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An Ecological Model of Factors Contributing to Adult's Adherence to Dietary Recommendations in Dysphagia Management

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Abstract

ADHERENCE IN DYSPHAGIA

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Purpose: The purpose of this study was to develop a preliminary ecological model of factors

affecting adherence to dysphagia dietary recommendations grounded in the currently

available dysphagia literature and guided by the general healthcare literature.

Methods: A rapid review of two electronic databases was conducted in April 2021. Searches

were limited to English-language empirical studies published in peer-reviewed journals that

explored adherence specifically to dysphagia dietary recommendations.

Results: The literature search resulted in 930 unique abstracts, of which 14 articles were

accepted. Multiple factors were identified as having an influence on adherence. Based on the

guiding framework of an ecological model, these factors were grouped into three levels: the

individual, the caregiver, and the environment. The dysphagia-specific factors were then

compared to those affecting adherence in the general healthcare literature. A visual model

incorporating the dysphagia- and healthcare-related factors, or the "Ecological Model of

Factors Affecting Adherence in Dysphagia and Healthcare", was subsequently developed.

Conclusions: Improving adherence to dysphagia dietary recommendations is crucial for the

improved outcomes. The ecological model can serve as a tool for speech-language

pathologists in their clinical practice to identify those factors that contribute to adherence,

including factors that may be modifiable. Targeting interventions at increasing the likelihood

of adherence will maximize the effectiveness of these recommendations for individuals with

dysphagia.

Keywords: dysphagia; swallowing; deglutition; compliance; adherence; ecological model

1 Introduction

Dysphagia is a prevalent and debilitating health condition, estimated to occur in
approximately 8% of the population worldwide (Cichero et al., 2017) and up to 91% of the
population aged 70 years of age or older (Ortega et al., 2017). The significant physical and
emotional consequences of the disease can markedly reduce quality of life and increase
mortality (Guyomard et al., 2009; Ekberg et al., 2002). Dysphagia can lead to dehydration,
malnutrition, failure to thrive, and aspiration pneumonia, all of which can lead to death
(Chadwick et al., 2002; Namasivayam-MacDonald et al., 2017). Eating and drinking during
mealtimes are also important components of daily social interaction and relationships (e.g.,
Mintz & Du Bois, 2002). Cultural rituals and celebrations, such as birthdays and holidays,
and other social gatherings often involve food and drink. Individuals diagnosed with
dysphagia may have difficulty participating in such social interactions or they might avoid, or
be excluded from, being part of these events completely (McQuestion et al., 2011; Patterson
et al., 3013). In addition, dysphagia can strip away the pleasure associated with mealtimes,
resulting in individuals eating as a matter of necessity and hunger only (Ullrich & Crichton,
2015).
In light of these negative consequences of dysphagia on the individual, speech-
language pathologists (SLPs) are challenged to provide the most effective interventions
possible. A variety of treatments are used in dysphagia management, including dietary
modifications, postural adjustments, and rehabilitative exercises (Groher & Crary, 2020;
Suiter & Gosa, 2019). Diet modification has become a fundamental aspect of treatment of
both acute and chronic dysphagia for many speech-language pathologists (Carnaby &
Harenberg, 2013; Garcia & Chambers, 2010; Ney et al., 2009; Sura et al., 2012). Diet
modification refers to the processes of changing food and liquid consistency (Garcia &
Chambers, 2010). Often the goal in using diet modification is to prevent the occurrence of
adverse events, such as aspiration pneumonia or choking, and to ensure adequate nutrition

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(Sura et al., 2012). It has been reported that approximately 28 – 47% of residents living in nursing homes receive modified diets (Castellanos, 2004; Vucea, 2019).

However, for such a compensatory dysphagia intervention to be effective, patient compliance and/or adherence is needed (Low et al., 2001). While frequently used interchangeably in the literature, compliance refers to the extent to which a patient consistently follows healthcare advice and recommendations (Soares, 2009), whereas adherence acknowledges and incorporates the effect of personal knowledge, motivation and social context on the extent to which a patient follows agreed upon recommendations (McKay & Verhagen, 2015). In other words, adherence is thought to be more patientcentered than compliance as the healthcare plan is built upon a mutual agreement between the clinician and patient. Thus, the concept of adherence will be the focus in this paper. Ultimately, in order for dietary modifications to meet the intervention goals of increased oral intake and the prevention of negative consequences, adherence is needed and patients must actually be consuming the recommended modified textured food and drinks. Yet, not all patients follow these recommendations. For example, one study reported that 21% of their 140-person sample did not follow the swallowing recommendations of the SLP (Low et al. 2001). Another study revealed a non-adherence rate of 43.5% to modified diets (Shim et al., 2013). In addition, some individuals with dysphagia are dependent on their caregivers and healthcare providers (e.g., nursing staff) for following these recommendations due to cognitive and physical limitations (Krekeler et al., 2018). Yet still, adherence is not fully achieved. For example, Chadwick et al. (2003) revealed that the average compliance rate of caregivers was 76.9%.

Decreased adherence is not limited to dysphagia management alone. Even with the availability of effective and efficacious therapies for many health conditions more generally, complications and mortality still commonly occur, suggesting the likely important contribution of adherence (Jan et al., 2011; Low et al., 2001). Research suggests that higher

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patient adherence can result in up to 26% better treatment outcomes (Berry et al., 2008). Better understanding the factors related to adherence, particularly modifiable factors that target barriers to adherence, can ultimately improve intervention effectiveness and health outcomes. Given the frequent use of diet modifications, in light of the challenges with implementation, it is important to investigate what factors may increase adherence.

