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How do speech-language pathologists perceive their influence over patient adherence regarding dysphagia recommendations?

Charlene D. Shin

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How Do Speech-Language Pathologists Perceive Their Influence Over Patient
Adherence Regarding Dysphagia Recommendations?

by

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Thesis

Eastern Michigan University

In partial fulfillment of the requirements for the degree of

MASTER OF ARTS

in

Speech-Language Pathology

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SLP PERCEPTIONS OF INFLUENCE ON PATIENT ADHERENCE

Abstract

This qualitative research study explored speech-language pathologists' (SLP) perceptions regarding their potential to influence patient adherence to dysphagia recommendations. Five SLPs holding the CCC-SLP were interviewed in an open-ended format, and the transcriptions of the interviews were the data for this study. The SLP interviews provided a glimpse into SLP interpretations of patients' fears, concerns, and comprehension of their dysphagia and the recommendations they were given. The themes identified within the data were SLP education for patient and family, respect for patient decisions, SLP understanding of barriers to patient adherence to dysphagia recommendations, family buy-in and practical support, perpetuation of bad feelings toward SLPs, personality clashes, and provider continuity. After an analysis of the findings, the Health Belief Model (HBM) was posed as the framework through which the themes could be applied to improve therapeutic practice in SLP.

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Chapter 1: Introduction

Background Information

Review of dysphagia & resulting pneumonias. The Mayo Clinic (2008) defines dysphagia as difficulty or discomfort with swallowing, and the American Speech-Language-Hearing Association (ASHA, 2018) defines dysphagia as “problems involving the oral cavity, pharynx, esophagus, or gastroesophageal junction.” Dysphagia affects approximately 15 million people in the United States with an additional 1 million people being diagnosed annually (Carnaby & Harenberg, 2013). People most at risk for dysphagia are older patients with neurological diseases, among those, dementia, Parkinson's disease, and stroke victims are most susceptible to the condition (Carrión et al., 2014). The presence of dysphagia is often symptomatic of disease or other health issue and can be disruptive to daily living. People with dysphagia are at risk for choking and aspiration pneumonia, and 55% of individuals with dysphagia are at risk for malnutrition and dehydration (Bhattacharyya, 2014; Howard, Nissenon, Meeks, & Rosario, 2018; Kenny, 2015; Martino & McCulloch, 2016). The 2012 National Health Interview Survey reported that in the United States 1 in every 25 adults experience dysphagia. Among those adults, 57% reported that they felt that their disordered swallowing was moderate or more severe, but only 22% sought help from a health care professional (Bhattacharyya, 2014).

Aspiration is defined as the misdirection and subglottic penetration of oropharyngeal or gastric contents into the larynx and lower respiratory tract (Komiya, Ishii, & Kadota, 2015; McCurtin et al., 2018). Preserved swallow function and the cough reflex are important defenses against oropharyngeal aspiration, and proper dysphagia management is paramount to reduce risks for aspiration as well as infection and other morbidities (Marik & Kaplan, 2003; McCurtin et al., 2018; Smithard, 2016). ASHA reports that approximately 22% of adults

over 50 years of age are affected by dysphagia (2018). Dysphagia affects 68% of patients in extended health care facilities, and dysphagic patients who aspirate are at an increased risk of acquiring pneumonia (ASHA, 2018; Cabre et al., 2010; McCurtin et al., 2018; Rosenvinge & Starke, 2005; Smithard, 2016). As of 2015, aspiration pneumonia and community-acquired pneumonia together are the leading cause of death in the hospitalized elderly, and aspiration pneumonia is the second most common source of infection among nursing home residents (Hollaar et al., 2017; Teramoto, Yoshida, & Hizawa, 2015). Aspiration pneumonia is the leading cause of death both for patients with dysphagia accompanying neurologic disorders as well as for nursing home residents (DeLegge, 2002; Marik & Kaplan, 2003). A distressing 50% of patients affected are found to have clinically significant aspiration, and furthermore, an estimated one third of patients with dysphagia are expected to develop pneumonia (ASHA, 2018; Lanspa, Jones, Brown, & Dean, 2013). ASHA (2017) and the Agency for Health Care Research and Quality (AHRQ) report that approximately 60,000 individuals die each year from such complications.

The National Institute of Health (2013) reports that the incidence, mortality, and morbidity rates of aspiration pneumonia are significantly greater than the rates predicted by traditional severity assessments used by medical professionals. A presentation of aspiration pneumonia is widely known among health care professionals to be a poor prognostic indicator, and due to these high rates of mortality and morbidity, patients presenting with aspiration pneumonia in emergency rooms are nearly always admitted to a hospital where they are expected to receive swallowing intervention (Lanspa et al., 2013).

Role of the speech-language pathologist. The assessment and management of dysphagia are primarily the responsibility of speech-language pathologists (SLPs) (Rosenvinge & Starke, 2005; Smithard, 2015; Smithard, 2016). Rehabilitation for dysphagia

traditionally includes education about the disorder; prescription of maneuvers and compensatory strategies to reduce risks and improve the safety of swallowing, modifying the texture of the diet (mechanical soft, ground, chopped, pureed, thickened), and avoidance of unsafe feeding methods (Carnaby & Harenberg, 2013; Kenny, 2015; Martino & McCulloch, 2016).

ASHA's 2007 SLP Survey reported that the majority of services provided by SLPs who worked with adults in health care settings were in the area of swallowing intervention at 46% (ASHA, 2007). ASHA's 2009, 2011, 2013, 2015, and 2017 Surveys showed a steady decrease in percentage of time spent for dysphagia intervention in adult clinical services, with most recent statistics reporting 39%, more than double the second most common area of intervention of dementia, at 15% (ASHA, 2017). Of the number of SLPs whose work involved the management of dysphagia in adults, 84% indicated that they recommended the use of thickened liquids—also known as a form of a modified diet, as an effective treatment for dysphagia. It was reported that a mere 46% of patients adhered to thickened liquid recommendations, and only 50% of patients in all developed countries adhered to their treatment guidelines in general (Garcia, Chambers, & Molander, 2005; Howard et al., 2018; Rosenvinge & Starke, 2005).

Despite the distressing statistics surrounding dysphagia and resulting pneumonias, little progress has been made in establishing a more effective recommendation than the use of thickened liquids to treat dysphagia in health care settings (Martino & McCulloch, 2016). Although commendable efforts have been made in systematic research to explore and establish a more efficacious treatment method than modified diets, there is a surprising lack of published controlled studies that succeed in doing so (Martino & McCulloch, 2016). One systematic review of the current literature in dysphagia treatments declared that research in the area of dysphagia is “still in its infancy” (Foley, Teasell, Salter, Kruger, & Martino, 2008). Correspondingly, little research has been conducted to examine what alternatives patients

pursue when they choose not to adhere to their thickened liquid recommendations. Patient adherence to dysphagia treatment recommendations, such as the thickened liquid diet or other modified diets, is crucial not only for patient health, safety, and comfort, but also to minimize complications, reduce lengths of hospital stays, and mitigate overall health care expenditures (Altman, Yu, & Schaefer, 2010; Martino et al., 2005; McCurtin et al., 2018; Potts, 2008).

Justification

This study aims to explore SLPs' beliefs about the impacts that their behavior and demeanor toward the patient make in influencing how the patient feels about his or her dysphagia/treatment recommendations and their decision whether or not to follow the recommendations. The findings of this research will contribute to the professional knowledge base regarding patient adherence to recommendations made by SLPs by better understanding how SLPs interpret their own potential to influence patient adherence. If SLPs do not understand their potential to influence patient adherence, we are missing opportunities to improve patient comprehension and incidence of successful outcomes.

Research has previously been conducted around patients' perspectives and how they can impact treatment outcomes (McCurtin et al., 2018; Potts, 2008). Patients reported that although they understood the reasoning behind the dysphagia treatment recommendations such as a thickened liquid diet, they had issues adhering to the recommendations because they considered it to be a burden (McCurtain et al., 2018). In another study, patients reported that if they did not like the taste or texture of the modified foods, if the thickening agents or tools to modify the food were out of financial reach, or if they did not understand or agree with the reasoning behind the recommendations, they had low adherence rates (Potts, 2008).

Research Question

The primary question that this investigation aims to answer is “How do speech-language pathologists perceive their influence on patient adherence regarding dysphagia treatment recommendations?” Through this study, the hope is to address if and how SLPs believe their behavior and demeanor toward the patient affects how the patient feels about his or her dysphagia or treatment recommendations. Do SLPs understand the potential they hold to influence patient adherence? Lastly, I hope to explore how SLPs interpret patients’ fears, concerns, and comprehension of their dysphagia and the recommendations they are given, and how they translate those perceptions into their therapeutic practice.

Review of the Literature

The health belief model (HBM) was selected as the theoretical framework for this research on speech-language pathologists’ perceptions of patient adherence because the model provides a lens of social psychological theory through which to view patient adherence in relation to the SLP. The HBM considers “motivational and cognitive factors” rather than “sociodemographic characteristics and vague allusions to global attitudes” to predict or explain patient adherence and health behaviors (Katatatsky, 1977, p. 236). The model is founded on the predictive values of the individual’s health beliefs and perceptions, which are subjective to every individual and always subject to change, and this can be a functional and practical way in which to explore the therapeutic practice of SLPs (Katatatsky, 1977; Rosenstock, Strecher, & Becker, 1988).

Patient adherence. Adherence to medical recommendations is crucial for improved health outcomes; the odds of a favorable health outcome is almost three times greater for patients who adhere to treatment plans than those who are non-adherent (DiMatteo, Giordani, Lepper, & Croghan, 2002). According to Miller and Hayes (2000), the term *compliance* has fallen into disfavor within the medical community. The term is said to connote “a paternalistic relationship

between the physician and patient” and that noncompliance indicates that the patient is exhibiting “deviant behavior” or “weakness of character,” and these align with what health professionals today call the *medical model*, a term coined by the psychiatrist, R.D. Laing in the 1970s (Laing, 1972). In the present day, the World Health Organization proposes that adherence is impacted by the health care provider-patient relationship, disease, treatment, patient characteristics, and socioeconomic factors (Haskard Zolnierek, & DiMatteo, 2009). The term, *adherence* is used in this paper in preference over “compliance,” because it better represents the complex relationships between patient, provider, and treatment (Miller & Hayes, 2000).

As advances are made in medical, psychosocial, and behavioral knowledge, health care professionals are learning to center their treatment planning and decision-making around the individual patient (Rathert, Wyrwich, & Boren, 2013). This is referred to as patient-centered care. The term “adherence” also better reflects the consideration that following a treatment regimen is not always a clear-cut choice for patients; adherence encompasses several factors, all of which are considered within the health belief model (HBM; Rosenstock et al., 1988).

The health belief model. The HBM (Figure 1) is a behavior-change and value-expectancy construct that Rosenstock and colleagues at the U.S. Public Health Service developed in the early 1950s to help scientists understand “the widespread failure of people to accept disease preventives” (Janz & Becker, 1984, p. 2). It has since been applied to patients’ adherence with prescribed medical regimens (Janz & Becker, 1984). The HBM is one of the most commonly used theoretical frameworks to illustrate health behaviors (Becker, 1974). Katatatsky (1977) said it most concisely when she summarized the elements of the HBM:

- the individual’s perceptions of his susceptibility to the disease (condition) and his perception of the seriousness or severity of the disease;

- the individual's perceptions of the possible benefits weighed against the possible barriers to taking action;
- internal and external “cues to action”; and
- various demographic, social, psychological, and structural variables which also interact in the decision-making process.

