoes.” He further elaborated, it gets stuck, and I can’t swallow it down.” Participant S05 (strongly Anglo oriented) discussed triggers in regards to body posture and pacing while eating. She stated, “When you drink water out of a drinking fountain, you bend over to drink. I would say that is not the best way for me to drink.”

Figure 16

Summary of trigger statements for Interview I and II for all Phase II participants



Definition: Events, activities, or situations that result in a sign or symptom of dysphagia.

ID	S03	S07	S05
Exemplars		If I eat fast, sometimes it happens too.	Those things only happen when I'm not being careful.
		I didn't really have too much liquid to push it down, so maybe that's why it wasn't going down all the way.	Drinking out of a drinking fountain where you bend over is not the best way for me to drink.
		If it would have been potatoes, it would have gotten stuck.	If I get excited in my mind, it is just going to get worse.
			I only get caught up once in a while when I forget, and I don't slow down.

Chapter 5

Discussion

The goals of this pilot investigation were to 1) identify the relationship between acculturation and (a) dysphagia related quality of life and (b) health related stigma, 2) determine the relationship between dysphagia severity and (a) dysphagia related quality of life and (b) stigma, and 3) identify the quality of life experiences for Hispanic New Mexicans with dysphagia secondary to non-degenerative, non-terminal disease.

Acculturation and Quality of Life

In our study, there was a very-weak to moderate correlation between level of acculturation and quality of life across SWAL-QOL clusters. A moderate level of association was observed with the clusters comprising items quantifying physical symptoms. A weak association was observed between level of acculturation and mental and social health, as well as a very-weak association between fatigue and acculturation. Qualitatively in Phase II, the relationship between acculturation was observed. In fact, as acculturation increased, symptom reporting increased. Variable relationships between level of acculturation and quality of life have also been reported in the literature, and it has been postulated that the relationship between quality of life and acculturation may differ among cultural groups (Emery et al., 2004). A positive link between acculturation and quality of life was reported for Hispanic psychiatric patients (Thoman & Surís, 2004), a negative association was reported for Vietnamese immigrant women in transnational marriages in Taiwan (Yang & Wang, 2011), and a population study among Chinese immigrants found no association (Lieber, Chin, Nihira, & Mink, 2001). In our investigation, we divided quality of life into subsets related to physical symptoms, mental and social well-being, and fatigue. We propose that the link between level of acculturation and quality of life may be better explained in the qualitative analysis rather than the correlational analysis.

Physical symptoms. Although not statistically significant, there was a moderate correlation between the level of acculturation and the impact on quality of life due to dysphagia symptoms. Similarly, in Vietnamese-Americans, somatic symptoms were more likely to be reported by those with a higher level of acculturation (Nguyen et al., 2007). An example from the Hispanic population in this investigation can be found in the comparison of symptoms reported by S02 (Mexican balanced bicultural) and S05 (strongly Anglicized). Both individuals were classified as having mild dysphagia as measured by the MASA. S02 reported that the impact of dysphagia symptoms on quality of life was minimal, while S05 reported that her quality of life was severely impacted by her dysphagia symptoms. Further, S03 (very Mexican oriented) was classified as having moderate dysphagia as measured by the MASA, and she reported that the impact of her dysphagia on quality of life was minimal to mild.

It is important to note that S02 and S05 differed not only by level of acculturation, but also by gender. Gender differences in symptom reporting have been noted; non-Hispanic females and German females report symptoms more frequently and utilize medical services more often than males (Ladwig, Marten-Mittag, Formanek, & Dammann, 2000), and women with cardiac disease are more likely to report a lower quality of life compared to males (Emery et al., 2004). Yet, in this investigation, a review of gender-specific responses did not reveal any gender bias for this variable.

Mental and social health. The correlation between level of acculturation and the impact of mental and social well-being on quality of life was weak. The literature is variable regarding this relationship. For example, Vietnamese-Americans (Nguyen & Peterson, 1993) and Puerto Ricans (Ramos, 2005) with a higher level of acculturation reported an increase of depression based symptoms compared to those with a lower level of acculturation. For Mexican-Americans, adults with a higher level of acculturation reported a decreased presence of psychological distress compared to those with a lower level of acculturation (González, Haan, & Hinton, 2001; Hovey, 2000; Hovey & King, 1996). Yet, for Mexican-American elementary students, no relationship was observed between level of acculturation and depression (Bauman, 2008).

Closer consideration of our Hispanic participants revealed that all female participants in the group expressed a similar (moderate) impact on quality of life related to mental health and social well-being regardless of level of acculturation. Two of the three males reported minimal to no impact on quality of life. These gender differences are not surprising when drawing from previous research. Adolescent females experienced greater psychological distress compared to males (Avison & McAlpine, 1992), females reported a greater sense of anxiety compared to males (Robichaud, Dugas, & Conway, 2003), and although levels of agreeableness, extraversion, and conscientiousness were significantly higher among females, females reported a higher frequency of depression compared to males (Goodwin & Gotlib, 2004). Further, the literature suggests that women have an increased social connectedness compared to men (Baumeister & Sommer, 1997; Clancy & Dollinger, 1993). Gender differences were not directly investigated in this study, but should be considered an important variable in future investigations. Given the variability in the literature and weak correlation in the current study between level of acculturation and mental and social health, further investigation is warranted.

Fatigue. Fatigue, is often used as a general health measurement (McHorney et al., 2002). Fatigue may result from dysphagia (Nguyen et al., 2005; van Leeuwen et al., 1999). In the current data set, the correlation was very-weak between fatigue and level of acculturation. The literature is mixed regarding the relationship of acculturation and fatigue. When utilizing language preference as a measure of acculturation, English-speaking Hispanics with chronic fatigue syndrome reported more fatigue than Spanish-speaking Hispanics (Torres-Harding, Mason-Shutter, & Jason, 2008). However, a relationship between level of acculturation and fatigue was not observed when the ARSMA-II was used to evaluate level of acculturation (Chimata, Jason, Taylor, & Tortes-Harding, 2006).

Age may influence level of fatigue. Cordero and colleagues (2012) noted their finding of higher reports of fatigue with lower acculturated Hispanics was minimized when the age of the participant was considered. That is, fatigue was more related to age than to level of acculturation (Cordero, Loredo, Murray, & Dimsdale, 2012). Our data did not control for age. However, upon inspection of the fatigue data, consideration of age did not alter the findings in this study of only 6 individuals. More research is warranted utilizing a larger participant base with age matching to evaluate the relationship between level of acculturation in Hispanics and fatigue (Cordero et al., 2012).

Acculturation and Stigma

Disease related stigma was assessed using the stigma portion of the Neuro-QoL. Preliminarily, as acculturation level increased, the presence of stigma increased. Comparison of this finding to current literature is limited due to the small amount of research regarding cross-cultural beliefs towards illness, cause of illness, as well as disability (Bebout & Arthur, 1992; Maestas & Erickson, 1992; Salas-Provance et al., 2002). To date, one study was identified evaluating the relationship between stigma and acculturation. For Latinos with drug addiction stigma decreased with level of acculturation (Flórez et al., 2015).

With the exception of one participant, there was a strong relationship between level of acculturation and stigma, although not statistically significant. Despite a low level of acculturation S03 (very Mexican oriented) did not yield a reduction in stigma. This difference may be explained by the presence of a facial paralysis—the only individual to report obvious physical consequences from the dysphagia-causing medical event (Chu, Farrag, Ishii, & Byrne, 2011). Therefore, stigma ratings may differ for individuals with physical disability.

It is also plausible that the difference can be explained through gender; careful consideration of the data in this investigation revealed that stigma was linked to gender in the current investigation, although not statistically significant. In fact, the average scores for females ranged from 2.3-2.7, where for males they averaged from 1.0 to 1.9. All male participants stated that they *never*, or *rarely feel embarrassed* about their illness. All females stated a range of feelings from *sometimes feeling embarrassed* to *always feeling embarrassed* about their illness. Further, females reported that they were made fun of because of their illness. In comparison, none of our male participants reported the occurrence of teasing.

Physical disability and gender may each play a role in the feelings of stigma. Of these, gender may have a stronger role. Qualitative data supports the presence of stigma-related gender differences in individuals with obvious skin disease (Vlassoff et al., 2000). Men were more concerned with economic prospects, whereas women were more concerned about physical appearance and life changes. In the current investigation, regardless of level of acculturation, females felt concerned about physical appearance and males did not.

While stigma was higher in females compared to males, level of acculturation did impact some aspects measured in the stigma scale. Two females (S01 and S05) with the two highest levels of acculturation, stated that they avoid making friends because of their illness, and they blame themselves for their illness. S03, the female with the lowest level of acculturation, and all male participants stated that they never avoid making friends, nor do they blame themselves for their illness.

It is hypothesized that the relationship between level of acculturation and (a) swallowing related quality of life, and (b) health-related stigma, is a function of acculturation and aspects specific to traditional Hispanic culture. That is, a lower quality of life, and increased presence of stigma was reported for those with a higher level of acculturation (or a higher level of integration into the mainstream U.S. culture, which is defined as an individualistic culture) (Caldwell-Harris & Ayçiçegi, 2006). Therefore, the decline in perceived stigma and increase in quality of life for those with a lower level of acculturation can potentially be attributed to the values of traditional Hispanic culture, that is, collectivism. In fact, for those with a lower level of acculturation, the focus is not on the self, rather the community at large (for example, the family as a whole). Even more so, the personal needs of an individual are inferior to that of the group needs as a whole (Gregory & Munch, 1997).

