Dysphagic patient compliance with thickened liquid recommendations

Carrie Potts

Follow this and additional works at: http://commons.emich.edu/theses

Part of the Speech Pathology and Audiology Commons

Recommended Citation
http://commons.emich.edu/theses/195
Dysphagic Patient Compliance with Thickened Liquid Recommendations

by

Carrie Potts

Thesis

Submitted to the Department of Special Education

Eastern Michigan University

in partial fulfillment of the requirements

for the degree of

MASTER OF ARTS

in

Speech-Language Pathology

Thesis Committee:

Sarah M. Ginsberg, Ed.D., CCC-SLP, Chair

Willie P. Cupples, Ph.D., CCC-SLP

Flora Hoodin, Ph.D.

July 1, 2008

Ypsilanti, Michigan
DEDICATION

To my grandfather, Dr. William F. Sager, my first teacher
ACKNOWLEDGMENTS

This work would not have been possible without the support of several sources. First, I would like to thank the members of my committee for all of their time spent in guiding me through my research activities and providing with me invaluable feedback throughout the various stages of this process. I would especially like to thank the Chair of my committee, Dr. Sarah M. Ginsberg, for being not only a wonderful mentor, but a friend as well.

Secondly, special thanks go out to all of the hospital staff members that agreed to participate in this research for their efforts in identifying and referring patients to this study. This study never would have happened without you!

Finally, I would like to acknowledge The American Speech-Language-Hearing Association for their support of this study through the 2006-2007 Students Preparing for Academic and Research Careers (SPARC) Award.
ABSTRACT

In light of the growing prevalence of dysphagic patients on Speech-Language Pathologists’ caseloads and the frequent prescription of thickened liquids as a treatment strategy (Garcia, Chambers & Molander, 2005; Low, Wyles, Wilkinson & Sainsbury, 2001; Robbins, Nicosia, Hind, Gill, Blanco, & Logemann, 2002), our limited understanding of the factors that contribute to patient adherence presents a significant challenge to the management of dysphagia. The purpose of this qualitative study was to better understand the decisions patients make regarding dysphagia recommendations. Drawing upon adherence/compliance research from the field of behavioral medicine, the results of this study revealed a complex interplay of factors that lead to dysphagic patient adherence (or non-adherence) with thickened liquid recommendations. Finally, the data suggest directions for future research and potential clinical implications for improving patient adherence.
TABLE OF CONTENTS

Dedication........................................................................................................................ii

Acknowledgements..........................................................................................................iii

Abstract............................................................................................................................iv

Chapter 1: Introduction....................................................................................................1

  Background Information, Problem Statement, Justification, and Significance...1

  Theoretical Framework...........................................................................................4

  Purpose of the Study ............................................................................................7

  Research Questions............................................................................................8

Chapter 2: Review of Literature......................................................................................9

Chapter 3: Methods..........................................................................................................12

Chapter 4: Presentation and Analysis of Data .................................................................16

  Perceived Susceptibility.......................................................................................16

  Perceived Severity...............................................................................................17

  Perceived Benefits and Barriers to Action...........................................................19

  Cues to Action......................................................................................................21

  Self-Efficacy Expectations...................................................................................23

  Patient-Generated Strategies................................................................................24

Chapter 5: Conclusions....................................................................................................25

  Summary of Results.............................................................................................25

  Inferences and Potential Clinical Implications ....................................................26

  Limitations/Delimitations of the Study.................................................................30
LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Constructs of the Health Belief Model</td>
</tr>
<tr>
<td>2</td>
<td>Demographic Characteristics of Patients</td>
</tr>
<tr>
<td>3</td>
<td>Constructs of the Health Belief Model with Applications from the Data</td>
</tr>
</tbody>
</table>

LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The Health Belief Model of Behavioral Medicine</td>
</tr>
</tbody>
</table>
Chapter 1: Introduction

Background Information, Problem Statement, Justification, and Significance

Dysphagia is a medical term used to describe difficulty with swallowing. In adults, dysphagia is typically associated with neurologic diseases such as cerebrovascular accidents (strokes) and Parkinson’s disease (Logemann, 1994). It has been estimated that 50% of patients experience dysphagia immediately following strokes alone (Parker, Power, Hamdy, Bowen, Tyrrell & Thompson, 2004). Dysphagia affects 68% of patients in extended care facilities and as many as 30% of elderly patients admitted to acute care hospitals (Rosenvinge & Starke, 2005). A 2001 American Speech-Language-Hearing Association (ASHA) Omnibus Survey found that 100% of Speech-Language Pathologists (SLPs) in residential health care settings and 92% of SLPs in hospitals were involved in the diagnosis and treatment of dysphagia.

Among the most common forms of treatment for dysphagia is the use of thickened liquids and other dietary modifications. When thickened liquids are recommended for a patient’s diet, it suggests that the patient is at risk for normal fluids, such as juice, coffee, or tea entering the trachea and potentially proceeding to the lungs. This event is referred to as aspiration. In patients whose health is already compromised and may be aspirating chronically, aspiration episodes may lead to pneumonia and death due to pneumonia. Normal drinking liquids are thickened most commonly by adding corn-starch-based powders to hot or cold drinks in order to obtain a higher viscosity of the liquid. This higher viscosity is intended to slow the movement of the drink, making it easier to control for patients who have oropharyngeal dysfunction, delays in the initiation
of the pharyngeal phase of the swallow, or compromised protection of the airway. The practice of thickening liquids is intended to promote a higher level of patient quality of life as well as to maintain adequate hydration. By allowing patients to continue receiving oral-intake rather than non-oral alternatives, it is believed that patients will be more emotionally and socially satisfied as the intake of food and drink is commonly important to patient quality of life (Garcia, Chambers & Molander, 2005).

