

---

Theses and Dissertations

---

2011

# Patient awareness of dysphagia

Darci Lynn Sturtz Becker  
*University of Iowa*

Copyright 2011 Darci Becker

This dissertation is available at Iowa Research Online: <http://ir.uiowa.edu/etd/925>

---

## Recommended Citation

Becker, Darci Lynn Sturtz. "Patient awareness of dysphagia." PhD (Doctor of Philosophy) thesis, University of Iowa, 2011.  
<http://ir.uiowa.edu/etd/925>.

---

Follow this and additional works at: <http://ir.uiowa.edu/etd>

 Part of the [Speech and Hearing Science Commons](#)

PATIENT AWARENESS OF DYSPHAGIA

by

Darci Lynn Sturtz Becker

An Abstract

Of a thesis submitted in partial fulfillment  
of requirements for the  
Doctor of Philosophy degree in Speech and Hearing Science  
in the Graduate College of  
The University of Iowa

May 2011

Thesis Supervisor: Professor Jerry Moon

## ABSTRACT

The purpose of this study was to explore the nature of reduced patient awareness of oropharyngeal dysphagia. While patient awareness of dysphagia has been explored in individuals before participating in formal swallowing assessments, no studies have been identified in the literature that have explored awareness after patients have participated in an examination and received information about their dysphagia. In addition, the relationship between patient compliance and reduced awareness, as well as the application of stages of change in this population were explored.

Twenty-one inpatients and outpatients, newly diagnosed with oropharyngeal dysphagia, participated in this study. A retrospective analysis found that 40% of participants demonstrated reduced awareness of their dysphagia *before* participating in a videofluoroscopic swallowing examination. Reduced pre-examination awareness of dysphagia occurred most frequently in those with general medical diagnoses versus neurological or structural diagnoses. Reduced pre-examination awareness was not significantly associated with a reduced cough response following aspiration.

Exploration of post-examination patient awareness of dysphagia, the primary intent of this study, revealed that 19% of patients demonstrated reduced awareness of their dysphagia, even *after* receiving specific verbal and visual information regarding their diagnosis. Reduced post-examination awareness of dysphagia occurred equally in those with structural and neurological diagnoses and was not noted in those with general medical diagnoses. Reduced post-examination awareness was not significantly associated with a reduced cough response following aspiration. Consistent with the literature on reduced patient awareness of deficit, patient awareness of dysphagia was modality

specific. That is, some patients with reduced awareness of dysphagia demonstrated awareness of other deficits and vice versa. Overall, participants demonstrated more awareness of concomitant speech impairments than dysphagia and less awareness of concomitant cognitive impairments than dysphagia. No significant relationship between general cognitive impairment and reduced patient awareness of dysphagia was found.

Exploration of diet compliance in inpatient participants revealed no instances of noncompliance, while hospitalized, from the day of the swallowing examination until the day of participation in the study. However, only 67% of these patients requested permissible foods or drinks when compliance was sampled during the study protocol, suggesting that inpatients with newly diagnosed dysphagia may be less compliant if restricted items become accessible. No significant relationship between patient awareness of dysphagia and diet compliance, as sampled during the study protocol, was found in both inpatients and outpatients. The relationships between patient awareness of dysphagia and patient compliance for both swallowing strategies and exercise regimens were also not significant, though these analyses were limited by the small number of participants who had been prescribed strategies and independent exercise programs at the time of their study participation. Lastly, analysis of the relationship between patient compliance and action or post-action stages of change, revealed no significant association between these variables.

Abstract Approved: \_\_\_\_\_  
Thesis Supervisor

\_\_\_\_\_  
Title and Department

\_\_\_\_\_  
Date

PATIENT AWARENESS OF DYSPHAGIA

by

Darci Lynn Sturtz Becker

A thesis submitted in partial fulfillment  
of requirements for the  
Doctor of Philosophy degree in Speech and Hearing Science  
in the Graduate College of  
The University of Iowa

May 2011

Thesis Supervisor: Professor Jerry Moon

Copyright by

DARCI LYNN STURTZ BECKER

2011

All Rights Reserved

Graduate College  
The University of Iowa  
Iowa City, Iowa

CERTIFICATE OF APPROVAL

---

PH.D. THESIS

---

This is to certify that the Ph. D. thesis of

Darci Lynn Sturtz Becker

has been approved by the Examining Committee for the thesis requirement for the Doctor of Philosophy degree in Speech and Hearing Science at the May 2011 graduation.

Thesis Committee: \_\_\_\_\_  
Jerald Moon, Thesis Supervisor

\_\_\_\_\_  
Eileen Finnegan

\_\_\_\_\_  
Carlin Hageman

\_\_\_\_\_  
Michael Karnell

\_\_\_\_\_  
Douglas Van Daele

## TABLE OF CONTENTS

LIST OF TABLES	iv
LIST OF FIGURES	v
CHAPTER I INTRODUCTION	1
Anosognosia	4
Denial	8
Impact of Impaired Awareness	9
Aims of the Present Study	12
CHAPTER II METHODS	18
Participants	18
Procedure	18
CHAPTER III RESULTS	27
Pre-examination Awareness of Dysphagia	27
Post-examination Awareness of Dysphagia	28
Patient Compliance with Diet Recommendations	30
Patient Compliance with Swallowing Strategies/Maneuvers	31
Patient Compliance with Exercise Regimens	32
Stages of Change	32
CHAPTER IV DISCUSSION	34
Pre-examination Awareness of Dysphagia	34
Post-examination Awareness of Dysphagia	36
Patient Compliance with Diet Recommendations	45
Patient Compliance with Swallowing Strategies/Maneuvers	46
Patient Compliance with Exercise Regimens	47
Stages of Change	48
Summary of Findings	49
Limitations	50
Clinical Applications	50
Future Directions	52
APPENDIX A: MINI-MENTAL STATE EXAMINATION	59
APPENDIX B: PATIENT INTERVIEW	61
APPENDIX C: PATIENT COMPLIANCE WITH DIET RECOMMENDATIONS	63



APPENDIX D: PATIENT COMPLIANCE WITH SWALLOWING STRATEGIES/MANEUVERS	64
APPENDIX E: PATIENT COMPLIANCE WITH EXERCISE REGIMENS	65
APPENDIX F: STAGES OF CHANGE	66
REFERENCES	67

## LIST OF TABLES

Table 1.	Participant Information	54
Table 2.	Etiology of Participants' Dysphagia As Classified By Neurological, Structural and General Medical Diagnoses	55
Table 3.	Summary of Findings for Four Participants Demonstrating Reduced Post-Examination Awareness of Their Dysphagia	56

## LIST OF FIGURES

- Figure 1. Patient Awareness of Dysphagia Pre- and Post-Videofluoroscopic Swallowing Study Across Three Diagnostic Groups 57
- Figure 2. Proportion of Patients with Awareness of Impairments

## CHAPTER I

### INTRODUCTION

Individuals who exhibit signs or symptoms of oropharyngeal dysphagia are often referred for an instrumental swallowing examination. Some patients arrive at the radiology suite reporting that a swallowing problem exists, possibly having generated the examination referral themselves by describing their dysphagia symptoms to medical personnel. Findings of an objective swallowing assessment may subsequently confirm the patient's perception of swallowing difficulty.

Other patients, however, present with no subjective complaints of dysphagia. Some demonstrate no overt signs of swallowing difficulty, such as in the case of silent aspiration, and are unaware that a problem exists until it is identified during the instrumental examination. Others present with overt signs of dysphagia, such as coughing when eating or drinking, but do not complain of dysphagia as they may attribute the symptoms to something other than a swallowing problem.

Several studies have explored the relationship between patients' self-perceptions of swallowing function prior to or concurrent with swallowing examinations and the subsequent findings of objective assessments (Bird, Woodward, Gibson, Phyland, & Fonda, 1994; Boczko, 2006; Bushmann, Dobmeyer, Leeker, & Perlmutter, 1989; Ding & Logemann, 2008; Horner & Massey, 1988; Litvan, Sastry, & Sonies, 1997; Logemann, 1995; Newton, Newton, Pearl, & Davidson, 1994; Parker et al., 2004; Pauloski et al., 2002; Rhodus, Moller, Colby, & Bereuter, 1995; Robbins, Logemann, & Kirshner, 1986; Walther, Rodell, & Deroover, 1990). Evidence from many of these studies confirms that

patients' impressions of their swallowing do not always correlate with the findings of objective assessments and cannot be relied upon to identify all swallowing problems.

While most of these studies included smaller numbers of subjects and focused on one medical diagnostic category, a recent study by Ding and Logemann (2008) investigated this topic with by studying 103 patients with various medical diagnoses. They concluded that the relationship between subjective complaints of dysphagia and objective assessments of swallowing function may depend greatly on the patient's underlying medical diagnosis. In their study, patients with neurological disorders were found to have the lowest correlation with expert ratings in their self-perception of the presence, location and severity of swallowing difficulties. Those with structural deficits correlated moderately with expert ratings and those with general medical diagnoses correlated highly.

Few hypotheses have been offered by authors from these studies to explain reduced awareness of dysphagia. Ding and Logemann (2008) suggest that in those with neurological impairments the presence of "damaged neural connections within the brain or peripherally" may result in "inaccurate patient perception" of swallowing function. In those with structural deficits, they offer that reduced patient awareness may result from "damaged peripheral sensory nerve endings" providing fewer "sensory feedback cues" during swallowing. And in those with general medical diagnoses, the authors suggest that because "the sensory system, including the sensory receptors, peripheral and central sensory pathways" are relatively unaffected, patients subjective complaints correlated highly with expert ratings (Ding & Logemann, 2008).

In a small study by Parker et al. (2004), patients' awareness of signs and symptoms of dysphagia during a clinical assessment was explored. 59% of patients in their study demonstrated poor awareness of their dysphagia symptoms. When patients were asked the question "Do you have a swallowing problem?" only three individuals or 11% of participants acknowledged the presence of a swallowing problem; only two of whom had been judged as having good awareness of their dysphagia symptoms.

Of note, is that in all of these studies which have explored patient awareness of dysphagia, patient's subjective impressions of their swallowing function were obtained *before* or concurrent with objective assessments, and therefore, before evidence of the individual's "true" swallowing abilities was available to them. Given this study design, attributing reduced patient awareness of dysphagia to impaired sensation or inaccurate perception of swallowing function seems logical, particularly in cases where patients present with no overt symptoms.

These explanations alone, however, appear to fall short in explaining a phenomenon that speech-language pathologists often encounter in clinical practice. That is, that some patients identified as having dysphagia, even those without neurological diagnoses, continue to demonstrate reduced awareness of their swallowing problem, even *after* receiving substantial, objective evidence of their dysphagia from the medical team.

The clinical presentation of reduced patient awareness of dysphagia has been observed to vary by this author. For example, some individuals, when questioned about their dysphagia after the findings of objective swallowing assessments have been revealed to them, will report, sometimes adamantly, that they do not have a swallowing problem. Such individuals may subsequently refuse to follow prescribed diet

recommendations, swallowing strategies or swallowing exercise regimens, despite encouragement or reiteration of the findings that led to the recommendations. Other individuals may comply fully with the prescribed recommendations during their hospital stay, yet report spontaneously or when asked directly that they do not have a swallowing problem, raising concerns about the level of compliance they will maintain following discharge from the hospital.

Interestingly, no published studies have been identified that have explored the issue of reduced patient awareness of dysphagia in individuals *after* they have participated in a swallowing examination and received evidence that they have a swallowing impairment. This is surprising given that evidence of impaired patient awareness of dysphagia has often been encountered in clinical practice by this author and that reduced patient awareness of deficit has been studied extensively for other conditions.

#### Anosognosia

Anosognosia, a term first coined by Babinski (1914) to describe an individual's failure to recognize hemiparesis, is used more broadly today to describe a lack of subjective experience for a wide range of neurological and neuropsychological disturbances (Prigatano, 2009). Though it has been studied extensively in individuals with hemiplegia or motor impairment following stroke or traumatic brain injury (Baier & Karnath, 2005; Bisiach, Vallar, Perani, Papagno, & Berti, 1986; Orfei et al., 2007; Vuilleumier, 2004), it has also been noted with a variety of other neurological deficits, including aphasia (Lebrun, 1987; Rubens & Garrett, 1991), apraxia (Berti, Ladavas, &

Della Corte, 1996) deafness (Bisiach, Vallar, Perani, Papagno, & Berti, 1986), hemianopia, memory loss, and dementia (Jehkonen, Laihosalo, & Kettunen, 2006)

Anosognosia has been reported most often following damage to the right hemisphere of the brain (Baier & Karnath, 2005; Orfei et al., 2007; Starkstein, Fedoroff, Price, Leiguarda, & Robinson, 1992). Some have suggested, however, that individuals with left hemisphere damage may have been underrepresented in these studies, since assessments of anosognosia have typically relied heavily on verbal competence (G. Cocchini, Beschin, Cameron, Fotopoulou, & Della Sala, 2009).