Dysphagia Severity and Quality of Life

Severity of dysphagia has been shown to have a significant impact on quality of life (Eslick & Talley, 2008); in fact, for patients with head and neck cancer, quality of life dropped with increased dysphagia severity (Nguyen et al., 2005). This was not the case in our dataset, which showed an inconsistent relationship between dysphagia severity and the various quality of life clusters. The current data showed a weak to moderate correlation between dysphagia severity and SWAL-QOL Cluster 1 (burden, eating, food, mental health, and social), and Clusters 2 (symptoms, fear, and communication). That is, as dysphagia severity increased quality of life decreased as measured by Cluster 1 and 2 of the SWAL-QOL.

Oddly, a moderate negative relationship was observed between dysphagia severity and fatigue (SWAL-QOL Cluster 3). While the literature is replete with data showing an increase in fatigue with disease severity (Tödt et al., 2014), there are also some investigations that support a gender difference in fatigue with women experiencing more fatigue as a result of disease severity (Akechi, Kugaya, Okamura, Yamawaki, & Uchitomi, 1999; Redeker, Lev, & Ruggiero, 2000). Age has also been shown to impact levels of fatigue. Indeed in our dataset, the females reported fatigue more than the males (1.98 for females and 4.40 of 5 for males, where 5 represents no impairment) and the eldest individuals showed a greater level of fatigue compared to the youngest participants (fatigue rating of 2.6 for the eldest and 4.1 of 5 for the youngest, where 5 represents no impairment).

Dysphagia Severity and Stigma

Increased dysphagia severity mildly correlated with increased stigma. Similarly, in the literature, degree of depression has been shown to be a strong predictor of perceived stigma (Pyne et al., 2004), and individuals with atopic dermatitis and increased disease severity felt more stigmatized than those with a lower disease severity (Wittkowski, Richards, Griffiths, & Main, 2004).

Regardless of disease severity, female participants had the highest stigma ratings. Studies have shown a link between gender and reporting of symptoms as females report symptoms more frequently compared to men (Kroenke & Spitzer, 1998; Ladwig et al., 2000).

Phase II Themes

Three individuals with various levels of acculturation (very Mexican oriented, slightly Anglo oriented/bicultural, and strongly Anglo oriented) participated in Phase II of this investigation. All three individuals provided insight into their respective quality of life experiences. Multiple exemplars were provided in a variety of situations where the presence of dysphagia led to swallow safety concerns and emotional experiences. Specific themes related to emotional experiences included: stigma, distrust, fear, frustration, impact and acceptance; swallow safety themes included: treatment differences, symptoms, triggers and compensatory strategies. When the observed themes were totaled across participants, *symptoms* (90 statements), *compensatory strategies* (34 statements), *impact* (27 statements), *acceptance* (26 statements), *frustration* (24 statements), *stigma* (23 statements), and *religion* (14 statements) occurred the most frequently. Stigma, frustration, acceptance, impact, symptoms and compensatory strategies were noted across all participants. Symptoms, religion, stigma, frustration, and compensatory strategies, changed as a function of level of acculturation. Some themes differed between S03 (Level I: Very Mexican Oriented per ARSMA-II) and S05 (Level IV: Strongly Anglicized per ARSMA-II) with minimal to no observance of these themes for S07 (Level III: Strongly Anglo oriented bicultural per ARSMA-II.

In Phase II, the lack of specific content obtained from S07 (strongly Anglo oriented bicultural) may have been more strongly linked with his diagnosis of TBI and the limitations resulting from that diagnosis. Throughout Interview 1 and 2, he shared information regarding memory loss following his brain injury. He stated that he wished his memory was better, that he “has the memory of a 70-year old”, and he “can’t remember anything.” The reporting of memory loss following a traumatic brain injury is consistent with the literature (Umile, Sandel, Alavi, Terry, & Plotkin, 2002).

Symptoms. Across the three participants, the frequency of statements regarding *symptoms* increased from 3 to 43 as level of acculturation increased. Therefore, it is hypothesized that, if acculturation level is low (very Mexican oriented) for Hispanic individuals residing in the U.S., then the likelihood of symptom reporting is low. S03 did not speak about the symptom of pain; however, she spoke of *symptoms* relating to mealtime and food or liquid falling from her mouth. Participant S07 spoke of *symptoms* the most frequently (on 43 occasions), and on 10 of those occasions *symptoms* were related to pain. Participant S07 spoke about pain in the context of choking on liquids, such as water, which he felt was aspiration. Across all of the themes identified for S07, *symptoms* was the theme that he discussed most frequently. He shared details about mealtimes as well as symptoms related to non-mealtime events. When asked to share aspects about his swallowing and the impact that it has on his life, expressions with multiple symptom related details were shared.

Participant S05 spoke of *symptoms* on 41 different occasions; however, on 20 occasions she discussed pain specifically. Participant S05 provided symptomatic details that are consistent with laryngopharyngeal reflux (LPR), which according to the literature is consistent with pain (Koufman, 1991; Noordzij et al., 2002). Of all the themes identified for S05, *symptoms* appeared to be the most prevalent quality of life experience. When asked to share details about her swallowing and its impact on her life, she initially shared details related to symptoms. For both S07 and S05, the theme of symptoms was the most predominant.

Stigma. *Stigma*, which was reported by all participants, ranged from physical changes such as facial paralysis to swallow related events such as choking in public. The presence of stigma from medical conditions has been reported in patients with dysphagia (Miller, Noble, Jones, & Burn, 2006), and for individuals with facial paralysis (Prakash, Hariohm, Vijayakumar, & Bindiya, 2012). Additionally, there is an associated stigma from being unable to eat (Hamdy, 2003). For S03, feelings of *stigma* were specific to appearance due to partial facial paralysis following her stroke. However, this theme did not appear to inhibit her daily activities. As she stated that she still attends social events; however, she is just more cautious and a slightly nervous that food may fall from her mouth. S07 reported a sense of *stigma* while choking during social activities with friends. In comparison, Participant S05 spoke of *stigma* in a general sense. She reported the perceived *stigma* of utilizing supplemental oxygen, as well as *stigma* due to dysphagia. Further, regardless of theme frequency, *stigma* appeared to be one of the greatest quality of life changes for both S07 and S05. That is, S07 spoke of how although he still attends social events; he no longer does so as frequently as a result of dysphagia. To a similar extent, S05 stated that she no longer accepts dinner dates, and does not tell anyone about her difficulty swallowing. The relationship observed between level of acculturation and reported stigma is consistent with the findings of Phase I and the literature. Therefore it is hypothesized that, if acculturation level is low (very Mexican oriented) for Hispanic individuals residing in the U.S., then the likelihood of reporting and perception of stigma is low.

Acceptance. It has been hypothesized that coping/*acceptance* behaviors can vary as a function of acculturation (Kuo, 2014), as well as by specific contexts and conditions (Yakushko, Watson, & Thompson, 2008). In our data set, only S03 (very Mexican oriented) and S05 (strongly Anglicized) shared details about a sense of coping. As acculturation level increased, the number of *acceptance* statements also increased. It has been speculated that in the United States, more acculturated individuals have more interpersonal and social resources (e.g., a larger social network) for coping with stress. However, individuals with a lower level of acculturation displayed a more individualistic coping pattern and did not rely on others as often as those with a higher level of acculturation (Mena, Padilla, & Maldonado, 1987). Thus, it can be hypothesized that the increase in the frequency of *acceptance* statements for S05 compared to S03 was due to the likelihood of additional social supports and/or coping preference (e.g., individualistic coping). However, neither participant was asked about their social network explicitly, and requires further consideration. Yet, S05 mentioned participation in social events, where S03 did not. Exploring social network differences as a function of acculturation requires further consideration and/or investigation. S03 reported that her strength and *acceptance* came as a result of her Catholic faith. In fact, during the interview, she frequently ended her sentences with, "Thanks be to God." Therefore, it can be hypothesized that for S03 her religious beliefs facilitated the acceptance process.

While *acceptance* was not the most frequent theme for S03, it appeared with some prominence. She spoke about her difficulty swallowing being hereditary, and that if it was indeed hereditary that it "was her lot." In comparison, S05 spoke of *acceptance* frequently, but it didn't appear to be a dominant theme for her. Further, S05 used a tone that often denoted sarcasm and lacked sincerity, a tone rarely expressed by S03. Therefore, based on this dataset, expressions of acceptance may vary by tone as a function of acculturation.

Frustration. Although it has been discussed that frustration is part of the acculturative process (Bhugra, 2003), no published data have quantified the relationship between level of acculturation and disease-related frustration. In this investigation, the frequency of *frustration* statements decreased as level of acculturation increased as observed with S03, S07, and S05. The type of *frustration* based statements varied across participants. Although limited in frequency, S03 spoke of *frustration* in the context of lifestyle changes, as she felt like she had less time to complete essential daily living activities. S07 spoke of *frustration* in the context of dysphagia-related events, and the impact on his quality of life. S05, in comparison, discussed *frustration* with symptoms such as lack of adequate sleep, and *frustration* with treatment. For S05, the presence of *frustration* appeared to have a significant impact on quality of life. Thus, it can be hypothesized that if acculturation level is low (very Mexican oriented) for Hispanic individuals residing in the U.S., then, the likelihood of frustration as a result of disease is low.