In a recent study of the practice patterns of SLPs who are routinely involved in dysphagia management, 84% indicated that the use of thickened liquids is an effective strategy for treating dysphagia (Garcia et al., 2005). In this same study, 26% reported recommending thickened liquids for 26-50% of their patients and 23% reported recommending thickened liquids for 51-75% of their patients. In a related study of dysphagia practices, Low, Wyles, Wilkinson & Sainsbury (2001) found that SLPs recommended modifications of fluids to 59% of their patients and modifications of food to 93% of their patients.

The body of dysphagia literature in the field of Speech-Language Pathology frequently uses the term “compliance” to describe a patient’s ability to follow through with a recommendation. In other bodies of literature, however, particularly those in the field of behavioral medicine, the term “compliance” has fallen into disfavor (Miller & Hays, 2000). According to the authors:

Compliance connotes a paternalistic relationship between the physician and patient and that the noncompliant patient performs deviant behavior or exhibits weakness of character. "Adherence" better represents the more complex web
among patient, provider, and medication and reflects the fact that following a medication regimen is not necessarily a simple choice. (176)

In order to capture the complexity of health-related decisions and actions, there is a need within the field of Speech-Language Pathology to change the preferred terminology when describing patient behaviors. Toward this end, the terms “compliance” and “noncompliance” have been changed to “adherence” and “non-adherence,” respectively, to designate patient behaviors as they have been described by Speech-Language Pathologists in the past. Use of the term “adherence” will hopefully facilitate the clinical recognition of the complexity of this phenomenon and the need to implement strategies towards its improvement.

Patient non-adherence with dietary recommendations presents a significant barrier to the management of dysphagia. Research indicates that as few as 36% of patients with dysphagia recommendations adhere to those recommendations (Leiter & Windsor, 1996). Studies of adherence patterns have shown that thickened liquids are the least likely recommendations to be adhered to (Low et al., 2001). Nonetheless, prescribing thickened liquids was described in 2002 as “one of the most frequently used compensatory interventions in hospitals and long-term care facilities” (Robbins, Nicosia, Hind, Gill, Blanco, & Logemann, 2002).

The common practice of recommending thickened liquids despite our growing awareness of low patient adherence is most troubling in light of the dangers of non-adherence to the patient. Patients are commonly discharged from hospital settings with recommendations of the use of thickening agents as the primary method of managing their dysphagia (Garcia et al., 2005; Low et al., 2001; Robbins et al., 2002) despite the
significant reporting of patient dissatisfaction with this modification. The consequences of non-adherence with dysphagia recommendations include aspiration pneumonia, dehydration, weight loss, readmission to the hospital and death (Low et al, 2001).

At this time, much of what we know regarding dysphagic patient adherence is statistical/correlational and is focused on patients residing within institutional settings, such as hospitals and nursing homes. Little has been done thus far to investigate what alternatives patients pursue when they choose not to adhere to their thickened liquid recommendations and what factors influence their decisions. Research is needed to help speech-language pathologists appreciate and understand the factors that contribute to patient adherence to dysphagia dietary recommendations. Increased awareness of these issues may help therapists create more effective treatment regimens and understand how they can influence the decisions their patients make. This study contributed to meeting this need by examining the health behaviors of four dysphagic patients in order to identify factors that influenced their adherence to thickened liquid recommendations.

*Theoretical Framework*

The field of behavioral medicine has increasingly recognized the wide-spread phenomenon of non-adherence. Research has shown that recommended changes in habitual behaviors, including dietary modifications, are even less frequently adhered to than medication regimens and scheduled appointments for treatment (Clark & Becker, 1998). Moreover, studies of health behavior emphasize the consequences of poor adherence to medical recommendations, including increased cost, morbidity, and the skewing of therapeutic efficacy research (Dunbar-Jacob, Burke, & Puczynski, 1995).
Measures taken to increase patient adherence continually stress the importance of identifying factors affecting adherence. These include, but are not limited to, continuity of care, the patient’s beliefs about the seriousness of the condition, the patient’s beliefs about his or her ability to carry out the treatment regimen, and the quality of the relationship between the patient and the health care provider (Meichenbaum & Turk, 1987). The intrusiveness, duration, frequency, and complexity of the recommendation also contribute to patient adherence. The more disruptive the regimen to the patient's lifestyle, the longer the patient is expected to adhere, the more often in a day the patient is expected to do something, and the more steps involved in the recommendation, the greater the concern for adherence (Levensky, 2005).

In the 1950s, social psychologists developed the Health Belief Model to attempt to explain and predict health behaviors (Glanz, Lewis, & Rimer, 1997; University of Twente, 2004; see Figure 1). The model was originally developed in response to the failure of a free tuberculosis screening program but has since been adapted to explain a diverse body of health-related behaviors (Glanz et al., 1997).
The Health Belief Model is based on the understanding that health behaviors are related to the desire to avoid an illness (or get well if ill) and the belief that a specific health action will prevent that illness (or improve the condition; Clark & Becker, 1998; Glanz et al., 1997, University of Twente, 2004). It is explained in terms of several constructs, including the individual’s perceived susceptibility to the condition; the perceived severity of the condition; the perceived benefits of the health action, or the individual’s belief in the efficacy of the action; perceived barriers, or the individual’s beliefs about the tangible and psychological costs of a health behavior; and cues to action, or factors such as education and media information, that motivate a person to act (Clark & Becker, 1998). More recently, the construct of self-efficacy was added to the original model in order to account for the individual’s beliefs about his or her ability to carry out a health behavior (Meichenbaum & Turk, 1987). Following Glanz, Lewis &
Rimer’s model (1997), Table 1 provides an explanation of each of the constructs represented by the Health Belief Model.

Table 1.