Factors Influencing Adherence

The combination of a variety of internal (e.g., motivation, buy-in) and external (e.g., staff and social support) factors ultimately contribute to adherence rates across dysphagia treatment recommendations (Krekeler et al., 2018). However, few studies have investigated adherence to dysphagia recommendations related to diet modifications and aspiration precautions, and even fewer have focused on adherence as the primary outcome. Across the available studies, though, a number of factors have been suggested to be related to adherence that could serve as useful treatment targets or indicators of increased risk of nonadherence. Patients' mental health status has been identified as a factor influencing the degree of patient adherence (Colodny, 2005; Seshadri et al., 2018). Patients who are in denial of their swallowing impairment or those who are feeling angry and demonstrate aggression toward others might be less adherent to the recommendations made by the SLP (Colodny, 2005). Other mental health factors, such as anxiety, fear, and social embarrassment have also been found to have a negative influence on adherence levels (Seshadri et al., 2018). Additional eating-related factors, such as dissatisfaction with modified diets and lack of supervision, have also been suggested to hinder adherence (Colodny, 2005; Low et al., 2001; McCurtin et al., 2018; Shim et al., 2013). Further, patients' degree of knowledge regarding the recommendations influence adherence (Chadwick et al., 2003; Low et al., 2001; Rosenvinge & Starke, 2005; Seshadri et al., 2018). Interestingly, many of these factors can yield both a negative and positive effect on adherence, depending on how they are implemented. Finally, the presence of other health factors that co-exist with dysphagia may decrease adherence

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levels, such as multiple chronic conditions and sensory impairments (Leiter & Windsor, 1996).

Conversely, adherence to healthcare recommendations more broadly has been frequently studied and therefore offers additional insight into what factors may play a role in dysphagia management. In particular, the literature exploring adherence to dietary and medication consumption recommendations may be most relevant to dysphagia. One of the most significant factors that has been suggested to play a role is a patient's knowledge of the benefit of the suggested recommendations (Herrema et al., 2018; Khambati et al., 2017), similar to findings in the dysphagia-specific literature regarding knowledge of the recommendations (Chadwick et al., 2003; Low et al., 2001; Rosenvinge & Starke, 2005; Seshadri et al., 2018). For example, Lum et al. (2018) identified the main cause of medication nonadherence to be a patient's perception of how important the medication recommendation was as compared to others. Similarly, they found that caregiver perception of importance was also a main contributor to medication nonadherence (Lum et al., 2018). Thus, both patient and caregiver beliefs regarding which aspects of care are most important affects which recommendations are most likely to be followed. Patient educational level also plays a role in adherence; patients with higher educational levels tend to be more likely to follow healthcare recommendations, which could be related to increased knowledge of health consequences and increased trust in the healthcare system (Yilmaz & Colak, 2018). In addition, involving the patient in the decision-making process has a significantly positive effect on improving adherence (Herrema et al., 2018; Mikulka, 2016). For example, the more a recommendation fits with a patient's everyday life routine, the more willing the patient is to make the necessary changes (Herrema et al., 2018). Furthermore, patient adherence to recommended foods, in particular, is affected by the patient's preferences regarding taste, texture, and smell (Herrema et al., 2018; Mikulka, 2016), mapping onto the dissatisfaction patients with

dysphagia have reported regarding modified foods and liquids (Colodny, 2005; McCurtin et al., 2018; Shim et al., 2013).

Another contributing factor for adherence identified in the healthcare literature is cognitive abilities (Guimaraes et al., 2015). Higher levels of cognition are associated with higher levels of adherence and vice versa. Mental health and specific cognitive factors also appear to contribute to adherence, in line with previous findings in the dysphagia literature (Colodny, 2005; Seshadri et al., 2018). For example, Stringham et al. (2018) identified that anxiety and posttraumatic stress (PTSD) have a significant effect on decreased adherence for medication use among veterans. Positive caregiver support has been found to increase patient motivation, encouraging patients to follow clinical recommendations (Pereira et. al., 2015). Conversely, negative support provided from the caregiver can significantly decrease adherence. For example, if a caregiver is feeling depressed or stressed, it can negatively influence the patient, decreasing the patient's motivation and willingness to follow recommendations. Similarly, caregivers working outside the home is predictive of decreased swallow-related QOL and is hypothesized to be related to a lack of ability to provide support for meal needs as frequently (Guimaraes, et al., 2015).

Other factors external to the patient and caregiver also appear to influence adherence. The physician-patient relationship is one such important factor (Berry et al., 2008; Endevelt, & Gesser-Edelsburg, 2014). Physicians that spend more time getting to know their patients are able to develop stronger rapport and trust with their patients (Berry et al., 2008). This allows those physicians to develop a more individualized treatment approach while considering their patients' cultural differences. Thus, a stronger relationship is often associated with greater adherence with recommendations. Additional support can also be beneficial. For example, health professionals providing counseling sessions to their patients was associated with increased adherence (Zhao et al., 2018). Cost of treatment has also been found to influence adherence, with increased cost being associated with decreased adherence

(Stringham et al., 2018). Finally, a team approach can be very effective in managing multiple patient conditions, consequently improving overall adherence (Kapoor et al., 2016).

Creating a Model-Based Framework to Understand Adherence

Adherence is ultimately a complex human behavior that is influenced by a number of internal and external variables, particularly in dysphagia management (Krekeler et al., 2018; 2020). Given this complexity, the use of model-driven intervention approaches that can support a better understanding of patient adherence in dysphagia management has been previously suggested (Krekeler et al., 2020). While more commonly used in other subdisciplines, model development in dysphagia is still relatively new. Krekeler and colleagues (2020) developed a conceptual model for adherence to dysphagia treatment recommendations. Based on their review of the literature, the authors identified 14 factors affecting adherence to dysphagia treatment recommendations, grouped across three broad categories (health factors, patient factors, contextual factors). Based on these findings, the authors were able to generate two related models – a main model that described the various factors influencing adherence across these three categories and a clinician-centered submodel that identified modifiable risk factors for decreased adherence that could be addressed in clinical practice.

Significantly, these recent models were primarily centered around adherence to exercise and behavioral recommendations. Given the more limited research on dietary recommendation adherence in dysphagia, this topic has been underrepresented in the previous conversations (Krekeler et al., 2018, 2020). Yet, developing a model grounded in theory and literature findings for adherence to dietary recommendations is equally as beneficial as it can contribute to increased swallow safety. Thus, the purpose of the current study was to address this gap in the literature and develop a model specifically targeting diet modifications, framing the more limited extant dysphagia literature within the larger healthcare literature. Further, based on the previous findings from the dysphagia-specific

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literature, the ecological and health belief models were selected as guiding frameworks, as described further below.