Compensatory strategies. Across the three participants, the frequency of statements regarding *compensatory strategies* decreased as level of acculturation increased. It has been reported that individuals with dysphagia utilize compensatory measures prior to medical treatment. In fact, for individuals with oculopharyngeal muscular dysphagia and dysphagia, over 85% of individuals utilized a compensatory strategy similar to the Mendelsohn maneuver where they prolonged their hyolaryngeal elevation when swallowing (Palmer, 2011). For S03 (very Mexican oriented) 13 statements regarding *compensatory strategies* were observed. S07 (slightly Anglo oriented bicultural) spoke of the use of *compensatory* measures on 11 occasions, while S05 spoke of *compensatory strategies* on 10 occasions. S03 spoke of *compensatory strategies* in the sense of preventing dysphagia related events by preparing herself before she swallows; yet, she also shared details about *compensatory* measures such as having a napkin in the event that a dysphagia related event did occur. Similarly, S07 spoke of *compensatory* measures that were utilized in the moment of a dysphagia related event, as well as preparatory measures such as discerning if a piece of food will be difficult or easy to swallow. Participant S05 spoke of *compensatory* measures in the context of meal pacing, as well as body posture while swallowing. She did not share any details regarding *compensatory* measures that were suggested through medical intervention. As details regarding the use of *compensatory* measures were shared across all individuals regardless of level of acculturation, and appeared to be a significant theme for all, a preliminary conclusion is that acculturation does not appear to predict the use of compensatory strategies.

Impact. The literature suggests that dysphagia negatively impacts quality of life (Leow et al., 2010). All three participants spoke of the *impact* of having dysphagia in varying contexts. Participant S03, spoke of the change in time needed to complete a meal as a result of her dysphagia. However, this did not appear to be a significant theme for her. Details regarding dietary changes, and frequency of social engagement events were shared by S07. He stated that there are certain foods that he no longer eats, and that he does not participate in social events as frequently because of his dysphagia. Impact appeared to be a moderately significant theme for him. In comparison, S05 spoke of how her health has deteriorated significantly, how previous leisure activities had to be terminated, and how her diet has changed. This appeared to be a significant theme for her. Given the variation of impact across participants, it can be hypothesized that, if acculturation level is low (very Mexican oriented) for Hispanic individuals residing in the U.S., the impact of dysphagia is low.

Religion. This theme was present in two of the three participants. Yet, across the two participants, differences in tone were identified. S03 was the only participant to mention *religion* with a consistent spiritual tone, and she did so on 12 occasions throughout the interviews. *Religion* appeared to be a major theme for S03, as she stated that her “faith is everything.” Participant S05 spoke of *religion* on two occasions. In contrast to S03, when S05 mentioned God, it appeared that she did so colloquially. That is, she stated in regards to marriage, “God forbid.” This bold tone was never observed in

S03. Consequently, it can be hypothesized that if acculturation level is low (very Mexican oriented) for Hispanic individuals residing in the U.S., the likelihood of reference to religion is high.

Although there is a limited amount of evidence evaluating the relationship between acculturation and *religion* (Gattino, Miglietta, Rizzo, & Testa, 2016), the findings of this investigation are consistent with the literature. Less acculturated Hispanics report a stronger identification with Catholicism, and they are more likely to identify themselves as Catholic (Olmedo & Padilla, 1978). Additionally, lower levels of acculturation were correlated with religiosity for Turkish Belgians (Güngör, Bornstein, & Phalet, 2012). Thus, it can be hypothesized that in the current study, *religion* was a function of acculturation; as acculturation increased the presence of religion was not observed. However, it should be noted that S07 was not explicitly asked about religious beliefs.

Limitations and Future Directions

Limitations of the investigation include a small sample size, and varying etiologies resulting in indefinite conclusions for Phase I. Also, there was an uneven distribution of acculturation level across participants. No participants were classified as Level II (Mexican oriented to approximately balanced bicultural) or Level V (very assimilated; Anglicized) per ARSMA-II. In addition, quality of life experiences for other ethnic populations residing in New Mexico is warranted.

A larger sample size is warranted in order for a clearer conclusion between the relationship between level of acculturation and (a) swallowing related quality of life and (b) stigma, as well as between the level of dysphagia severity and (a) swallowing related quality of life and (b) stigma. Sample size also limited the statistical analysis. Spearman's rank correlation was performed despite the fact that the assumption of monotonicity could not be assessed in this small sample size.

As an initial pilot investigation specific aspects were selected for evaluation. However, the data would be strengthened by assessing other parameters. For example, gender and age may play into quality of life and perceived stigma. These variables were not included in this investigation.

While this current investigation did not assess social well-being, there is some evidence evaluating the impact of social network and acculturation (Yoon, Lee, & Goh, 2008). Specifically, the acculturation process is facilitated when one is socially mainstreamed and this may aid in a sense of well-being (Yoon et al., 2008; López, Ehly, & García-Vásquez, 2002). Additionally, it would be warranted to investigate social network as a function of acculturation and whether this predicts acceptance.

Clinical Implications and Conclusions

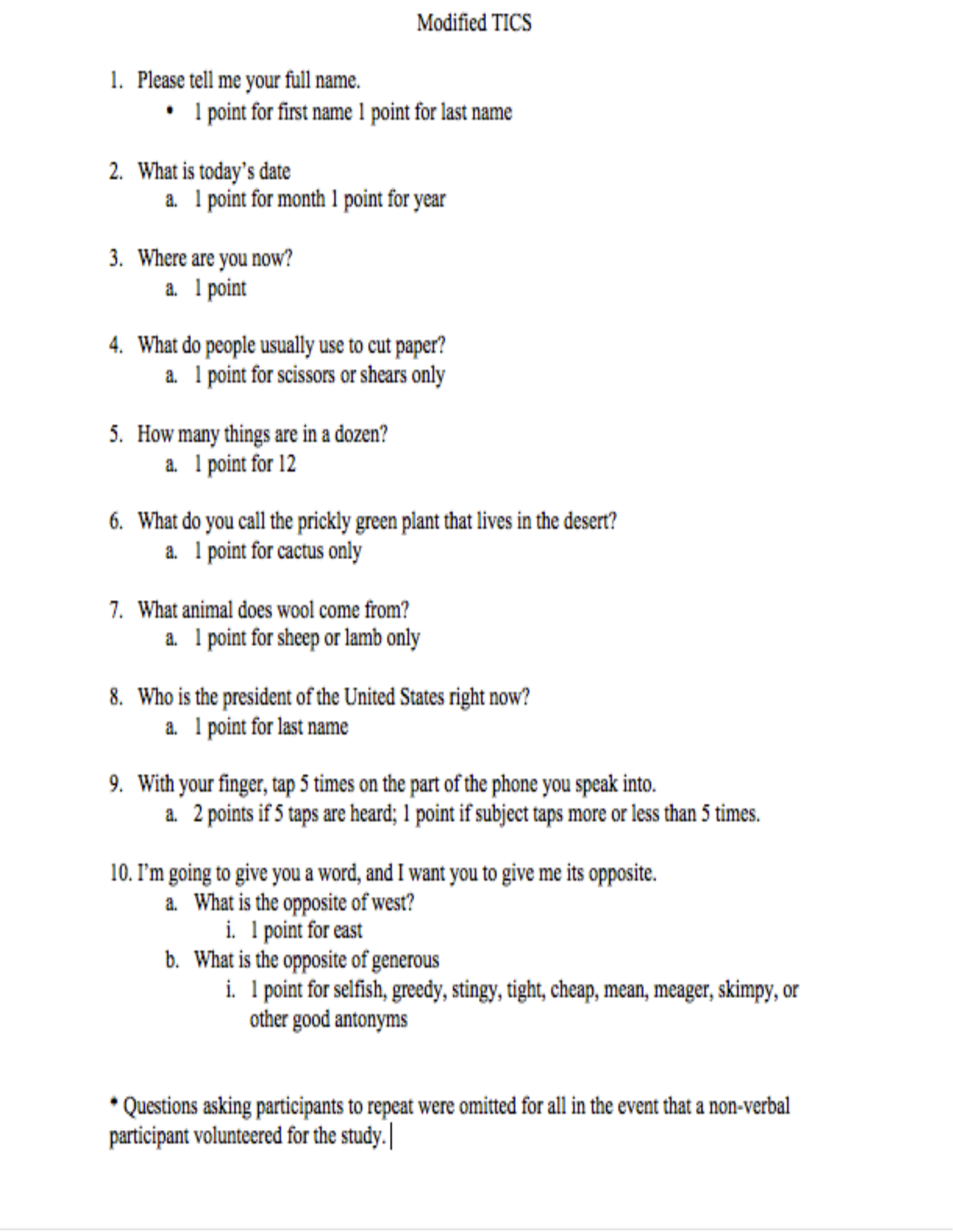
As made evident from this study, quantitative and qualitative methodologies can and should complement one another. That is, although quantitative measures such as the SWAL-QOL can be utilized to measure treatment efficacy (Manor, Mootanah, Freud, Giladi, & Cohen, 2013), the medical interview (also known as ethnographic or semi-structured interviewing) is the most versatile and valuable diagnostic and therapeutic tool of the practicing clinician (Clark & Kruse, 1990). This method is dynamic, open-ended, provides the patient with the opportunity to select the information that they feel is important, and prompts the clinician to ask the right questions in the right ways (Westby, Burda, & Mehta, 2003).To honor patient preferences, an important component of evidence based practice, clinicians must first understand a patient's cultural beliefs, preferences, hopes, and fears (Dollaghan, 2007; McMurtry & Bultz, 2005). It is essential that in this movement toward corporate medicine, we do not loose sight of the importance of being a clinician who serves as a trained and skilled listener and observer. It is in this interview that key elements of patient preference, family and cultural belief and practices, as well as key elements to differential diagnosis can be unearthed.