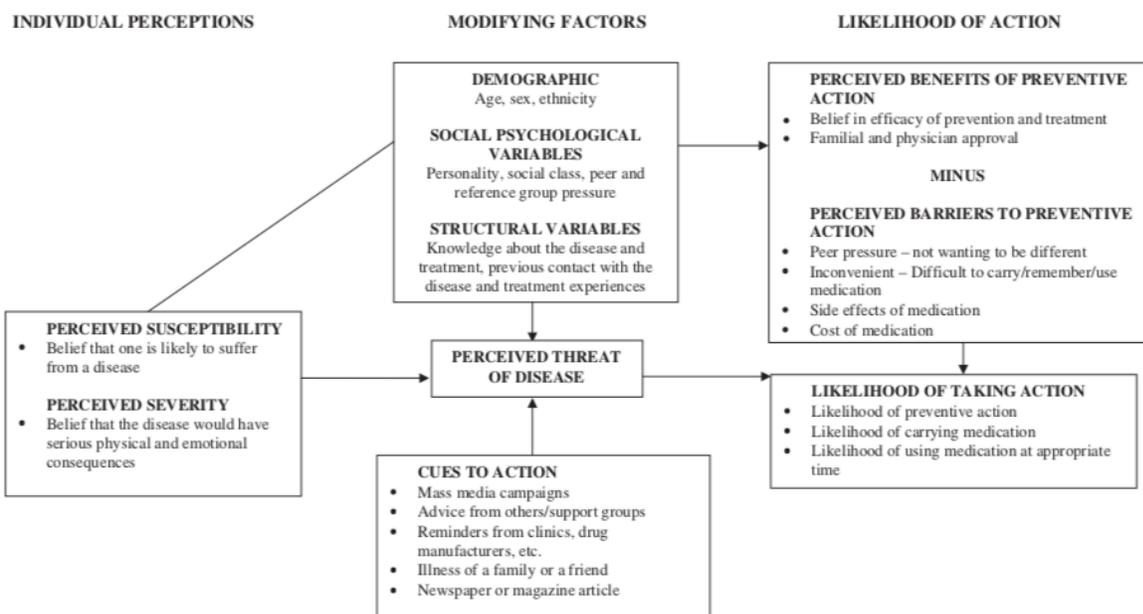


Figure 1. The health belief model. Reprinted from “Evaluating the effectiveness of health belief model interventions in improving adherence: A systematic review” by C. Jones, H. Smith, & C. Llewellyn, 2014, *Health Psychology Review*, Vol. 8, p. 255.

Rosenstock (1988) found that patient health decision-making and behaviors depended on the simultaneous interactions of patient motivation, patient perception of vulnerability, and perceived benefit of adhering to medical recommendations. The individual's health beliefs are centered around his or her perception of net threat versus net benefit, and this serves as his or her orientation to the decision-making process (Kataatatsky, 1977)

The founders of the HBM defined *perceived susceptibility* as “whether or not an individual regarded himself or herself as susceptible to acquiring an illness or being harmed due to engaging or not engaging in a behavior,” and *perceived severity* was defined as “the subjective belief of an individual regarding the extent of harm that can occur by performing or not performing a health behavior” (Rosenstock et al., 1988). The model proposes that perceived severity, together with perceived susceptibility, contributes to the patient’s perception of threat.

The patient may identify various barriers as standing in the way of performing the “health behavior,” and these could include financial burden of completing the health behavior, dangers involved in completing the health behavior, or if there are side-effects or if the behavior itself is perceived as being unpleasant or inconvenient (Rosenstock et al., 1988). The perception of threat is weighed against the patient’s individual perceptions of the benefits of following the prescribed recommendation or medical advice, and this then translates into the resulting action or health behavior. The patient’s willingness to undertake the recommended health behavior is comprised of motivations, belief that performing the health behavior will reduce the threat, and various modifying factors such as demographic data (Katatatsky, 1977). Since the 1950s, the HBM has been further developed and adapted to help psychologists and health care providers—among others—to understand, explain, and predict why people make the medical decisions they do.

Use of the HBM to understand patient adherence to dysphagia recommendations has not been researched. Until 1974, the HBM was mostly used as a tool for retrospective analysis of patient health behaviors (Janz & Becker, 1984). When used as a prospective tool for predicting and anticipating patient health behaviors, studies have revealed that outcomes were “encouraging” and produced significance ratios that were better than studies where the HBM was used in a retrospective design (Janz & Becker, 1984). In 1992, the HBM was used to study mammography usage and researchers discovered that the most reliable indicator whether a

patient would perform a recommended health behavior was the patients' individual perception of the severity of the condition (Stein, Fox, Murata, & Morisky, 1992). Bishop and colleagues (2015) reported that the results of a systematic review of the HBM over a 10-year span found that "perceived susceptibility was also a strong contributor to preventative health behaviors, and perceived barriers were the most powerful HBM dimension among all included studies" (p. 3025). Other researchers over the years have found that a perception of fewer benefits when contrasted to perceived barriers was highly correlated with greater rates of non-adherence to medical recommendations (Bishop et al., 2015).

The HBM could be used to increase the understanding of how individuals' perceptions are influenced by health care providers in order to improve patient engagement in safer health care, and hopefully result in improved prognosis (Bishop, Baker, Boyle, & MacKinnon, 2015). There is potential to improve patient adherence by anticipating the influential factors that contribute to it. In understanding the variables that influence patient decision-making, health care providers can facilitate clinical recognition of patient nonadherence, acknowledge the patient as an active participant in individualized treatment planning and medical decision-making process, and additionally, implement strategies to improve patient adherence.

Use of modified texture diets for dysphagia management. The practice of modifying the texture of a patient's diet, as widely used as it is, is not a fail-safe method. The use of thickened liquids to manage dysphagia has been reported to frequently lead to patient dehydration and malnutrition as a result of patient non-compliance (Garcia et al., 2005; Howard et al., 2018). Research has been conducted to explore the reasons why patients so frequently eschew their modified diet recommendations, such as thickened liquids. Potts (2008) reported that patients often lacked the appropriate skills and/or education necessary to correctly carry out their modified diet, such as not knowing how to thicken liquids to the

appropriate consistency for safe consumption. Another explanation for why patients may choose not to adhere to the thickened liquid diet was inadequate emotional support or self-esteem (Potts, 2008). A modified diet could be a drastic change in the lives of patients who were accustomed to consuming and enjoying whatever food they wanted, when they wanted (McCurtin et al., 2018). The change in mode of food intake was often perceived as burdensome regarding the time required to plan meals ahead and prepare the thickened liquids, the financial adjustments necessary to purchase and acquire the thickening agents, and the difficulty adjusting to the changes in flavor and texture of the food and drink (Howard et al., 2018; McCurtin et al., 2018).

Implications of educational intervention. Attempts to improve patient adherence have been made across the medical field over a wide range of types of patient condition, care settings, and medical disciplines (Jones, Smith, & Llewellyn, 2014). A systematic review of the literature surrounding patient adherence and techniques used by medical caregivers in attempt to improve patient adherence reported that “the most commonly used technique to change behavior was providing information about health consequences to participants” (p. 261). Practitioners considered teaching a new behavior to patients as a less effective method of improving patient adherence (Jones et al., 2014). Even less frequently used methods included regulation of the health behavior, threat and reward systems, and techniques involving social support (Jones et al., 2014). The study revealed that provider-led intervention sessions most commonly reported significant improvement in patient adherence. Surprisingly, the study also suggested that when information was given to patients in the form of written or audio materials, that the improvement of patient adherence was less significant than if the information was presented with a combination of written and audio materials together with a health professional (Jones et al., 2014). On educating patients, Bishop (2015) said,

While many patient safety strategies are aimed at raising awareness during hospitalization including information packets and posters, patients are often at a disadvantage for acquiring new information when their primary concern is their illness. It has been shown that between 40 and 80% of the information that is presented to patients is forgotten immediately, and memory is often affected by the perceived importance of the information relayed. Messages regarding patient safety may not be perceived as important as diagnostic information while hospitalized, thus getting lost in the myriad of information and decisions that must be made (p. 3025).

Purpose and Objective of the Study

If speech-language pathologists are aware of the high incidence of non-adherence to dysphagia recommendations, why haven't the recommendations or the way they are presented to patients changed? It is possible that more can be done to align patient perceptions of their dysphagia with the professional perspective in order to improve prognoses and reduce infection and mortality rates; increased awareness may help professionals improve treatment procedures and understand the extent to which patient decision-making is affected by them. The purpose of this study is to gain insight into how SLPs working in health care settings with patients diagnosed with dysphagia perceive their influence on patients' adherence to treatment recommendations.

Chapter 2: Methods

A qualitative research approach was used to explore how speech-language pathologists perceive their influence on patient adherence to the dysphagia recommendations they make. The qualitative method was chosen for this investigation because of the broad range of data that can be collected and inferred from the rich text of a deeply descriptive interview (Bogdan & Biklen, 2007). In-depth interviews allow and enable the researcher to maximize data collection by extending and extracting deep information beyond initial responses and rationales (Qualitative Research Consultants Association, 2018). In order to explore the relationships between the beliefs of participating SLPs and of the social and professional contexts that they work, individual, in-depth, semi-structured, and open-ended interview format were used (Bogdan & Biklen, 2007). This allowed participants to speak openly about their thoughts and opinions regarding their experiences working with adult dysphagia patients. Five participants were interviewed, and data collection was stopped when saturation occurred (Bogdan & Biklen, 2007).

Study Population

All participants were speech-language pathologists who had experience working with adult patients with dysphagia. Each SLP interviewed held the Certificate of Clinical Competence (CCC-SLP; ASHA, 2018). Participants were recruited in a manner outlined by the IRB approval process using a convenience sampling method, and only SLPs available in the Greater Ann Arbor and Detroit areas were contacted to participate in the study. Participants volunteered after being contacted through email, and then participants were interviewed in a face-to-face, individual interview format regarding his or her experiences and perceptions regarding patient adherence with dysphagia treatment recommendations. In order to protect the

identities of the research participants, potentially identifying information such as gender and place of employment have been altered or omitted from this report.

There were five participants who were interviewed for this research. Their names are Avery, Dana, Morgan, Pat, and Thomas. Avery works at a large university hospital where she has been employed for almost her entire career and has 27 years of experience as a SLP. Currently, her case load consists primarily of elderly people receiving services geared toward end-of-life care. Pat and Dana are both SLPs at a health network that primarily serves individuals who have had brain and spinal cord injuries. At the rehabilitation facility where Pat works, his case load primarily consists of long-term inpatients, ranging in age from 18 and older, and he typically sees each patient several times per week. Pat has 22 years of experience as a SLP and has worked at the same facility for most of his career. At Dana's facility, she works primarily with newly injured patients of all ages who can be qualified as short-term inpatients. Dana has 12 years of experience as a SLP. Morgan works at a skilled nursing facility primarily treating older adults receiving acute and subacute care. She has 27 years of experience as a SLP. Thomas currently works at a university-run clinic as a supervising SLP. He has over 30 years of experience in the field and has worked in a wide range of settings serving adult patients with dysphagia in all places he has held employment. Table 1 charts the research participants' employment settings.