A variety of regions of the brain have been implicated in individuals with anosognosia. These have typically involved frontal-parietal and frontal-temporal-parietal regions (Berti, Ladavas, & Della Corte, 1996; Pia, Neppi-Modona, Ricci, & Berti, 2004; Starkstein, Fedoroff, Price, Leiguarda, & Robinson, 1992). There is also growing evidence that many of these patients have subcortical lesions. More recently, a special role of the dorsal prefrontal cortex of the right hemisphere and the right insular cortex were implicated in anosognosia for hemiplegia and related phenomena (Prigatano, 2010). No single anatomical location, however, has been identified which accounts for anosognosia in all patients (Prigatano, 2010).

Prevalence rates in studies of anosognosia for hemiplegia have been difficult to estimate. Rates ranging from 10-58% have appeared in a variety of studies (Appelros, Karlsson, & Hennerdal, 2007; Bisiach, Vallar, Perani, Papagno, & Berti, 1986; Cutting, 1978; Maeshima et al., 1997; Nathanson, Bergman, & Gordon, 1952; Orfei et al., 2007; Starkstein, Fedoroff, Price, Leiguarda, & Robinson, 1992; Stone, Halligan, & Greenwood, 1993). The wide range in reported prevalence may be the result of biases in



patient selection, such as selecting patients immediately versus long after stroke onset (Orfei et al., 2007; Pia, Neppi-Modona, Ricci, & Berti, 2004) or differences in criteria used to identify the presence of anosognosia (Baier & Karnath, 2005). Given these rates of prevalence, anosognosia, at least for hemiplegia, does not appear to be a rare occurrence.

Clinical descriptions of individuals considered to have anosognosia for hemiplegia typically describe individuals as denying their deficits, such as stating they are capable of moving a paretic limb; overestimating their abilities, such as stating they move their limbs no differently than others do; or attributing their impairments to more benign causes, such as fatigue or arthritis. These false beliefs have been noted to persist despite logical arguments and contradictory evidence, with some individuals producing bizarre explanations to defend their convictions (Orfei et al., 2007).

To date, a clear understanding of the etiology of anosognosia is lacking. Proposed theories, however, are rather abundant. Absence of somatosensory input has been proposed as one cause of anosognosia (Levine, 1990). Evidence, though, has discounted that sensory loss is a necessary condition for anosognosia, as several studies of patients with hemiplegia have reported double dissociations for anosognosia and sensory impairments. That is, studies have reported that some individuals with anosognosia of hemiplegia have intact sensation of their affected limbs, while others with sensory loss of limbs present with intact awareness of their hemiplegia (Berti, Ladavas, & Della Corte, 1996; Bisiach, Vallar, Perani, Papagno, & Berti, 1986; Davies, Davies, & Coltheart, 2005; Marcel, Tegner, & Nimmo-Smith, 2004). In some studies of patients with hemiplegia, researchers have even found the incidence of anosognosia to be slightly

higher in those without sensory loss than those with sensory loss (Marcel, Tegner, & Nimmo-Smith, 2004). In addition, the argument that impaired sensory feedback is critical for explaining anosognosia does not explain deficits of poor awareness for some deficits, such as cognitive disorders (Venneri & Shanks, 2004)

Global cognitive impairment (Jehkonen, Laihosalo, & Kettunen, 2006; Marcel, Tegner, & Nimmo-Smith, 2004; Small & Ellis, 1996) has been proposed as another cause of impaired patient awareness. Evidence, however, has shown that while disorientation or confusion may be a factor in some cases, anosognosia may be present without disorientation, confusion, or general intellectual impairment, as measured by performance on psychometric tests, such as the Mini-Mental State Examination (Jehkonen, Laihosalo, & Kettunen, 2006; Marcel, Tegner, & Nimmo-Smith, 2004; Small & Ellis, 1996). In addition, evidence that patients may be anosognosic for one impairment, but not another (Berti, Ladavas, & Della Corte, 1996; Bisiach, Vallar, Perani, Papagno, & Berti, 1986; Jehkonen, Laihosalo, & Kettunen, 2006) also suggests that global cognitive impairment does not provide a complete explanation for the etiology of anosognosia.

Impairment of specific cognitive functions, such as frontal lobe functions or memory (Cocchini, Beschin, & Sala, 2002; Davies, Davies, & Coltheart, 2005; Marcel, Tegner, & Nimmo-Smith, 2004; Starkstein, Fedoroff, Price, Leiguarda, & Robinson, 1992; Vuilleumier, 2004) have also been proposed. Evidence from studies exploring measures of anosognosia and performance on traditional tests of frontal lobe functioning (Jenkinson, Edelstyn, Stephens, & Ellis, 2009; Marcel, Tegner, & Nimmo-Smith, 2004) or performance on tests of memory (Berti, Ladavas, & Della Corte, 1996; Cutting, 1978) have yielded inconsistent findings, however. While some studies have found an

association between anosognosia and frontal lobe functioning, others have not found an association between these variables.

Still others have speculated that the false beliefs held by neurological patients with anosognosia may be the neurological analogue of poor insight observed in those with psychosis (Cooke, Peters, Kuipers, & Kumari, 2005). Specific investigations of individuals with delusions have found evidence of particular reasoning abnormalities or biases, such as the tendency to “jump to conclusions,” in these individuals (Freeman, Garety, Kuipers, Fowler, & Bebbington, 2002; Garety, Hemsley, & Wessely, 1991). While such descriptions of individuals with delusions appear to mirror the clinical observations of individuals with anosognosia, no studies have been identified which have examined specifically examined the probabilistic reasoning abilities in patients with anosognosia.

### Denial

While anosognosia has been reported for a wide range of neurological and neuropsychological disturbances, denial of illness has also been observed in individuals without documented neurological dysfunction, such as those with cancer, spinal cord injury, and heart disease (Kortte & Wegener, 2004). While the terms anosognosia and denial do appear interchangeably in the literature, some authors make a clear distinction between these conditions (Orfei et al., 2007).

Recently, Prigatano (2010) presented a model which attempts to differentiate these disorders of self-awareness. In his model, the term *anosognosia* is used to refer to a syndrome of complete unawareness by an individual of a lost neurological and/or neuropsychological function. The terms impaired self-awareness, however, are used to

classify a syndrome in which individuals demonstrate partial awareness of their impairments. Partial syndrome awareness can then be further differentiated by the presence of non-defensive and/or defensive (i.e. denial) methods of coping (Prigatano, 2010).

Prigatano (2010) acknowledges that when evidence of denial, or defensive methods of coping, is present in individuals, it can be difficult to measure and treat, often requiring observations over a lengthy period of time. Prigatano and Klonoff developed The Clinician's Rating Scale as a means of identifying and differentiating these phenomena (Prigatano & Klonoff, 1998). According to this scale, individuals with impaired self-awareness without denial may appear perplexed, unclear or seemingly neutral when given feedback about their impairments. On the contrary, patients exhibiting denial of disability are described as becoming irritated and even agitated with feedback; discounting feedback regarding their deficit; or being quick to provide a logical argument to counteract unpleasant perceptions about themselves.

#### Impact of Impaired Awareness

It is proposed that exploring the prevalence and nature of reduced patient awareness of dysphagia is important for many reasons. Not only do clinical observations suggest potentially negative ramifications of reduced patient awareness, but evidence exists in the literature for other deficits that impaired of awareness may negatively impact patient adherence to therapy activities (Trahan, Pepin, & Hopps, 2006), development of a working alliance with therapists (Schonberger, Humle, Zeeman, & Teasdale, 2006), and the functional or rehabilitation outcomes (Gialanella & Mattioli, 1992; Gialanella, Monguzzi, Santoro, & Rocchi, 2005; Hartman-Maeir, Soroker, Oman, & Katz, 2003;

Jehkonen, Laihosalo, & Kettunen, 2006; Kortte & Wegener, 2004; Maeshima et al., 1997; Pedersen, Jorgensen, Nakayama, Raaschou, & Olsen, 1996; Prigatano, 2005, 2009, 2010; G. Prigatano, 2010)

In addition, with regard specifically to reduced awareness of dysphagia, the potential exists for flaws in the referral process in settings where referrals are based solely on patient's self-complaints of swallowing difficulty. Failing to identify patients with dysphagia can potentially lead to serious adverse health events, such as choking or pneumonia. By learning more about the prevalence and nature of impaired patient awareness for dysphagia, members of the medical community may become more effective at identifying dysphagia in individuals who deny the presence of swallowing problems.

There is evidence that lack of patient awareness of dysphagia may result in changes in swallowing performance and potentially impact health outcomes. In a study by Parker et al. (2004), patients with dysphagia who were classified as demonstrating poor awareness of dysphagia signs drank water significantly faster and took significantly larger volumes of water per swallow on a timed water test than individuals who demonstrated good awareness of dysphagia signs. In addition, these patients reportedly experienced a greater number of health complications within 3 months, including pneumonia and death, as compared to individuals reported to have good awareness of their dysphagic symptoms (Parker et al., 2004).

With improved understanding of impaired awareness of dysphagia, patients with poor awareness may be better identified, so that necessary measures such as increased mealtime supervision, may be employed to ensure their safety with eating. Improved

understanding of impaired patient awareness of dysphagia may also yield information on ways to improve patients' awareness of their dysphagia, so that needs for supervision or assistance can be reduced over time and individuals can regain independence with eating.

Assessment of dysphagic patients' quality of life is also crucial in advancing our understanding of the impact of swallowing interventions on patients with dysphagia.

Widely used assessments, such as the SWAL-QOL or MD Anderson Dysphagia Inventory, however, are replete with questions that appear to presume patient awareness of a swallowing problem. For example, questions on the SWAL-QOL include statements, such as "Dealing with my *swallowing problem* is very difficult. My *swallowing problem* is a major distraction in my life. My *swallowing problem* depresses me. I am upset by my *swallowing problems*". It is proposed that currently available measures of quality of life may not provide a valid measure of the impact of dysphagia in those with impaired awareness of their swallowing problem and that quality of life ratings may be inflated in those with reduced patient awareness of dysphagia and not effectively capture the impact of dysphagia on the individual's life. If this is the case, there may be benefit in conducting a preliminary assessment of patient awareness of dysphagia before administering currently available quality of life assessments. Development of quality of life assessments, that demonstrate reliability and validity in patients with reduced awareness of their dysphagia, may also be useful.

Lastly, evidence of impaired patient awareness can also create ethical dilemmas for speech-language pathologists. While patients have the right to exercise autonomy and refuse medical advice regarding the management of their dysphagia, demonstration of informed consent may be questionable when patients display evidence that they lack full

awareness of their disorder. Unfortunately, when speech-language pathologists encounter these ethical issues in individuals with evidence of reduced awareness of their swallowing problems, the literature presently offers little guidance in terms of identifying and measuring impaired patient awareness of dysphagia.

Aims of the Present Study:

Based on this review of the literature, the following aims are proposed:

1. Explore patients' awareness of dysphagia *prior* to participating in a videofluoroscopic swallowing evaluation.
  - a. Retrospectively, identify the proportion of individuals with reduced awareness of dysphagia *prior* to participating in an examination. Compare findings with those of Ding and Logemann (2008) who also explored patients' pre-examination awareness of swallowing difficulty in those with a variety of medical conditions.
  - b. Determine whether the proportion of patients with reduced awareness of dysphagia differs between those with neurological, general medical or structural diagnoses. It is hypothesized that, like the findings of Ding and Logemann (2008), those with neurological diagnoses will be least likely to demonstrate awareness of their dysphagia.

2. Explore patients' awareness of dysphagia three to seven days *after* participating in a videofluoroscopic swallowing evaluation.
  - a. Identify the proportion of individuals with reduced awareness of dysphagia *after* participating in an examination and receiving a diagnosis of oropharyngeal dysphagia. No published studies have explored this topic.
  - b. Determine whether the proportion of patients with reduced awareness of dysphagia differs between those with neurological, general medical or structural diagnoses. It is hypothesized that those with neurological diagnoses will be least likely to demonstrate awareness of their dysphagia.
  - c. Determine whether reduced post-examination awareness of dysphagia is associated with the type of response to aspiration.

The relationship between patients' subjective complaints of dysphagia and whether a silent or audible response to aspiration was noted under videofluoroscopy, has been explored in only one small study of eleven patients (Horner & Massey, 1988). Those authors found that subjective, pre-examination complaints of dysphagia were less in patients who subsequently demonstrated silent aspiration on a videofluoroscopy (37.5%) than those who demonstrated audible aspiration (100%). No studies, however, have been identified which have explored the relationship between silent or audible aspiration and patient awareness of dysphagia after a formal swallowing examination.