* Constructs of the Health Belief Model *

<table>
<thead>
<tr>
<th>CONSTRUCT</th>
<th>EXPLANATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Susceptibility</td>
<td>Beliefs about the likelihood of coming down with a condition</td>
</tr>
<tr>
<td>Perceived Severity</td>
<td>Beliefs about the seriousness of a condition and/or its consequences</td>
</tr>
<tr>
<td>Perceived Benefits</td>
<td>Beliefs about the ability of an action to reduce the individual’s susceptibility to a condition and/or reduce its severity</td>
</tr>
<tr>
<td>Perceived Barriers</td>
<td>Beliefs about the tangible and psychological costs of a health behavior</td>
</tr>
<tr>
<td>Cues to Action</td>
<td>Factors that motivate a person to act</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>Confidence in one’s ability to carry out a health behavior</td>
</tr>
</tbody>
</table>

According to this model, demographic, personal, and social characteristics are capable of influencing health behaviors, but these are believed to work through their ability to modify individual perceptions and motivation, rather than function as direct causes of health behaviors themselves (Welch & Thomas-Hawkins, 2005). Because of its ability to explore a wide variety of short and long-term health behaviors (Glanz et al., 1997), the Health Belief Model provides a useful theoretical framework for examining the issue of dysphagic patient adherence.

*Purpose of the Study*

The purpose of this study was to gain insights into the decision-making process of patients who had been diagnosed with dysphagia and had received a recommendation to thicken their liquids by their SLP. Of particular interest were the patient’s feelings about
the thickened liquid recommendation they received and why they did or did not choose to follow their SLP’s advice. This study used research from the field of behavioral medicine as a theoretical framework for investigating the factors that potentially influence the dysphagic patient’s adherence to thickened liquid recommendations.

Research Questions

The goal of this study was to increase our understanding of the factors that influence dysphagic patients’ adherence to thickened liquid recommendations. The study attempted to answer the following questions: How do patients feel about their recommendations? Why do they choose to follow or not follow these recommendations? What alternative methods do patients turn to in order to manage their swallowing problems?
Speech-Language Pathologists regularly advise their patients to use a thickening agent for drinks despite the fact that they recognize that almost 50% of their patients have a “strong dislike” for drinking thickened liquids (Garcia et al., 2005). In a related study, 75% of patients questioned indicated that they did not like using a thickener in their drinks (Macqueen, Taubert, Cotter, Stevens & Frost, 2003). Non-adherence with dysphagia recommendations, such as modification of liquids, appears to be widespread and has serious consequences. Of patients who reported that they made a conscious decision not to adhere with SLP and physician recommendations to alter their behaviors related to swallowing, 86% died within one year of receiving the advice. This is in significant contrast to only 39.5% (p<0.05) of patients dying who reported “always” or “sometimes” adhering with dysphagia recommendations (Low et al., 2001). Thickened liquids were the least likely recommendation to be adhered to. The authors speculate that non-adherence with modified liquids may be due to strong patient preferences for liquids to be in their “familiar form” (p. 126); unacceptable alterations in taste; and the perception that thicker liquids may be less “thirst quenching” (p. 126). In a small sample study of patients with dysphagia, Leiter and Windsor (1996) found that 72% of SLPs estimated that their patients were adhering to dysphagia recommendations when in fact only approximately 36% of patients were adhering to their recommended treatments.

Poor patient adherence to dietary and liquid modifications for dysphagia has also been attributed to poor patient awareness of their condition (Parker et al., 2004; Rosenvinge & Starker, 2005). Patients whose dysphagia is due to stroke are particularly
at risk for not being able to understand clinical indicators of aspiration, such as coughing associated with oral-intake (Parker et al., 2004). Over half of the patients in this study reported having no awareness that they had a swallowing problem, despite the evaluation and treatment of their condition. Dysphagic patients who live in institutional settings were found to be more likely to adhere to liquid modifications, in large part due to the fact that fewer alternatives were made available to them (Low et al., 2001). As patients experience less independence in the preparation of their own food and drink, they become more dependent on the choices made available to them by nursing and aid staff within these institutions. In other words, they are more likely to adhere, but not necessarily by choice.

Aside from issues of poor patient awareness, little research has been conducted to identify factors that influence patients’ decisions to adhere to dysphagia diet and liquid modifications. Often the reasons for non-adherence are based on researchers’ speculation, such as preferences for liquids in their familiar form, altered taste, decreased gratification (Low et al., 2001), or are generically stated as “patient dislike” for liquids that have been thickened (Garcia et al., 2005).

To date, only one study has been conducted that specifically attempted to identify factors that influenced patients’ decisions not to adhere to their dysphagia recommendations (Colodny, 2005). In this study of 63 patients who had been identified as “noncompliant,” patients reported not adhering to the recommendations for one of the following reasons: denial of dysphagia, dissatisfaction with the food preparations, assuming a calculated risk of non-adherence behaviors, rationalizing their non-adherence, minimizing the severity of their condition, verbalizing adherence while not acting in a
manner consistent with verbalizations, projecting blame on the SLP or deflecting non-adherence by referring to an external authority (Colodny, 2005). This study provides a significant landmark for our understanding of issues related to adherence with dysphagia recommendations. However, it also has several limitations. The author attempted to study only patients who had already been identified as not adhering to their recommendations, all of whom lived in a nursing home at the time of the study. No patients were studied who were demonstrating any adherence with their recommendations. Additionally, this study considered non-adherence with a wide variety of recommendations, including behavioral strategies, dietary modifications, and avoiding oral intake altogether (NPO meaning “Nothing by mouth”). Finally, no patients who lived in family homes were included in this study.
Chapter 3: Methods

This qualitative study focused on the experiences of four adult patients, ranging in age from 66 to 83 years, who were identified as having dysphagia by a hospital SLP. Only patients for whom the dietary modification of thickened liquids was recommended and who were living in a non-institutional setting were included in the study. This included patients of both genders who were living independently, with spouses, children, or other family care-givers. All patients interviewed for the study were Caucasian. Patients who were cognitively incapable of completing an informed consent form were excluded from this study. Assessment of patient orientation as well as the individual’s independence in activities of daily living was used to determine the patient’s ability to respond to study questions. The patients included in this study represent a range of patient conditions, experiences, diagnoses, ages, and genders. Table 2 displays the demographic characteristics of the patients interviewed for this study.
Table 2.