Ecological Model. It is apparent that there is not one singular factor contributing to behavioral adherence, particularly as related to diet modification recommendations. The factors described across the previous literature appear to span various levels of influence, such as those related to the individual patient, caregiver, and the environment. Thus, rather than a focus on identifying one key factor, a more appropriate model for increasing adherence must incorporate the various levels of factors that influence the behavior. The notion that multiple levels of factors influence a behavior is at the core of ecological models (Sallis et al., 2008). The ecological model was first developed by Bronfenbrenner (1977) to study the interaction of children with their mothers by studying the individual, the environment, and the interaction between the individual and the environment. Developing from that initial purpose, ecological models frame human behavior in context, recognizing the influence of multiple variables on behavior, ranging from the environment to the individual themself (Sallis et al., 2008). In addition, this model also accounts for the possibility of these different levels interacting together, which further impacts behavior. By taking a more wholistic view of human behavior and the contributors to behavior, multiple targets become the focus of intervention, facilitating treatment success and improved outcomes (Cohen et al., 2000; Sallis et al., 2008). Ecological models have been previously used to develop effective and meaningful interventions targeting behavioral changes such as healthy eating habits and smoking cessation (Sallis et al., 2008; Sogari, 2018). Thus, such a model holds similar promise for facilitating similarly positive change as related to adherence to dysphagia dietary recommendations.

Health Belief Model. Notably, some of the factors identified in the dysphagia literature as having an effect on adherence to dysphagia diet recommendations are also related to the individual's inner feelings and mental status (Colodny, 2005; Seshadri et al.,

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2018). Thus, even while focusing on the multiple levels of influence as suggested by the ecological model, it is equally as important to draw from the tenets of the health belief model for the innermost, or individual, level of the ecological model. The health belief model was initially developed with the primary intention to understand why some individuals do not follow disease prevention strategies and do not participate in disease screening tools (Champion & Skinner, 2008). The model consists of six components: perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cue to action, and self-efficacy. Perceived susceptibility and perceived severity refer to an individual's beliefs of the risk of getting an illness and how serious that illness and its associated consequences are. Perceived benefits refers to the individual's beliefs about the effectiveness of the intervention for resolving the illness, while perceived barriers refers to the individual's beliefs about possible obstacles to recovery or for performing the health-related behavior. Cue to action refers to internal and external cues that alert and motivate the individual for possible change. Self-efficacy refers to the individual's self-perceived ability to change the behavior, or their self confidence in being able to change the behavior. The health belief model has been previously used to motivate individuals to be involved in the assessment and intervention of their health, such as self-breast examination and smoking cessation (DiClemente et al., 1991). Combinations of these six components have also been suggested to play a role in dysphagia management (Krekeler et al., 2018). Thus, such a model holds similar promise for facilitating similarly positive change as related to adherence to dysphagia dietary recommendations.

Given the more-narrow focus of the health belief model (i.e., targeted at only the individual themselves), the health belief model is serving as a support for the development of a more primary ecological model of dysphagia management.

Ecological Model of Dysphagia Management. Using theoretical models in assessing and treating dysphagia is relatively new (Krekeler et al., 2020). However, due to the

complexities involved in managing dysphagia, the use of such models in all aspects of dysphagia therapy can help ensure positive outcomes. Adherence to dysphagia dietary recommendations is essential for improving patient's health and for preventing negative consequences. It is clear that the factors influencing this adherence are widespread, encompassing the individual, the caregiver, and the broader environment. Thus, developing an ecological model of factors affecting adherence to dietary recommendations, that is grounded in the previous literature base and that integrates important components of health beliefs, could facilitate improved adherence to these recommendations.

Current Study

The purpose of the current study was to construct an ecological model of dysphagia management, targeting factors suggested to influence adherence to dysphagia dietary recommendations. In order to develop the model, a rapid review of behavioral adherence in the dysphagia-specific literature was conducted; these results were then integrated with the suggestions previously provided across the general healthcare literature. Throughout the model development process, the methods and analyses were grounded in the principles of both the ecological model and health belief model. The resulting ecological model of dysphagia management can provide a more comprehensive and systematic framework for considering the factors influencing adherence to dysphagia diet recommendations, ultimately improving behavioral outcomes.

227 Methods

Search Process

To construct a preliminary ecological model of factors affecting adherence in dysphagia, a rapid review was conducted to capture as wide a range of potential factors as possible. Rapid reviews are often used to meet specific healthcare needs and to help healthcare professionals engage in a more timely decision-making process (Khangura, et al., 2012). They utilize similar principles as systematic reviews but require a shorter time to

complete (Polisena et al., 2015). The main purpose and advantage of a rapid review is that it aids health care professionals in providing evidence-based clinical health decisions in a timelier matter. There currently is no standard methodology on how rapid reviews are conducted (Haby, et al., 2016; Polisena et al., 2015). For the purposes of developing a preliminary model that would broadly capture all potential influencing factors in the current study, we followed the primary procedures of a systematic review, although not all eligible databases were searched and risk of bias was not assessed.

A comprehensive literature search was conducted in April 2021 to identify articles related to adherence to dysphagia-related dietary recommendations in the adult population. The electronic databases that were searched for relevant articles included Medline and PubMed. All searches used two-word combinations, with one relating to adherence (compliance OR adherence OR noncompliance) and the second to the field of dysphagia (dysphagia OR deglutition OR swallowing). Given that compliance and adherence are often used interchangeably in the literature, they were treated as such within the literature search. Searches were limited to English-language papers. A librarian assisted with the search process and removal of duplicate articles. Reference lists of pertinent articles were crosschecked to ensure that all relevant articles were reviewed.