Since reduced sensation or sensory impairment has been speculated as one cause of silent aspiration (Ramsey, Smithard, & Kalra, 2005), findings from studies which have examined the relationship between sensory impairment and patient awareness for other deficits, such as hemiplegia, may also yield important information pertinent to this question. Evidence from these studies has not supported a relationship between these variables. For example, individuals with sensory impairment have been found to possess good awareness of their deficits, while others with intact sensation have been found to lack awareness of their deficits. Some studies have even found the incidence of anosognosia to be slightly higher in those without than those with sensory loss (Berti, Ladavas, & Della Corte, 1996; Bisiach, Vallar, Perani, Papagno, & Berti, 1986; Davies, Davies, & Coltheart, 2005; Marcel, Tegner, & Nimmo-Smith, 2004). (Marcel, Tegner, & Nimmo-Smith, 2004). Given these findings, it is hypothesized that type of response to aspiration will not be associated with patient awareness of dysphagia.

- d. Compare patient awareness of dysphagia with patient awareness for other conditions, such as limb, speech or cognitive impairments.

Previous studies have concluded that patient awareness for one condition may be dissociated with awareness for another (Berti, Ladavas, & Della Corte, 1996; Bisiach, Vallar, Perani, Papagno, & Berti, 1986; Jehkonen, Laihosalo, & Kettunen, 2006). Given these findings, it is hypothesized that patient awareness of dysphagia may be dissociated from patient awareness for other impairments. In addition, it is predicted that the proportion of individuals with reduced awareness of dysphagia will be greater than the

proportion of those with reduced awareness of limb or speech impairment, given that swallowing, unlike movement of the limbs, is not a visible act and that impaired swallowing and the clinical signs of dysphagia may not be well understood by the general population.

e. Determine whether reduced post-examination awareness of dysphagia is associated with general cognitive impairment, as measured by the Mini-Mental State Examination (MMSE; Cockrell & Folstein, 1988). It is hypothesized that like studies of impaired patient awareness for hemiplegia (Jehkonen, Laihosalo, & Kettunen, 2006; Marcel, Tegner, & Nimmo-Smith, 2004; Small & Ellis, 1996), patient awareness of dysphagia will not be strongly associated with general cognitive impairment. It is predicted that some individuals who perform within normal limits on the MMSE will demonstrate reduced awareness of their dysphagia, while others who demonstrate some degree of cognitive impairment will demonstrate good awareness of their dysphagia.

f. Determine whether post-examination awareness of dysphagia is associated with patient compliance for prescribed swallowing interventions. Given that impaired awareness of deficits has been found to be related to poor treatment adherence (Trahan, Pepin, & Hopps, 2006), it is hypothesized that individuals with reduced awareness of dysphagia will be less likely to comply with prescribed swallowing recommendations.

g. Determine whether patient compliance with prescribed recommendations is associated with action of post-action stage of change (Prochaska, DiClemente, & Norcross, 1992).

Stages of change is a model of health behavior change that has been applied in many settings to a variety of populations undergoing behavioral change. It asserts that an individual's decisions about behavioral change are influenced by their beliefs and intentions.

Supported by several lines of research, it proposes that over time, individuals intentionally moves through stages of behavioral change (Prochaska, DiClemente, & Norcross, 1992). In the first stage, precontemplation, individuals may be unaware or underaware of their problems. This stage is characterized by no intention to change behavior in the foreseeable future with individuals in this stage likely to endorse statements, such as "As far as I'm concerned, I don't have any problems that need changing". In the second stage, contemplation, people are aware that a problem exists and are seriously considering taking action, but have not yet made a commitment to do so. Individuals in this stage are likely to endorse statements, such as, "I have a problem and I really think I should work on it". At the third stage, preparation, individuals are intending to take action in the very near future. Action, the fourth stage, is marked by individuals taking action to modify their behavior and overcome their problems. Individuals in this stage might acknowledge statements, such as "I am actively working on my problem". The final stage, maintenance, is characterized by continued action and maintenance of the new behavior (Prochaska, DiClemente, & Norcross, 1992). The application of this model to the study of patients with a newly diagnosed swallowing

disorder may be beneficial, as these individuals are often encouraged to make short or long-term behavioral changes in their diet, swallowing behaviors and daily regimens. It is hypothesized that patient compliance with swallowing recommendations will be associated with action or post-action stages of change.

## CHAPTER II

### METHODS

#### Participants

Approval for this study was granted by the Genesis Health System Institutional Review Board in March of 2010. A target sample size of 20 patients was established for this study by principle investigator and the dissertation committee. This was based in part on findings from a power analysis, using pilot data collected by the principle investigator in 2009.

Twenty-one patients (18 inpatients and 3 outpatients) from four Genesis Health System facilities participated in this study between March of 2010 and January of 2011. Information regarding individual participants' age, sex, etiology of dysphagia and type of response to aspiration is presented in Table 1.

The etiology of participants' dysphagia was classified into one of three medical diagnostic categories: neurological, structural or general medical diagnoses. Information regarding the age, gender and specific medical diagnoses of each of these diagnostic groups is presented in Table 2. As shown in this table, 24% of participants had dysphagia that was attributed to structural diagnoses, 33% had dysphagia attributed to general medical diagnoses, and 43% had dysphagia attributed to neurological diagnoses.

Criteria for inclusion into this study included: adequate alertness to participate in all aspects of the study and newly diagnosed dysphagia, or disordered swallowing, at the oral and/or pharyngeal stages of swallowing. For the purposes of this study, a diagnosis of dysphagia required evidence of aspiration, defined as the presence of contrast material below the true vocal folds, during a videofluoroscopic swallowing evaluation.

Determination of the presence of aspiration was based on the consensus of the attending speech-language pathologist and radiologist who jointly conducted the radiographic swallowing study.

Criteria for exclusion included: individuals with a history of documented aspiration on a previous videofluoroscopic swallowing evaluation, due to oral and/or pharyngeal impairment; premorbid cognitive deficits, significant enough to warrant continuous supervision in their home environment; language impairments, significant enough to prevent the individual from sufficiently understanding and verbalizing sentence-level information; or severely reduced speech intelligibility.

#### Procedure

Inpatients or outpatients who presented with evidence of aspiration during a videofluoroscopic swallowing evaluation, as a result of oral and/or pharyngeal impairment, were invited to participate in this study by the attending speech-language pathologist. If the individual agreed to participate, informed consent was obtained and participants were enrolled within 3-7 days of their videofluoroscopic swallowing study. Once enrolled, information regarding the individual's pre-swallow study response to the routinely posed question "Do you have a swallowing problem?" was obtained. The participants' pre-examination awareness of the presence of dysphagia was scored on a dichotomous scale, with a *yes* response indicating awareness of dysphagia and a *no* response indicating reduced patient awareness of dysphagia.

The type of response patients exhibited following aspiration was taken from the speech-language pathologists' reports and then corroborated with information in the radiologists' reports. In cases where specific information regarding patient response to

aspiration was absent or unclear in the radiologists' reports, the principle investigator reviewed the recorded swallowing study and assigned a classification. Patients were classified as demonstrating an immediate (i.e. within 5 seconds), consistent cough response following aspiration or a reduced cough response (i.e. silent aspiration, delayed cough or inconsistent cough) following aspiration.

Once enrolled in the study, each participant received the following information, a minimum of one day before the study interview:

- Told verbally that “dysphagia,” a “swallowing problem” or a “swallowing impairment” was noted during their videofluoroscopic evidence of a swallowing study.
- Told verbally that evidence of “aspiration,” or “food or drink entering the wrong pipe” was noted during their videofluoroscopic swallowing study.
- Told verbally that aspiration did or did not produce a cough response during their videofluoroscopic swallowing study.
- Shown one occurrence of aspiration from their recorded videofluoroscopic swallowing study.

Three to seven days after their videofluoroscopic swallowing evaluation, a follow-up interview was conducted. At this time, the Mini-Mental State Examination (MMSE), as shown in Appendix A, was administered. Scoring of the MMSE was completed as suggested in the article by Folstein (Folstein, Folstein, & McHugh, 1975).

A structured, face-to-face interview, as detailed in Appendix B, was completed by the principle investigator. Questions were posed to assess each individual's awareness of the presence of dysphagia; awareness of coexisting motor, speech and/or cognitive

deficits; awareness that a swallowing test had recently been completed and the general findings from the swallowing test. Care was taken to ask all questions in a neutral manner.

To assess patients' awareness of their dysphagia, patients were first asked a general question regarding any health problems that they were currently experiencing, followed specifically by the question, "Do you have a swallowing problem?" If the individual denied dysphagia when asked specifically, they were given the following information: "Your speech therapist tells me that you had a swallowing test on (insert date) in which you were given a variety of items to eat and drink, such as ice cream/barium liquid/pudding/graham cracker. She/he tells me that were diagnosed with a swallowing problem that day, since some of the items that you tried to swallow went down the wrong pipe into your lungs." and then asked, "Do you agree with your therapist that you have a swallowing problem?"

Patient awareness of the presence of dysphagia was scored initially using a dichotomous scale. This scale permitted comparisons between patient awareness of dysphagia and patient awareness for limb impairment, cognitive impairment, and speech impairment, which were assessed via direct yes/no questions.

Patient awareness for the presence of dysphagia was further classified using a modification of Bisiach's 4-point scale (Bisiach, Vallar, Perani, Papagno, & Berti, 1986). Bisiach's scale was designed to measure anosognosia related to motor impairment and is frequently used in studies of anosognosia for hemiplegia. Modifications to account for swallowing impairment follow:



0- Patient demonstrates awareness of the presence of dysphagia= A swallowing problem is spontaneously reported or mentioned by the patient following a general question about his complaints.

1-Mildly reduced patient awareness of the presence of dysphagia= A swallowing problem is reported only following a specific question about one's swallowing.

2-Moderately reduced patient awareness of the presence of dysphagia= A swallowing problem is acknowledged only after the patient is told: "Your speech therapist tells me that you had a swallowing test on \_\_\_\_\_ in which you were given a variety of items to eat and drink. She/he tells me that you were diagnosed with a swallowing problem that day, since some of the items that you tried to swallow went down the wrong pipe into your lungs."

3-Severely reduced patient awareness of the presence of dysphagia=No acknowledgement of a swallowing problem can be obtained even upon hearing a verbal recount of their abnormal performance on a recent swallowing x-ray and the subsequent diagnosis of a swallowing problem by their speech-language pathologist.

Limitations in the use of Bisiach's scale were identified early in the study, however. Conclusions drawn by Baier and Karnath (2005) also suggest limitations of this scale. Baier and Karnath (2005) explored whether an individual's lack of acknowledgement of a disorder, in response to a general question about symptoms, should warrant a rating that suggests *impairment* or whether this phenomenon may actually be within the normal range. These authors found a high degree of similarity in their study between patients rated as "0" and those rated as "1" on several clinical variables. In addition, they found that 94% of patients in their sample rated as level "1," or classified as having mildly reduced patient awareness, did not have appear to lack acceptance of their deficit, but simply perceived other symptoms of theirs as being more relevant or noteworthy, when asked a general question of their complaints (Baier & Karnath, 2005).

The findings of Baier and Karnath (2005) were consistent with those in this study as many patients who did not state the presence of dysphagia when asked a general question about current health symptoms, immediately acknowledged a swallowing problem when asked specifically, “Do you have a swallowing problem?” In addition, some of the individuals who only affirmed the presence of a swallowing problem after a specific question, provided the most accurate and detailed explanations, regarding the nature of their swallowing impairment.

Given these findings, awareness of dysphagia was subsequently classified as follows:

2 –Awareness of the presence of dysphagia= The presence of a swallowing problem is acknowledged in response to the specific question, “Do you have a swallowing problem?” and consistently throughout the interview

1-Partial awareness of the presence of dysphagia (Reduced)= The presence of a swallowing problem is denied in response to the specific question, “Do you have a swallowing problem?” but acknowledged at least once throughout the interview, such as following a reiteration of the findings of the swallowing examination.

0-Lacking awareness of the presence of dysphagia (Reduced)= The presence of a swallowing problem is denied in response to the specific question, “Do you have a swallowing problem?” and consistently throughout the interview, despite a reiteration of the findings of the swallowing examination.

Patient awareness of impaired limb functioning was assessed by asking “Do you have a problem using your legs?” and “Do you have a problem using your arms?”

Impaired leg functioning was determined to be present if documentation in the medical chart, by a licensed physical therapist, indicated that lower extremity functioning was outside of normal limits at the time of the patient’s admission to the hospital. Impaired arm functioning was determined to be present if documentation in the medical chart, by a licensed occupational therapist, indicated that upper extremity functioning was outside of

normal limits at the time of the patient's admission to the hospital. Patient awareness of a speech impairment was assessed by asking "Do you have a speech problem?" A speech impairment was determined to be present if documentation in the medical chart, by a licensed speech-language pathologist, indicated that speech production abilities were outside of normal limits at the time of the patient's admission to the hospital. Cognitive impairment was determined to be present if the patient's score on the Mini-Mental State Examination was outside of normal limits, that is, a score less than 23.