Table 1
Research Participants' Employment Settings

Participant	Setting										
	Hospital	Homecare	Acute Care	Subacute Care	Outpatient	Inpatient	Skilled Nursing	Long Term Rehab	Short Term Care	Acute Rehab	Subacute Rehab
Avery	*✓		✓	✓	*✓	✓		✓	✓		
Dana						*✓		*✓	*✓	*✓	
Morgan						*✓	*✓	*✓			✓
Pat					*✓	*✓		*✓			✓
Thomas	✓	✓			*✓	✓				✓	✓

Verified participant employment demographics. ✓ indicates setting worked where adult dysphagia patients were treated, and * indicates descriptor of current employment.

Procedures

Data collection. All participants were interviewed in individual sessions lasting approximately one hour. The interviews were audio recorded with participant consent, and these recordings were transcribed to be used as the data for this research. Any potentially identifying information was omitted or replaced with pseudonyms in order to protect the identities of the participants. A semi-structured interview format and open-ended questions were used to allow the participants to respond based on their unique point of view, and to allow the researcher to ask follow-up questions as necessary (Bogdan & Biklen, 2007). The guiding questions asked during the interview related to direct past or current experiences working with adult dysphagia patients who both did and did not choose to adhere to treatment recommendations; These questions can be found in Appendix A. Participants were encouraged to speak freely regarding their perceptions of patients, their professional relationships with the patients, why they thought

patients chose to adhere or not adhere to recommendations, and any other aspects they found significant in these interactions.

Data analysis. All interviews were audio recorded and then transcribed, and the transcripts of the interviews were the data for this research. The transcriptions were analyzed initially to develop codes based on the individual narratives (Bogdan & Biklen, 2007; Vaismoradi, Turunen, & Bondas, 2013). After the data were assigned a code, they were then compared across each participant to construct common themes that emerged from the axial coding process and reflected the shared perspectives from each participant (Creswell, 2003; Vaismoradi et al., 2013). The themes that were developed were rectified by comparing and contrasting them to existing published literature (Vaismoradi et al., 2013). The themes that were identified through the analysis process are described in Chapter 3.

Chapter 3: Results

Introduction

The results of this study revealed several factors that speech-language pathologists perceived as factors that affected patient adherence to dysphagia recommendations. SLPs identified these factors as follows:

- respect for the patients' decision to disregard medical recommendations and incompatible personalities within the SLP and patient relationship;
- degree of education that the SLP provided to the patients and their families and degree of education that the SLP provided to medical support staff;
- medical staffs' overall knowledge about aspiration risk;
- family "buy in" to the recommendations and treatment plans.

Morgan. Morgan is a SLP with over 20 years of experience working with dysphagic patients. She currently works at a skilled nursing facility and subacute rehabilitation center for both long-term and short-term care. She believes that SLPs do not have any impact on patient adherence. She believes strongly that patients will do what they want, regardless of SLP intervention. Morgan also brought up the impact that the families and support staff at the facility have on patient adherence to her recommendations. She thinks that besides providing corrective education when possible, there is little she can do to make a difference in patient outcomes.

Dana. Dana disagrees with Morgan. She thinks that the interactions that SLPs and other health care professionals have with patients immensely affect patients' decision-making as well as patient outcomes, so she prioritizes building rapport with the patients and families in her role as a SLP. Dana works at a rehabilitation center for traumatic brain injuries and works with acute and subacute care patients. Since the patient population in this facility is largely made up of severely and newly injured people who either have low cognitive function or do not make their

own medical decisions, she says that providing education to families and loved ones is essential to maximize treatment outcomes.

Pat. Pat, like Morgan, believes that patients will do whatever they want in terms of following or not following dysphagia treatment recommendations. He thinks it is crucial to take the patient and loved ones' wishes into consideration when developing a treatment plan and making recommendations, and this usually results in better adherence to the recommendations made. Pat does not perceive aspiration pneumonia to be a serious risk when measured up against other factors including overall health and quality of life.

Avery. Avery feels that SLP's personalities have a large role in patient adherence and outcomes. Like Dana, she believes that building rapport with the patients and loved ones is important because patients will be more receptive to listening to the reasons that support her recommendations. She says that this is the most important aspect of her role as a SLP. Avery works at a large university hospital alongside many other SLPs, physicians, and medical staff. She sees her role as a consultant above anything else. Avery also believes that patient non-adherence can typically be attributed to "low health literacy."

Thomas. Thomas feels that educating the patients and their families, as well as the entire medical team involved, regarding safe and appropriate dysphagia management is significant for patient adherence and outcomes. He has over 30 years of experience in the field and has worked in a very wide range of settings serving adult dysphagic patients. The data suggests that although he values the patients' perceived quality of life, he will do anything he can to keep a patient "in compliance" with the clinically safest recommendations.

Educating Patients and Families

Thomas felt that “compliance is based on how well you educate.” Dana felt that her role in patient dysphagia management was “educating, spending the time with them [and] making sure that they feel comfortable with the diet that they’re on.” Thomas described that when he took more initiative to explain the reasoning for a specific recommendation, patients and their families were “more comfortable about asking questions” and gaining a better understanding about the concerns at hand. Avery agreed. She said, “I think some of it is just people getting a better understanding and then feeling like they’re talking to somebody who is reasonable and not, it’s my way or the highway.” Dana also agreed:

I think educating and keeping them in the whole plan of care process is so important. So they can see how scary, life threatening, dangerous it can be not to adhere to our guidelines and recommendations.

Furthermore, Dana and Morgan both felt that the level of education and the materials they need to provide were “patient specific.” Dana described that “for the [cognitively] higher-level clients, I might have to justify it [recommendations] more. Morgan agreed. She said, “I think it depends on the patient. With some people you can educate until you’re blue in the face and they don’t care. Other people, yeah maybe more education might influence them, but I think it’s patient dependent.” For patients who have better prognoses, Morgan suggested that she would “probably educate a little bit heavier” and “push a little bit harder” for them to agree with the treatment recommendations that she deemed to be best. She felt that she needed to provide patients with “an ongoing education throughout their treatment course.” Dana elaborated on some of her educational techniques:

I’ll give them the pamphlets, I’ll show them the videos, I’ll take them for swallow studies, I educate them verbally, you know. I’ll have them sit through sessions, so I can say, see look. Did you see the audible coughs, or audible swallows, or whatever.

Thomas suggested that having other multidisciplinary professionals on board with educating patients and families improved patient adherence by way of accountability. He said, "It is really important for the whole team that is working with the client to educate too. The doctor needs to say, 'It is really important to keep you healthy. When you get up, you want to be able to use your walker. We don't want you falling.'" It is the same kind of thing. "You really need to listen to the SLP and work with them, so you can eat that diet safely. We don't want you choking." That kind of thing.

Dana reasoned that if she were the patient or loved one, she would want her health care provider to explain and educate her regarding the treatment process. To illustrate how importantly she saw her role as an educator, she said, "For me personally, I educate up to the wazoo." She described her perspective:

I know for me if I was an outsider, and I was the loved one, I would want to know. I need the data, I need to know why, you know, what's the research behind, or what's the basis behind you putting my loved one through physical therapy or thickened [liquids] or whatnot. So, I usually do go above and beyond and kind of explain.

Respect for Patients' Decisions

Pat, Dana, and Morgan agreed that it was important to respect the decisions of patients and their loved ones, even if it meant going against the safest recommended route of intervention. Avery suggested that she supported her patient's goals and respected their pursuit of a higher quality of life. She said, "I'm also telling them that I'm there to balance what would be a recommendation with what would be perceived by them as quality of life."

Although Pat usually assumed that he was more knowledgeable than his patients when it came to dysphagia and aspiration pneumonia, he proposed, "I think they (patients) should do what I say—I went to school for this so of course I know best." He accepted that not everyone

would agree that the most clinically safe option—in terms of reducing risk for aspiration pneumonia—would be the best option for them. He reasoned, “Everyone comes from a different frame of reference, so you just have to present the facts.” He felt that patient adherence to a recommendation was not a black and white subject: “There’s a lot of things we need to think about. We need to do what’s best for your family. What are your end goals?”

Pat described that although he makes his recommendations objectively based on what he sees in his clinical observations as well as in video-fluoroscopic studies, he would understand if a patient or family member decided to pursue a higher quality of life by choosing to go against professional recommendations in order to eat whatever they wanted. He suggested that patient quality of life was more important than the concept of adherence to professional recommendations: “I don’t worry about non-compliance. We will just make it as safe as we can.” Pat explained that he always provided his professional recommendations but still remained receptive to what his patients and their loved ones had to say. He described how he typically presented options for intervention to his patients:

I lay it out. You say, ok, so this is what we saw. I kind of lay out the different treatment options and let them choose. It’s respectful to let them choose the path that they want if given all the education and what’s [the reasoning] behind it. I think people need to have the ability to choose the path that they want to go down.

Dana felt similarly:

I lay out the facts for them. I let them know, this is where we’re at. You know. I give them best case scenarios, I give them worst case scenarios. And at the end of the day I let them decide.

Morgan explained that she would make recommendations based on what was clinically safest for the patient, but that ultimately, the treatment plans to be put in place were up to the

patients: “The patient has the right to refuse.” In the case that patients decided that the recommendation—the most clinically safe option—did not fit their desired diet, they held the power to change the treatment plan. She explained:

We have to make those recommendations because it’s what is clinically safest for the patient. From a quality of life standpoint, if a patient chooses to eat [a regular diet when a modified has been recommended], this is the diet that they’re going to eat but my clinical recommendations are still going to be that [have not changed].”

Morgan explained that “even though they’re choosing not to follow our recommendations,” after a patient refuses the recommended method of intervention, she was still going to be “educating regarding safe swallow guidelines and safe strategies.” She suggested that “in this type of setting [an inpatient, long-term, subacute, skilled nursing facility], we have to respect the patients right to refuse” because there are only “so many things” that the patients have control over. The diet they eat is one of those things.

Dana, Pat, and Morgan all explained that they also made their professional recommendations based on their clinical observations. However, if the patients or their loved ones did not like the modification to the regular diet and wanted to continue consuming a regular diet, the SLPs would do their best to ensure that the patient and their loved ones were making informed decisions by giving additional information about the risks of their decision. Dana felt that expecting patients to adhere to a strict treatment plan was “unrealistic.” She speculated, “I think there are some stern speech-paths out there that expect you to follow everything to a T and are kind of unrealistic in setting guidelines.”

To match more “realistic” expectations, the facilities that these SLPs work at offer “official non-compliance forms” that patients and loved ones have to sign in order to officially go against professional medical recommendations. Morgan said, “They have to sign off that they

understand the risks, even if they're not choosing to follow the recommendations." If patients wanted to utilize this option, Pat, Dana, and Morgan all said they would prescribe and teach strategies that the patient could adopt to make consumption of the regular diet as safe as possible. Morgan explained that when the noncompliance forms are signed, "We do a goal for strategies. Are they using the safest strategies to eat? Do they need to eat slower or take smaller bites? Do they need to do a chin tuck? Whatever. So, it's more a goal for strategies as opposed to a diet tolerance goal." In this regard, the SLPs were modifying the patients' treatment plans so that nonadherence became adherence to a modified treatment plan.