Study Selection

Only studies with published abstracts were considered for this review. Studies were considered for inclusion based on the following: (a) if they were empirical articles and/or articles that presented original intervention research (i.e., review articles, position papers, practice guidelines, and other non-empirical papers were not included); (b) data from the adult population could be extracted; (c) adherence was measured as part of the methods and discussed in the results; and (d) adherence related to dietary and/or aspiration precaution recommendations (i.e., adherence related to swallowing exercises or other compensatory strategies was not included). The first and second authors examined all identified articles

using the inclusion criteria. The first step included eliminating articles based on title and abstract. The remaining articles were then reviewed in depth using the same inclusion criteria and rated by the same reviewers. Disagreements between raters were resolved via discussion until a consensus was reached.

Data Extraction

Data extracted from the accepted articles included: participants' demographic information (e.g., age, dysphagia-associated diagnosis); the primary aim of the study, including whether adherence was the primary aim; factors identified in the study that affected adherence; and whether the effect on adherence was positive or negative.

Model Generation

The model generation process, including the data extraction methods, was grounded in the principles of both the ecological model and the health belief model. Building on that theoretical framework, the following guidelines were implemented to develop the model itself: identify the desired outcome related to the health condition in question (i.e., adherence to dietary recommendations), identify potential modifying factors related to the desired health care outcome (e.g., individual-, caregiver-, and environmental-level factors as suggested by the ecological and health belief models), identify relationships between these factors, and narrow down factors to include only those most relevant concepts (Earp & Ennett, 1991; Krekeler et al., 2020; Rimer & Glanz, 2005).

To start the preliminary model development process, we first examined all data extracted from the studies to identify those factors that served as facilitators or barriers to adherence. Next, we engaged in a more wholistic review of all the factors extracted, attempting to identify patterns of classification across the factors. Based on the guiding theoretical frameworks and the empirical data, the classifications were based on three levels, including individual, caregiver, and environmental factors. Individual factors include those influencers that are within the patient themselves (e.g., personality, cognition, self-efficacy),

which either increase or decrease a behavior. Caregiver factors relate to those factors associated with other individuals who provide support, especially individuals who provide support to those who are not independent, such as family and healthcare staff. Finally, factors related to the environment are those factors related to policies, procedures, costs, and training requirements, such as within a healthcare organization. We also documented any factors that were identified across multiple levels (e.g., knowledge), which can have a unique effect on adherence.

The factors identified and extracted as part of the rapid review process were then compared to the findings from the more general healthcare literature described above. Specifically, results from studies exploring adherence to dietary and medication consumption recommendations were primarily considered given that they are the most relevant to dysphagia. Close attention was directed to those unique factors that did not appear across the limited dysphagia literature base. These factors were then classified across the same three theoretical levels confirmed in the dysphagia literature, including individual, caregiver, and environmental factors.

A preliminary list of factors that may contribute to adherence to dysphagia diet recommendations based on the dysphagia-specific and general healthcare literature was then generated. This list was reviewed by the research team for clarity and redundancy. The final list of factors was then visually represented, grouped together based on their common levels of influence. This figure formed the developed ecological model.

306 Results

Literature Retrieval

The results of the literature search are summarized in Figure 1. The initial search yielded 2967 articles, 851 articles in Medline and 2116 articles in PubMed. This was then reduced to 930 unique articles after duplicates were removed. All articles were reviewed by both raters to ensure that they were written in English, published in a peer-reviewed journal,

and met the inclusion criteria. Following title and abstract review, 38 articles remained for further analysis. Agreement between the two raters before reconciliation on rejecting or accepting abstracts based on title/abstract review was 96.9%. The remaining articles underwent full-text review by both raters. Systematic review articles, articles investigating dysphagia only in the pediatric population, articles related to adherence to swallowing exercises (rather than dietary recommendations), and articles where adherence was not measured/discussed as part of the results and discussion sections were excluded. Agreement between the two raters before reconciliation on rejecting or accepting articles based on full review was 92%. The article set for the rapid review was narrowed down to a final list of 14 articles. The reference lists of these articles were reviewed for any additional relevant titles that may have been missed in the original search. One additional article was reviewed, but was determined not to meet the inclusion criteria.

<<Insert Figure 1 around here>>

Study Characteristics

The characteristics of the 14 included studies are summarized in Table 1. Adherence was the main target of the study in 11 of the articles and was a secondary finding reported for the remaining articles. All of the articles included adult participants, with participants being the care recipients or patients in nine studies, the caregivers (formal or informal) in four studies, and both care recipients/patients and caregivers in one study. Eight studies reported participant ages; among those studies, the mean age of care recipients/patients ranged from 40.1 to 80.5 years and only one study reported the mean age of caregivers at 48.2 years. The number of participants varied across the studies, from 8 to 184 participants, which could be attributed, in part, to differing study designs, settings, and targeted populations. Dysphagia-associated diagnoses among the care recipients/patients also varied and included brain lesions, cancer, cardiovascular accidents, cerebral palsy, intellectual impairments, neurodegenerative disease, and respiratory disease. Finally, the studies utilized different

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quantitative (e.g., cross sectional) and qualitative (e.g., interviews) study designs, with some using a mixed method approach.

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Main Findings in the Dysphagia Literature

The 14 articles were closely examined and the factors influencing adherence were extracted. These factors were then grouped into the levels suggested by the ecological model, including individual, caregiver, and environmental. The factors will be described below according to these groupings. The majority of factors reported across the 14 studies were at the individual level followed by caregiver factors, with few environmental level factors discussed or studied.

Various individual factors were identified across nine articles, encompassing emotional, psychological, and cognitive factors that influence adherence to dysphagia dietary recommendations. One of the major factors identified was patients' dissatisfaction with modified diets (Colodny, 2005; McCurtin et al., 2018; Robbertse & Beer, 2020; Shim et al., 2013). Patients were either dissatisfied with the texture of the modified food and liquids (Colodny, 2005; McCurtin et al., 2018; Shim et al., 2013), or with the taste of the modified food and liquids (Colodny, 2005; McCurtin et al., 2018; Shim et al., 2013). Another study reported that the inconvenience of preparing the modified diet was a major reason for their dissatisfaction (Shim et al., 2013) as well as the unappealing nature of the modified texture foods (McCurtin et al., 2018). Dissatisfaction with the modified diet was reported by the patients themselves (Colodny, 2005; McCurtin et al., 2018; Shim et al., 2013) and also observed and reported by nurses caring for patients with dysphagia (Robbertse & Beer, 2020). When patients were not satisfied with their modified diet, it negatively affected their adherence. Another commonly occurring factor was the individual's level of knowledge about the recommended diet (Chadwick et al., 2003; Low et al., 2001; McCurtin et al., 2018; Rosenvinge & Starke, 2005; Seshadri et al., 2018). This included knowledge regarding why

they were placed on a modified diet, what modified diet they were on, how to use thickeners and prepare their modified diet, and what the consequences were of not following the recommended diet. The more knowledgeable the individual with dysphagia was about the benefit and the rationale behind the recommended diet, the more likely they were to adhere to the recommendations. For example, post-stroke patients reported nonadherence to the recommended modified diet as related to their lack of knowledge regarding the reason they were placed on the modified diet (McCurtin et al., 2018). Given this lack of knowledge, they reported that they felt that they did not need to be on a modified diet.