Patient compliance for three types of swallowing recommendations was explored: diet, swallowing strategies/maneuvers and exercise regimens. First, patient compliance with the diet recommendations was assessed as described in Appendix C. This assessment was comprised of two parts: diet compliance for all potential eating opportunities in the days following diagnosis and a one-time sampling of diet compliance during the study protocol.

Diet compliance for all potential eating opportunities, in the days following diagnosis, was assessed by having the patient's primary speech-language pathologist complete the following statement: "Given the information shared by my patient, his/her family, other staff and my own observations, I believe that this patient is always/sometime/never compliant with the diet recommendations I prescribed". In addition, patients self-rated their compliance for all potential eating opportunities, in the days following diagnosis, by answering the question, "Since your swallowing test, have you always, sometimes, or never followed the diet recommendations given to you?"

A one-time sampling of diet compliance was completed by asking patients to identify one permissible drink and food item that could be obtained to assess their

swallowing ability during the study protocol. Participants' knowledge of their current recommended diet was also assessed, either spontaneously, via yes-no questions, or multiple choice options.

Patient compliance with the second type of recommendation, prescribed swallowing strategies/maneuvers, was assessed as described in Appendix D. This assessment involved observing each patient take three sips and three bites of permissible items; having patients self-report their compliance by answering the question, "When you eat or drink, do you always, sometimes or never use the swallowing strategies of (insert patient's strategies)?"'; and having the patient's primary speech-language pathologist rate compliance by completing the statement, "Given the information shared by my patient, his/her family, other staff and my own observations, I believe that this patient is always, sometimes or never compliant with the swallowing strategies/maneuvers I prescribed." This assessment was not completed in patients who were receiving nothing by mouth (NPO) and in patients for whom no swallowing strategies/maneuvers had been prescribed.

Patient compliance with the third type of recommendation, prescribed exercise regimens, was assessed as described in Appendix E. This assessment involved asking participants to demonstrate their prescribed exercise regimen; having participants self-report their compliance with the regimen by answering the question, "Do you always, sometimes or never perform your swallowing exercises as prescribed by your therapist?"; and having the patient's primary speech-language pathologist rate the participants compliance as "always," "sometimes," or "never." This assessment was not completed in patients for whom no independent swallowing exercise regimens had been prescribed.

The last portion of the study protocol was designed to assess the stage of change participants were presently functioning in. Participants were read or shown five statements, each representing one of the stages of change: pre-contemplation, contemplation, preparation, action or maintenance. The statements, shown in Appendix F, were based on those suggested by Prochaska, DiClemente and Norcross (1992) and modified to make them applicable to individuals with swallowing problems. Individuals were asked to select the statement they “most identified with.”

## CHAPTER III

### RESULTS

#### Pre-examination Awareness of Dysphagia

Once enrolled in the study, patients' pre-examination response to the routinely posed question "Do you have a swallowing problem?" was obtained. Data was available for 20 out of 21 patients, as one patient was not asked this question prior to their swallow study. 40% (8/20 patients) of individuals were classified as demonstrating reduced pre-examination awareness of their dysphagia.

Of the eight patients identified with reduced pre-examination awareness of their dysphagia, 50% had been diagnosed with a general medical condition, 37.5% of patients had been diagnosed with neurological condition and 12.5% of patients had been diagnosed with a structural condition as the primary etiology of their dysphagia. A one-sample chi-square test was completed to determine if the proportions across diagnostic categories differed significantly from proportions of equal probability (i.e. 33.3%) across groups. This analysis yielded a p-value of 0.417 indicating that the obtained proportions did not differ significantly from proportions of equal probability.

When patients were classified by type of response following aspiration, 50% of patients (2/4 patients) with an immediate, consistent cough response demonstrated reduced pre-examination awareness of their dysphagia and 41% of patients (10/16 patients) with a reduced cough response demonstrated reduced pre-examination awareness of their dysphagia. An analysis of the relationship between type of aspiration response and patient awareness of dysphagia was completed using Fisher's exact test.

This test yielded a one-tailed p-value of 0.656, indicating no significant association between these two variables.

#### Post-examination Awareness of Dysphagia

All patients were interviewed 3-7 days after their swallowing assessment. At this time, all patients had received verbal information about their dysphagia and had been shown at least one occurrence of aspiration from their recorded swallowing study. At the time of the follow-up interview, 19% (4/21 patients) of patients were classified as demonstrating reduced post-examination awareness of their dysphagia. This proportion is reduced from 40% of patients who demonstrated reduced awareness of their dysphagia *prior* to their swallowing examination. A related samples McNemar Test yielded a p-value of 0.453, indicating that the change in the proportions of pre-examination reduced awareness and post-examination reduced patient awareness was not significant.

Of the four patients considered to have reduced awareness of the presence of their dysphagia, all were further classified as demonstrating partial awareness of their dysphagia, as they demonstrated both acknowledgement and lack of acknowledgement of the presence of dysphagia during the course of the interview. No patients in the study were classified as lacking complete awareness of the presence of dysphagia. That is, none consistently denied a swallowing problem when asked a general question about their health, a specific question about the presence of dysphagia and when objective evidence of their dysphagia was reiterated.

When classified by medical diagnosis, none of the study participants with general medical diagnoses demonstrated reduced post-examination awareness of the presence of dysphagia, compared to 57% prior to the examination; 22% (2/9 patients) of study

participants with neurological diagnoses demonstrated reduced awareness of the presence of dysphagia after their study, compared to 37% prior to the examination; and 40% (2/5 patients) of study participants with structural diagnoses demonstrated reduced awareness of the presence of dysphagia after their study, compared to 20% prior to the examination.

Among the four patients identified as having reduced post-examination awareness of their swallowing problem, two patients had neurological diagnoses and two patients had structural diagnoses. No patients classified as demonstrating reduced post-examination awareness had a general medical condition. A one-sample chi-square test was completed to determine if the proportions across diagnostic categories differed significantly from proportions of equal probability (i.e. 33.3%) across groups. This analysis yielded a p-value of 1.0 indicating that the obtained proportions did not differ significantly from proportions of equal probability.

All four patients with reduced post-examination awareness of dysphagia demonstrated a reduced cough response following aspiration. Specifically, three patients demonstrated silent aspiration and one patient demonstrated a delayed cough response following aspiration (greater than 5 seconds). An analysis of the relationship between type of aspiration response and patient awareness of dysphagia was completed using Fisher's exact test. This test yielded a one-tailed p-value of 0.398, indicating no significant association between these variables.

Regarding patient awareness for coexisting impairments, 50% (4/8) of study participants demonstrated reduced awareness of a cognitive impairment, 33% (4/12) of study participants demonstrated reduced awareness of an impairment in arm functioning, 24% (4/17) of study participants demonstrated reduced awareness of an impairment in leg



functioning, and 10% (1/10) of study participants demonstrated reduced awareness of a speech impairment. This is compared to 19% of study participants, who demonstrated reduced post-examination awareness of their dysphagia.

The relationship between patient awareness of dysphagia and general cognitive functioning, as measured by the MMSE, was explored. Of the individuals who demonstrated good awareness of their dysphagia, 12 scored within normal limits on the MMSE and five scored in the moderate impairment range. Of those individuals with reduced awareness of dysphagia, one scored within normal limits, one scored in the mild impairment range and two scored in the moderate impairment range. No individuals in this study scored in the severe impairment range. An independent groups t-test comparing the mean MMSE scores of patients with awareness of dysphagia and those with reduced awareness of dysphagia yielded a one-tailed p-value of 0.099. These findings do not support a significant relationship between general cognitive impairment and patient awareness of dysphagia.

#### Patient Compliance with Diet Recommendations

Some of the analyses reported below considered inpatients and outpatients separately, given the unique circumstances of these individuals. Other analyses pooled the data for all participants.

Ratings of diet compliance, for all potential eating opportunities in the days following diagnosis, were solicited from each participants' primary speech-language pathologist at the time patients completed the study protocol. Since none of the outpatients had begun receiving therapy services by a speech-language pathologist at the time of the study interview, data for this measure is reported for inpatients only.

100% (18/18) of inpatients were judged by their primary speech-language pathologist to have *always* been compliant with their prescribed diet recommendations during their hospitalization (i.e. from the day of diagnosis until the day that the study protocol was completed). 67% (12/18) of those same individuals demonstrated compliance with their recommended diet when compliance was sampled during the study protocol. Four out of the six patients who were not compliant when diet compliance was sampled during the protocol, demonstrated knowledge of their recommended diet, by spontaneously reporting the diet or responding to yes/no and multiple-choice questions.

When examining diet compliance, as sampled during the study protocol, data for both inpatients and outpatients was also pooled together. 70% (14/20) of inpatient and outpatient participants were compliant with their recommended diet.

An analysis of the relationship between patient awareness of dysphagia and compliance with diet, as sampled during the study protocol, was completed using Fisher's exact test. This analysis yielded a one-tailed p-value of 0.657, indicating no significant association between these variables.

The relationship between general cognitive functioning and patient compliance with diet recommendations, as sampled during the study protocol, was explored by performing an independent groups t-test. This analysis yielded a one-tailed p-value of 0.484, suggesting no significant relationship between these variables.

#### Patient Compliance with Swallowing Strategies/Maneuvers

Eight of the 21 study participants had been prescribed swallowing strategies/maneuvers by the time of the study interview. 50% of these individuals (4/8 patients) demonstrated total compliance with their swallowing strategies/maneuvers

during the study protocol. An analysis of the relationship between patient awareness of dysphagia and patient compliance with strategies/maneuvers was completed using Fisher's exact test. This test yielded a one-sided p-value of 0.5, indicating no significant association between these two variables.

#### Patient Compliance with Exercise Regimens

Twelve of 21 study participants had been prescribed exercise regimens by the time of their study interview. 100% of these individuals demonstrated compliance with their exercise regimens *during* speech-language sessions, as documented in the medical record by their speech-language pathologists.

Eight of the twelve participants had been instructed to complete their exercise regimens *independently* outside of speech-language sessions. According to each patient's primary speech-language pathologist, only 63% of these patients were judged to *always* be compliant with their independent exercise regimens. An analysis of the relationship between patient awareness of dysphagia and patient compliance with independent exercise regimens was completed using Fisher's exact test. This analysis yielded a one-sided p-value of 0.643, indicating no significant association between these two variables.

#### Stages of Change

Participants were instructed to select one of five statements, adopted from the Transtheoretical Stages of Change model, they most identified with. None of the four participants who denied the presence of a swallowing problem, when asked, "Do you have a swallowing problem?" during the study interview, subsequently selected the only stages of change statement containing the phrase, "I don't have a swallowing problem." Rather, all four participants who denied the presence of dysphagia selected one of the

four remaining statements which began with the phrase, “I have a swallowing problem...”.

An analysis of the relationship between diet compliance, as sampled during the study protocol, and action or post-action stage of change was completed using Fisher’s exact test. Findings yielded a one-tailed p-value of 0.221, indicating no significant association between these variables.

## CHAPTER IV

### DISCUSSION

This purpose of this study was to explore patient awareness of swallowing problems in the days immediately after individuals receive a formal diagnosis of oropharyngeal dysphagia. These days are often characterized by a flurry of activity in which medical personnel diagnose the presence of dysphagia, educate patients and families on the disorder and its manifestations, and offer recommendations to manage or improve the dysphagia. In some cases, patients may be faced with difficult ethical dilemmas at this time, such as making decisions about alternative nutrition sources when oral intake is deemed to be risky.

#### Pre-examination Awareness of Dysphagia

Once patients with identified dysphagia were enrolled in this study, a retrospective analysis was completed to determine patients' awareness of their dysphagia *before* participating in their swallowing examination. 40% of participants demonstrated reduced awareness of their dysphagia by responding "no" when asked, "Do you have a swallowing problem?" prior to their examination.

This finding along with those of other studies (Bird, Woodward, Gibson, Phyland, & Fonda, 1994; Boczko, 2006; Ding & Logemann, 2008; Horner & Massey, 1988; Newton, Newton, Pearl, & Davidson, 1994; Parker et al., 2004) provides evidence that patients' impressions of their swallowing function do not always agree with the findings of objective assessments and suggests that patients' reports of swallowing problems cannot be relied upon solely for identifying those with oropharyngeal dysphagia.

The prevalence of patients with reduced pre-examination awareness of dysphagia is similar to that reported in a larger study by Ding and Logemann (2008), which also included patients with a wide variety of medical diagnoses. In their study, 46% of patients who were subsequently diagnosed with dysphagia, did not report swallowing difficulties at the time of their examination.