Based on the results of this investigation, culture impacts how individuals cope with disease, report symptoms, and seek help. To aid in optimal dispensing of health care services, the clinical interviewer must be respectful of the cultural parameters under which the patient is operating. Although culture does impact how individuals cope with disease, there is some degree of variability within each specific culture. Being aware of these cultural differences will facilitate services that are culturally competent for those who are under our care.

This data supports the need for considering culture and level of acculturation as both variables can influence symptom reporting, identification of triggers that can result in dysphagia, the impact that dysphagia has on quality of life, as well as help-seeking behaviors. However, it should be noted that these conclusions are preliminary, and further investigation is warranted.

List of Appendices

APPENDIX A



Modified TICS

1. Please tell me your full name.
    - 1 point for first name 1 point for last name
2. What is today's date
    a. 1 point for month 1 point for year
3. Where are you now?
    a. 1 point
4. What do people usually use to cut paper?
    a. 1 point for scissors or shears only
5. How many things are in a dozen?
    a. 1 point for 12
6. What do you call the prickly green plant that lives in the desert?
    a. 1 point for cactus only
7. What animal does wool come from?
    a. 1 point for sheep or lamb only
8. Who is the president of the United States right now?
    a. 1 point for last name
9. With your finger, tap 5 times on the part of the phone you speak into.
    a. 2 points if 5 taps are heard; 1 point if subject taps more or less than 5 times.
10. I'm going to give you a word, and I want you to give me its opposite.
    a. What is the opposite of west?
        i. 1 point for east
    b. What is the opposite of generous
        i. 1 point for selfish, greedy, stingy, tight, cheap, mean, meager, skimpy, or other good antonyms

* Questions asking participants to repeat were omitted for all in the event that a non-verbal participant volunteered for the study.

Appendix A (cont.)

What Month are we in?

July	December	October

What is the year?

2015	2016	2014

Where are you right now?

Rio Rancho	UNM	Home

What do people use to cut paper?

Scissors	Knife	Saw

How many things are in a dozen?

6	12	9

What do you call the prickly green plan that lives in the desert?

Tumbleweed	Thistle	Cactus

What animal does wool come from?

Goats	Sheep	Cow

Who is the current President?

Barack Obama	George Bush	Ronald Regan

What is the opposite of generous?

Needy	Selfish	Poor

What is the opposite of west?

East	North	South

Appendix A (cont.)

With your finger, tap 5 times on the part of the phone you speak into.

Appendix B

IMPORTANT NOTE: We understand that you may have a number of physical problems. Sometimes it is hard to separate these from swallowing difficulties, but we hope that you can do your best to concentrate ***only*** on your ***swallowing problem.*** Thank you for your efforts in completing this questionnaire.

1. Below are some general statements that people with ***swallowing problems*** might mention. In the last month, **how true** have the following statements been for you.

(circle one number on each line)

	Very much true	**Quite a bit true**	**Somewhat true**	**A little true**	**Not at all true**
Dealing with my swallowing problem is very difficult.	1	2	3	4	5
My swallowing problem is a major distraction in my life.	1	2	3	4	5

2. Below are aspects of day-to-day eating that people with ***swallowing problems*** sometimes talk about. In the last month, **how true** have the following statements been for you?

(circle one number on each line)

	Very much true	**Quite a bit true**	**Somewhat true**	**A little true**	**Not at all true**
Most days, I don't care if I eat or not.	1	2	3	4	5
It takes me longer to eat than other people.	1	2	3	4	5
I'm rarely hungry anymore.	1	2	3	4	5
It takes me forever to eat a meal.	1	2	3	4	5
I don't enjoy eating anymore.	1	2	3	4	5

3. Below are some physical problems that people with ***swallowing problems*** sometimes experience. In the last month, **how often** you have experienced each problem as a result of your swallowing problem?

(circle one number on each line)

	Almost always	**Often**	**Sometimes**	**Hardly ever**	**Never**
Coughing	1	2	3	4	5
Choking when you eat food	1	2	3	4	5
Choking when you take liquids	1	2	3	4	5
Having thick saliva or phlegm	1	2	3	4	5
Gagging	1	2	3	4	5
Drooling	1	2	3	4	5
Problems chewing	1	2	3	4	5
Having excess saliva or phlegm	1	2	3	4	5
Having to clear your throat	1	2	3	4	5
Food sticking in your throat	1	2	3	4	5
Food sticking in your mouth	1	2	3	4	5
Food or liquid dribbling out of your mouth	1	2	3	4	5
Food or liquid coming out your nose	1	2	3	4	5
Coughing food or liquid out of your mouth when it gets stuck	1	2	3	4	5

4. Next, please answer a few questions about how your ***swallowing problem*** has affected your diet and eating in the last month.

(circle one number on each line)

	Strongly agree	**Agree**	**Uncertain**	**Disagree**	**Strongly disagree**
Figuring out what I can and can't eat is a problem for me.	1	2	3	4	5
It is difficult to find foods that I both like and can eat.	1	2	3	4	5

Appendix B (cont.)

5. In the last month, **<u>how often</u>** have the following statements about communication applied to you because of your ***swallowing problem***?

(circle one number on each line)

	All of the time	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
People have a hard time understanding me.	1	2	3	4	5
It's been difficult for me to speak clearly.	1	2	3	4	5

6. Below are some concerns that people with ***swallowing problems*** sometimes mention. In the last month, **<u>how often</u>** have you experienced each feeling?

(circle one number on each line)

	Almost always	**Often**	**Sometimes**	**Hardly ever**	**Never**
I fear I may start choking when I eat food.	1	2	3	4	5
I worry about getting pneumonia.	1	2	3	4	5
I am afraid of choking when I drink liquids.	1	2	3	4	5
I never know when I am going to choke.	1	2	3	4	5

7. In the last month, how often have the following statements **<u>been true</u>** for you because of your ***swallowing problem***?

(circle one number on each line)

	Always true	**Often true**	**Sometimes true**	**Hardly ever true**	**Never true**
My swallowing problem depresses me.	1	2	3	4	5
Having to be so careful when I eat or drink annoys me.	1	2	3	4	5
I've been discouraged by my swallowing problem.	1	2	3	4	5
My swallowing problem frustrates me.	1	2	3	4	5
I get impatient dealing with my swallowing problem.	1	2	3	4	5

Appendix B (cont.)

8. Think about your social life in the last month. How strongly would you agree or disagree with the following statements?

(circle one number on each line)

	Strongly agree	**Agree**	**Uncertain**	**Disagree**	**Strongly disagree**
I do not go out to eat because of my swallowing problem.	1	2	3	4	5
My swallowing problem makes it hard to have a social life.	1	2	3	4	5
My usual work or leisure activities have changed because of my swallowing problem.	1	2	3	4	5
Social gatherings (like holidays or get-togethers) are not enjoyable because of my swallowing problem.	1	2	3	4	5
My role with family and friends has changed because of my swallowing problem.	1	2	3	4	5

9. In the last month, **how often** have you experienced each of the following physical symptoms?

(circle one number on each line)

	All of the time	**Most of the time**	**Some of the time**	**A little of the time**	**None of the time**
Feel weak?	1	2	3	4	5
Have trouble falling asleep?	1	2	3	4	5
Feel tired?	1	2	3	4	5
Have trouble staying asleep?	1	2	3	4	5
Feel exhausted?	1	2	3	4	5

Appendix B (cont.)

10. Do you now take any food or liquid through a feeding tube?

(circle one)

No 1

Yes... 2

11. Please circle the letter of the one description below that best describes the consistency or texture of the food you have been eating most often in the last week.

Circle one:

A. Circle this one if you are eating a full normal diet, which would include a wide variety of foods, including hard to chew items like steak, carrots, bread, salad, and popcorn.

B. Circle this one if you are eating soft, easy to chew foods like casseroles, canned fruits, soft cooked vegetables, ground meat, or cream soups.

C. Circle this one if you are eating food that is put through a blender or food processor or anything that is like pudding or pureed foods.

D. Circle this one if you take most of your nutrition by tube, but sometimes eat ice cream, pudding, apple sauce, or other pleasure foods.

E. Circle this one if you take all of your nourishment through a tube.

12. **Please circle the letter** of the one description below that best describes the consistency of liquids you have been drinking most often in the last week.

Circle one:

A. Circle this if you drink liquids such as water, milk, tea, fruit juice, and coffee.

B. Circle this if the majority of liquids you drink are thick, like tomato juice or apricot nectar. Such thick liquids drip off your spoon in a slow steady stream when you turn it upside down.

C. Circle this if your liquids are moderately thick, like a thick milkshake or smoothie. Such moderately thick liquids are difficult to suck through a straw, like a very thick milkshake, or drip off your spoon slowly drop by drop when you turn it upside down, such as honey.

D. Circle this if your liquids are very thick, like pudding. Such very thick liquids will stick to a spoon when you turn it upside down, such as pudding.

E. Circle this if you did not take any liquids by mouth or if you have been limited to ice chips.

13. In general, would you say your health is:

	(circle one)
Poor	1
Fair	2
Good	3
Very Good	4
Excellent	5

General Questions About You

What is the date of your birth?

Please write in your date of birth here: ______ / ______ / ______
month day year

What is your age today? _______

Are you –

(circle one)

Male 1

Female 2

What is your main racial or ethnic group?

(circle one)

White or Caucasian, but not Hispanic or Latino 1

Black or African-American, but not Hispanic or Latino 2

Hispanic or Latino 3

Asian 4

Other 5

What is the highest year of school or college you have ever completed?

(circle one number)

1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	**16**	**16+**
Grade School								High School				College				Post Graduate

Appendix B (cont.)

What is your current marital status?

	(circle one)
Never married	1
Married	2
Divorced	3
Separated	4
Widowed	5

Did anybody help you complete this questionnaire?