Moreover, a patient's emotional and mental status also affected their level of adherence (Colodny, 2005; Seshadri et al., 2018). Feelings of denial, anger, aggression, dishonesty, blaming, and stress all led to decreased adherence to dysphagia dietary recommendations (Colodny, 2005). Relatedly, loss of control in choosing what they want to eat, the need to be dependent on others, and the loss of enjoyment in eating and drinking also resulted in increased nonadherence to the recommended modified diet (Balandin et al., 2009; Colodny, 2005). This behavior of nonadherence could be appropriately framed as a volitional choice to not follow the diet recommendations, as a way for the individual to regain control over their body and what to eat and drink. Other psychoemotional factors that influenced adherence included depression, embarrassment, the burden of the modified diet on social interactions, and a fear of choking and the consequences of aspiration (Balandin et al., 2009; Seshadri et al., 2018). Lastly, age appeared to also have an effect on adherence, with younger adults being less likely to follow their dysphagia dietary recommendations (Low et al., 2001).

A variety of factors related to the individuals caring for the patient with dysphagia, such as nurses, spouses, or other caregivers, were also found to influence adherence to dysphagia dietary recommendations. Caregiver factors were identified in 7 of the 14 articles included in the rapid review. Perception of importance was one factor identified as having an influence on adherence (Crawford et al., 2007; Smith-Tamaray et al., 2011). Those caregivers

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who perceived high importance of following the SLP recommendations for safe eating and drinking experiences were more motivated to implement and make sure the dysphagia recommendations were met. Disagreement with the SLP recommendations was another factor identified across multiple studies (Colodny, 2001; Robbertse & Beer, 2020). Caregivers who did not agree with the recommended diet, often did not put the needed effort in to follow those recommendations. For example, in the study conducted by Robbertse and Beer (2020), 45% of nurses reported that they did not agree with the SLP dietary recommendations. Knowledge and experience were also identified as important contributors to adherence. Informal caregivers' level of knowledge and formal caregivers' (e.g., healthcare staff) level of experience, which is also related to knowledge, were identified to have a significant effect on adherence to dietary recommendations across multiple studies (Chadwick et al., 2002; Colodny, 2001; Robbertse & Beer, 2020; Rosenvinge & Starke, 2005; Smith-Tamaray et al., 2011). Thus, the more experienced and/or knowledgeable the caregiver was, the higher the adherence to dysphagia recommendations. Finally, for individuals who were dependent on others for feeding and/or following the SLP recommendations, the presence of supervision throughout the meal played a factor in increasing or decreasing adherence (Low et al., 2001; Rosenvinge & Starke, 2005). For example, 73% nonadherence to SLP dietary recommendations was noted in inpatients due to a lack of supervision (Rosenvinge & Starke, 2005). Two studies described specific environmental factors that played a role in adherence, particularly as related to dysphagia diet recommendations in institutionalized settings. Patients and hospital wards that received pre-thickened liquids showed better rates of adherence (Rosenvinge & Starke, 2005). In addition, the development of new facility-wide

measures and policies aimed at increasing education about dysphagia management had a

positive influence on increasing adherence (Rosenvinge & Starke, 2005). Finally, there was

increased adherence in settings where SLPs were core and respected members of the health

team and settings where there were enough and stable staffing of SLPs (Smith-Tamara et al., 2011). When the SLPs are recognized as an important member of the team providing health services to the patient, their dietary recommendations are acknowledged and more likely to be followed. In addition, with proper staffing, SLPs working in the setting can have more reasonable caseload and workload requirements, allowing them time to provide appropriate education and additional services.

The Ecological Model

The review of the 14 articles identified in the rapid review, in combination with the results previously identified from the general healthcare literature, revealed the presence of various factors that contribute or may contribute to adherence to dysphagia dietary recommendations. Drawing on the guiding frameworks from the ecological and health belief models, these factors were mapped onto the individual, caregiver and environmental levels of influence. The resulting visual representation of this model, "The Ecological Model of Factors Affecting Adherence in Dysphagia and Healthcare", is presented in Figure 2.

<<Insert Figure 2 around here>>

431 Discussion

While adherence is not a new concept in the general healthcare literature, a more systematic focus on adherence in the dysphagia literature is relatively new. Given the crucial role that adherence to dysphagia dietary recommendations plays in realizing the benefits of these recommendations, a better understanding of the factors that contribute to adherence is needed. Therefore, the goal of this research study was to develop a preliminary model of these contributing factors that can be used as a framework for addressing adherence to dysphagia dietary recommendations. To build the model, a rapid review was conducted to identify relevant articles in the dysphagia literature; the factors extracted from the dysphagia literature were then mapped onto factors previously described in the more general healthcare literature. As guided by the tenets of the ecological and health belief models and as based on

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the results of the rapid review, we then developed a visual representation of the model, "The Ecological Model of Factors Affecting Adherence in Dysphagia and Healthcare" (Figure 2).

Factors in the Dysphagia Literature

Across the dysphagia literature, adherence to dysphagia dietary recommendations emerged as a complex activity, influenced by factors across multiple levels. Thus, in order to effectively increase adherence, a more comprehensive approach is needed, which relies on better understanding the different levels of influence on the behavior.