Of the eight patients with reduced pre-examination awareness of a swallowing problem, four had general medical diagnoses, three had neurological diagnoses and one had a structural diagnosis. These results suggest that individuals with a wide array of diagnoses may demonstrate reduced awareness of their dysphagia. The results also differ from Ding and Logemann's (2008) findings, in that the highest proportion of patients with reduced awareness did not occur in those with neurological diagnoses. Conclusions regarding potential differences between this study and Ding and Logemann's (2008) are limited, however, given the small number of individuals with reduced awareness in this study.

The relationship between pre-examination awareness of dysphagia and type of response with aspiration was explored. 63% of those with a reduced cough response (i.e. silent aspiration, delayed cough or inconsistent cough) following aspiration demonstrated reduced awareness of their dysphagia. 50% of those with an immediate, consistent cough response demonstrated reduced awareness of their dysphagia. No significant relationship between patient awareness of dysphagia and cough response with aspiration was found.

Given these findings, other variables, such as chewing problems, difficulty triggering a timely swallow response or the presence of post-swallowing pharyngeal residual, may provide more substantial evidence of a swallowing problem to individuals,

than coughing upon aspiration. This may be true given that coughing, unlike these other variables, can also be a benign event.

#### Post-examination Awareness of Dysphagia

The primary intent of this study was to explore patients' post-examination awareness of dysphagia, as no studies have been identified in the literature on this topic. Study participants were interviewed three to seven days after their swallowing evaluation. Prior to the interview, all patients received specific verbal information about their dysphagia and were shown at least one occurrence of aspiration from their recorded swallowing study. This information was presented to ensure that any evidence of reduced patient awareness of dysphagia was not the result of failure, on the part of medical personnel, to inform patients about the findings of their examination, as might be the case in a busy medical setting. In addition, the decision to show each participant a portion of their swallowing study was added to give credibility to the information presented and to potentially aid the patient in understanding the information.

The time frame of three to seven days was selected to allow time for patients to have received information regarding their dysphagia and to have personally experienced the effects of any implemented swallowing recommendations. By the time of the study interview, nearly all participants had experienced significant diet modifications, implemented as a result of the findings of their swallowing evaluation. One-third of patients were receiving either nothing by mouth or only ice chips. 38% of patients were restricted from thin liquids and were receiving thickened liquids of nectar or honey consistency only. 52% of patients were receiving some modification of food textures, such as a pureed diet, mechanical soft diet, or shaved meats.

In addition to receiving specific verbal and visual information regarding their dysphagia and personally experiencing the effects of diet modifications, most patients had also begun receiving services by a speech-language pathologist. During speech therapy sessions, activities aimed at improving individuals' swallowing abilities were initiated and it is likely that their dysphagia was discussed further.

Despite the variety of information participants had received about their dysphagia, 19% of participants (4/21) demonstrated reduced awareness of their dysphagia at the time of the follow-up interview, by responding “no” when asked, “Do you have a swallowing problem?”. Of the four patients who demonstrated reduced awareness of their dysphagia, none were classified as demonstrating a complete lack of awareness of their dysphagia (i.e. consistently denying a swallowing problem throughout the interview despite reiteration of objective evidence of their dysphagia). Rather, all four participants were classified as demonstrating partial awareness of their swallowing problem, as they both acknowledged and denied the presence of dysphagia over the course of the interview.

Two of the four individuals demonstrating partial awareness of their dysphagia, accurately reported some details of their dysphagia, but seemed to be wavering on whether they, personally, believed it to be a “problem” or at least believed it to be a problem at the present time. The dialogue with one of these patients, an individual with a neurological diagnosis, is given below:

Subject A: “I’m having trouble with food. They’re afraid if I swallow it’ll get in my lungs. Here...” (participant handed her list of swallowing exercises to the principle investigator)

Interviewer: “Do you have a swallowing problem?”

Subject A: “I don’t think it’s much of a swallowing problem.”

Interviewer: “Your speech therapist tells me that you had a swallowing test on (date inserted) and were given a variety of items to eat and drink,



such as (items inserted). She tells me you were diagnosed with a swallowing problem that day, since some of the items that you tried to swallow went down the wrong pipe into your lungs. Do you agree with your therapist that you have a swallowing problem?

Subject A: "No."

Later when this individual was asked to state which of five statements from the stages of change they most identified with, the individual selected "I have been working on improving my swallowing problem for a while" then spontaneously verbalized "I guess I have a problem." Despite denying the presence of a swallowing disorder, this individual also reported that they always did their swallowing exercises twice per day and it was noted that a list of swallowing exercises was located on their table during the interview.

The dialogue with the second patient, an individual with a structural diagnosis, is given below:

Interviewer: "Do you have a swallowing problem?"

Subject B: "No."

Interviewer: "Have you had any swallowing tests recently?"

Subject B: "Yes, it went down the other chute when I swallowed."

Interviewer: "Your speech therapist tells me that you had a swallowing test on (date inserted) and were given a variety of items to eat and drink, such as (items inserted). She tells me you were diagnosed with a swallowing problem that day, since some of the items that you tried to swallow went down the wrong pipe into your lungs. Do you agree with your therapist that you have a swallowing problem?"

Subject B: "100%...I don't think I do... But she showed me... I don't think I do... I'm not going to argue with her. She showed me."

Later when this individual was asked to state which of five stages of change they most identified with, the individual selected: "I have a swallowing problem and I have decided to start working on improving it". After the interview, when asked informally

why conflicting responses were given, the individual stated “I never would have thought I had trouble swallowing. I thought I was perfect. I guess I’m not.”

Prigatano (2010) has proposed that individuals with a partial syndrome of unawareness, can be differentiated into two categories: those using defensive methods of coping, such as denial, and those using non-defensive methods of coping (Prigatano, 2010). He suggests that individuals exhibiting denial of disability become irritated, possibly even agitated, when given feedback; often discount feedback regarding their deficit; and may be quick to provide a logical argument to counteract unpleasant perceptions about themselves (Prigatano & Klonoff, 1998). While neither of these two patients exhibited signs of irritation or agitation during the interview, their responses do suggest a discounting of feedback about their swallowing performance that they have received by others.

The responses of the remaining two individuals appear more characteristic of impaired self-awareness without denial as described by Prigatano (2010). He states that such individuals are often perplexed and demonstrate a neutral reaction or appear unclear about feedback about their impairment. The dialogue with these patients is as follows:

Interviewer: “Do you have a swallowing problem?”

Subject C: “No.”

Interviewer: “Have you had any swallowing tests?”

Subject C: “Yes.”

Interviewer: “What were the results of your swallowing x-ray?”

Subject C: “On a thick diet”

Interviewer: “Your speech therapist tells me that you had a swallowing test on (date inserted) and were given a variety of items to eat and drink, such as (items inserted). She tells me you were diagnosed with a swallowing problem that day, since some of the items that you tried to swallow went down the wrong pipe into your lungs. Do you agree with your therapist that you have a swallowing problem?”

Subject C: “Yes”

Interviewer: “Do you have a swallowing problem?”

Subject D: “No”

Interviewer: “Have you had any swallowing tests?”

Subject D: “Yes.”

Interviewer: “What were the results of your swallowing x-ray?”

Subject D: “It’s obviously changed the way I eat. Liquid diet regimens five portions a day and will not eat regular food because of swallowing...Hangs on the epiglottis. Goes in the wrong place.”

Interviewer: “Your speech therapist tells me that you had a swallowing test on (date inserted) and were given a variety of items to eat and drink, such as (items inserted). She tells me you were diagnosed with a swallowing problem that day, since some of the items that you tried to swallow went down the wrong pipe into your lungs. Do you agree with your therapist that you have a swallowing problem?:

Subject D: “Yes”

As noted in the above responses, some patients both acknowledged and denied the presence of dysphagia over the course of their interview. Interestingly, Ding and Logemann (2008) also casually mention a similar phenomenon in some of the patients from their study. They state:

“a small percentage of patients answered the first question by indicating that they have swallowing problems, but answered the third and fourth question regarding the location and severity of their swallowing problems by indicating that they do not have a swallowing problem.”

Ding and Logemann’s (2008) explanation for these inconsistencies in their patients’ responses, is that individuals may have responded that they have a swallowing problem because they have been told so by staff or family, but when asked to specify the location or severity were unable to provide such information. It is suggested, however, that if the study participants simply did not know the location and severity of the dysphagia, they would have more likely responded with a comment, such as “I don’t know” when asked this information, rather than indicating that they “do *not* have a swallowing problem.”

Perhaps the vacillation between denying and acknowledging the presence of a swallowing problem observed in some patients of this study is better explained by the conclusions offered by Marcel, Tegner and Nimmo-Smith (2004). In their study, they reported that some patients gained awareness that a deficit is present during particular instances of performance failure, however, in some cases, this insight was short-lived. Marcel et al. (2004) theorized that unless information regarding specific instances of performance failure is incorporated into an individual's generic or long-term knowledge of their bodies, an individual may not demonstrate awareness of having a deficit (e.g. "I have a plegia."). They conclude that concurrent awareness of particular instances of failure (e.g. "I had difficulty attempting to tie my shoes.") and awareness of having a deficit (e.g. "I have a plegia.") appear to be independent of one another and that there may be benefit in differentiating among these types of awareness rather than using the single term *awareness* (Marcel, Tegner, & Nimmo-Smith, 2004).

Marcel and colleagues' explanation appears consistent with the information communicated by three of the four participants, as described above. That is, while these individuals did not demonstrate awareness of having a deficit (e.g. "I have a swallowing problem."), they demonstrated awareness of particular instances of swallowing failure that occurred during their swallowing examination (e.g. "I'm having trouble with food. They're afraid if I swallow it'll get in my lungs.", "It went down the other chute when I swallowed.", "Hangs on the epiglottis. Goes in the wrong place.>").

The association between reduced post-examination awareness of dysphagia and underlying etiology of dysphagia (i.e. neurological, structural or general medical diagnoses) was explored. Among those patients who demonstrated reduced post-

examination awareness of dysphagia, no patients had general medical diagnoses, which is reduced from 57% before the swallowing test; 22% of patients had neurological diagnoses, which is reduced from 37% before the swallowing test; and 40% of patients had structural diagnoses, which is increased from 20% before the swallowing test.

In those with neurological and general medical diagnoses, overall awareness improved following post-examination education, particularly for those with general medical conditions. However, the proportion of individuals with impaired awareness increased in those with structural diagnoses, as one individual in the group indicated the presence of a swallowing problem prior to the swallowing examination, but denied a problem in the post-examination interview. It is noted that this patient was eating an oral diet at the time of the initial swallowing examination reporting “everything is going down the wrong way”. The patient was subsequently made NPO after the videofluoroscopic swallowing study and had remained so for the five days preceding the post-examination interview. Perhaps because the patient had not been eating by mouth at the time of the post-examination interview and therefore, experienced a significant reduction in the frequency of incidences of swallowing difficulty, this individual concluded that a swallowing problem no longer existed at the time of the post-examination interview. Similarly, another patient when asked “Do you have a swallowing problem?”, replied “They say I do, but it doesn’t seem as bad since drinking the heavy stuff.” These instances illustrate how individuals may be perceptive enough to realize that their dysphagic symptoms have reduced, but may conclude that this implies a swallowing problem no longer exists, rather than considering other potential causes.

The relationship between patient awareness of dysphagia and type of response to aspiration was explored. 100% of participants (4/4) with reduced awareness of dysphagia demonstrated a reduced cough response, following aspiration. No significant relationship between type of response to aspiration and awareness of dysphagia was found, however, as 71% of those with a reduced cough response demonstrated awareness of their dysphagia. As mentioned previously, there may be benefit in exploring the relationship between patient awareness of dysphagia and other dysphagic symptoms that don't also occur under "normal" circumstances, such as chewing problems, difficulty triggering a swallow and significant pharyngeal residue.

The relationship between patient awareness of dysphagia and general cognitive functioning was explored. A significant relationship between these variables was not found, however, when mean MMSE scores of those with awareness of their dysphagia were compared to scores of those with reduced awareness of dysphagia. As predicted, some individuals who performed within normal limits on the MMSE demonstrated reduced awareness of their dysphagia, while others who performed in the impaired range on the MMSE, demonstrated good awareness of their dysphagia. These findings are consistent with other studies which have explored the association between patient awareness of deficit and general cognitive functioning. They suggest that while cognitive impairment may be a contributing factor to reduced awareness, it alone does not appear to explain the presence of reduced awareness.

The relationship between patient awareness of dysphagia and awareness for other conditions was explored. 50% of participants with cognitive impairments demonstrated awareness of their cognitive deficit, 67% of participants with impaired arm functioning and 76% of participants with impaired leg functioning demonstrated awareness of their limb impairments, and 90% of participants with dysarthria demonstrated awareness of their speech impairment. These proportions are compared to 81% of participants with dysphagia who demonstrated awareness of their swallowing impairment.