*Demographic Characteristics of Patients*

<table>
<thead>
<tr>
<th>Patient*</th>
<th>Gender</th>
<th>Age</th>
<th>Living Situation</th>
<th>Food/Drink Preparation</th>
<th>Relevant Diagnoses</th>
<th>Recommendation(s)</th>
<th>Continuing Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>George</td>
<td>Male</td>
<td>83</td>
<td>Alone, children providing around-the-clock care</td>
<td>Children</td>
<td>CVA, dysphagia</td>
<td>Nectar thick liquids</td>
<td>In-home speech therapy 2-3x/week</td>
</tr>
<tr>
<td>Karen</td>
<td>Female</td>
<td>66</td>
<td>With husband</td>
<td>Husband and Self</td>
<td>C2 Fracture with Cervical Fusion, dysphagia</td>
<td>Honey thick liquids as inpatient, discharged home on nectar thick liquids</td>
<td>Outpatient speech therapy 2x/week</td>
</tr>
<tr>
<td>Walter</td>
<td>Male</td>
<td>83</td>
<td>With son</td>
<td>Self</td>
<td>CVA, pneumonia, dysphagia</td>
<td>Nectar thick liquids, chin tuck with swallow</td>
<td>In-home speech therapy 3x/week</td>
</tr>
<tr>
<td>Steve</td>
<td>Male</td>
<td>77</td>
<td>With wife</td>
<td>Wife</td>
<td>CVA, dysphagia</td>
<td>Honey thick liquids, pureed foods, chin tuck with swallow</td>
<td>Outpatient speech therapy 2-3x/week</td>
</tr>
</tbody>
</table>

*pseudonym

Three local hospitals participated as research sites in this study. After being identified as meeting the criteria for the study by a hospital SLP, patients were offered the opportunity to participate in this research. Following referral from the hospital clinician, initial contact with the patient was made by telephone. At that time, they were asked if they would still like to participate in the study. If they declined, they were thanked for their time and wished a good recovery. If they agreed, an interview was scheduled at the preferred time and place of the patient.

The primary method of data collection consisted of semi-structured, open-ended interviews, which are, according to Denzin & Lincoln (2003), the most appropriate method of gaining increased understanding of the patient’s perspective. Primary
questions attempted to identify the perspectives of patients to guide the outcome rather than the interviewer directing or seeking a particular outcome. All interviews lasted approximately one hour each. See Appendix A for a sample interview protocol.

With patient permission, interviews were audio-taped and then transcribed. Using Creswell’s guidelines (1994) for the analytic processing of data, analysis of interview transcripts took place concurrently with data collection. This system of data reduction and interpretation consisted of several stages. The first stage, open coding, allowed for the identification of data categories. Patient quotations, taken directly from the interview transcripts, led to the development of “codes and category labels which [were] identified with short descriptions, known as in vivo codes” (italics in original, p. 302). Categories included setting/context codes, participant perspectives, and activity, strategy and relationship codes (Creswell, 1994; Denzin & Lincoln 2003). In the second stage, connections between categories were built as themes began to emerge in the data. This stage of data analysis was referred to as “axial coding.” Finally, selective coding took place whereby the categories and emerging themes identified in the first two stages were compared to each other to begin forming theoretical models (Denzin & Lincoln, 2003). These theoretical models addressed the factors that appear to influence or shape the patient’s thinking regarding dysphagia recommendations. According to Glesne (1999), this process of systematically analyzing data through the use of codes allows the data to be interpreted into relevant units to make better sense of their meanings.

All data were collected in the form of audio-tapes, transcriptions of the interviews, and handwritten notes based on the observations and interviews. Participants were given pseudonyms for identification on all data (including audio-tape and file
labels). Any identifying information, beyond the participants’ names, including institutional affiliation, was modified to protect their identity. Audio-tapes and paper documents were stored in the locked filing cabinet drawers in the locked office of the principal investigator. At the end of the study, all information containing protected health information was destroyed by shredding.
Chapter 4: Presentation and Analysis of Findings

This study explored the experiences of four dysphagic patients with thickened liquid recommendations. George, the first patient involved in this study, was living alone at the time of the interview and reported adhering to his thickened liquid recommendations largely because of the influence of his children, who provided him with round-the-clock care in 12-hour shift rotations. Karen, a 66-year-old woman who lived with her husband, also reported adherence to her thickened liquid recommendations and revealed several strategies that she had implemented independently in the management of her swallowing difficulties. Steve, who also lived in a private home with his spouse, acknowledged his wife’s role in his adherence to his thickened liquid recommendation through her preparation of his food and drinks. Finally, Walter, who was living with his grown son, reported some adherence to his thickened liquid regimen, but also revealed his rationale for not fully following through with his SLP’s recommendations.

Examination of patient interviews revealed several recurring themes in the data. Looking at these themes through the lens of this study’s theoretical framework guided the organization of the data into the constructs provided by the Health Belief Model.

Perceived Susceptibility

For the patients interviewed in this study, beliefs about the likelihood of being afflicted with a condition (in this case, difficulty with swallowing) appeared to be influenced primarily by the diagnosis of dysphagia by a hospital SLP. In other words, patients seemed to defer to the authority of a professional when forming their beliefs
about whether or not they had a problem. According to Walter, “I didn’t think I had a problem frankly until I got to [the hospital] and they started giving me tests and they said you’ve got a problem.” Echoing this sentiment, George stated, “The doctors know what to do and the carpenters know what to do… That’s the reason you pay them to tell you what’s wrong… He can’t help you if you don’t know what’s wrong with you.”