Within the model, individual level factors were varied and included dissatisfaction with modified diets, level of knowledge, negative emotions related to the dysphagia (e.g., denial, anger, aggression, dishonesty, blaming, stress, loss of control, depression, embarrassment, fear of choking), the burden of the modified diet on social interactions, and age. Patient's level of knowledge was revealed to be an influencing individual factor on adherence across multiple studies, with the more knowledgeable the individual being, the higher the adherence (Chadwick et al., 2003; Low et al., 2001; McCurtin et al., 2018; Rosenvinge & Starke, 2005; Seshadri et al., 2018). This finding emphasizes the necessity for educating patients on the risks associated with dysphagia, the components of the treatment plan, and the potential benefits of and rationale for the selected treatment plan. Not surprisingly, brief, but focused education on dysphagia has been found to lead to significant improvements in patient knowledge that is retained over time (e.g., McKinstry et al., 2010). Individuals with dysphagia have previously reported the value of dedicated time to reviewing instrumental assessment results, with the opportunity to ask questions in the moment, as well as individualized conversations about the impact of dysphagia, such as tailoring conversations to be about a specific meal the patient will be eating (Howells et al., 2020). Unfortunately, other individuals have noted that they do not even understand the role of the SLP (Howells et al., 2020), further emphasizing the importance of focused education, provided at the level the patient is currently at. Furthermore, increasing the patient knowledge

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level has the potential to reduce depression and increase quality of life (Chen et al., 2018), emphasizing the importance of providing patient education. For example, Chen and colleagues (2018) found that a swallowing exercise educational program resulted in improved emotional status and improved quality of life. The value of targeted enhancements of knowledge are well-aligned with the components of the health belief model. For example, such education can directly influence patients' perceptions of the severity of dysphagiarelated consequences, the effectiveness of treatment, the reduction of barriers, and their ability for change (self-efficacy), which would all be predicted to have a positive impact on behavior (adherence).

Dissatisfaction with the modified diet has also been associated with decreased adherence (Colodny, 2005; McCurtin et al., 2018; Robbertse & Beer, 2020; Shim et al., 2013). Across settings, modified textures have been found to be less desirable – for example, consumers of pureed foods find that they lack sensory appeal and variety, they may be indistinguishable from one another, and they lack natural flavor (Keller & Duizer, 2014; Keller et al., 2012). This relationship between dissatisfaction and decreased adherence is observed not only in relation to the food and liquid textures, but also with restrictions associated with other health diagnoses, such as diabetes (Ghimire, 2017). Relatedly, drinking and eating are generally happy and pleasurable acts and form a fundamental component of social engagement with others. Thus, placing a patient with dysphagia on a modified diet can strip enjoyment from eating and drinking and lead to negative psychosocial consequences such as increased isolation. Consequently, feelings of denial, anger, aggression, blaming, stress, loss of control, depression, and embarrassment can all arise. These feelings have been associated with decreased adherence in dysphagia management (Balandin et al., 2009; Colodny, 2005; Seshadri et al., 2018) and across other health domains (Sumlin et al., 2014). Certainly, the decision to modify a patient's diet should not be taken lightly, and is often considered a last resort for increasing swallowing safety as there may be negative

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consequences to these recommendations that must be considered during the management process. It is clearly important to consider the role that dissatisfaction plays in adherence, combined with the value of individualized education.

A number of interrelated caregiver factors, across both formal and informal care providers, also emerged as relating to adherence and included perception of importance, disagreement with the SLP recommendations, knowledge, level of experience, and supervision. Notably, knowledge appeared as an influencing factor at both the individual and caregiver levels. The influence of caregiver level of knowledge on intervention implementation, patient support, and treatment outcomes has been established across dysphagia and other healthcare domains. For example, when educational programs about dysphagia were provided to nurses, the number of patients who were identified as having or being at risk for dysphagia increased (Hansell & Heinemann, 1996). Informal care providers, such as family members, have previously reported not being prepared for the severity and chronicity of their loved ones' dysphagia and feeling as though they did not receive enough support during the recovery process, with a particular lack of practical, personalized information free from medical jargon (Nund et al., 2014). Similar to findings among patients, many informal care providers have indicated not understanding the role of the SLP in dysphagia management (Nund et al., 2014). Thus, it is not surprising that improved education, particularly individualized education, can lead to increased adherence. Caregiver experience, another contributor to adherence, likely also interacts with education and overall knowledge base as caregivers with greater experience likely also present with an increased degree of knowledge related to dysphagia management. These more experienced caregivers who may be more knowledgeable about dysphagia overall, may similarly be more aware of the importance of dysphagia management and adherence to treatment recommendations. These findings are similar to results revealed across the more general healthcare literature; for example, nurses' pain management for cancer patients has been found to be highly correlated

with their knowledge base (Jang et al., 2016). Further, the success of health interventions more broadly is highly influenced by the level of experience of the health professional involved (Laffel et al., 1992); the more familiar they are with the diagnosis, procedure, and medication, the better the outcome. Finally, agreement with the health recommendations by caregivers was also found to be associated to increased adherence in dysphagia as well as across other health domains (Bogardus et al., 2004; Colodny, 2001; Robbertse & Beer, 2020). This factor is likely also related to the previously described caregiver factors as increased knowledge about dysphagia and dysphagia management, increased experience, and greater awareness of the importance of recommendations may result in increased agreement with the health recommendations – and increased likelihood of implementation.

Pre-thickened liquids, and improvements in the facility-wide practices and policies (e.g., increasing education, reducing caseload size, utilizing a team approach) were the factors identified at the environmental level. There are multiple studies available that have investigated the use of pre-thickened liquids (Huppertz et al., 2020; Kotecki & Schmidt, 2010; McCormick et al., 2008). Positive outcomes were not only observed in increasing adherence, but also in terms of cost effectiveness; pre-thickened liquids were also found to be less time consuming for SLPs and nurses (Kotecki & Schmidt, 2010). In addition, setting policies and procedures were also identified as influencing factors. These settings and policies can either have a positive or negative effect on adherence. For example, in settings where SLPs have an appropriate caseload, they can allocate more time to each of their patients. This can help SLPs provide a more tailored education and treatment plan, and thus improve education.