Evidence that patient awareness of motor impairment occurred more often than awareness of cognitive impairment is consistent with other studies which have explored patient awareness of deficits (Anderson & Tranel, 1989; Hartman-Maeir, Soroker, Oman, & Katz, 2003). Contrary to predictions, the proportion of individuals with reduced awareness of dysphagia was not greater than the proportion of individuals with reduced awareness of motor impairment. It is noted, however, that criteria used by therapists for determining the presence of a motor “problem” may have been different or more stringent than that used by the study participants.

Analyses of findings for single individuals also confirmed that different levels of awareness for different conditions may occur within an individual. For example, some patients with reduced awareness of dysphagia acknowledged awareness of other deficits, such as cognitive, speech or limb impairment; others with awareness of dysphagia lacked awareness for these deficits. These observations support conclusions by others that anosognosia may be modality specific (Prigatano, 2010).

In the course of exploring factors that may contribute to reduced awareness of dysphagia, the heterogeneity of the four participants identified as having reduced

awareness became evident. The assorted findings for all analyses completed with these individuals are displayed in Table 3. These findings support reports in the literature that describe anosognosia as a complex and multifaceted phenomena that manifests itself differently and to different degrees in individuals (Orfei et al., 2007).

The last portion of this study examined patients' compliance for prescribed swallowing recommendations. Specifically, patient compliance for diet recommendations, swallowing strategies/maneuvers, and exercise regimens were explored.

#### Patient Compliance with Diet Recommendations:

Initially, participants' diet compliance for all potential eating opportunities, in the days following diagnosis, was explored in inpatients. All inpatients (18/18) were reported to have been 100% compliant with prescribed diet recommendations during their hospitalization (i.e. from the day of diagnosis until the day that the study protocol was completed). However, only 67% (12/18) of these patients requested permissible foods or drinks when compliance was sampled during the study protocol. This finding suggests that inpatients with newly diagnosed dysphagia may be less compliant if restricted items become accessible. Further probing indicated that several of the noncompliant individuals possessed knowledge of their recommended diet, suggesting that factors, other than lack of knowledge regarding the appropriate diet, contributed to their noncompliance. Given the limited access to food and drink inherent in medical settings, a more valid measure of patient compliance with diet recommendations might be obtained by studying individuals who are not hospitalized or residing in a medical facility.



When data for inpatients and outpatients with prescribed diet recommendations were pooled together, 70% (14/20) of patients demonstrated diet compliance, when sampled during the study protocol. An analysis of the relationship between patient awareness of dysphagia and diet compliance, as sampled during the study protocol, found no significant association between these variables. Given these findings, patient awareness of dysphagia may be less important for diet compliance, than other variables. It is also possible that these findings might differ if diet compliance is studied over time or beyond the acute stage of one's diagnosis.

An analysis of the relationship between general cognitive functioning and diet compliance, as sampled during the study protocol, was also completed. No association, however, was found between these variables.

#### Patient Compliance with Swallowing Strategies/Maneuvers

Patient compliance with swallowing strategies/maneuvers was explored in both inpatients and outpatients. It is felt that this method of measuring patient compliance is ideally suited to avoid potential confounds imposed by the physical limitations of supervised settings, as both inpatients and outpatients have equal opportunity to implement strategies. Unfortunately, only eight of the 21 patients in this study had been prescribed swallowing strategies/maneuvers by the time of their study interview. The low frequency of prescribed strategies/maneuvers was unanticipated and appears to be a practice pattern that may have been adopted to minimize potential complications from noncompliance. For example, it appeared that more restrictive diets, requiring few or no recommended strategies, were frequently recommended for study participants, as

opposed to less restrictive diets that might require the consistent use of strategies/maneuvers.

Of the eight patients with prescribed strategies and maneuvers, only 50% demonstrated total compliance with their strategies when eating and drinking during the study protocol. It is noted that one potential difficulty in rating compliance with swallowing strategies and maneuvers is that some strategies which are typically offered, such as “take small sips and bites” are subjective. Even strategies which appear to be more objective and easily measured, such as the use of a chin tuck when drinking liquids, may be difficult to judge. Intra-rater and inter-rater reliability measures, therefore, would be a necessary part of future studies.

An analysis exploring patient awareness of dysphagia and compliance with swallowing strategies/maneuvers revealed no significant association between these two variables. Statistical power, however, was limited by the small number of participants in this analysis.

#### Patient Compliance with Exercise Regimens

Patient compliance with prescribed exercise regimens was also explored in this study. Only 12 of the 21 patients had been prescribed exercise regimens by the time of their study interview. According to documentation in the medical record, 100% of participants were judged to be compliant with the completion of their exercises *during* speech-language sessions. Of the 12 patients, eight had been instructed to perform their exercise regimens *independently* outside of speech-language sessions. Only 63% of these patients, however, were judged by their primary speech-language pathologists to be totally compliant with their independent exercise regimens. This finding illustrates that

while patients may be compliant with their exercise regimens when encouraged and instructed by their therapists during therapy sessions, they are less likely to demonstrate compliance when performing exercises on their own.

No significant relationship between patient awareness of dysphagia and compliance with independent exercise regimens was found. Statistical power, however, was limited by the small number of participants in this analysis.

#### Stages of Change

The last portion of this study considered the application of the stages of change model, a model that characterizes the process of behavioral change, to the study population. Participants were presented with five statements, each based on a stage of change, and selected the statement that best characterized their current behavior. Interestingly, none of the four patients in the study who denied the presence of dysphagia at the beginning of the interview, when asked, “Do you have a swallowing problem?” subsequently identified with the only stage of change that included the phrase “*I don't have a swallowing problem*”. Rather, all participants who denied that they had a swallowing problem in the study interview went on to state that they most identified with one of four statements that began, “*I have a swallowing problem and...*” It is unknown why this discrepancy occurred. Perhaps participants were simply more drawn to the latter portion of each statement, which pertained to their present level of action, than the initial portion of the statement which characterized their perception of whether they had a swallowing problem.

An analysis exploring the relationship between self-identified stage of change and diet compliance, as sampled during the study protocol, was completed. The findings of

this analysis did not indicate a significant relationship between these two variables.

A format modeled after the original Stages of Change Questionnaire, in which multiple statements characterizing each stage of change are presented to individuals, may have yielded different findings, as this questionnaire has been shown to have good concurrent and predictive validity (DiClemente & Hughes, 1990) and internal consistency (Carey, Purnine, Maisto, and Carey, 1999) in studies of substance-related disorders. It is also possible that the application of stages of change to the study population, a group of individuals only recently diagnosed with a disorder may simply not be a good fit, given that for many of the study participants, the need for behavioral change may be short-term. Instead, it may be more appropriate to apply this model to the study of individuals needing to make long-term changes in their eating habits, for example, as a result of chronic dysphagia.

#### Summary of Findings

This study included multiple aims. A summary of the findings follows:

- Pre-swallowing examination
  - 40% of participants demonstrated reduced awareness of their dysphagia.
  - Those with general medical diagnoses were most likely to demonstrate reduced awareness of their dysphagia, as compared to those with neurological or structural diagnoses.
  - No significant association between pre-examination awareness of dysphagia and type of response to aspiration was found.

- Three to seven days post-swallowing examination
  - 19% of patients demonstrated reduced awareness of their dysphagia.
  - Reduced awareness occurred equally among those with neurological and structural diagnoses.
  - No patients with general medical diagnoses demonstrated reduced post-examination awareness of dysphagia.
  - Participants were less likely to be aware of cognitive or limb impairments than dysphagia
  - Participants were more likely to be aware of speech impairments than dysphagia.
  - No significant associations between post-examination awareness of dysphagia and type of response to aspiration or general cognitive functioning were found.
  - No significant associations between awareness of dysphagia and compliance with diet, compliance with strategies/maneuvers or compliance with exercise regimens were found.
  - General cognitive functioning and action/post-action stages of change were also not found to be significantly associated with diet compliance.

### Limitations

The reduced accrual rate of participants was a limitation of this study. Given the rate of eligible participants noted during the pilot data collection period, it was anticipated that at least 20 participants would be enrolled in this study within five

months. At the five month period, only 12 participants had enrolled in the study. Accrual rate appeared to be limited largely to discharge of patients to non-Genesis facilities before the eligibility period; patient factors, such as medical complications during the eligibility period; and the addition of exclusion criteria that were not used in the pilot data phase. Given these circumstances, the data collection period was extended for four additional months. A revision to the study protocol which expanded the eligibility period from 5-7 days to 3-7 days was also implemented, once approved by the Genesis IRB. At the end of nine months, the minimum goal of 20 participants was achieved. Despite meeting the target of 20 participants, data for two of the outcome measures, patient compliance with swallowing maneuvers and exercise regimens, was limited by unforeseen practice patterns in acute care.

#### Clinical Applications

This study yielded several suggestions for clinical practice. First, specifically educating medical staff on the prevalence of reduced pre-examination and post-examination awareness of dysphagia is important to adequately detect dysphagia in patients. If staff relies solely on patients' reports of swallowing, then a number of individuals with dysphagia may be overlooked. Education efforts should be widespread to include all medical units, as reduced awareness did not occur exclusively in populations typically associated with reduced awareness, such as those with neurological diagnoses, but occurred in patients with a wide array of diagnoses. In addition, medical staff should understand that patient awareness of potential signs and symptoms of dysphagia, awareness of the presence of signs of dysphagia as they occur, and awareness that a swallowing problem exists may all occur independent of one another.

Secondly, speech language pathologists who evaluate and treat individuals with dysphagia are encouraged to assess patient awareness of dysphagia as part of their comprehensive evaluations of patients. Awareness should be assessed in a direct manner (e.g. “Do you have a swallowing problem?”), as the findings of this study suggest that awareness cannot be inferred from patients’ compliance with swallowing recommendations or willingness to participate in therapy activities. Understanding patients’ level of awareness for their dysphagia is critical when issues, such as those relating to patient autonomy, quality of life, and patient safety arise in the rehabilitation process. It is also recommended that assessments of awareness be repeated until individuals consistently demonstrate awareness, as this study provided evidence that some individuals may vacillate between acknowledging and denying the presence of dysphagia, even in the course of a single conversation.

#### Future Directions

This study sparked many different ideas for future research. First, studies focused on providing the best foundation of knowledge for patients with newly diagnosed dysphagia are suggested. In particular, the benefit of providing visual evidence of dysphagia versus verbal information alone might be explored. Secondly, given the paucity of literature on the topic, additional studies of impaired patient awareness of dysphagia are warranted. Specifically, studying the relationship between concurrent awareness of particular instances of swallowing difficulty and awareness of having a deficit, how awareness of dysphagia changes over time, and whether awareness can be improved with intervention are recommended. Lastly, though this study did not support a relationship between patient awareness of dysphagia and compliance with swallowing

recommendations in the acute stage of diagnosis, there may be benefit in exploring the relationship between patient awareness of dysphagia and long-term compliance for swallowing interventions.



Table 1. Participant Information

<b>Participant</b>	<b>Age</b>	<b>Sex</b>	<b>Etiology of Dysphagia</b>	<b>Patient Response to Aspiration</b>
1	94	F	General medical: left upper extremity radiculopathy	Reduced sensitivity
2	95	F	Neurological: Right temporal CVA	Reduced sensitivity
3	78	F	Neurological: Pontine CVA	Good sensitivity
4	88	F	Neurological: Left periventricular CVA	Reduced sensitivity
5	67	M	General medical: Coronary artery bypass grafting surgery	Reduced sensitivity
6	77	M	Structural: Large-cell lymphoma	Reduced sensitivity
7	75	F	Neurological: Progressive bulbar palsy	Reduced sensitivity
8	74	M	Neurological: Parkinsonism	Reduced sensitivity
9	70	M	General medical: Pneumonia	Reduced sensitivity
10	69	M	General medical: Leukemia	Good sensitivity
11	85	M	Structural: 360 degree decompression surgery	Good sensitivity
12	81	F	General medical: COPD exacerbation	Reduced sensitivity
13	84	M	Structural: Osteophyte	Reduced sensitivity
14	69	M	General medical: generalized weakness	Reduced sensitivity
15	71	M	Neurological: Multiple bilateral CVAs	Reduced sensitivity
16	85	M	Neurological: Pontine medullary CVA	Reduced sensitivity
17	30	F	Neurological: Right middle cerebral artery CVA	Good sensitivity
18	67	M	Structural: Discectomy, Osteophylectomy	Reduced sensitivity
19	93	F	Neurological: CVA	Reduced sensitivity
20	65	M	Structural: laryngeal cancer	Reduced sensitivity
21	90	F	General medical: Probable pneumonia	Reduced sensitivity

Table 2. Etiology of Participants' Dysphagia As Classified By Neurological, Structural and General Medical Diagnoses