For Karen, perceived susceptibility to swallowing problems was influenced not only by the diagnosis of dysphagia by a hospital SLP but also by episodes of choking she had experienced in the past. She reported:

Before the accident, I choked a few times… Where it started from was not just from the surgery or collar, but because of the problems I was having before… I knew that ahead of time but I didn’t know about the liquid... and then they did the first swallow study and they found that the liquid was aspirating.

In this case, the diagnosis of dysphagia by a hospital SLP confirmed and furthered Karen’s beliefs about her pre-existing susceptibility to the condition.

Perceived Severity

Murray and Sullivan (2006) cite aspiration pneumonia as the “driving force” behind the growing subspecialty of dysphagia management in speech-language pathology. For George, the fear of pneumonia appeared to drive his beliefs about the seriousness of his condition. “Well, if that’s what it takes to keep me from getting pneumonia, okay,” stated George when asked how he felt about being placed on thickened liquids. When asked the same question, Karen replied:
I know it’s for my own good and I’m not going to jeopardize anything so I’m going to stay on [thickened liquids] until they tell me I can get off from it, but I can’t wait for that day to come because I’m looking forward to a big glass of ice water. But I’m afraid to do anything like that because I don’t want to jeopardize anything. I don’t want to go back into the hospital with pneumonia or something like that.

For these two patients, the fear of pneumonia appeared to directly influence their beliefs about the seriousness of their conditions and, in turn, their decisions to adhere to their dysphagia recommendations.

Interestingly, Walter, a patient diagnosed with pneumonia after the onset of his swallowing difficulty, reported conflicting beliefs about the seriousness of his condition. Describing his reaction to his diagnosis of dysphagia, Walter stated:

Once again I didn’t really know I had a problem swallowing. They told me I had a problem and I didn’t know I had a problem. So they gave me this thickened liquid at the rehabilitation center. Is it serious? I don’t know… They said I had that touch of pneumonia. This swallowing thing contributed to that I guess.

Later in the interview, Walter spoke about the education he received at the hospital regarding his dysphagia diagnosis: “They said you’ve got to be on the thickened liquid so they gave me some and I said, ‘okay.’ Nothing was explained to me really as far as I can recall.” In Walter’s case, the education he received, which falls under the Cues to Action construct (see below), seemed to influence his perceptions about the seriousness of the condition. This interplay of influencing factors points to the multi-faceted nature of health-related behaviors.
Perceived Benefits and Barriers to Action

According to the Health Belief Model, the net effects of a health action (in this case, adhering to a thickened liquid recommendation) directly influence the likelihood of taking a recommended health action. The net effects of a health action are calculated by weighing the perceived benefits of the action against the perceived barriers to that action. For the patients interviewed in this study, the perceived benefits of adhering to the thickened liquid recommendation had to do with their beliefs about the ability of the thickened liquids to prevent pneumonia. As explained above, George and Karen both stated their belief that the thickened liquids would prevent them from getting pneumonia. While she did not explicitly cite the prevention of pneumonia, Steve’s wife, the primary caregiver, described her feelings about having to prepare thickened liquids for her husband: “If it’s going to help him, I don’t mind at all. It doesn’t take that long you know.” For Steve’s wife, the benefits of the thickened liquids—their ability to help her husband—outweighed the barriers to the action, the time it took to prepare the liquid.

The preparation of the thickened liquids also factored into Walter’s perceived barriers to adhering to the thickened liquid recommendation. He stated, “It’s kind of a pain to mix it up…To me it’s a pain but I got to do it so I do it… It’s just an inconvenience.”

Sensory reactions to the thickened liquids were frequently cited in patients’ descriptions to the thickened liquids. Describing the first time she was presented with thickened coffee, Karen stated:

The breakfast tray I got…had a cup of coffee there. It was covered and I took the cover off and you know it looked like the coffee was winking at me. I think I did
try it and it was like I can’t do this so I just put the cover on and I haven’t had coffee since.

George also described a strong reaction to the thickened liquids: “[It’s] terrible, the taste. It’s bad. They put it in milk and the milk looks like it’s something you are going to make cement with.” According to Steve, “It’s not too good, but I drink it… It’s just like jello… It’s pretty strange, but I drink it.” Although the taste/texture represented a barrier to adherence to the thickened liquid recommendation, Steve also cited the benefits of the thickened liquids: “It’s the only way I can swallow good.”

Describing his inability to drink water thickened to his recommended nectar consistency, Walter cited “laziness” as a barrier to his adherence:

I got to have water. Once in a while I’ll cheat with just plain water. God I just love it. I want a whole glass of water. Not a whole glass but maybe 3-4 oz of water just plain, plain water… I’ve succumbed to I’ve got to have water. I don’t know what it is. I don’t know why. Maybe it’s because I’m lazy and I want a drink of water so bad that I’m too lazy to make it with some thickener. Maybe that’s the reason. I have no particular problem with drinking it with thickener. Maybe that’s the answer. I’m too darn lazy.

Walter also rationalized his non-adherence when it came to thickening his water when he said:

On the average or more than average I use [the thickener]. As a matter of fact 95% of the time I use it. There’s a few cheats but it doesn’t amount to anything. [Water] is the only thing I cheat with. But again I don’t think it’s that much to
make a difference. I like to believe that it’s not. I’ve convinced myself that it does not make a big difference because of the amount I’m taking.

In this case, after weighing the perceived benefits of drinking thickened water against the barriers to drinking the thickened water, Walter decided not to adhere to the thickened liquid recommendation. This statement also reveals his conflicting emotions about his behaviors in regard to his adherence to his thickened liquid recommendation. For Walter, the decision not to adhere to this aspect of his thickened liquid recommendation appeared to be the result of the interplay of a number of factors, including the perceived benefits and barriers to action, his beliefs about the severity of the condition, and his beliefs about the ability of the thickened liquids to prevent pneumonia.

_Cues to Action_

The Health Belief Model states that cues to action influence patients’ decisions regarding health-related behaviors. For these four patients, education, the hope of returning to a normal diet, and social support represented recurring factors in their decisions whether or not to adhere to their dysphagia recommendations.