The majority of factors identified as influencing adherence within the dysphagia literature were at the individual and caregiver levels. It is plausible that there are more individual and caregiver level factors that influence this behavior as compared to environmental level factors. Perhaps, more likely, it is also possible that previous research

has been primarily focused on person-level factors, such as those related to the patient and those related to the caregiver. This can be attributed to the fact that impairment-based approaches are more widely used in dysphagia management and that environmental, or system-wide, changes are more difficult to achieve. These findings support the need for more research in the area of adherence, especially looking into influencing factors at the environmental level and how those may interact with the previously revealed person-level factors.

Integrating the Healthcare Literature

Factors affecting compliance in the general healthcare literature were also integrated into the current model, given the paucity of dysphagia-specific research. While some of these factors were similar to the factors identified in the dysphagia literature, a number of unique, but seemingly relevant, factors emerged. These factors could also be grouped into the three levels of the ecological model: individual, caregiver, and environment.

A patient's knowledge level was a factor identified at the individual level in both the dysphagia and healthcare literature, supporting its strong influence on adherence and well-aligned with the health belief model (Chadwick et al., 2003; Herrema et al., 2018; Khambati et al., 2017; Low et al., 2001; McCurtin et al., 2018; Rosenvinge & Starke, 2005; Seshadri et al., 2018). Patient preference was also identified as an influencing factor on adherence in the healthcare literature (Herrema et al., 2018; Mikulka, 2016). This factor is closely related to the dissatisfaction with the recommended diet observed in the dysphagia literature given that modified diets are generally not what patients would prefer (Colodny, 2005; McCurtin et al., 2018; Robbertse & Beer, 2020; Shim et al., 2013). Relatedly, patient's involvement in the healthcare decision making process was identified as an influencing factor in the general healthcare literature (Herrema et al., 2018; Mikulka, 2016). This is likely extremely relevant in dysphagia, as patients are more motivated to follow the recommendations when they have been involved in the decision making, particularly in light of the common dissatisfaction

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associated with many aspects of modified diets. Importantly, this shared decision-making process is a fundamental component of defining adherence as compared to compliance, further emphasizing its importance to consider in clinical practice. Other unique factors identified in the healthcare literature were anxiety, cognitive abilities, and post-traumatic stress disorders (PTSD) (Guimaraes et al., 2015; Stringham et al., 2018). These factors were deemed to be additionally relevant to dysphagia adherence as they are related to the individual's emotional and mental status, which have been previously shown to impact adherence to dysphagia diet recommendations (Colodny, 2005; Seshadri et al., 2018).

At the caregiver level, knowledge and perception of importance were common factors in both the healthcare and dysphagia literature (Chadwick et al., 2002; Colodny, 2001; Crawford et al., 2007; Lum et al., 2018; Robbertse & Beer, 2020; Rosenvinge & Starke, 2005; Smith-Tamaray et al., 2011). Together, this suggests that both patient and caregiver "buy in", which draws heavily on their understanding of the medical condition and treatment options, are needed to maximize adherence. Other factors emerging from the healthcare literature included lack of a caregiver, the strength of the physician-patient relationship, and the presence of positive or negative support (Berry et al., 2008; Endevelt, & Gesser-Edelsburg, 2014; Guimaraes, et al., 2015). The negative impact of a lack of a caregiver can likely extend to dysphagia adherence. Patients who are unable to be independent are often unable to, for example, thicken their liquids appropriately or prepare their modified diet without caregiver help and support. Thus, without the presence of a caregiver, they will be less likely to adhere to dysphagia dietary recommendations given logistical barriers. In addition, the more positive the caregiver support is, the more adherent the patient often is to the recommendations. Lastly, the observed relationship between the physician-patient relationship and adherence in the healthcare literature is likely also present in the case of dysphagia. When the relationship between an SLP and patient is stronger, there is generally an increase in trust in the SLP and what they recommend, thus increasing adherence. In fact,

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medical mistrust – including a lack of trust in the individual healthcare providers as well as the overall healthcare system – has been observed to be one of the most prominent barriers to medication adherence (Hall & Heath, 2021; Kelly et al., 2020). Thus, it is crucial for healthcare providers to prioritize the therapeutic alliance between themselves and their patients.

At the environmental level, there were no overlapping factors between the healthcare and the dysphagia literature. This can be attributed to the fact that there were only two articles that investigated environmental factors in dysphagia. The unique factors identified in healthcare included counselling sessions, the use of a team approach, cost of treatment, cultural considerations, and individualized treatment (Kapoor et al., 2016; Stringham et al., 2018; Zhao et al., 2018). All of these factors are likely equally as valuable in improving adherence to dysphagia dietary recommendations. Implementing aspects of counselling into SLP therapy sessions through psychoeducation can increase patient and caregiver knowledge, which has been shown to increase adherence (Zhao et al., 2018). It is also important to refer patients and informal caregivers to a mental health provider as appropriate. More formal counselling can help address some of the negative emotions associated with dysphagia that may negatively impact adherence. Cost of medical services and medication has been noted in healthcare literature to also have a strong influence on adherence (Law et al., 2012; Soumerai et al., 2006; Stringham et al., 2018). Studies in medication adherence reported poor adherence levels with high out of pocket medication costs (Soumerai et al., 2006). Skipping doses, taking smaller doses to delay refill, choosing which medication to get, and using generic brands are some of the nonadherence methods used by patients. Providing more affordable medical services and medication, can increase patient's willingness to visit health care professionals, and to adhere to their recommendations. As applied to dysphagia therapy, when patients are able to pay for the costs associated with assessment and therapy sessions as well as needed supplies (e.g., thickeners), adherence may be maximized. Another

contributing factor to adherence in healthcare is cultural considerations (Jin & Acharya, 2015; McQuaid, 2018). It is crucial to respect and acknowledge cultural differences that may impact beliefs related to the disease itself and its trajectory and the acceptance of different treatments. SLPs must develop individualized treatment plans that integrate each patient's unique background and needs. Such individualization and respect can lead to better patient satisfaction, increased adherence, and ultimately better treatment outcomes.