	(circle one)
No, I did it myself	1
Yes, someone helped me fill it out	2

IF SOMEONE HELPED YOU FILL OUT THIS QUESTIONNAIRE, how did that person help you?

	(circle one)
Read you the questions and/or wrote down the answers you gave	1
Answered the questions for you	2
Helped in some other way	3

Please write today's date here: ________ / ________ / ________
month / day / year

Appendix C

Neuro-QOL Item Bank v1.0 –Stigma

Stigma

Please respond to each question or statement by marking one box per row.

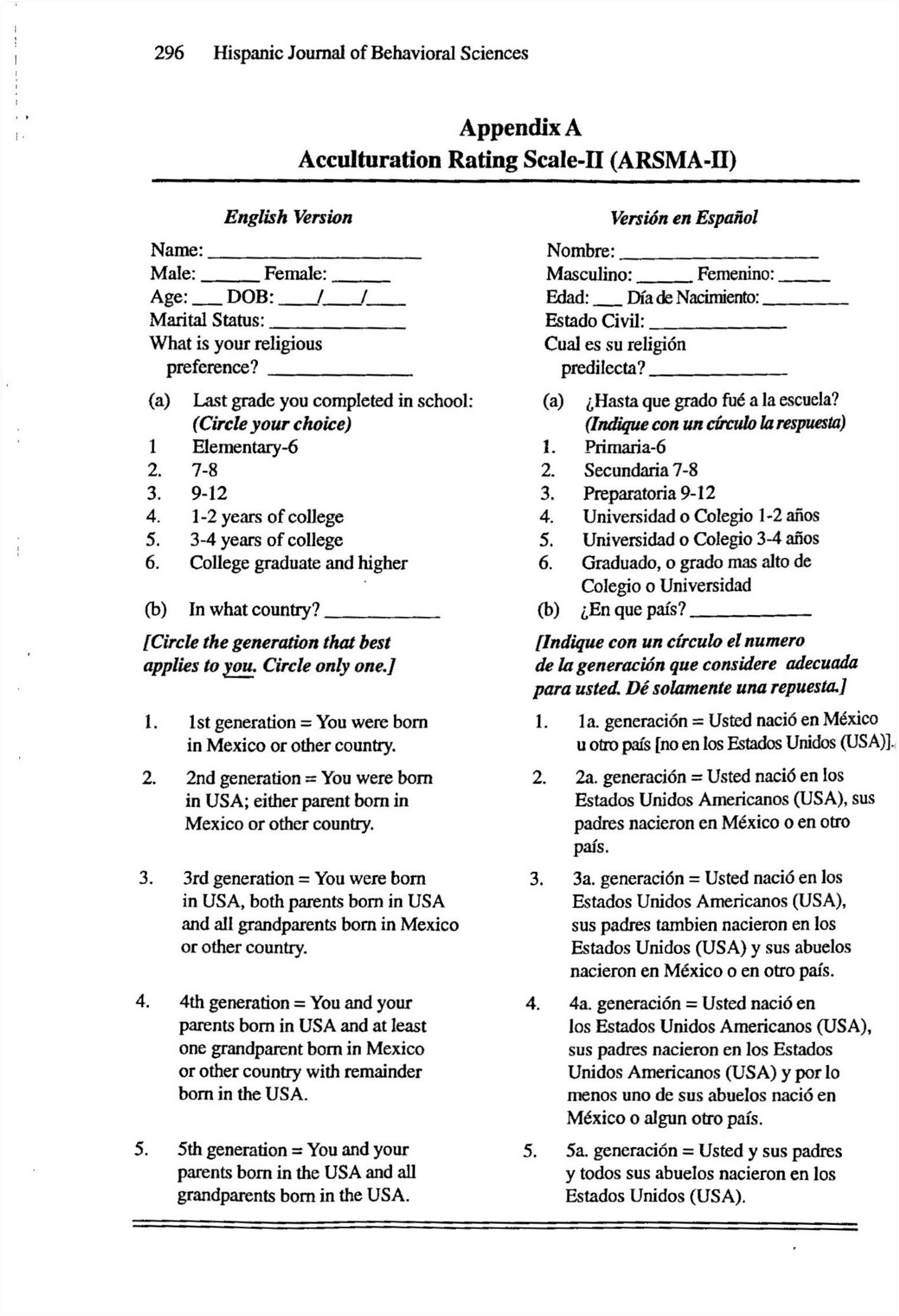
	Lately…	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
NQSTG02	Because of my illness, some people avoided me.………………………………	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG04	Because of my illness, I felt left out of things ……………………………………	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG08	Because of my illness, people avoided looking at me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG16	I felt embarrassed about my illness………...	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG01	Because of my illness, some people seemed uncomfortable with me…………	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG17	I felt embarrassed because of my physical limitations ….……………………………	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG05	Because of my illness, people were unkind to me ……………………………..	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG21	Some people acted as though it was my fault I have this illness.…………………	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG07	Because of my illness, I felt embarrassed in social situations ……………………...	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG03	Because of my illness, I felt emotionally distant from other people………………	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG14	Because of my illness, people tended to ignore my good points …………………	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG11	Because of my illness, I was treated unfairly by others.……………………..	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG19	Because of my illness, I felt different from others ……………………………………	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG10	Because of my illness, I worried about other people's attitudes towards me………	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG15	Because of my illness, I worried that I was a burden to other………………………….	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Appendix C (cont.)

Neuro-QOL Item Bank v1.0 –Stigma

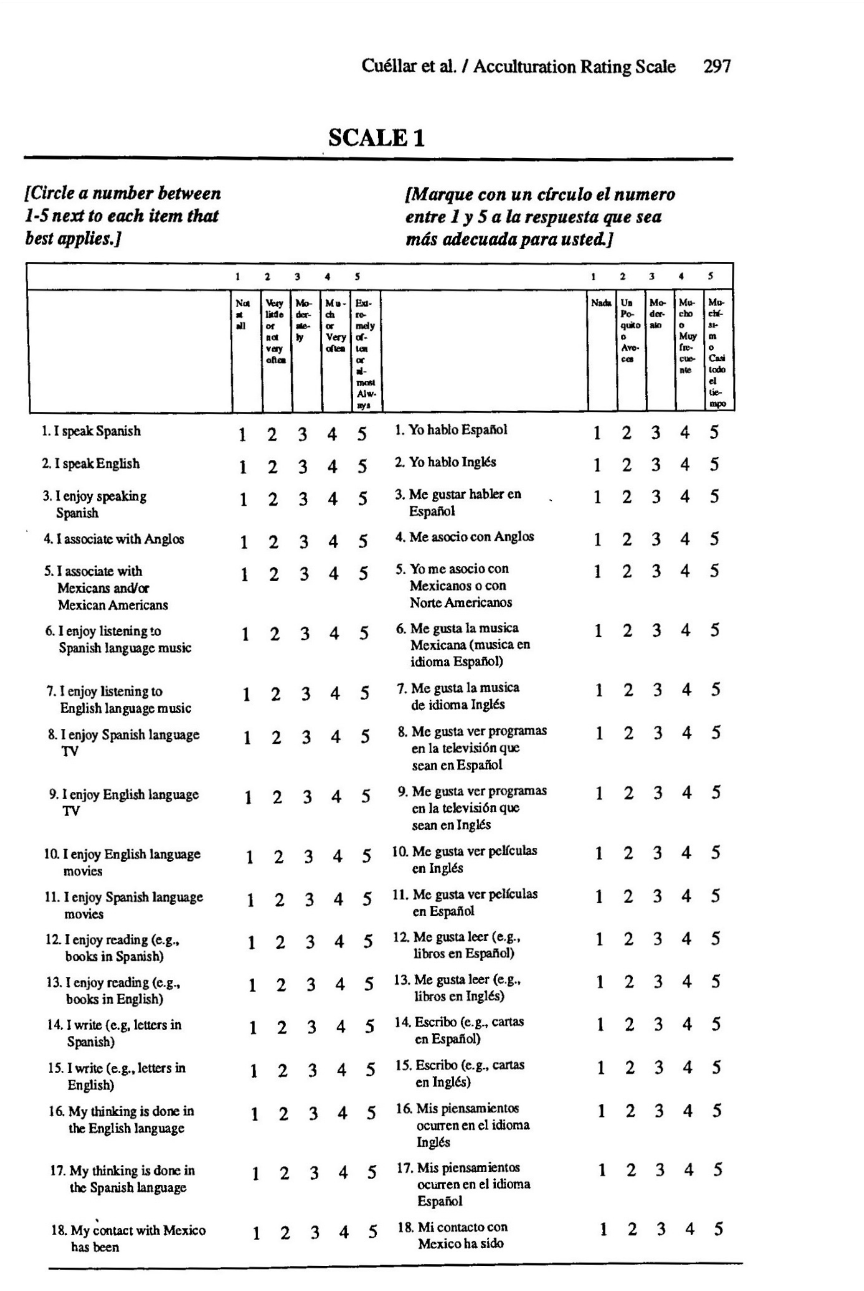
	Lately…	**Never**	**Rarely**	**Sometimes**	**Often**	**Always**
NQSTG06	Because of my illness, people made fun of me……………………………………...	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG12	I was unhappy about how my illness affected my appearance.………………….	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG09	Because of my illness, strangers tended to stare at me……...….……………………...	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG26	I lost friends by telling them that I have this illness………………………………...	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG13	Because of my illness, it was hard for me to stay neat and clean……..……………...	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG18	I felt embarrassed about my speech…………………………………….	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG22	I avoided making new friends to avoid telling others about my illness……………	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG20	I tended to blame myself for my problems.…………………………………	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
NQSTG25	People with my illness lost their jobs when their employers found out about it…	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Appendix D ARSMA-II