Medical diagnosis	Number of patients	Total	Age (mean $\pm$ SD years)	Male/Female (ratio)
Neurological diagnoses		9	76.5 years $\pm$ 19 years	3 males 6 females
Stroke	7			
Progressive bulbar palsy	1			
Parkinsonism	1			
Structural diagnoses		5	75.6 years $\pm$ 9 years	5 males
Abdominal mass	1			
Laryngeal CA	1			
Cervical surgery	2			
Cervical osteophyte	1			
General medical diagnoses		7	77.1 years $\pm$ 11 years	4 males 3 females
Heart surgery	1			
Pneumonia	2			
Leukemia	1			
COPD	1			
Left upper extremity radiculopathy	1			
Generalized weakness	1			

Table 3. Summary of Findings for Four Participants Demonstrating Reduced Post-Examination Awareness of Their Dysphagia

	Subject A	Subject B	Subject C	Subject D
Age	88	77	71	65
Gender	Female	Male	Male	Male
Etiology	Neurological	Structural	Neurological	Structural
Pre-examination response to “Do you have a swallowing problem?”	No	Yes	Yes	No
Post-examination response to “Do you have a swallowing problem?”	No	No	No	No
Patient response to aspiration	Reduced sensitivity	Reduced sensitivity	Reduced sensitivity	Reduced sensitivity
Diet at the time of post-examination interview	Dysphagia I diet; Honey consistency liquids	Nothing by mouth except ice chips	Dysphagia III diet; Nectar consistency liquids	Dysphagia III diet; Nectar consistency liquids
MMSE Score	16=Moderate	26=WNL	18=Moderate	21=Mild
Diet Compliance during protocol	Yes	No	Yes	Yes
Strategy compliance during protocol	NA: No strategies prescribed	NA: No strategies prescribed	No (Sometimes)	NA: No strategies prescribed
Exercise compliance during speech sessions	Yes	Yes	Yes	NA: No exercises yet completed in speech sessions
Exercise compliance for independent exercise program, per SLP rating	Sometimes	Always	NA: Pt not yet given independent exercise program	NA: Pt not yet given independent exercise program
Awareness of limb impairments: leg/arm	Yes/No	Yes/Yes	Yes/No	No/NA
Awareness of cognitive impairment	Yes	NA: WNL per MMSE	Yes	No
Awareness of speech impairment	Yes	Yes	Yes	No
Self-identified “Stage of Change”	5=Maintenance	4=Action	3=Planning	3=Planning

Figure 1. Patient Awareness of Dysphagia Pre- and Post-Videofluoroscopic Swallowing Study Across Three Diagnostic Groups

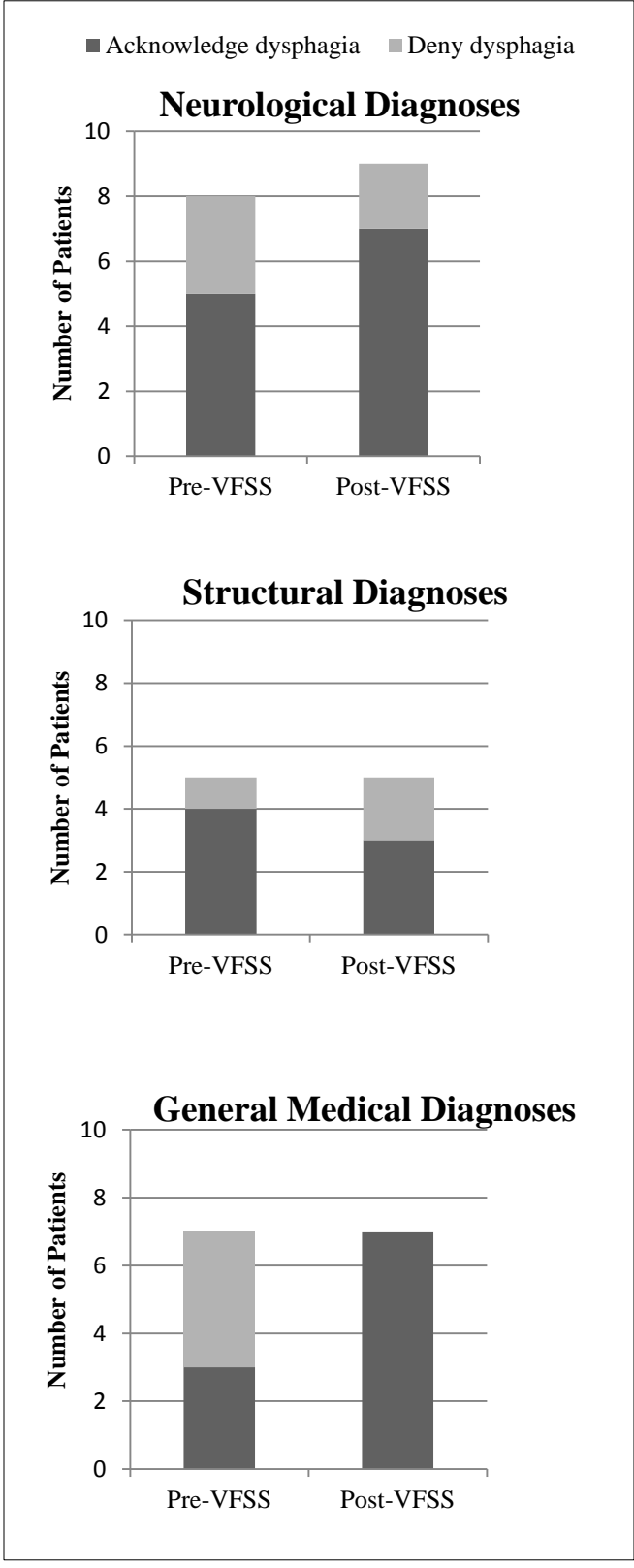
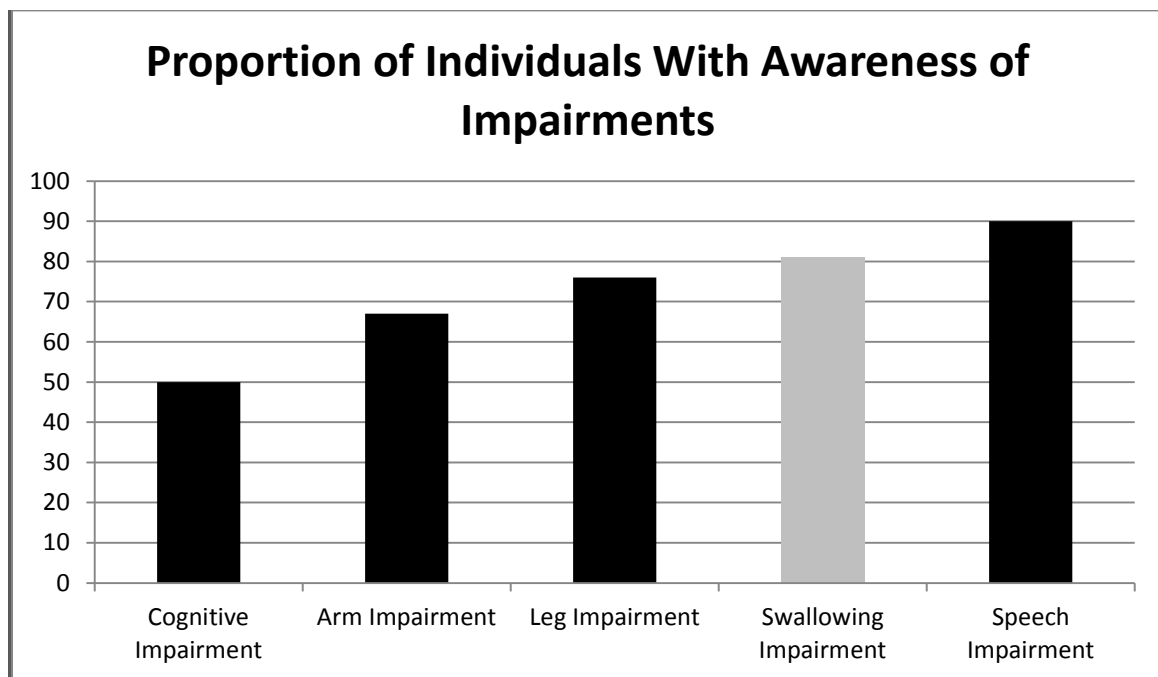


Figure 2. Proportion of Patients with Awareness of Impairments



## APPENDIX A

## Mini-Mental State Examination (Cockrell &amp; Folstein, 1988)

1. What is the year? (1 point)
  2. What is the season? (1 point)
  3. What is the date? (1 point)
  4. What is the day? (1 point)
  5. What is the month? (1 point)
  6. What city are we in ( 1 point)
  7. What state are we in? (1 point)
  8. What country are we in? (1 point)
  9. What is this building? (1 point)
  10. What floor are we on? (1 point)
  11. I'd like to test your memory. Please say these words: boat, cucumber, and wire.  
(3 points)
  12. Begin with 100 and count backwards by 7s. (5 points)
  13. Can you name the 3 objects I named before? (3 points)
  14. Name the following items (pencil, watch) (2 points)
  15. Repeat the following: "No ifs ands or buts" (1 point)
  16. "Take a paper in your right hand, fold it in half, and put it on the floor".  
(3 points)
-

17. Read and obey the following: "Close your eyes." (1 point)

18. Write a sentence. (1 point)

19. Copy this design: (1 point)

Score of 23-30: WNL

Score of 21-22: Mild impairment

Score of 10-20: Moderate impairment

Score of 9 or less: Severe impairment

---

## APPENDIX B

## PATIENT INTERVIEW

In general, tell me what kinds of problems you are currently experiencing (with regard to your health and daily functioning).

If individual does not spontaneously mention information regarding use of legs, arms, speech or thinking and memory, ask the following:

Do you have a problem using your legs?

Do you have a problem using your arms?

Do you have a speech problem?

Do you have a thinking or memory problem?

If the patient does not spontaneously mention information regarding swallowing problems, ask:

Do you have a swallowing problem?

---

If patient acknowledges swallowing problems, he/she will be asked:

What kind of swallowing problem do you have?

Do others think that you have a swallowing problem?

Have you had any swallowing xrays or tests?

What were the results of your swallowing xray?



If patient does not acknowledge swallowing problems, he/she will be asked:

Have you had any swallowing xrays or tests?

What were the results of your swallowing xray?

He/she will then be told:

“Your speech therapist tells me that you had a swallowing test on  
(insert date) in which you were given a variety of items to eat and drink,  
such as ice cream/barium liquid/pudding/graham cracker/. She/he tells me  
that were diagnosed with a swallowing problem that day, since some of  
the items that you tried to swallow went down the wrong pipe into your  
lungs.”

and asked:

Do you agree with your therapist that you have a swallowing problem?”

## APPENDIX C

## PATIENT COMPLIANCE WITH DIET RECOMMENDATIONS

Direct observation of compliance:

- Ask the patient to identify a drink and food of choice in order to “demonstrate their swallowing abilities”

Self-report of compliance:

- Ask patient “What kind of diet were you recommended to eat and drink following your swallowing study on (date)”
- If patient can’t specify what his diet recommendations are, ask “Are you supposed to eat only \_\_\_\_\_(insert recommended food level)\_\_\_\_\_ food items and drink only \_\_\_(insert recommended liquid consistencies\_\_\_?”
- Ask patient “Since that test would you say that you have always, sometimes or never followed the diet recommendations given to you?”

Therapist report of compliance:

- 2- Given the information shared by my patient, his/her family, other staff and my own observations, I believe that this patient is **always** compliant with the diet recommendations I prescribed.
- 1- Given the information shared by my patient, his/her family, other staff and my own observations, I believe that this patient is **sometimes** compliant with the diet recommendations I prescribed.
- 0- Given the information shared by my patient, his/her family, other staff and my own observations, I believe that this patient is **never** compliant with the diet recommendations I prescribed.

## APPENDIX D

## PATIENT COMPLIANCE WITH SWALLOWING STRATEGIES/MANEUVERS

## Assessment of Patient Compliance with Swallowing Strategies/Maneuvers

## Direct observation of compliance:

- Does individual use prescribed strategies or maneuvers always, sometimes or never while drinking 3 sips and eating 3 bites of selected items

## Self-report of compliance:

- Ask patient “What safe swallowing strategies or maneuvers have you been shown or told to use while eating/drinking?”
- If patient does not list any or all of his/her prescribed swallowing strategies or maneuvers them, ask patient “Have you been shown or told to (supply all prescribed strategies and maneuvers)?”
- Ask patient “When you eat or drink do you always, sometimes or never use those strategies?”

## Therapist report of compliance:

- 2- Given the information shared by my patient, his/her family, other staff and my own observations, I believe that this patient is **always** compliant with the swallowing strategies and maneuvers that I prescribed.
- 1- Given the information shared by my patient, his/her family, other staff and my own observations, I believe that this patient is **sometimes** compliant with the swallowing strategies and maneuvers that I prescribed.
- 0- Given the information shared by my patient, his/her family, other staff and my own observations, I believe that this patient is **never** compliant with the swallowing strategies and maneuvers that I prescribed.