Thomas and Morgan felt that non-adherence to the prescribed recommendations was inevitable. Morgan said, "You can educate but you can't make them [adhere]." Thomas and Morgan both compared following prescribed modified texture diets to going on a diet to lose weight. Thomas said, "Everyone wants to lose weight, but it is really hard" to follow a strict diet. He speculated, "It's the same thing." Similarly, Morgan said, "They'll sneak stuff every once in a while. It's like following weight watchers." Thomas postulated that as long as patients were educated about their decisions, his hopes for their outcomes would generally be "just make sure at least they know the education and the rationale behind it even though they might not be following through."

Dana thought that non-adherence to professional recommendations was "more of them making the personal decision" to go against specific instructions rather than a result of a lack of adequate knowledge or education. She considered the patients' happiness as an important factor in their decision-making process. Dana said, "Food brings quality of life—I feel that they are choosing to make their loved one happy over the consequences of what might be." Regarding how much she would choose to educate families, she said, "I can educate until I'm blue in the face, but they're going to do what they're going to do behind closed doors." However, she is

empathetic towards this decision, and said, “I would be pissed if I was on a mechanical soft diet too.” Morgan agreed. She stated, “If it were my parent and they were 90 and wanted to eat, I’d let them eat too.” Dana further speculated, “I don’t know what I would do in that situation,” so she felt that there is no need to “make them feel worse than they already are.” She described a typical scenario:

It’s just the nature of the beast. You can make your recommendations, you can educate, then you can have them say, ‘yep, I understand completely,’ but then the next day you hear what they [the patient’s family] brought in for the loved one to eat or drink. It has happened so many times in my career.

Thomas suggested that he was not afraid to let patients know when he thinks they are making a “poor decision.” He viewed communicating the severity of patients’ outcomes as “very important.” If a patient was not utilizing learned strategies outside of therapy, he would take it upon himself to intervene: “I’m going to show you how important that [strategy] is. All that is [you are] doing is you are getting really lazy and you are getting weaker.” If he advised a modified diet and the patient insisted that he or she wanted to be on a regular diet, Thomas would be “very open” in communicating his disapproval. He gave an example of how he might “reason with” the patient: “Listen, you can’t even swallow your own saliva right now, how do you think you are going to eat a hamburger?” I was pretty direct.” Thomas has been as candid as directly telling a patient, “You shouldn’t be eating.” If his attempt to reason with them did not work, he would talk about published works on the dangers of abnormal swallows and the dangers of aspiration. He said, “If they say ‘that is a risk I want to take,’ there are all those studies out there about how much someone can aspirate.” But if after that, a patient still chose not to follow recommendations, he would say, “We agree to disagree.” He concluded, “At that point, you have given it your best shot.”

Dana empathizes with patients when they don't always adhere to her prescribed diet recommendations and said, "I see where they are coming from." She described food and socializing in the dining room as "such big parts of life" that "bring so much happiness to people." Ultimately, Dana would respect their decision. She felt that it was not her place to argue, but only to educate. On the topic, she said, if "they're making a poor decision, I can tell them that. But at the end of the day it is their decision." She explained, "I want to be as realistic as possible, as far as our therapy treatment and prognosis goes, but at the end of the day I want to put a smile on their faces too. They're human."

SLP Perception of Barriers to Adherence

Avery explained that educating the patients and families as much as possible was her way of building rapport and establishing trust. She speculated that people often viewed her as "a person of authority," so she tried to be as open with them as possible. She said, "As long as I'm keeping—especially the family, up to date about what's going on, that they seem to display what I perceive as trust. And so, I think that's probably- it's establishing rapport." She does her best to "anticipate what the needs might be" in each interaction. She felt that being an attentive SLP could positively impact her relationships with her patients and their loved ones. She does her best to anticipate the specific needs of the patients and families in each interaction. Avery stated,

I can try to predict what might be problems for following through with what I'm recommending. Being aware of my patient- can they read? Can they cognitively use memory skills, can they learn new information, and then if they can't do they have family that will help with that?

When interacting with patients, there were "signs and tells" that Avery looked for in order to determine how much "health literacy" or resources the patient possessed and would have access to respectively, and she tailored her interactions to support those determined needs. For

example, she may have asked a patient where they lived, and if it is in “the middle of nowhere,” Avery might assume “that when they go home, they’re not going to have access to a quick grocery.” She said, “I always ask people ‘do you have questions? Is there anything about this that doesn’t make sense?’ If I leave it too open ended assuming that they will ask questions, they may not.” Other questions she might ask included, “Are you working right now?” and “Who’s at home?”; she used these as clues to determine if the patient had any income or family support to assist them throughout the intervention process. This was a skill she claimed she garnered over many years of experience. When asked if she thought that new SLPs or SLPs who “don’t take the time” to be as attentive and anticipate the patients’ specific needs would be able to gather as much patient data, she said,

“I think that most people who go onto our field are caring people—and if they aren’t, then they chose the wrong field. So I think for the most part everybody is there to try to do good, but I think there is a difference.”

“Family Buy-In”

SLPs also recognized that the mere presence of family support was an influential factor when considering how well a patient adhered to prescribed dysphagia recommendations. When it came to family, Thomas believed “the more involved, the better.” Dana agreed. She said, “Loved ones can be a barrier, because sometimes the client will comply but the family won’t.” She felt it was important to educate families as much as the patients “so we are all on the same page and they can see why we are making the recommendations we are making.” Thomas described how families’ intent could have a positive effect on patient adherence:

For example, if you would show swallowing technique that you want them to use—small bites—and have the patient show you and then have the wife say, ‘Would you consider that a small bite?—Now what would you say? Would you say that is a small bite?—No,

I think that is a little too much... So, I think the more open, and the more you can educate, and the more you can demonstrate—I think they are more comfortable asking questions.

Thomas felt that having family involved in the consulting as well as in the treatment process “improved compliance” as well as overall understanding of the recommendations, saying, “It is so helpful.” He said he would “always try to have a family member present.” Morgan felt that regarding who perpetuates non-adherence in the inpatient setting, “family and patient are probably at the same level,” so having the family on board with the treatment plan can make a big difference. To the same effect, Thomas and Avery expressed that educating the family was important because they could be there to support and educate the patient if the patient was not following the prescribed recommendations. Thomas illustrated how helpful family could be in intervention:

Especially when they say, “Now dad, you just can’t be drinking your water like that. You’ve got to take a sip and put it down.” It really helps when they are there. Especially in the hospital setting, there is usually a family member there pretty much most of the day and night.

When asked how often Thomas expected patients to adequately adhere to the modified diet recommendations that he gave, he explained that since a large number of the patients seen had degenerative cognitive impairments, adequate adherence relied heavily on “family buy in.” He stated, “A lot of times, unless you get the family buy-in it’s not going to happen.” Avery expected that patients would adequately adhere to her dysphagia recommendations for modified diets “probably 75% of the time” if “I’m working with the patient and the families.” She described that if she “explained the rationale for food texture and the liquid texture and the strategies” to the families, they would be more likely “to be on board.” With family involved,

patients would also have better adherence rates “because most of the time, the patient cannot follow through on their own—they either physically can’t do it on their own or cognitively can’t do it on their own.” Avery said she was “always hoping for family.” She postulated,

If you have family and they’re going to be attentive, you might do a little bit better... But for someone who can potentially become more medically well, if you have family there who are vigilant—no matter what their beliefs are, people tend to do better because just the spiritual well-being and emotional well-being of having family involved. So, I meet a lot of people who appear to have no family, no involvement, no one’s ever there and... I think they languish. I don’t think they end up doing as well. Especially when they’re really medically compromised or too cognitively compromised.

Multidisciplinary Influence on Dysphagia Recommendations

One recurrent theme that emerged in the data was the impact that the support staff within the treatment facilities had on patient adherence to dysphagia recommendations. Avery, Morgan, and Thomas agreed that nurses and aids who interacted with the patients sometimes negatively influenced patient adherence to prescribed modified texture diets. Patients who live at inpatient facilities for any amount of time interact with nurses, aids, and food-service workers who could make dire mistakes that negatively affect patient adherence. Morgan said, “Nurses and aids will sometimes slip up and miss the change in the patient’s chart or forget about it.” Thomas described similar problems he faced with nurses and support staff:

It happens. You are going to have a client who is NPO [nothing by mouth] and they are going to get a regular tray. It just happens. And then the minute anyone sees that, on a stroke or rehab unit, everyone has to be able to get that tray out of there whether it is housekeeping or the nurse or the speech pathologist or the OT.

When asked if Morgan thought these types of mistakes were due to a lack of knowledge about the seriousness of the consequences that administration of incorrect food and drink textures could be, she said, “It’s an oversight.” She elaborated, “The majority of the nurses and aids are aware of how detrimental that can be for the patient’s health, but I don’t know that they all understand the risks of aspiration.” Furthermore, she believed that the support staff had so many other tasks and duties they needed to complete during their shifts, that changes in the patient’s chart could fall through the cracks: “It’s not their priority in getting through their day.”

Morgan viewed educating nurses and aids as an ongoing uphill “battle” and “longstanding issue.” She explained that nurses and patient aids who worked in her facility and who sequentially would have the most direct contact with the patients would sometimes “slip up” and pass thin liquids when a thickened liquid was prescribed. She reported of this kind of mistake “probably happens weekly” at her facility. If a patient aspirated, it could be detrimental to them, but Morgan did not appear to think that support staff making a mistake like this one was very significant. She defended them, and said, “They may just miss it or they may look at it and forget because they’re just used to passing thin liquid to everyone.” When asked if she thought that the mistakes were a result of carelessness or lack of proper training, she defended the support staff further, and explained, “They’re not being careless, they’re human.”

Thomas felt that it was his role as a SLP to educate not only the patients and their families, but “the whole unit too.” He described that when he saw or heard that an incorrect tray was issued to a patient, “I always called them on it if I knew about it. And I feel comfortable doing that.” And then he would let them know that he “disapproved” and explained that “the reason we don’t want that is because it can easily go down the wrong way.”

Morgan said that in attempt to prevent errors made by the support staff that negatively impact patient adherence and increase aspiration risk, her facility employed “task lists” that

catalogued which patients were on prescribed modified diets. They took this “preventative” step but still, “sometimes mistakes are made.” She said that when someone sees a mistake like that being made, they attempt to talk to the nurses and “informally educate” them about dysphagia and aspiration, as well as “post the information in all the correct locations.” She elaborated

It’s a long-standing issue in this type of setting. I’ve worked at a different long-term care setting and the same issue is present at all of those. And my colleagues who are at other long-term care settings... it’s just the battle that... and even in the hospitals. When I was in the hospital, you have that battle as well.”

Avery thought that medical professionals including physicians should have a better understanding of the swallow mechanism as well as the general role of the SLP. When asked how she felt that dysphagia outcomes could improve, she said, “If there’s anything I could change, it would be how do we help medical professionals who are new in the field, understand the complexities of oropharyngeal esophageal swallowing? And to understand that our role as speech pathologist is more related to oral and pharyngeal swallowing.”