Appendix A
Acculturation Rating Scale-II (ARSMA-II)

English Version	***Versión en Español***
Name: ______________	Nombre: ______________
Male: _____ Female: _____	Masculino: _____ Femenino: _____
Age: ___ DOB: ___/___/___	Edad: ___ Día de Nacimiento: ________
Marital Status: ___________	Estado Civil: ___________
What is your religious preference? ___________	Cual es su religión predilecta? ___________
(a) Last grade you completed in school: ***(Circle your choice)***	(a) ¿Hasta que grado fué a la escuela? ***(Indique con un círculo la respuesta)***
1 Elementary-6	1. Primaria-6
2. 7-8	2. Secundaria 7-8
3. 9-12	3. Preparatoria 9-12
4. 1-2 years of college	4. Universidad o Colegio 1-2 años
5. 3-4 years of college	5. Universidad o Colegio 3-4 años
6. College graduate and higher	6. Graduado, o grado mas alto de Colegio o Universidad
(b) In what country? __________	(b) ¿En que país? __________
[Circle the generation that best applies to you. Circle only one.]	***[Indique con un círculo el numero de la generación que considere adecuada para usted. Dé solamente una repuesta.]***
1. 1st generation = You were born in Mexico or other country.	1. 1a. generación = Usted nació en México u otro país [no en los Estados Unidos (USA)].
2. 2nd generation = You were born in USA; either parent born in Mexico or other country.	2. 2a. generación = Usted nació en los Estados Unidos Americanos (USA), sus padres nacieron en México o en otro país.
3. 3rd generation = You were born in USA, both parents born in USA and all grandparents born in Mexico or other country.	3. 3a. generación = Usted nació en los Estados Unidos Americanos (USA), sus padres tambien nacieron en los Estados Unidos (USA) y sus abuelos nacieron en México o en otro país.
4. 4th generation = You and your parents born in USA and at least one grandparent born in Mexico or other country with remainder born in the USA.	4. 4a. generación = Usted nació en los Estados Unidos Americanos (USA), sus padres nacieron en los Estados Unidos Americanos (USA) y por lo menos uno de sus abuelos nació en México o algun otro país.
5. 5th generation = You and your parents born in the USA and all grandparents born in the USA.	5. 5a. generación = Usted y sus padres y todos sus abuelos nacieron en los Estados Unidos (USA).



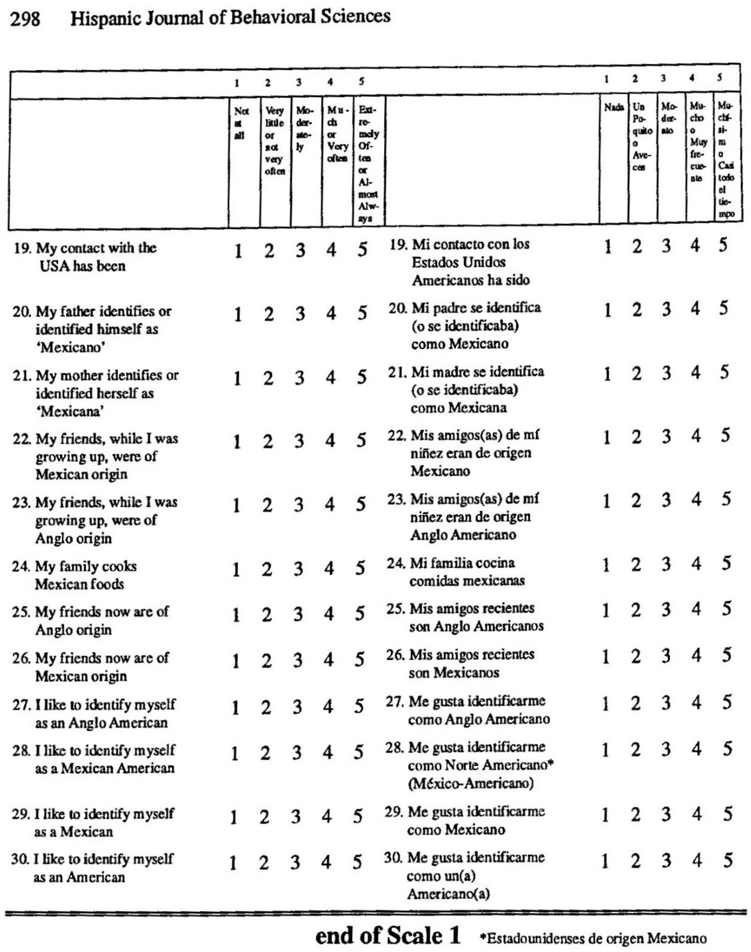
SCALE 1

[Circle a number between 1-5 next to each item that best applies.]

[Marque con un círculo el numero entre 1 y 5 a la respuesta que sea más adecuada para usted.]

	1	2	3	4	5		1	2	3	4	5
	Not at all	Very little or not very often	Moderately	Much or Very often	Extremely often or almost Always		Nada	Un Poquito o Aveces	Moderato	Mucho o Muy frecuente	Muchísimo o Casi todo el tiempo
1. I speak Spanish	1	2	3	4	5	1. Yo hablo Español	1	2	3	4	5
2. I speak English	1	2	3	4	5	2. Yo hablo Inglés	1	2	3	4	5
3. I enjoy speaking Spanish	1	2	3	4	5	3. Me gustar habler en Español	1	2	3	4	5
4. I associate with Anglos	1	2	3	4	5	4. Me asocio con Anglos	1	2	3	4	5
5. I associate with Mexicans and/or Mexican Americans	1	2	3	4	5	5. Yo me asocio con Mexicanos o con Norte Americanos	1	2	3	4	5
6. I enjoy listening to Spanish language music	1	2	3	4	5	6. Me gusta la musica Mexicana (musica en idioma Español)	1	2	3	4	5
7. I enjoy listening to English language music	1	2	3	4	5	7. Me gusta la musica de idioma Inglés	1	2	3	4	5
8. I enjoy Spanish language TV	1	2	3	4	5	8. Me gusta ver programas en la televisión que sean en Español	1	2	3	4	5
9. I enjoy English language TV	1	2	3	4	5	9. Me gusta ver programas en la televisión que sean en Inglés	1	2	3	4	5
10. I enjoy English language movies	1	2	3	4	5	10. Me gusta ver películas en Inglés	1	2	3	4	5
11. I enjoy Spanish language movies	1	2	3	4	5	11. Me gusta ver películas en Español	1	2	3	4	5
12. I enjoy reading (e.g., books in Spanish)	1	2	3	4	5	12. Me gusta leer (e.g., libros en Español)	1	2	3	4	5
13. I enjoy reading (e.g., books in English)	1	2	3	4	5	13. Me gusta leer (e.g., libros en Inglés)	1	2	3	4	5
14. I write (e.g, letters in Spanish)	1	2	3	4	5	14. Escribo (e.g., cartas en Español)	1	2	3	4	5
15. I write (e.g., letters in English)	1	2	3	4	5	15. Escribo (e.g., cartas en Inglés)	1	2	3	4	5
16. My thinking is done in the English language	1	2	3	4	5	16. Mis piensamientos ocurren en el idioma Inglés	1	2	3	4	5
17. My thinking is done in the Spanish language	1	2	3	4	5	17. Mis piensamientos ocurren en el idioma Español	1	2	3	4	5
18. My contact with Mexico has been	1	2	3	4	5	18. Mi contacto con Mexico ha sido	1	2	3	4	5

Appendix D (cont.)