## APPENDIX E

## PATIENT COMPLIANCE WITH EXERCISE REGIMENS

## Direct observation of compliance:

- Ask patient to show you his swallowing exercise regimen
- If patient does not show you all of his prescribed exercises ask him/her, “Have you been told to (insert each prescribed exercise)?”

## Self-report of compliance:

- Ask patient, “Do you always, sometimes or never perform your swallowing exercises on a daily basis?”

## Therapist report of compliance:

- 2- Given the information shared by my patient, his/her family, other staff and my own observations, I believe that this patient is **always** compliant with the swallowing exercise regimen I prescribed.
- 1- Given the information shared by my patient, his/her family, other staff and my own observations, I believe that this patient is **sometimes** compliant with the swallowing exercise regimen I prescribed.
- 0- Given the information shared by my patient, his/her family, other staff and my own observations, I believe that this patient is **never** compliant with the swallowing exercise regimen I prescribed.

APPENDIX F  
STAGES OF CHANGE

“Please listen to the following statements and tell which one you most identify with:

1-As far as I’m concerned, I don’t have a swallowing problem that needs to be worked on (pre-contemplation).

2-I have a swallowing problem and I really think I should start working on improving it (contemplation).

3-I have a swallowing problem and I have decided to start working on improving it (planning).

4-I have begun working on improving my swallowing problem (action).

5-I have been working on improving my swallowing problem for a while (maintenance).”

## REFERENCES

- Anderson, S., & Tranel, D. (1989). Awareness of disease states following cerebral infarction, dementia, and head trauma: standardized assessment. *Clin Neuropsychol*, 3, 327-229.
- Appelros, P., Karlsson, G. M., & Hennerdal, S. (2007). Anosognosia versus unilateral neglect. Coexistence and their relations to age, stroke severity, lesion site and cognition. *Eur J Neurol*, 14(1), 54-59.
- Baier, B., & Karnath, H. O. (2005). Incidence and diagnosis of anosognosia for hemiparesis revisited. *J Neurol Neurosurg Psychiatry*, 76(3), 358-361.
- Berti, A., Ladavas, E., & Della Corte, M. (1996). Anosognosia for hemiplegia, neglect dyslexia, and drawing neglect: clinical findings and theoretical considerations. *J Int Neuropsychol Soc*, 2(5), 426-440.
- Bird, M. R., Woodward, M. C., Gibson, E. M., Phyland, D. J., & Fonda, D. (1994). Asymptomatic swallowing disorders in elderly patients with Parkinson's disease: a description of findings on clinical examination and videofluoroscopy in sixteen patients. *Age Ageing*, 23(3), 251-254.
- Bisiach, E., Vallar, G., Perani, D., Papagno, C., & Berti, A. (1986). Unawareness of disease following lesions of the right hemisphere: anosognosia for hemiplegia and anosognosia for hemianopia. *Neuropsychologia*, 24(4), 471-482.
- Boczko, F. (2006). Patients' awareness of symptoms of dysphagia. *J Am Med Dir Assoc*, 7(9), 587-590.
- Bushmann, M., Dobmeyer, S. M., Leeker, L., & Perlmutter, J. S. (1989). Swallowing abnormalities and their response to treatment in Parkinson's disease. *Neurology*, 39(10), 1309-1314.
- Cocchini, Beschin, & Sala, D. (2002). Chronic anosognosia: A case report and theoretical account. *Neuropsychologia*, 40, 2030-2038.
- Cocchini, G., Beschin, N., Cameron, A., Fotopoulou, A., & Della Sala, S. (2009). Anosognosia for motor impairment following left brain damage. *Neuropsychology*, 23(2), 223-230.
- Cockrell, J. R., & Folstein, M. F. (1988). Mini-Mental State Examination (MMSE). *Psychopharmacol Bull*, 24(4), 689-692.

- Cooke, M. A., Peters, E. R., Kuipers, E., & Kumari, V. (2005). Disease, deficit or denial? Models of poor insight in psychosis. *Acta Psychiatr Scand*, *112*(1), 4-17.
- Cutting, J. (1978). Study of anosognosia. *Journal of Neurology, Neurosurgery and Psychiatry*, *41*, 548-555.
- Davies, M., Davies, A., & Coltheart, M. (2005). Anosognosia and the two-factor theory of delusions. *Mind and Language*, *20*(2), 209-236.
- DiClemente, C. C., & Hughes, S. O. (1990). Stages of change profiles in outpatient alcoholism treatment. *J Subst Abuse*, *2*(2), 217-235.
- Ding, R., & Logemann, J. A. (2008). Patient self-perceptions of swallowing difficulties as compared to expert ratings of videofluorographic studies. *Folia Phoniatr Logop*, *60*(3), 142-150.
- Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res*, *12*(3), 189-198.
- Freeman, D., Garety, P. A., Kuipers, E., Fowler, D., & Bebbington, P. E. (2002). A cognitive model of persecutory delusions. *Br J Clin Psychol*, *41*(Pt 4), 331-347.
- Garety, P. A., Hemsley, D. R., & Wessely, S. (1991). Reasoning in deluded schizophrenic and paranoid patients. Biases in performance on a probabilistic inference task. *J Nerv Ment Dis*, *179*(4), 194-201.
- Gialanella, B., & Mattioli, F. (1992). Anosognosia and Extrapersonal Neglect as Predictors of Functional Recovery following Right Hemisphere Stroke. *Neuropsychol Rehabil*, *2*(3), 169-178.
- Gialanella, B., Monguzzi, V., Santoro, R., & Rocchi, S. (2005). Functional recovery after hemiplegia in patients with neglect: the rehabilitative role of anosognosia. *Stroke*, *36*(12), 2687-2690.
- Hartman-Maeir, A., Soroker, N., Oman, S. D., & Katz, N. (2003). Awareness of disabilities in stroke rehabilitation--a clinical trial. *Disabil Rehabil*, *25*(1), 35-44.
- Horner, J., & Massey, E. W. (1988). Silent aspiration following stroke. *Neurology*, *38*(2), 317-319.
- Jehkonen, M., Laihosalo, M., & Kettunen, J. (2006). Anosognosia after stroke: assessment, occurrence, subtypes and impact on functional outcome reviewed. *Acta Neurol Scand*, *114*(5), 293-306.

- Jenkinson, P. M., Edelstyn, N. M., Stephens, R., & Ellis, S. J. (2009). Why are some Parkinson disease patients unaware of their dyskinesias? *Cogn Behav Neurol*, 22(2), 117-121.
- Kortte, K. B., & Wegener, S. T. (2004). Denial of Illness in medical Rehabilitation Populations: Theory, Research, and Definition. *Rehabilitation Psychology*, 49(3), 187-199.
- Lebrun, Y. (1987). Anosognosia in aphasics. *Cortex*, 23(2), 251-263.
- Levine, D. N. (1990). Unawareness of Visual and Sensorimotor Defects: A Hypothesis. *Brain and Cognition*, 13, 233-281.
- Litvan, I., Sastry, N., & Sonies, B. C. (1997). Characterizing swallowing abnormalities in progressive supranuclear palsy. *Neurology*, 48(6), 1654-1662.
- Logemann, J. A. (1995). Dysphagia: evaluation and treatment. *Folia Phoniatr Logop*, 47(3), 140-164.
- Maeshima, S., Dohi, N., Funahashi, K., Nakai, K., Itakura, T., & Komai, N. (1997). Rehabilitation of patients with anosognosia for hemiplegia due to intracerebral haemorrhage. *Brain Inj*, 11(9), 691-697.
- Marcel, A. J., Tegner, R., & Nimmo-Smith, I. (2004). Anosognosia for plegia: specificity, extension, partiality and disunity of bodily unawareness. *Cortex*, 40(1), 19-40.
- Nathanson, M., Bergman, P. S., & Gordon, G. G. (1952). Denial of illness; its occurrence in one hundred consecutive cases of hemiplegia. *AMA Arch Neurol Psychiatry*, 68(3), 380-387.
- Newton, H. B., Newton, C., Pearl, D., & Davidson, T. (1994). Swallowing assessment in primary brain tumor patients with dysphagia. *Neurology*, 44(10), 1927-1932.
- Orfei, M. D., Robinson, R. G., Prigatano, G. P., Starkstein, S., Rusch, N., Bria, P., et al. (2007). Anosognosia for hemiplegia after stroke is a multifaceted phenomenon: a systematic review of the literature. *Brain*, 130(Pt 12), 3075-3090.
- Parker, C., Power, M., Hamdy, S., Bowen, A., Tyrrell, P., & Thompson, D. G. (2004). Awareness of dysphagia by patients following stroke predicts swallowing performance. *Dysphagia*, 19(1), 28-35.
- Pauloski, B. R., Rademaker, A. W., Logemann, J. A., Lazarus, C. L., Newman, L., Hamner, A., et al. (2002). Swallow function and perception of dysphagia in patients with head and neck cancer. *Head Neck*, 24(6), 555-565.



- Pedersen, P., Jorgensen, H., Nakayama, H., Raaschou, H., & Olsen, T. (1996). Frequency, Determinants, and Consequences of Anosognosia in Acute Stroke. *Journal of neurological rehabilitation, 10*, 243-250.
- Pia, L., Neppi-Modona, M., Ricci, R., & Berti, A. (2004). The anatomy of anosognosia for hemiplegia: a meta-analysis. *Cortex, 40*(2), 367-377.
- Prigatano. (2005). Disturbances of self-awareness and rehabilitation of patients with traumatic brain injury: a 20-year perspective. *J Head Trauma Rehabil, 20*(1), 19-29.
- Prigatano. (2009). Anosognosia: clinical and ethical considerations. *Curr Opin Neurol*.
- Prigatano. (2010). *The Study of Anosognosia*. New York: Oxford University Press.
- Prigatano, & Klonoff. (1998). A Clinician's Rating Scale for Evaluation Impaired Self-Awareness and Denial of Disability After Brain Injury. *The Clinical Neuropsychologist, 12*(1), 56-67.
- Prigatano, G. (2010). *The Study of Anosognosia*.
- Prochaska, J. O., DiClemente, C. C., & Norcross, J. C. (1992). In search of how people change. Applications to addictive behaviors. *Am Psychol, 47*(9), 1102-1114.
- Ramsey, D., Smithard, D., & Kalra, L. (2005). Silent aspiration: what do we know? *Dysphagia, 20*(3), 218-225.
- Rhodus, N. L., Moller, K., Colby, S., & Bereuter, J. (1995). Dysphagia in patients with three different etiologies of salivary gland dysfunction. *Ear Nose Throat J, 74*(1), 39-42, 45-38.
- Robbins, J. A., Logemann, J. A., & Kirshner, H. S. (1986). Swallowing and speech production in Parkinson's disease. *Ann Neurol, 19*(3), 283-287.
- Rubens, A., & Garrett, M. (1991). Anosognosia of linguistic deficits in patients with neurological deficits. In G. Prigatano & D. Schacter (Eds.), *Awareness of Deficit after Brain Injury* (pp. 40-52). New York: Oxford University Press.
- Schonberger, M., Humle, F., Zeeman, P., & Teasdale, T. W. (2006). Working alliance and patient compliance in brain injury rehabilitation and their relation to psychosocial outcome. *Neuropsychol Rehabil, 16*(3), 298-314.
- Small, M., & Ellis, S. (1996). Denial of hemiplegia: an investigation into the theories of causation. *Eur Neurol, 36*(6), 353-363.

- Starkstein, S. E., Fedoroff, J. P., Price, T. R., Leiguarda, R., & Robinson, R. G. (1992). Anosognosia in patients with cerebrovascular lesions. A study of causative factors. *Stroke*, *23*(10), 1446-1453.
- Stone, S. P., Halligan, P. W., & Greenwood, R. J. (1993). The incidence of neglect phenomena and related disorders in patients with an acute right or left hemisphere stroke. *Age Ageing*, *22*(1), 46-52.
- Trahan, E., Pepin, M., & Hopps, S. (2006). Impaired awareness of deficits and treatment adherence among people with traumatic brain injury or spinal cord injury. *J Head Trauma Rehabil*, *21*(3), 226-235.
- Venneri, A., & Shanks, M. F. (2004). Belief and awareness: reflections on a case of persistent anosognosia. *Neuropsychologia*, *42*(2), 230-238.
- Vuilleumier, P. (2004). Anosognosia: The neurology of beliefs and uncertainties. *Cortex*, *40*, 9-17.
- Walther, E. K., Rodel, R., & Deroover, M. (1990). [Rehabilitation of deglutition in patients with pharyngeal carcinoma]. *Laryngorhinootologie*, *69*(7), 360-368.