Avery believed that the support staff in the treatment facilities could influence patients’ expectations about the SLP consultation before the initial interaction between SLP and patient. This could negatively impact rapport with the SLP from the onset. She was convinced that the support staff—and even novice physicians—would sometimes lead patients to believe that SLPs were “policing” their diets and “preventing them” from consuming the foods and drinks that they desired. Avery said, “I think sometimes they think of it as sort of a gate keeping. The speech-language pathologist will come see you and we’ll figure out what kind of diet you will be on.” She explained that her frustration with this perpetuation was that more often than not, she was being consulted because the patient likely had an abnormal swallow and needed to be downgraded in their diet and she would likely “recommend that they’re not eating.” However, in

the patients' eyes, "I just didn't let them eat. So, I'm the bad guy." She suggested that because of this, in a way, patients were being set up for disappointment before she even met with them. Avery suggested that nurses with more training, education, and/or experience were better at understanding what SLPs do as well as the reasoning behind the recommendations given. Since the nurses and patient aids interacted with the patients before she can meet with them, the patients would form these perspectives before they had been educated about the reasoning for the recommendations. She said,

Most of the time, people don't really know why I'm there. If I'm recommending that the patient be NPO, then I have to spend time discussing what that means, because a lot of times, people perceive that the SLP just needs to come in and then I can eat. And the nurses perpetuate that.

Personality Clashes

The SLPs interviewed had differing opinions as to whether their own personalities could sway a patient's choice to adhere to a treatment recommendation or not. Morgan felt strongly that "it doesn't have anything to do with me." Choosing to adhere to a professional recommendation was "the patient's own decision" and she said, "It's not on me." She described that the decision to go against medical recommendations was "based on whether or not they're thirsty, or if they are frustrated with the food options" more so than her personality. Dana, however, felt that the personality of the SLP had a direct impact on whether the patient chose to adhere to the recommendations given. She claimed, "I'm a pretty laid-back person, I'm not going to go in there and demand things." She described her strategy of building rapport as "more of the coddling and the coaching." She said, "They feel more open, and comfortable with talking to me about maneuvers, or about prognosis, or if things are going to get better or worse, or what's wrong." She illustrated how she might act with patients and their families saying that she

was “constantly giving hugs and going above and beyond.” In speaking of patient rapport, Dana felt, “You have to win them over.”

To achieve a good rapport with patients and their families, Avery explained that “you have to put your personal feelings and all of that outside the door.” She elaborated that often, there were family members “who can really rub you the wrong way” and could be “inappropriate” or say “inappropriate statements.” She described “As a younger clinician I think I might have probably bristled or had to change a facial expression or maybe I said something that was kind of arguing.” She went on, “You can’t ever argue. You just can’t.” She suggested that in order to maintain a good relationship with the patients and especially the families, clinicians needed to “come from their point of view” and recognize “they are scared.”

Thomas also suggested that SLP personalities could affect patient involvement in their treatment and intervention process. He felt that building rapport with the patients and families was important because better rapport meant that they would be “more comfortable asking questions” and opening up about their concerns. He stated that developing relationships took time and usually did not happen in the first visit: “You have to develop some rapport with them for a while.”

Provider Continuity

To further illustrate how significant a strong rapport was when interacting with patients, Dana explained that she and her colleagues would go as far as changing who the therapist for specific patients is because the patient-SLP relationship played such a large role in patient decision-making and outcomes. She reasoned, “There are always personality conflicts and not everyone is going to like you. But they might like so-and-so better than you.” She explained that a scenario like this has happened several times in her career. She said, “You’re not going to listen to me but you’re going to listen to my colleague? Let’s try this. And we’ve done that

quite a few times, we'll switch therapists." She claimed, "Even with the same recommendations," with a different SLP "we can see a difference in the patient's level of adherence." Avery has had the same experience. She said, "I've had, you know, a few patients who have fired me in the past. And then, you know, you get another SLP in there. Sometimes it's just personalities." Dana felt that if a patient "likes you,"

it makes therapy so much easier. It makes them want to work with you, it makes them so much more excited for speech therapy, it makes them excited to get better, it makes them adhere to our rules and our guidelines more, I mean, everybody's life is so much easier.

Gender, Ethnicity, Socioeconomics

Only one SLP identified the factors of gender, ethnicity, and socioeconomic status as likely variables that influenced patient adherence to dysphagia recommendation. Avery, who is a SLP with 35 years of experience working with adults with dysphagia felt that gender and ethnicity in combination with socioeconomic status were telling variables of how well a patient would adhere to her recommendations, and how well their families might support them.

Regarding gender, Avery stated, "They [women] seem to have a sense of 'ok this is where we're at. I get it, I understand it.' Where men tend to be a little behind." Regarding ethnicity and gender in combination, Avery said,

I work with people who are Caucasian who are low socioeconomic status, and then African American people who are low socioeconomic status. I still feel like there's something about African American women that is more... even if they come from that.. maybe they're just raised from birth to have a better sense of how to take care of people and... it seems to be more realistic... and more accepting.

At one point in the interview, Avery seemed to suggest that people who come from different cultural backgrounds may tend to have less of an understanding of "health literacy."

She said, “I’ll be honest, I’m still finding that people coming from other cultures where I’m probably having to work through an interpreter, do not have good health literacy. Even through an interpreter, [they] just don’t understand what I’m talking about.” She explained that language was not necessarily the barrier here, as supported by her attempts to mitigate disintegration. She said, “Even when I use pictures and diagrams, a head and neck model, they just don’t understand. I don’t know how to get around that.” Avery injected a disclaimer that “there are always exceptions.” She speculated, “If I’m working with someone who is Asian who came from... you know, a big city, [and] they have a good education, I’m not necessarily finding a problem. I truly think it has to do with socio-economic status.”

The other four participants did not spontaneously mention gender, ethnic background/culture, or socioeconomic status in their interviews. When Morgan was asked directly if she thought that education level of the patient contributed at all to adherence, she said, “Not necessarily. We see very educated people here because of the university community. And we also see some not highly educated people. And I’ve had adherence and dis-adherence on both ends of that spectrum.”

Chapter 4: Analysis

Introduction

The speech-language pathologists in this study identified factors that they perceived to influence patient adherence to dysphagia recommendations. The themes identified within the data:

- SLP education for patient and family,
- respect for patient decisions,
- SLP understanding of barriers to patient adherence to dysphagia recommendations,
- “family buy-in,”
- multidisciplinary influence on dysphagia recommendations,
- personality clashes,
- provider continuity

These findings suggested that SLP’s perceived that relationships with the patients and families, the interactions of the hospital staff (nurses and patient aids), and the SLP’s individual and idiosyncratic personalities were areas that SLPs perceived as factors affecting patient adherence to prescribed diet texture modifications. The discussions surrounding these subjects, perhaps unsurprisingly, were not unanimous. Additionally, while the SLPs in this study generally expressed reluctance to admit to any responsibility in low rates of patient adherence, they acknowledged that respect for the patients’ right to disregard medical recommendations, family support of the recommendations and treatment plans, and the degree of education provided to the patients and their families all affected patient adherence to dysphagia recommendations.

Speech-Language Pathologist Provided Education for Patient and Family

The SLPs in this study felt that educating the patient and family or loved ones about the swallowing disorder and the recommendations were essential for adequate adherence and positive outcomes. Dana indicated the significance of educating: “So they can see how scary, life threatening, dangerous it can be not to adhere to our guidelines and recommendations.” Thomas expressed that he would be “very open” in communicating his disapproval of when a patient did not adhere to his recommendations. Morgan described that in scenarios where the patient chooses to go against recommendations: “They have to sign off that they understand the risks.” Dana, Pat, and Thomas revealed that they use the same practice at their respective places of employment.

Respect for Patients’ Decisions

A systematic review of the interview data revealed that SLPs in this study had varying beliefs on how extensively to “push” when educating patients and their families regarding what the most beneficial method of intervention would be given their dysphagic conditions. Pat felt that patient adherence to medical recommendations was not a black and white subject. He stated, “There’s a lot of things we need to think about... it’s respectful to let them choose the path that they want.” He also suggested that because “everyone comes from a different frame of reference,” it was important to just “present the facts” and hope they understood the benefits of adherence to the prescriptions. Dana felt that regardless of if patients or their families understood the benefits of adherence, since “food brings quality of life,” that families would break adherence because they were “choosing to make their loved one happy over the consequences of what might be.” Regarding how much she would choose to educate, she said, “I can educate until I’m blue in the face, but they’re going to do what they’re going to do behind closed doors.” In the same vein, Thomas and Morgan felt that non-adherence to prescribed recommendations were inevitable. The SLPs described adherence to a modified diet as being

comparable to trying to lose weight, and that despite the knowledge of the benefits, simply stated, “It’s really hard.” Morgan also felt, “the patient has the right to refuse.”

Despite these beliefs, the SLPs felt that if patients and their families were knowledgeable about the disorder and the reasons behind the action being taken to resolve the health concerns, they were more likely to support patient adherence and become active participants of the intervention process. To achieve this end goal, SLPs often took it upon themselves to educate as much as they could in order to increase patient adherence.

Speech-Language Pathologists’ Understanding of Barriers to Adherence

The participating SLPs in this study revealed what they perceived to be barriers to patient adherence. One factor that was recognized as a barrier was the loss of the ability for patients to eat “whatever they want,” which could be interpreted as a potential threat to the patient’s perceived quality of life. The SLPs also felt that patients may anticipate the burdens of following the dietary change recommendations. Avery disclosed that she perceived barriers to patient adherence to be “access to a quick grocery” to easily access the required materials for adequate adherence and “if the patient had any income or family support to assist them throughout the intervention process.”

Other factors that the participants mentioned in the interviews as barriers to adherence included lack of adequate knowledge by either the patient, medical support staff, or patients’ families and loved ones; The SLPs in this study suggested they attempted to mitigate this barrier by educating as much as possible, and Dana and Morgan described their efforts as, “until I’m blue in the face.”

“Family Buy-In”

Regarding the involvement of loved ones in a patient’s treatment plan, Thomas felt that “the more involved, the better.” Dana described that she saw better adherence when she and the

patients' families were "all on the same page." Avery agreed, and said that compared to patients who had family involved in their intervention plans, patients who did not "languished."

A 2008 study that explored patient perceptions of their adherence to modified texture diets revealed that patients felt most confident in themselves to adequately adhere to their dysphagia recommendations when they had caregiver and family support. The SLP interview data in this study suggested that the SLPs felt that having family support, or "family buy-in," contributed to the likelihood that patients would adhere to their recommendations. Existing research on the relationship between social support and patient medical adherence suggested that these findings were aligned with the literature. The effects of "practical support"—which include regular reminders to take medication, assistance with purchasing materials needed, assistance with preparing appropriate diets, and transportation to and from medical visits—were discovered to be consistent with improved patient adherence (Scheurer, Choudhry, Swanton, Matlin, & Shrank, 2012).