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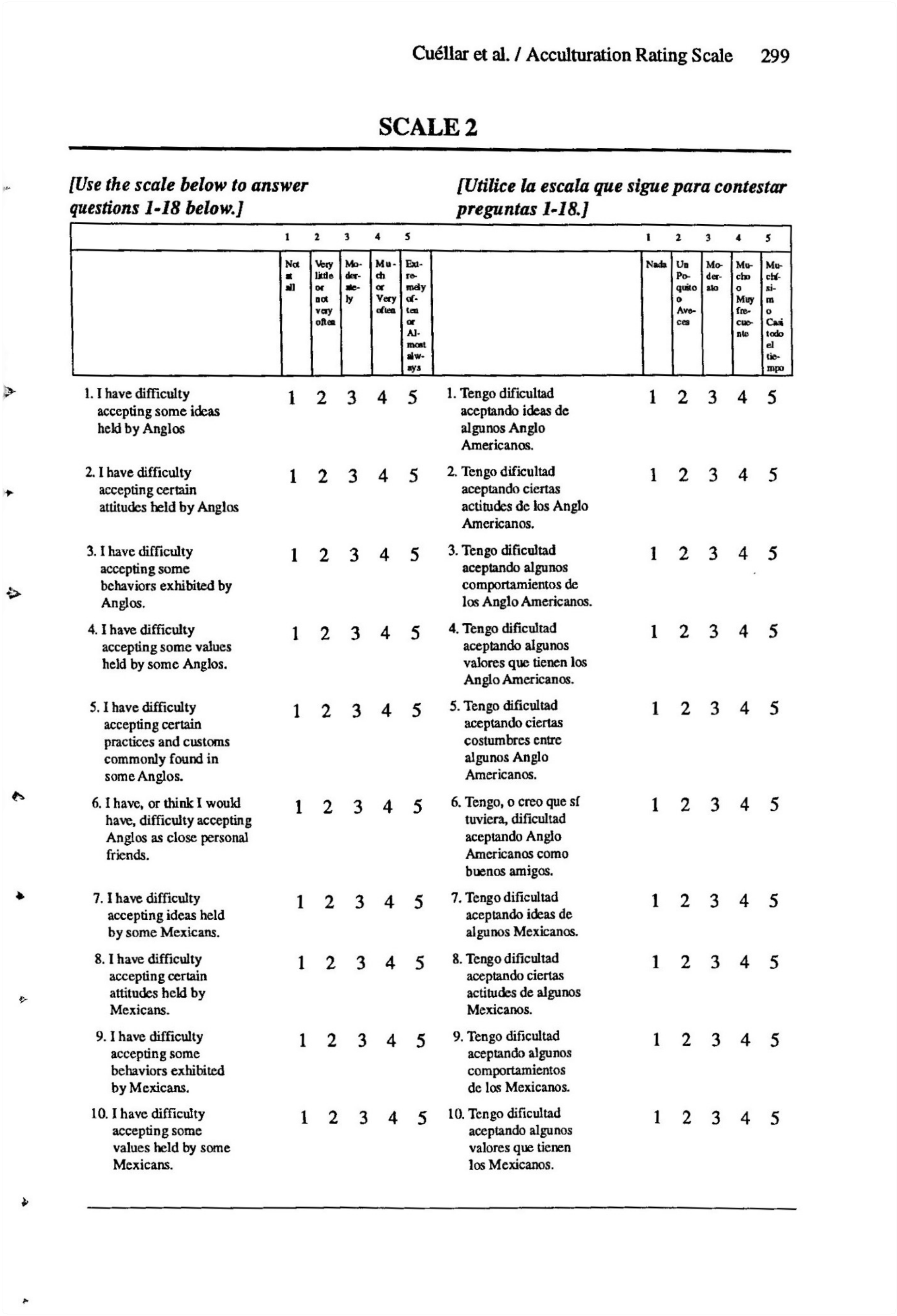
	1 Not at all	2 Very little or not very often	3 Moderately	4 Much or Very often	5 Extremely Often or Almost Always		1 Nada	2 Un Poquito o Aveces	3 Moderato	4 Mucho o Muy frecuente	5 Muchísimo o Casi todo el tiempo
19. My contact with the USA has been	1	2	3	4	5	19. Mi contacto con los Estados Unidos Americanos ha sido	1	2	3	4	5
20. My father identifies or identified himself as 'Mexicano'	1	2	3	4	5	20. Mi padre se identifica (o se identificaba) como Mexicano	1	2	3	4	5
21. My mother identifies or identified herself as 'Mexicana'	1	2	3	4	5	21. Mi madre se identifica (o se identificaba) como Mexicana	1	2	3	4	5
22. My friends, while I was growing up, were of Mexican origin	1	2	3	4	5	22. Mis amigos(as) de mí niñez eran de origen Mexicano	1	2	3	4	5
23. My friends, while I was growing up, were of Anglo origin	1	2	3	4	5	23. Mis amigos(as) de mí niñez eran de origen Anglo Americano	1	2	3	4	5
24. My family cooks Mexican foods	1	2	3	4	5	24. Mi familia cocina comidas mexicanas	1	2	3	4	5
25. My friends now are of Anglo origin	1	2	3	4	5	25. Mis amigos recientes son Anglo Americanos	1	2	3	4	5
26. My friends now are of Mexican origin	1	2	3	4	5	26. Mis amigos recientes son Mexicanos	1	2	3	4	5
27. I like to identify myself as an Anglo American	1	2	3	4	5	27. Me gusta identificarme como Anglo Americano	1	2	3	4	5
28. I like to identify myself as a Mexican American	1	2	3	4	5	28. Me gusta identificarme como Norte Americano* (México-Americano)	1	2	3	4	5
29. I like to identify myself as a Mexican	1	2	3	4	5	29. Me gusta identificarme como Mexicano	1	2	3	4	5
30. I like to identify myself as an American	1	2	3	4	5	30. Me gusta identificarme como un(a) Americano(a)	1	2	3	4	5

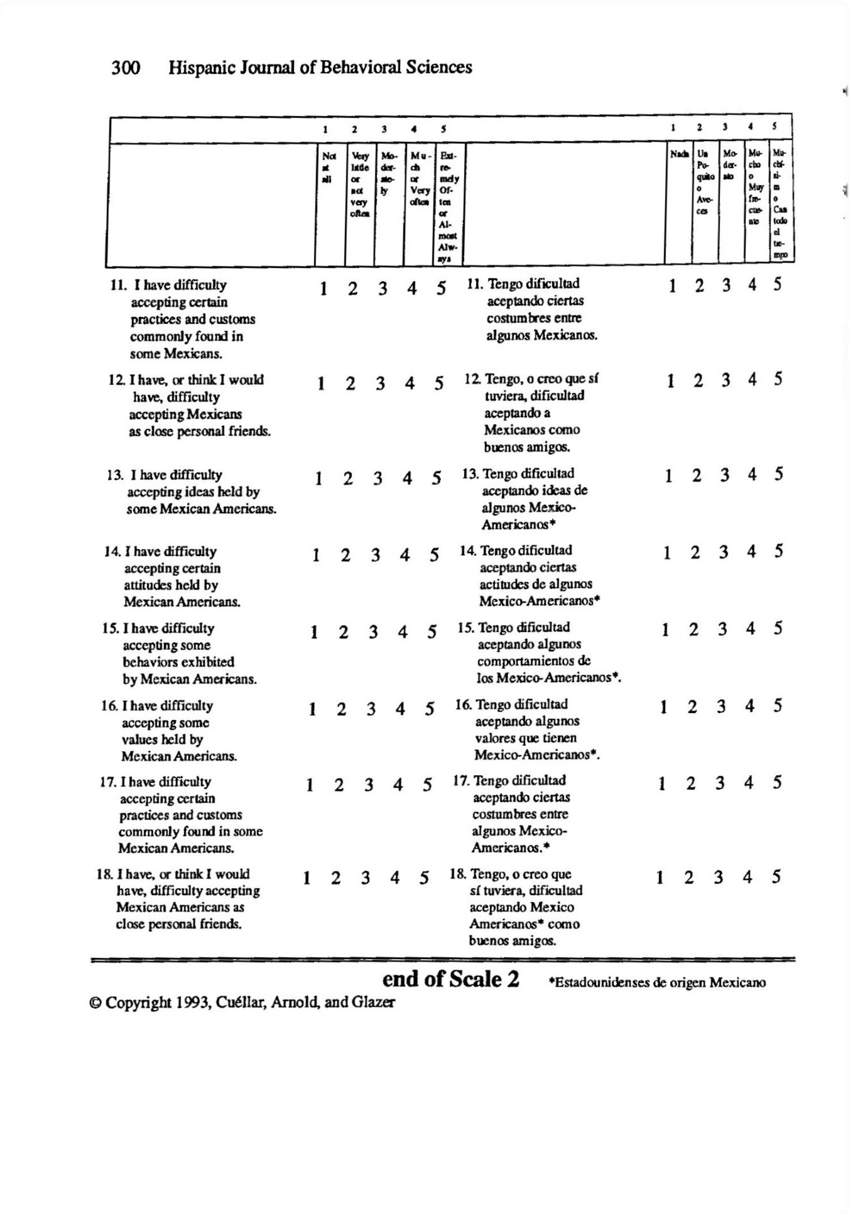
end of Scale 1 *Estadounidenses de origen Mexicano



SCALE 2

[Use the scale below to answer questions 1-18 below.]						*[Utilice la escala que sigue para contestar preguntas 1-18.]*					
	1	2	3	4	5		1	2	3	4	5
	Not at all	Very little or not very often	Moderately	Much or Very often	Extremely often or Almost always		Nada	Un Poquito o Aveces	Moderato	Mucho o Muy frecuente	Muchísimo o Casi todo el tiempo
1. I have difficulty accepting some ideas held by Anglos	1	2	3	4	5	1. Tengo dificultad aceptando ideas de algunos Anglo Americanos.	1	2	3	4	5
2. I have difficulty accepting certain attitudes held by Anglos	1	2	3	4	5	2. Tengo dificultad aceptando ciertas actitudes de los Anglo Americanos.	1	2	3	4	5
3. I have difficulty accepting some behaviors exhibited by Anglos.	1	2	3	4	5	3. Tengo dificultad aceptando algunos comportamientos de los Anglo Americanos.	1	2	3	4	5
4. I have difficulty accepting some values held by some Anglos.	1	2	3	4	5	4. Tengo dificultad aceptando algunos valores que tienen los Anglo Americanos.	1	2	3	4	5
5. I have difficulty accepting certain practices and customs commonly found in some Anglos.	1	2	3	4	5	5. Tengo dificultad aceptando ciertas costumbres entre algunos Anglo Americanos.	1	2	3	4	5
6. I have, or think I would have, difficulty accepting Anglos as close personal friends.	1	2	3	4	5	6. Tengo, o creo que sí tuviera, dificultad aceptando Anglo Americanos como buenos amigos.	1	2	3	4	5
7. I have difficulty accepting ideas held by some Mexicans.	1	2	3	4	5	7. Tengo dificultad aceptando ideas de algunos Mexicanos.	1	2	3	4	5
8. I have difficulty accepting certain attitudes held by Mexicans.	1	2	3	4	5	8. Tengo dificultad aceptando ciertas actitudes de algunos Mexicanos.	1	2	3	4	5
9. I have difficulty accepting some behaviors exhibited by Mexicans.	1	2	3	4	5	9. Tengo dificultad aceptando algunos comportamientos de los Mexicanos.	1	2	3	4	5
10. I have difficulty accepting some values held by some Mexicans.	1	2	3	4	5	10. Tengo dificultad aceptando algunos valores que tienen los Mexicanos.	1	2	3	4	5

Appendix D (cont.)