_Education._

For Walter, the limited education he felt he received regarding his dysphagia diagnosis and thickened liquid recommendation appeared to influence his perceptions about the seriousness of the condition. For the other patients, especially Karen and George, who pointed to their desire to prevent pneumonia, education about the consequences of dysphagia seemed to influence their decisions to adhere to their recommendations.
The hope of returning to a normal diet.

Three of the four patients interviewed for this study pointed to the hope of returning to a normal diet as a factor that weighed into their health-related decisions. George indicated, “Well you have to do everything they say in order to get off of this stuff. I’m going to get off of it in order to do the things I used to be able to do.” Similarly, Karen stated, “I’m going to stay on it until they tell me I can off from it, but I can’t wait for that day to come because I’m looking forward to a big glass of ice water.” Finally, Walter echoed this sentiment when he said, “Hopefully I can get out of that stuff pretty soon… I do what I’m told under these circumstances. So I’m hoping somebody will tell me that I can get off of that [thickener].” For these three patients, the hope that they would someday return to a normal diet provided a cue to adhering to the thickened liquid recommendation. Walter’s response also reiterated his deference to authority in determining whether or not his condition required intervention.

Social Support.

Every patient interviewed in this study reported a living situation where they had access to some kind of social support. For George, Karen, and Steve, family members (spouses and children) provided not only social support to the patients, but were also responsible, partially or wholly, for the preparation of the thickened liquids. Notably, Walter, the only patient who was entirely responsible for his food and drink preparation, was also the only patient who explicitly stated not adhering fully to the thickened liquid recommendation when it came to drinking water.

In George’s case, his five children shared a 12-hour shift rotation which allowed for round-the-clock care. One of George’s daughters, who was present during the
interview, interjected that she and her siblings “make” George adhere to the thickened liquids by preparing all of his drinks. For George, social support appeared to contribute largely to his adherence with his dysphagia recommendations.

Like George, Steve also experienced a great degree of social support. When asked who prepared his food and drink, Steve indicated the importance of the social support his wife provided: “She does. I don’t do it. Otherwise I’d probably die.” Steve’s response may also point to the influence of a patient’s self-efficacy expectations on their decision whether or not to adhere to a thickened liquid recommendation.

**Self-Efficacy Expectations**

Steve’s report that he would “probably die” if it weren’t for his wife’s preparation of his food and liquids not only highlights the importance of social support in his situation, but also may shed light on his beliefs about his ability to carry out the preparation of thickened liquids. Walter, when he spoke of his “laziness” when it came to prepared thickened water, may also have been referring to a larger issue of his self-efficacy expectations. He indicated some doubts about his ability to correctly follow his recommendations when he said, “I’d like to believe that I know what I’m doing in terms of how to prepare whatever I have to use [the thickener] for... but sometimes I overdo it and I don’t know why I do.” In Walter’s case especially, there seem to be a number of factors influencing his health-behaviors, including self-efficacy expectations, perceptions about the seriousness of the condition, and the education he received regarding his dysphagia diagnosis and thickened liquid recommendation.
Patient-Generated Strategies

In discussing their experiences with thickened liquid recommendations, several of the patients interviewed during this study referred to strategies they had implemented on their own in the management of their swallowing difficulties. One of Karen’s chief complaints about the thickened liquid was that she felt that none of it was “refreshing.” After one of her speech therapists suggested using lemon ice, Karen began using the lemon ice at home as way to have something refreshing in her diet. Karen also reported pureeing crackers in her soup to achieve a nectar thick consistency rather than adding thickener to her soups. Finally, all of the patients reported eating foods that didn’t have to be thickened, such as oatmeal and cream of wheat.
Chapter 5: Conclusions

Summary of Results

The results of this study revealed several factors that appeared to influence the participants’ adherence to their thickened liquid recommendations. Following the University of Twente’s model (2004), Table 3 provides a summary of the adherence factors identified in the data as they apply to the constructs of the Health Belief Model.

Table 3.

* Constructs of the Health Belief Model with Applications from the Data *

<table>
<thead>
<tr>
<th>CONSTRUCT</th>
<th>EXPLANATION</th>
<th>APPLICATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived Susceptibility</td>
<td>Beliefs about the likelihood of being afflicted with a condition</td>
<td>Dysphagia diagnosis Pre-existing difficulties swallowing</td>
</tr>
<tr>
<td>Perceived Severity</td>
<td>Beliefs about the seriousness of a condition and/or its consequences</td>
<td>Desire to prevent aspiration pneumonia</td>
</tr>
<tr>
<td>Perceived Benefits</td>
<td>Beliefs about the ability of an action to reduce the individual’s susceptibility to a condition and/or reduce its severity</td>
<td>Ability of thickened liquids to prevent aspiration pneumonia and/or prevent choking</td>
</tr>
<tr>
<td>Perceived Barriers</td>
<td>Beliefs about the tangible and psychological costs of a health behavior</td>
<td>Taste/texture of thickened liquids</td>
</tr>
<tr>
<td>Cues to Action</td>
<td>Factors that motivate a person to act</td>
<td>Education Social support Hope of returning to normal diet</td>
</tr>
<tr>
<td>Self-Efficacy</td>
<td>Confidence in one’s ability to carry out a health behavior</td>
<td>Beliefs about capability of correctly preparing thickened liquids and/or adhering to recommendation</td>
</tr>
</tbody>
</table>

The variety of adherence factors revealed in the data points to the multi-faceted nature of dysphagic patient adherence to thickened liquid recommendations. Previous
studies of dysphagic patient adherence have tended to oversimplify the phenomenon of non-adherence by attributing patient behaviors to just one of several factors (Colodny, 2005; Leiter & Windsor, 1996; Low et al., 2001). Viewing patient adherence in this light leads to the consideration of adherence factors as variables that operate independently of each other. The outcomes of this study indicate that health-behaviors related to patient adherence are the result of a complex interplay of several factors. This finding calls for a re-working in the way that Speech-Language Pathologists view the issue of patient adherence, one that recognizes the complex and multi-faceted nature of the phenomenon.