Multidisciplinary Influence on Dysphagia Recommendations

There is little to no research regarding how one discipline of medical professionals could influence patient perception of another discipline of medical professionals, and these data are particularly lacking in the field of SLP. There is literature pertaining to general interprofessional conflict among health care providers. Shah (2017) stated, "Health care professionals, who understand each other's roles and can work effectively together, have been shown to provide higher quality care" (p. 44). According to Shah, "To achieve desire[d] outcomes in patient care, it is essential to have good interpersonal relationship[s] in terms of cooperation, collaboration, listen, and respect the values or positions of each other" (Shah, 2017).

The SLPs in this study expressed frustration due to the negative effects on patient adherence that resulted from interference by other health disciplines. The participants felt that

physicians, nurses, and patient aids—intentionally or not—interfered with the SLP’s ability to build rapport with the patients, sometimes even before they had the opportunity to meet in person. Avery felt that nurses or patient aids who did not fully understand the scope of the role of the SLP would give patients the “wrong impressions” regarding what she as the SLP would be doing for them, which resulted in patients having “bad feelings” toward SLPs. She expressed that often times, before she even had a chance to introduce herself and her role as a SLP to the patients and families, they were given the idea that she would be “policing” their diets. The findings of Shah’s research (2017) suggested that optimal patient care results when health care providers of differing roles understand the scope of practice of other health care professionals and are able to communicate among themselves effectively. In relation to the HBM, this is a clear example of an external cue to action having a negative affect—towards a cue supporting non-adherence to the SLP recommendation.

Personality Clashes

When discussing patient adherence to professional medical recommendations in all areas of medicine, the personality of the health care provider as an influential factor is an idea that has been considered, though not extensively researched (Kerse, et al., 2004; Kim, Kaplowitz, & Johnston, 2004). The relationship between health care providers and patients is not a factor that can be easily or accurately measured due to the complexity of human connections, and so published studies on the topic often rely on patient reported data in the form of surveys (Kerse et al., 2004). Published studies on the topic report that outcomes of health care including patient adherence are “directly related to the interpersonal communication between the patient and the provider and are particularly related to the physician’s empathic communicative behaviors” (Kim et al., 2004)

Dana, Avery, and Thomas all agreed that relationships between the SLPs and the patients and their families had an impactful role in patient adherence to dysphagia recommendations. Dana felt that if a patient “likes you,” better adherence and outcomes resulted than if there was a “personality clash.” Thomas felt that building rapport was important because it was an essential component in ensuring that patients and their families were “comfortable” and as a result would be more likely to “open up” about their questions and concerns. Avery suggested that in order to give adequate educational information about the condition and her recommendations to them, it was important to establish rapport and trust with the patients and the families. Kim (2004) reported, “The effective use of empathic communicative skills may be one of the best ways to improve patient satisfaction and patient compliance,” which, when juxtaposed with this study, was a direct implication of the effect of SLP personality on patient adherence.

Provider Continuity

Another variable that was presented in the literature as significant for patient adherence was *provider continuity*,--or having the same medical care provider throughout the course of medical care (Kerse et al, 2004). A study on the effect of number of health care providers on medication refill adherence revealed that patients with just one consistent health care provider exhibited statistically better adherence than patients who had multiple different providers (four or more providers; Hansen et al., 2015). Research also showed that according to patient reports, maintaining the same health care provider throughout the course of medical care was an important component of the patients’ perception of a “good experience” (Kerse et al, 2004). We could connect these findings of the study to the existing research on the impacts of medical provider qualities and patient compliance to medical regimens. In having maintained the same medical provider for a patient, Hansen and colleagues (2015) speculated that “seeing multiple providers without proper coordination introduces increased risk of overlapping or contradictory

health care.” In maintaining the same provider, the patient and provider have more opportunities to build “trust and rapport,” and this results in greater adherence/compliance to the recommended regimens—also supporting the finding that the personality of the clinician impacts patient adherence (Hansen et al., 2015; Kerse et al., 2004).

There was a finding in this research that did not support the aspect of provider continuity in the literature regarding patient adherence. Dana explained in her interview that one tactic that she and her colleagues sometimes used to build stronger connections with the patients was to change the SLP on specific cases. She felt that sometimes, changing the health care provider for a particular patient was an easy way to establish rapport when it appeared that the personality of the patient and the personality of the SLP assigned to the case “clashed” enough to interfere with effective intervention. However, it appears that the SLP intentions for changing the SLP on the case—thus disrupting provider continuity—could be rationalized by the intention to optimize the provider-patient relationship and ultimately improve patient adherence. It would also appear that in Dana’s case, although the patient saw multiple SLPs, only one SLP would be the designated “health care provider” and the same provider would be maintained after a “personality match” was established. The other SLPs in the study did not identify intentionally changing care providers as a factor that they perceived as potentially affecting patient adherence. Avery described instances in her past when she had been fired by patients, and said, “You get another SLP in there. Sometimes it’s just personalities.” These episodes that Avery described support the notion that personality clashes have significance in therapeutic practice.

Chapter 5: Discussion

Data Alignment with the Health Belief Model

The HBM was founded on the belief that an individual's behaviors and actions in regard to their health are based on the ultimate goal of achieving good health (Glanz, Rimer, Viswanath, & Orleans, 2008; Rosenstock, 1988; Thompson, 2014). The model was segmented into the constructs of the individual's perceived severity of the condition, perceived benefits of the health action, perceived self-efficacy to perform the action, perceived barriers against achieving the goal of good health, and cues to action. (Clark & Becker, 1998; Glanz et al., 2008; Katatatsky, 1977; Thompson, 2014). For the analysis of these data, the HBM was used as a framework by which to view the factors that the SLPs in this study revealed to be influential factors in patient adherence to dysphagia recommendations. The themes that emerged from the data were placed into categories that corresponded with the constructions of the HBM in order to better understand their implications in therapeutic practice. Table 2 outlines suggestions for practical application in therapeutic practice.

Table 2
Suggestions for Practical Application

Health Belief Model construct	Corresponding theme(s) from data	SLP application	Examples of practical application
Perceived threat of the condition	SLP provided education for patient and family	<ul style="list-style-type: none"> • SLPs should educate patients and families about the consequences of non-adherence to their dysphagia recommendations 	<ul style="list-style-type: none"> • Provide informational pamphlets on the incidence, significance, and consequences of non-adherence and resulting complications
Perceived benefit of following SLP recommendations	Respect for patients' decisions	<ul style="list-style-type: none"> • SLPs should educate more on positive effects and long-term health benefits of adherence to their dysphagia recommendations 	<ul style="list-style-type: none"> • Keep patients and families accountable for their adherence to their dysphagia recommendations • Recognize adequate adherence and offer an incentive to continue following recommendations
Perceived barriers to adherence	"Family buy-in"	<ul style="list-style-type: none"> • SLPs should educate family on how to be active participants in the intervention process 	<ul style="list-style-type: none"> • Explain how important it is in the treatment process to maintain the strict dietary recommendations to discourage family bringing in "forbidden" food and drinks
Perceived self-efficacy	SLP anticipation of barriers to adherence	<ul style="list-style-type: none"> • SLPs should anticipate the barriers to adherence for each individual patient and tailor the education provided to the patient 	Ask direct or indirect questions to determine if the patient: <ul style="list-style-type: none"> • Has adequate income/ financial support for the treatment plan in place • Is literate • Has access to a grocery store or pharmacy • Has transportation for medical appointments
		<ul style="list-style-type: none"> • SLPs should spend time providing practical, hands-on education to patients and their families regarding preparing food and beverage items corresponding to the patient's modified texture diet 	<ul style="list-style-type: none"> • Provide lists of foods that apply to specific food textures • Give simple recipes for patients and families to use and modify
Cues to action	Multidisciplinary influence on dysphagia recommendations	<ul style="list-style-type: none"> • SLPs should educate treatment facility staff on the role of SLP to prevent misinformation in multidisciplinary interactions with patients and their families 	<ul style="list-style-type: none"> • Offer a workshop for members of multidisciplinary team that educates regarding each discipline's scope of practice and examples of common practical applications
	Personality clashes	<ul style="list-style-type: none"> • <i>More research needed</i> 	<ul style="list-style-type: none"> • Offer CEUs for SLPs in the field regarding the significance of personal/ working compatibility with patients • Develop systems that allow resolution, or suggest solutions for instances of "personality clashes"
	Provider continuity	<ul style="list-style-type: none"> • Change the SLP that is working with a patient in instances of incompatibility to promote better personality match when possible • Maintain the same SLP assigned to a patient throughout the course of treatment 	<ul style="list-style-type: none"> • Develop systems that promote compatibility matching SLPs with patients

HBM Construct: Perceived Threat of the Condition

The founders of the HBM defined patient perception of “threat” as the combination of his or her perception of the severity of the condition and his or her perceived susceptibility of the condition (Rosenstock et al., 1988). The current literature on the subject suggests there is a positive correlation of patient adherence and patient education from medical care providers (Jones et al., 2014). Research also supports that the most commonly used technique to improve patient adherence is educating patients about the consequences of poor health decisions (Jones et al., 2014).

SLP provided education for patient and family. A recurring topic that within the study data was regarding the education of patients and their families. All SLPs interviewed spoke about the importance of educating not only the patients, but also the loved ones involved in intervention. “Family buy-in” was a topic that arose multiple times in the data, and the SLPs felt that the more involved, or “on board,” families were, the easier and more likely the patient would be to adhere to the intervention plan. This was especially true for patients with cognitive deficiencies; Dana, Avery, and Thomas all mentioned that many patients with dysphagia have comorbidities that have already taken a toll on their executive functioning skills, and so the SLPs felt that education of family members could be more important than educating the patient.

The topic of SLP provided education may fall into several different constructs of the HBM. It may apply to self-efficacy, perceived severity, perceived benefit, or external cues to action. The knowledge that SLPs possess is shared through communication; therefore, SLPs need to be highly conscientious of the messages they communicate. If the SLP communicated to the patient more messages of support, more effective resources—and invested the time to answer any questions, the patient may be inclined to a higher self-efficacy for adherence following that open line of communication (Jones et al., 2014). If SLPs spent a greater amount of time

informing the patient and family about what risks may result of non-adherence as well as the benefits of proper adherence, the patient's perception of severity, threat, and benefit would increase, altogether increasing the likelihood of adherence (Jones et al., 2014). If the SLP communicated messages such as "disapproval" for non-adherence or understanding the patient's decision to choose a different plan, the patient may receive external cues to action that would sway them towards or away from adherence, respectively. If the SLP communicated positive messages of reinforcement in instances of adequate adherence, the patient may be more motivated to continue to adhere to recommendations. SLPs must recognize the significance of the messages they communicate to patients and their families in order to maximize the potential for patient adherence they have influence over.

HBM Construct: Perceived Benefit of Following SLP Recommendations

A study conducted by the Institute for Social Research at the University of Michigan (Singer et al., 2014) that investigated patient reasoning behind medical decision making suggested that the factors that patients deem as "important" reflected a "subjective weighing" of risks versus benefits, and could be used to predict whether the health behavior was completed or not, regardless of how "well informed" the patient was (Singer et al., 2014). The greater the difference between the importance[s] attached to [the] benefits and costs [is], the greater patient's confidence in their decision [is]" (p. 12). Singer (2014) suggested that the relationship between the value placed on costs or benefits was predictive of the individual's confidence in their decisions.