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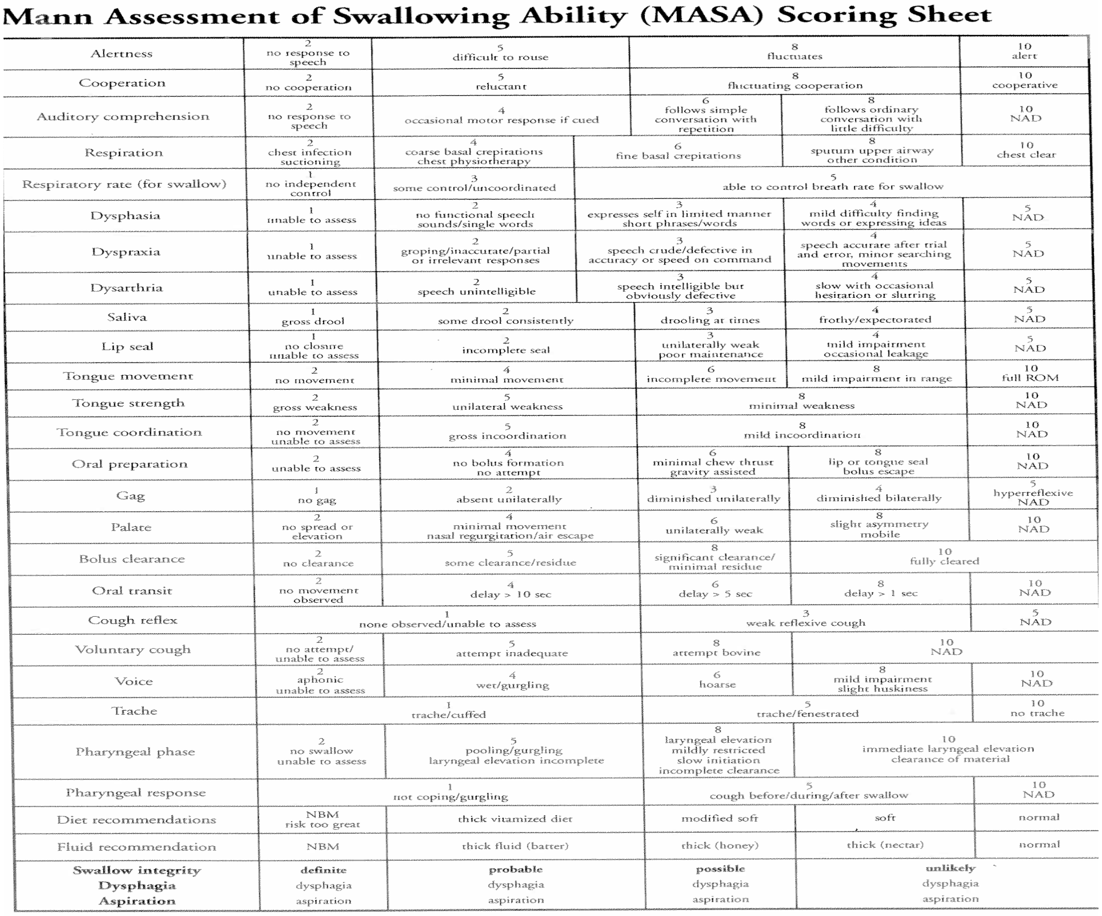
	1	2	3	4	5		1	2	3	4	5
	Not at all	Very little or not very often	Moderately	Much or Very often	Extremely Often or Almost Always		Nada	Un Poquito o Aveces	Moderado	Mucho o Muy frecuente	Muchísimo o Casi todo el tiempo
11. I have difficulty accepting certain practices and customs commonly found in some Mexicans.	1	2	3	4	5	11. Tengo dificultad aceptando ciertas costumbres entre algunos Mexicanos.	1	2	3	4	5
12. I have, or think I would have, difficulty accepting Mexicans as close personal friends.	1	2	3	4	5	12. Tengo, o creo que sí tuviera, dificultad aceptando a Mexicanos como buenos amigos.	1	2	3	4	5
13. I have difficulty accepting ideas held by some Mexican Americans.	1	2	3	4	5	13. Tengo dificultad aceptando ideas de algunos Mexico-Americanos*	1	2	3	4	5
14. I have difficulty accepting certain attitudes held by Mexican Americans.	1	2	3	4	5	14. Tengo dificultad aceptando ciertas actitudes de algunos Mexico-Americanos*	1	2	3	4	5
15. I have difficulty accepting some behaviors exhibited by Mexican Americans.	1	2	3	4	5	15. Tengo dificultad aceptando algunos comportamientos de los Mexico-Americanos*.	1	2	3	4	5
16. I have difficulty accepting some values held by Mexican Americans.	1	2	3	4	5	16. Tengo dificultad aceptando algunos valores que tienen Mexico-Americanos*.	1	2	3	4	5
17. I have difficulty accepting certain practices and customs commonly found in some Mexican Americans.	1	2	3	4	5	17. Tengo dificultad aceptando ciertas costumbres entre algunos Mexico-Americanos.*	1	2	3	4	5
18. I have, or think I would have, difficulty accepting Mexican Americans as close personal friends.	1	2	3	4	5	18. Tengo, o creo que sí tuviera, dificultad aceptando Mexico Americanos* como buenos amigos.	1	2	3	4	5

end of Scale 2 *Estadounidenses de origen Mexicano

Appendix E



Mann Assessment of Swallowing Ability (MASA) Scoring Sheet

Alertness	2 no response to speech	5 difficult to rouse	8 fluctuates		10 alert
Cooperation	2 no cooperation	5 reluctant	8 fluctuating cooperation		10 cooperative
Auditory comprehension	2 no response to speech	4 occasional motor response if cued	6 follows simple conversation with repetition	8 follows ordinary conversation with little difficulty	10 NAD
Respiration	2 chest infection suctioning	4 coarse basal crepitations chest physiotherapy	6 fine basal crepitations	8 sputum upper airway other condition	10 chest clear
Respiratory rate (for swallow)	1 no independent control	3 some control/uncoordinated	5 able to control breath rate for swallow		
Dysphasia	1 unable to assess	2 no functional speech sounds/single words	3 expresses self in limited manner short phrases/words	4 mild difficulty finding words or expressing ideas	5 NAD
Dyspraxia	1 unable to assess	2 groping/inaccurate/partial or irrelevant responses	3 speech crude/defective in accuracy or speed on command	4 speech accurate after trial and error, minor searching movements	5 NAD
Dysarthria	1 unable to assess	2 speech unintelligible	3 speech intelligible but obviously defective	4 slow with occasional hesitation or slurring	5 NAD
Saliva	1 gross drool	2 some drool consistently	3 drooling at times	4 frothy/expectorated	5 NAD
Lip seal	1 no closure unable to assess	2 incomplete seal	3 unilaterally weak poor maintenance	4 mild impairment occasional leakage	5 NAD
Tongue movement	2 no movement	4 minimal movement	6 incomplete movement	8 mild impairment in range	10 full ROM
Tongue strength	2 gross weakness	5 unilateral weakness	8 minimal weakness		10 NAD
Tongue coordination	2 no movement unable to assess	5 gross incoordination	8 mild incoordination		10 NAD
Oral preparation	2 unable to assess	4 no bolus formation no attempt	6 minimal chew thrust gravity assisted	8 lip or tongue seal bolus escape	10 NAD
Gag	1 no gag	2 absent unilaterally	3 diminished unilaterally	4 diminished bilaterally	5 hyperreflexive NAD
Palate	2 no spread or elevation	4 minimal movement nasal regurgitation/air escape	6 unilaterally weak	8 slight asymmetry mobile	10 NAD
Bolus clearance	2 no clearance	5 some clearance/residue	8 significant clearance/ minimal residue	10 fully cleared	
Oral transit	2 no movement observed	4 delay > 10 sec	6 delay > 5 sec	8 delay > 1 sec	10 NAD
Cough reflex	1 none observed/unable to assess		3 weak reflexive cough		5 NAD
Voluntary cough	2 no attempt/ unable to assess	5 attempt inadequate	8 attempt bovine	10 NAD	
Voice	2 aphonic unable to assess	4 wet/gurgling	6 hoarse	8 mild impairment slight huskiness	10 NAD
Trache	1 trache/cuffed		5 trache/fenestrated		10 no trache
Pharyngeal phase	2 no swallow unable to assess	5 pooling/gurgling laryngeal elevation incomplete	8 laryngeal elevation mildly restricted slow initiation incomplete clearance	10 immediate laryngeal elevation clearance of material	
Pharyngeal response	1 not coping/gurgling		5 cough before/during/after swallow		10 NAD
Diet recommendations	NBM risk too great	thick vitamized diet	modified soft	soft	normal
Fluid recommendation	NBM	thick fluid (batter)	thick (honey)	thick (nectar)	normal
Swallow integrity **Dysphagia** **Aspiration**	**definite** dysphagia aspiration	**probable** dysphagia aspiration	**possible** dysphagia aspiration	**unlikely** dysphagia aspiration	

Appendix F

1. Tell me about your health.
2. Tell me about a typical mealtime.
3. Tell me about your swallowing.
4. Give me an example of when your swallowing caused you difficulty.
5. Tell me how your swallowing is a major distraction in your life.
6. Tell me how the time needed to complete a meal impacts your daily activities.
7. Tell me how the fear of choking changes your likelihood of drinking or eating in public.

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