Finally, there is a need within the field of Speech-Language Pathology to move away from the viewing of patient behaviors as an issue of “compliance.” As noted earlier, the term “compliance” has typically been used within the field of Speech-Language Pathology to describe patient behaviors related to professional recommendations. In other fields, however, especially the field of behavioral medicine, the term “compliance” connotes a paternalistic relationship between the patient and the health-care provider, and the “noncompliant” patient is typically viewed as deviant and/or weak (Miller & Hays, 2000). Conversely, the term “adherence” connotes a collaborative relationship between the patient and the health-care provider and recognizes the complex nature of health-related decisions and behaviors. In shifting towards the viewing of patient behaviors as an issue of “adherence” rather than “compliance,” Speech-Language Pathologists need to acknowledge the importance of enlisting patients as equal contributors in the development of their management programs.
Inferences and Potential Clinical Implications

Studies of adherence interventions in the field of behavioral medicine indicate that health care providers are capable of affecting patient behaviors. Dunbar-Jacob et al. (1995) report that, “for the most part, the patient characteristics that influence adherence are potentially modifiable, rather than fixed characteristics over which the health care provider has no influence” (p. 323). One of the key adherence factors over which the health care provider holds influence is the continuity of care provided to the patient.

Notably, all four patients interviewed for this study were receiving some kind of continuing care, in the form of either outpatient or in-home speech therapy services. However, none of the patients reported that their speech therapy services addressed the correct preparation of thickened liquids, even for patients like Walter, who expressed concerns about his ability to prepare liquids to the appropriate consistency. When asked if the speech therapist who came to his home ever addressed the preparation of his thickened liquids, Walter replied: “No Ma’am… She made me some when I was sitting in that chair… She did it herself. She went out by herself to the kitchen and got the nectar quality.” Clark & Becker (1998) indicate that patients’ skills deteriorate over time, highlighting the need for follow-up care. According to the authors, “Patients must be taught how to use medicines and demonstrate their proficiency in every encounter with the clinician in order to correct deteriorating skills” (p. 23). Therapists who work with dysphagic patients in an outpatient or in-home setting have the unique opportunity to provide follow-up care that addresses patients’ skills in preparing food and liquids according to their dietary recommendations.
In addition to continuity of care, the education provided to patients regarding their dysphagia diagnosis and dietary recommendations represents another potentially modifiable adherence factor. According to Meichenbaum & Turk (1987), non-adherence to medical regimens may be based on misunderstanding or inadequate information regarding the condition (p. 48). Patient reports from the present study, most notably those of Karen, George, and Walter, indicate that the education they received regarding their dysphagia recommendations factored into their decision whether or not to adhere to the thickened liquid regimen. Dunbar-Jacob et al. (1995) suggest the following recommendations for providing patient instructions: create an open and honest environment, interview family members to identify their beliefs about the patient’s ability to carry out the regimen, simplify the regimen as much as possible, introduce the regimen in steps, and include the patient in family education. As we move towards the viewing of patients’ decision-making processes as an issue of adherence, Speech-Language Pathologists need to explore ways in which we can formulate relationships with our patients that foster open and honest communication about health behaviors. As indicated by Meichenbaum & Turk, 1987, “There is a critical need for the HCP to give patients the opportunity to express their point of view—goals, nature of the problem, and how they feel they should be treated” (p. 52).

Several studies from the field of behavioral medicine have investigated the role of social support in patient adherence (Clark & Becker, 1998; DiMatteo, 2004). Research indicates that there are many different variables of social support, including practical support, emotional support, unidimensional social support, and family cohesiveness (DiMatteo, 2004). According to the author, positive and supportive social interaction is
highly correlated with patient adherence to treatment regimens (pp. 212-213). Research also suggests that functional social support (i.e. the patient’s perceptions about the quality of the support network), is more important that the type of support (DiMatteo, 2004). In the present study, social support seemed to play an important role in the adherence of the three patients (Karen, George, and Steve) who shared the responsibility of preparing their thickened liquids, either partially or in full, with caregivers. Notably, Walter, the only patient who was solely responsible for the preparation of his food and drinks, was also the only patient who indicated not adhering to all aspects of his thickened liquid recommendation. This finding is consistent with DiMatteo’s suggestion (2004) that, “Among every 100 patients who are not receiving practical help with their treatment regimens, at least 65 can be expected to be noncompliant” (p. 213). Furthermore, research suggests an interaction between social support and a patient’s self-efficacy expectations. According to DiMatteo (2004), “emotional support may lead first to increased self-esteem and then to better adherence” (p. 213). This suggestion points to the need for more investigation into the interaction between social support and self-efficacy expectations with regard to their impact on dysphagic patient adherence.

Finally, behavioral medicine research suggests that health care providers can work indirectly on adherence by working on self-efficacy and encouraging self-monitoring (Dunbar-Jacob et al., 1995). DiMatteo (2004) indicates that increased self-esteem may lead to better adherence (p. 213). This suggests that Speech-Language Pathologists may indirectly influence patient adherence by addressing the patient’s confidence in his or her ability to follow through with their thickened liquid recommendation.
The results of this study suggest several aspects of the current model of service delivery within the field of Speech-Language Pathology that need to be explored further in terms of their relationship to dysphagic patient adherence to thickened liquid recommendations. These include:

- The influence of continuing care on patient behaviors
- The role of education in patients’ decisions regarding their adherence to thickened liquid recommendations
- The effect of intervention measures targeting patients’ self-efficacy expectations on patient adherence
- The relationship between self-efficacy expectations and social support, and their influence on patient adherence

**Limitations/Delimitations of the Study**

This study was limited to identifying factors that seem to influence dysphagic patient adherence to thickened liquid recommendations. In some cases this included the identification of patient-generated alternatives to thickened liquid recommendations for dysphagia management. However, this study did not attempt to investigate the effectiveness of such solutions. While this would certainly be an interesting direction for future research, the focus of this study was on how patients feel about the thickened liquid recommendation, not on the outcomes of patient adherence or non-adherence.