Respect for patients' decisions. The participants felt that "patients have the right to refuse" treatment if the recommendations did not align with what they perceived to promote their quality of life. The SLPs interviewed felt that every individual patient possesses a unique perception about what would enhance or interfere with his or her perceived quality of life.

Interestingly, the study data also suggested that patients and their families tended to focus less on the long-term benefits of adherence and more on the short-term costs of adherence. If SLPs spent time educating patients and their families about the benefits of adequate adherence of the recommended treatment plan, and the subsequent health benefits that would follow, perhaps patients would place a higher value on the long-term benefits of adequate adherence. While maintaining respect for the individual's perceived quality of life, as health care professionals and experts in dysphagia, it is important for SLPs to implement and share the knowledge they possess on the lasting effects that patient decisions have on their health.

HBM Construct: Perceived Barriers to Adherence

A comparison of the existing literature regarding barriers to adherence of the thickened liquid diet, or modified texture of diet (pureed, chopped, or mashed food), and the data for this research revealed that there is a gap in the factors that patients report as being barriers to adherence, and factors that SLPs considered as being the most influential barriers to adherence. Published literature on patient perceived barriers to adherence suggested that patients reported lack of “really understanding” their condition—as well as not understanding the purpose of the recommendations given as contributing to barriers of adherence to prescribed dysphagia treatments (McCurtin et al., 2018). The literature also suggested that “unpleasant experiences” after first following the prescribed diet changes were a barrier to adherence (McCurtin et al., 2018). These experiences included “disagreeable” taste of food and beverages, unexpected and “unfavorable” textures, and the feeling of “unquenched thirst” (Garcia et al., 2005; McCurtin et al., 2018; Potts, 2008; Rosenvinge & Starke, 2005). Other patient reported barriers to adherence to diet change recommendations included difficulty of the task and general fatigue (Krekeler et al., 2018; Rosenvinge & Starke, 2005).

“Family buy-in.” Although the SLPs in this study felt that family support was a positive contribute to patient adherence, it is important to also acknowledge the negative impact that family involvement can have on patient adherence in order to fully grasp the potential that SLPs have to improve patient adherence to dysphagia recommendations. While the positive contributions of “family buy-in” and “practical support” are not disqualified, SLPs should recognize that family members can be major players in non-adherence to SLP recommendations if there is a lack of comprehension or agreement with the treatment plan. The data revealed that the SLPs in this study often experienced patient non-adherence due to instigation or enablement by family members, sometimes in cases when the patient intended to be adherent to the recommendations. Family members and loved ones often have a highly influential role for patients who are experiencing illness or trauma, and so SLPs and health care providers should be aware of the potential to improve patient adherence through that influence.

SLPs should not only educate family about the consequences of poor health behaviors or non-adherence but enlist family and loved ones in the implementation of the treatment plan. The notion of “practical support” should be amplified and families should be made aware of the positive impact that they have the potential to make on their loved one’s health and outcomes. By doing so, SLPs can work to eliminate the potential barrier to adherence, while also increasing the likelihood of patient self-efficacy and the family’s knowledge about the disorder and treatment plan.

HBM Construct: Perceived Self-Efficacy

Self-efficacy in relation to the HBM refers to the patient’s expectation or confidence of how adequately he or she will be able to achieve the health behavior (Glanz et al., 2008). A

2009 study of health beliefs and patient self-care in diabetes revealed that “greater self-efficacy may contribute to perceptions of better treatment effectiveness” (Harvey & Lawson, 2009).

Bishop and colleagues defined self-efficacy as “the preventability of the error and the effectiveness of patient actions” (2015).

SLP perception and anticipation of barriers to adherence. The SLPs in this study revealed that factors that they considered to be barriers to patient adherence included the following:

- financial status,
- patient perceived quality of life (i.e., “choosing to make their loved ones happy over the consequences of what might be”),
- access to a quick grocery,
- literacy level,
- understanding of the disorder.

A review of the literature suggested that there is a gap between what SLPs perceive to be barriers to patient adherence and what patients perceive to be barriers to adherence. One area that overlaps between the two is the aspect of patient understanding of the disorder and treatment (McCurtin et al., 2018). SLPs have the potential to mitigate patient non-comprehension in order to increase patient self-efficacy and subsequently, adherence and outcomes. A suggestion for improvement in SLP is practical, hands-on, and patient-specific education about how to adequately adhere to the prescribed texture modification recommendations. Doing so will increase patient and family knowledge about dysphagia on a practical level, and therefore increase patient and family self-efficacy to adhere to the recommendations.

Rosenvinge and Starke (2005) published a study that reported that the most common reason for patient non-adherence to a thickened liquid recommendation was inappropriate and

incorrect preparation of the thickened liquids by hospital staff and/or domestic caregivers. The study revealed that after intervention—in which SLPs led education sessions for patients, domestic caregivers, and essential hospital staff of appropriate dysphagia management—there was no significant improvement in patient adherence to thickened liquid recommendations (Rosenvinge & Starke, 2005). Although this finding was discouraging and offered a contradiction to the practical application offered, it should be noted that there is room for improvement and growth in the field of SLP and in the subject of patient adherence. The findings of Rosenvinge's (2005) study encourages more research on patient and family education and practical knowledge. Perhaps SLPs need to improve or discover alternate methods of teaching patients with dysphagia and their families how to adequately adhere to the recommendation of modified texture and thickened liquid diets in order to improve patient self-efficacy, adherence, and outcomes.

HBM Construct: Cues to Action

Cues to action are additional motivations to act that the individual may experience. They could include “internal cues such as physical discomfort or changes in bodily functions that motivate the individual to seek treatment or a prevention of worse problems,” and they can also be external motivations such that the individual receives a message that is either positive or negative about the health outcome from another individual or media source (Carpenter, 2010; Katatatsky, 1977; Thompson, 2014). The data of this research revealed the following themes that SLPs have the potential to influence regarding cues to action, when correlated to the HBM:

- multidisciplinary influence on dysphagia recommendations,
- personality clashes,
- provider continuity.

Multidisciplinary influence on dysphagia recommendations. A finding of this research was that SLPs often observed and were frustrated by patients not adhering to their prescribed dysphagia recommendations as the result of support staff—often consisting of trained nurses and patient aids—unknowingly distributing the wrong texture of food and beverage to patients. When speaking about the errors, Morgan described it as “a long-standing issue.” Regarding preventative measures taken to eliminate staff errors, it appeared that even after the appropriate notes and documentation were made in their designated places, the support staff would frequently overlook them and administer a food or beverage consistency that could put the patient at risk for aspiration. This posed the question, were the mistakes made because staff did not receive adequate training and education regarding aspiration risk, or were they due to honest and unavoidable human error? In the scenario that the former was true, SLPs may be held responsible for providing the educational information to adequately inform treatment facility staff of the risks of aspiration, as well as the significance of the dangers of aspiration pneumonia to comorbidly ill patients. If SLPs can recognize their potential to make a difference in the day-to-day happenings within the treatment facilities, for example, during mealtimes when staff are distributing food and beverages to patients throughout the facility, there is potential to positively impact patient adherence.

Personality clashes. Regarding personal relationships with patients—or rapport—some of the SLPs interviewed felt they were significant in the patients’ decisions to adhere to the dysphagia recommendations or not. The SLPs who felt that building rapport with the patients and their families was significant recognized that their relationship with the patient and family could be a cue to action, consistent with the HBM. For those SLPs, it was important to establish “trust” between themselves and the patients in order to increase the likelihood that their recommendations would be adhered to.

There were SLPs in this study who felt that their personalities had nothing to do with whether or not a patient chose to adhere to the dysphagia recommendations. Based on the evidential findings, it could be stipulated that while SLP personalities may not have a direct influence on patient adherence, they may have a direct connection to how patients perceive the communication they have with their SLP. Kim (2004) suggested that outcomes of health care—including patient adherence—are “directly related to the interpersonal communication between the patient and the provider and are particularly related to the physician’s empathic communicative behaviors.”

Given the findings in the literature and study data, it appears that SLPs are not on the same page about how their demeanor towards the patient may affect patient perceptions of factors such as the quality of communication, or how patients perceive empathy. The phenomena of human connection is difficult to report and quantify, so research is lacking that explains how SLP personalities versus the patients’ personalities can affect treatment adherence and outcomes (Kerse et al., 2004). SLPs may have the potential to influence patient adherence as well as the overall patient perspective of the health care experience by being more conscientious about their interactions with them. As a profession, SLPs need to understand that there are qualities that they portray beyond raw evaluation and treatment that effect the outcomes of their therapeutic practice.

Provider continuity. Regarding provider continuity, the literature suggested that maintaining the same provider for a single patient throughout the course of his or her treatment process increased the likelihood that the patient would perceive his or her health care experience as a positive one (Hansen et al., 2015; Kerse et al., 2004). The nature of speech and language therapy as it currently stands already utilizes the model of using a single SLP per patient throughout the patient’s therapy experience. However, if SLPs are made aware of the positive

impacts on patient adherence that this one-to-one model can have, they can be more mindful of it and use it to further implement a patient-centered-care philosophy.

The data suggested that the SLPs agreed that in the scenario that a patient and SLP were not personally compatible, sometimes, the best option was to alter the SLP assigned to the case in order to facilitate the best possible relationship between patient and provider. Although this behavior directly contradicts the aforementioned notion that maintaining the same health care provider throughout the course of treatment is better for patient adherence, it was determined in the analysis of the data that the SLPs acted with the intention to enhance patient adherence and outcomes. If SLPs are aware of both the effects of using a one-to-one provider-to-patient model, as well as the benefits of a compatible match between provider and patient, SLPs may be able to use better discretion in their therapeutic practice to improve patient adherence and outcomes.

“Effective Communication Enhances Adherence”

Starting in the 1980s, the medical model, the traditional way of thinking that was best described as suggesting the connotation of a “paternalistic relationship” between the medical care provider and the patient has been replaced with other models such as biopsychosocial models and behavior-change models such as the health belief model (Haskard, Zolnieriek, & DiMatteo, 2009). The new models have taken favor in the health care community because they place an “emphasis on treating the patient as a whole person, including the biological, psychological, behavioral, and social aspects of their health” (Haskard, 2009). Currently, instruction in the medical training incorporates this new school of thought, partnering the patient with the medical caregivers to enhance the processes of patient evaluation, diagnosis, and intervention.

It was noted that participants often used the term “compliance” when describing their experiences working with adult patients with dysphagia. Avery was the only participant who

maintained use of the term, "adherence" throughout her interview. The use of verbiage utilized throughout the interviews suggested that the SLPs maintained the "old way" of medical model thinking. Thomas used the term "disapprove" to describe his take on patient decisions to go against recommendations. Pat demonstrated his paternalistic view when he said, "I think they (patients) should do what I say," and, "I went to school for this so of course I know best."

Haskard and colleagues (2009) suggested that the specific use of language in describing these processes is significant because "communication contributes to patients' understanding illness and the risks and benefits of treatment. Support, empathy, and understanding, collaborative partnerships, and patient-centered interviewing, require effective communication and enhance adherence." If SLPs are not mindfully applying this new knowledge, they are demonstrating that they do not understand or agree with the implications that communication can have on patient adherence, and ultimately, the patient's health and wellbeing.