Clinical Implications

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Certainly not all influencing factors identified in the current review are modifiable. However, a number of immediately implementable strategies to improve service delivery, treatment outcomes, and patient adherence are suggested. First, both patient and caregiver knowledge were identified as a factor influencing adherence across the dysphagia and healthcare literature. SLPs need to allocate sufficient time for education, which must include a clear and easily understandable description of the current impairments, the treatment recommendations, and the rationale for the recommendations. It is crucial that this education includes a discussion of what is important to the patients themselves. This conversation should be tailored specifically to what the patient needs, what they know, and what they are feeling, at a level that is appropriate for their current cognitive and emotional status. This time can also be used for the patients to express concerns and for the SLP to work with the patient to problem solve what may work best for them (e.g., types of modified foods that are more acceptable such as transitional foods). Unfortunately, a reality of clinical practice is that SLPs may face challenges to providing this individualized education, such as time constraints and productivity requirements. Clinicians may need to be creative in determining the best way to integrate patient and informal caregiver training into therapy sessions. For example, working with the dietitian or occupational therapist may allow for tailored discussions of dietary needs and meal preparation in a more functional format or activity. Considering formal strategies such as the teach-back method may also allow the clinician to target both

cognition and dysphagia education in a functionally relevant clinical activity. Use of multiple modalities of instruction, such as verbal discussion and visual handouts to take home, can further help maximize understanding and carryover despite in-therapy time constraints.

Dissatisfaction with the modified diet was another factor identified as negatively impacting adherence, which can be further targeted through education. Allocating dedicated time to providing education to patients and their informal caregivers can allow SLPs to discuss the reasons behind the current diet and ideas to help the patient adjust to the modified diet (e.g., recipes). These sessions can also provide time for sufficient training of the caregiver who will be taking care of the patient at home. This may increase patient's acceptance of the modified diet and caregiver understanding of the importance of the current diet. For formal caregiver education/training, healthcare facilities can build in required educational lectures by the SLPs to all health employees involved in taking care of patients with dysphagia. Ultimately, engaging in these crucial conversations about the importance of, strategies for, and barriers related to dysphagia dietary recommendations will facilitate more active participation by patients and their caregivers in the therapy plan.

Building trust is also important to promote patient and caregiver engagement in the therapy process and the patient-provider relationship. Taking the time to listen to patients and their caregivers, asking questions, and using ethnographic interviewing techniques will help ensure that they feel valued. Patients and caregivers must experience agency, or control, over their healthcare plan. This is particularly relevant for dysphagia dietary recommendations as patients' preferences may not align with what the medical team may deem to be "most safe". Ensuring a strong therapeutic alliance based on trust will facilitate these conversations and allow patients and caregivers to realize their important role in the development of the plan.

There are a number of additional considerations for clinical practice. First, important to any approach implemented is the need to acknowledge the multiple levels of influence impacting adherence, as suggested by the ecological model. Therefore, it is necessary to not

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only include the patient in our treatment plans. Caregivers should be a part of the patient's assessment and treatment sessions, which will also provide an opportunity to hear their concerns and answer their questions about the recommendations. Clinicians must also recognize and work to minimize potential environmental barriers that exist, that may limit successful adherence, particularly among individuals who do want to implement dietary modifications. Furthermore, some of the factors identified as influencing adherence are not able to be modified (e.g., personality characteristics). While it is important to focus on those factors that are modifiable when creating the treatment plan, it may be valuable to attend to the non-modifiable factors to identify who is at increased risk of non-adherence – and who may not be appropriate for recommendations of dietary modifications. Finally, it is important to ultimately acknowledge a patient's right to choose or refuse any given treatment recommendation. The SLP can make sure that the patient and caregiver were provided with ample education to facilitate their understanding of why these recommendations were chosen and to help structure their environment for success should they want to (e.g., considering the factors of the ecological model presented above); however, patient autonomy and agency must be recognized.

Limitations

The current study presents with some limitations. The specific inclusion criteria and keywords used might have resulted in missed studies, particularly studies not published in English. In addition, only two databases (Medline and PubMed) were used in the current study. The model also incorporated data from the general healthcare literature based on a descriptive review of the literature, so other non-dysphagia-specific factors may be relevant, but were not identified. Further, all of the factors extracted from the 14 dysphagia-specific articles were included in the model regardless of the number of times they appeared in the literature and no information about relative importance as compared to other factors or strength of influence could be ascertained. However, given the goal of this study to develop

an initial ecological model of factors affecting dysphagia dietary adherence, it was important to broadly explore and consider all factors. Therefore, additional research is needed to strengthen the model and future research should focus on not only identifying which factors affect adherence, particularly those healthcare-related factors not yet explored in the dysphagia literature, but also on investigating which combinations of factors across the levels of influence have the greatest impact. It will also be important for research to address how manipulations of these combinations of factors ultimately help improve adherence.

Conclusion

Adherence to dysphagia dietary recommendations is necessary for the success of this management approach. Yet, adherence is a complex human behavior. The goal of this study was to identify what network of factors may influence adherence to dietary recommendations across the individual, the caregiver, and the environment, leading to the development of an ecological model. This preliminary visual model can serve as a functional tool for SLPs to use in their clinical practices in order to improve treatment outcomes and patient satisfaction related to dietary modifications. Ultimately, to enhance treatment effectiveness, clinicians must engage their patients in the therapy process and explore opportunities to enhance patient and caregiver education related to the impairments, consequences, and treatment options related to dysphagia.

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999	Figure and Table Legends/Captions
1000	Figure 1. Flow diagram of the rapid review search process, including the number of articles
1001	identified, included, and excluded at each step
1002	Figure 2. The "The Ecological Model of Factors Affecting Adherence in Dysphagia and
1003	Healthcare" as guided by the dysphagia-specific (left) and general healthcare (right)
1004	literature, highlighting factors influencing adherence across three different levels (individual,
1005	caregiver, environment)
1006	
1007	Table 1. Characteristics of all studies meeting the criteria for inclusion in the rapid review
1000	
1008	