Finally, although analytic induction was used to guide the process of obtaining a purposeful study population (Bogden & Biklen, 2003), the geographical, time, and financial constraints of this investigation should indicate caution in applying the findings
to patients from other demographic backgrounds. The small sample size of this study and the nature of its qualitative design limit the generalization of the findings to larger groups. Generalizing is difficult because the patients who participated in this study cannot fully represent all groups or contexts. However, the qualitative design of this study allows for the transferability of the results in that the findings indicate learning that may apply to similar situations, directions for future study, and potential clinical implications (Eisner, 1998).

Directions for Future Study

Analysis of interviews with the four patients who participated in this study led to the identification of several factors related to their adherence to their thickened liquid recommendations. Comparison of these results with research from the field of behavioral medicine implies that several adherence factors are potentially modifiable. These include the continuity of care and the instructions and education provided to the patient and family as well as the patient’s sense of self-efficacy. As we learn more about the factors that influence dysphagic patient compliance, there is a need for more research into how the modification of one or more of these factors influences patient compliance.

Because the social support available to patients appeared to be such an important adherence factor for many of the participants interviewed during this study, there is a need for more investigation into the role of social support in patients’ decisions whether or not to adhere to recommended dietary modifications. Furthermore, exploration of the relationships between social support and other adherence factors, especially an
individual’s sense of self-efficacy, may shed further light on the decision-making processes of dysphagic patients.

This study is significant in that it represents another step forward in the direction of understanding dysphagic patient adherence to their dietary recommendations. Because of its limitations, however, this study just begins to scratch the surface of this issue. As the results indicate, dysphagic patient adherence to thickened liquids recommendations is a multi-faceted phenomenon, and there is a need for more research to identify and better understand the complex interplay of factors that influence patient behaviors. By doing so, we might be able to gain a clearer picture of the factors that are most salient in determining patient compliance.

Finally, several of the potential clinical implications revealed in the analysis of the data point to limitations placed on the service delivery model within the area of dysphagia management by the resources of our healthcare system. These include the amount of reimbursement patients are eligible to receive for speech therapy services as well as the support made available to professionals for follow-up care for patients and patient and family instruction. With this in mind, there is a need to explore the development of new service delivery models within the constraints of the resources of our current healthcare system, with the ultimate goal of informing future treatment protocol and improving dysphagia management.
References


Appendix A: Sample Interview Protocol

Q1: Have you ever been evaluated for your swallowing problems?

Yes

Q2(a): Do you know what test you had?

Q2(b): Do you know who you saw?

Yes

Q3: What did the SLP find?

Q4: What did the SLP tell you to do to help with your swallowing?

Q5: Do you know why they told you to ______?

Q6: How do you feel about what the SLP told you?

Q7: Are you following those recommendations?

Yes

No

Yes

Q8(a): How is that going?

Yes

No

Q8(b): What are you doing about your swallowing now?

Can you describe your diet for me?
- Do you eat a regular diet?
- Is there anything in particular that you eat or drink that causes you problems?
- Do you eat hard, crunchy foods?
- How do you handle drinking liquids?

Can you describe that for me/What do you think is wrong?

Memory Stimulation:
Our medical records indicate that on (date), you had a (name of test) with (SLP). Do you remember being seen by (name)?

No

Are you having any difficulty swallowing now?

No

Yes
Appendix B: Human Subjects Approval Letters
June 5, 2006

Dr. Sarah Ginsberg  
Special Education  
128 Porter

Dear Dr. Ginsberg:

The Human Subjects Institutional Review Board (IRB) of Eastern Michigan University has granted approval to your proposal, “Dysphagic Patient Compliance with Thickened Liquid Recommendations.”

After careful review of your completion application, the IRB determined that the rights and welfare of the individual subjects involved in this research are carefully guarded. Additionally, the methods used to obtain informed consent are appropriate, and the individuals participating in your study are not at a risk.

You are reminded of your obligation to advise the IRB of any change in the protocol that might alter your research in any manner that differs from that upon which this approval is based. Approval of this project applies for one year from the date of this letter. If your data collection continues beyond the one-year period, you must apply for a renewal.

On behalf of the Human Subjects Committee, I wish you success in conducting your research.

Sincerely,

[Signature]

Dr. Patrick Melia  
Administrative Co-Chair  
Human Subjects Committee

Copy: Steve Pernecky  
Bill Cupples
June 13, 2007

Dr. Sarah Ginsberg
128 Porter
Department of Special Education

Dear Dr. Sarah Ginsberg:

The Human Subjects Institutional Review Board (IRB) of Eastern Michigan University has granted approval to your continuation, “Dysphagic Patient Compliance with Thickened Liquid Recommendations.” Please note that if by next year you are continuing your proposal, it will be beyond the 3 year time frame and a full application document with supporting materials will be required.

After careful review of your completed application, the IRB determined that the rights and welfare of the individual subjects involved in this research are carefully guarded. Additionally, the methods used to obtain informed consent are appropriate, and the individuals participating in your study are not at risk.

You are reminded of your obligation to advise the IRB of any change in the protocol that might alter your research in any manner that differs from that upon which this approval is based. Approval of this project applies for one year from the date of this letter. If your data collection continues beyond the one-year period, you must apply for a renewal.

On behalf of the Human Subjects Committee, I wish you success in conducting your research.

Sincerely,

Deb de Laski-Smith, Ph.D.
Interim Dean
Graduate School
Administrative Co-Chair
University Human Subjects Review Committee

Note: If project continues beyond the length of one year, please submit a continuation request form by 06/13/08.

Reference # 070606C