Limitations and Delimitations of the Study

The purpose of this study was to investigate speech-language pathologists' perceptions of their influence over patient adherence—specifically to the common recommendation given to dysphagia patients, the modified texture of diet and thickened liquids. It was hoped that exploration of SLP perspectives would identify common perceptions of themselves in relation to the patients' decisions to adhere or not adhere to the SLP recommendations for dysphagia intervention.

A delimitation of this research lies in the foundation of the health belief model. Because it is not a "communication model," the HBM does not offer guidelines for "persuasive message design" (Thompson, 2014). It specifies the constructs and variables that have a role in patient

decision-making, and formulae for predicting if an individual will perform the health behavior or not, but the HBM “does not clarify how to change the audience’s beliefs about these variables” (Thompson, 2014). The use of the HBM as a framework was also a limitation of the study. As it was established as a framework through which to analyze the data from the onset of the research, the findings drawn from the data may be biased.

A delimitation of the study was the lack of follow-up interviews with participants to inquire about their thoughts regarding the influence that demographic variables may have on patient adherence to dysphagia recommendations. In review of the data and the HBM, it is possible that modifying factors such as gender, ethnicity, and socioeconomic status may have a larger influence on patient adherence to dysphagia recommendations than was concluded in this study.

Another delimitation of this study was the narrow sample of SLPs that were interviewed for data collection. Due to time and budget constraints of this research, all participants were selected using a convenience sampling method and were SLPs who live and work in the greater Ann Arbor and Detroit areas. The study population may not be a representative sample of SLPs on a national level, so the findings of this research should be considered with caution. Further research with a larger population of SLPs is needed to examine the trends of SLP perceptions surrounding patient adherence to dysphagia recommendations.

Possibilities for Future Research

Future research that would add to the learned information from this study and benefit the field of speech-language pathology might include an exploration of how effective informational materials are, if specific modalities of education work better than others for dysphagia management and perhaps specifically, for lower level cognitive patients that largely make up the adult dysphagia patient population. Other possibilities for future research include an exploration

of how to most effectively educate medical staff in the areas of dysphagia and aspiration in order to apply the knowledge on a day-to-day basis.

Gender, ethnicity, socioeconomic status: Not influential factors? An interesting finding in this study was found in data that did not emerge as a common theme within the SLP interviews. Avery spoke in detail about how she perceived the modifying factors of gender, ethnic and cultural background, socioeconomic status, and level of education as often playing a role in how well a patient adhered to treatment recommendations. When Morgan was asked directly if she thought that education level of the patient contributed at all to adherence, she said, “Not necessarily.” The other participants did not acknowledge these modifying factors as significant markers for patient adherence. Since Dana, Thomas, and Pat were not directly asked if they thought that gender, ethnicity, or socioeconomic status affected patient adherence, the data presented here could not be applied as a theme for this study.

Although these data were not considered a theme in the findings, it is significant to consider the value that a patient’s demographic background may have in his or her treatment process. A patient’s cultural traditions may determine the schema followed by relatives in the treatment process. Additionally, gender roles within the community may affect how a patient responds to a health provider’s expression of empathy, thus altering the relationship between the SLP and patient. These and other possible correlations between modifying factors and the outcomes of therapeutic practice—though difficult to pinpoint—may have varying levels of influence in patient adherence and may need to be considered as having more significance in therapeutic practice; this may be a fruitful finding to be considered for future research.

Conclusions

If SLPs do not understand their potential to influence patient adherence, they are missing opportunities to improve patient comprehension and incidence of successful outcomes. The

findings of this research showed that SLPs perceived their potential to influence patient and family education, and other medical staff's knowledge of aspiration risk and the significance of aspiration pneumonia. The research successfully explored the participating SLPs' beliefs about the impacts that their behavior and demeanor toward the patient could make in influencing how the patient felt about his or her dysphagia and treatment recommendations and their decision to follow the recommendations or not.

The findings of this study in combination with the literature suggest that SLPs have the potential to influence patient adherence more than they may realize. Although the SLPs in this study recognized aspects of their influential reach, the themes that emerged in the data did not arise in a unified voice—but rather in the forms of opinions and comments about potential changes that should be made. SLPs have the potential to affect patient perception in the areas recognized by the HBM. Table 2 outlines the areas that could benefit from a change in SLP perspective are sensitivity to personal differences, education of support staff, and education of patients and their families.

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APPENDICES

Appendix A

Guiding Interview Questions

1. How comfortable or uncomfortable do you think patients (and loved ones) feel about expressing their concerns to you?
2. How often do you anticipate that patients will adequately adhere to your recommendations, and what factors do you take into consideration?
3. What aspects of your interactions with patients do you think influences their decision to follow your recommendations?
4. What is your role in communicating to/with the patients regarding
 - a. the severity of their condition
 - b. their vulnerability to poor outcomes
 - c. their willingness to assist patients in overcoming barriers to adherence

Appendix B
IRB Approval Letter

Jul 26, 2018 4:37 PM EDT

Charlene Shin
Eastern Michigan University, Special Education

Re: Exempt - Initial - UHSRC-FY17-18-294 How Do Speech-Language Pathologists Perceive Their Influence on Patient Adherence to Dysphagia Treatment Recommendations?

Dear Dr. Charlene Shin:

The Eastern Michigan University Human Subjects Review Committee has rendered the decision below for How Do Speech-Language Pathologists Perceive Their Influence on Patient Adherence to Dysphagia Treatment Recommendations?. You may begin your research.

Decision: Exempt

Selected Category: Category 2. Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless: (i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

Renewals: Exempt studies do not need to be renewed. When the project is completed, please contact human.subjects@emich.edu.

Modifications: Any plan to alter the study design or any study documents must be reviewed to determine if the Exempt decision changes. You must submit a modification request application in [Cayuse IRB](#) and await a decision prior to implementation.

Problems: Any deviations from the study protocol, unanticipated problems, adverse events, subject complaints, or other problems that may affect the risk to human subjects must be reported to the UHSRC. Complete an incident report in [Cayuse IRB](#).

Follow-up: Please contact the [UHSRC](#) when your project is complete.

Please contact human.subjects@emich.edu with any questions or concerns.

Sincerely,

Eastern Michigan University Human Subjects Review Committee

Appendix C
Informed Consent Form

RESEARCH @ EMU

Informed Consent Form

Project Title: How Do Speech-Language Pathologists Perceive Their Influence on Patient Adherence to Dysphagia Recommendations?

Principal Investigator: Charlene D. Shin, B.A., Eastern Michigan University

Co-Investigator: Sarah M. Ginsberg, Ed.D., CCC-SLP, Eastern Michigan University

Faculty Advisor: Sarah M. Ginsberg, Ed.D., CCC-SLP, Eastern Michigan University

Invitation to participate in research

You are invited to participate in a research study. In order to participate, you must be a current speech-language pathologist who has experience with adult dysphagic patients. Participation in research is voluntary. Please ask any questions you have about participation in this study.

Important information about this study

- The purpose of the study is to explore and identify the common perspectives of speech-language pathologists working with adult dysphagic patients regarding patient adherence to dysphagia recommendations.
- Participation in this study involves a 1 hour (approximate) face-to-face interview and a possible brief follow-up interview via phone call. The interview(s) will be audio recorded for analysis.
- There are no foreseen risks for participants in this study.
- The investigator will protect your confidentiality by coding and/or omission of all identifying information within the interview transcript and all subsequent documents. All documents containing participant information and interview data will be stored in password protected files in a locked room to which only the investigator and co-investigator will have access.
- Participation in this research is voluntary. You do not have to participate, and if you decide to participate, you can stop at any time.

What is this study about?

The purpose of the study is to explore and identify the common perspectives and thoughts of speech-language pathologists regarding patient adherence to dysphagia recommendations.

What will happen if I participate in this study?

Participation in this study involves

- Participation in this study involves a face-to-face interview.
- The interview will last approximately 1 hour and will take place at the location of the participant's choosing for convenience and confidentiality purposes.
- There is a possibility of a brief follow-up interview via phone call, pending analysis of the initial interview.

We would like to AUDIO record you for this study. If you are AUDIO recorded, it will be possible to identify you through your VOICE. If you agree to be AUDIO recorded, sign the appropriate line at the bottom of this form.

What are the expected risks for participation?

There are no expected physical or psychological risks to participation.

The primary risk of participation in this study is a potential loss of confidentiality.

Some of the interview questions are personal in nature and may make you feel uncomfortable. You do not have to answer any questions that make you uncomfortable or that you do not want to answer. If you are upset, please inform the investigator immediately.

Are there any benefits to participating?

You will not directly benefit from participating in this research.

Benefits to society include a contribution to the shared knowledgebase of speech-language pathology and related professionals regarding patient adherence.

How will my information be kept confidential?

We plan to publish the results of this study. We will not publish any information that can identify you.

We will keep your information confidential by using a code to label data with the code linked to identifiable information in a key stored separately from data. Your information will be stored in a password-protected file on a password-protected computer locked in a room to which only the investigator and co-investigator have access to.

We will make every effort to keep your information confidential, however, we cannot guarantee confidentiality. Other groups may have access to your research information for quality control or safety purposes. These groups include the University Human Subjects Review Committee, the Office of Research Development, the sponsor of the research, or federal and state agencies that oversee the review of research, including the Office for Human Research Protections and the Food and Drug Administration. The University Human Subjects Review Committee reviews research for the safety and protection of people who participate in research studies.

If, during your participation in this study, we have reason to believe that elder abuse or child abuse is occurring, or if we have reason to believe that you are at risk for being suicidal or otherwise harming yourself, we must report this to authorities as required by law. We will make

every effort to keep your research information confidential. However, it may be possible that we have to release your research information. If this were to occur, we would not be able to protect your confidentiality.

Storing study information for future use

We will not store your information to study in the future. Your information will be labeled with a code and not your name. Your information will be stored in a password-protected file.

We may share your information with other researchers without asking for your permission, but the shared information will never contain information that could identify you.

What are the alternatives to participation?

The alternative is not to participate.

Are there any costs to participation?

Participation will not cost you anything.

Will I be paid for participation?

You will not be paid to participate in this research study.

Study contact information

If you have any questions about the research, you can contact the Principal Investigator, Charlene D. Shin, at cshin2@emich.edu or by phone at (570) 460-6330. You can also contact Charlene Shin's adviser, Dr. Sarah M. Ginsberg, at sginsberg@emich.edu or by phone at (734) 487-2722.

For questions about your rights as a research subject, contact the Eastern Michigan University Human Subjects Review Committee at human.subjects@emich.edu or by phone at 734-487-3090.

Voluntary participation

Participation in this research study is your choice. You may refuse to participate at any time, even after signing this form, without repercussion. You may choose to leave the study at any time without repercussion. If you leave the study, the information you provided will be kept confidential. You may request, in writing, that your identifiable information be destroyed. However, we cannot destroy any information that has already been published.

Statement of Consent

I have read this form. I have had an opportunity to ask questions and am satisfied with the answers I received. I give my consent to participate in this research study.

Signatures

Name of Subject

Signature of Subject

Date

I have explained the research to the subject and answered all his/her questions. I will give a copy of the signed consent form to the subject.

Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date