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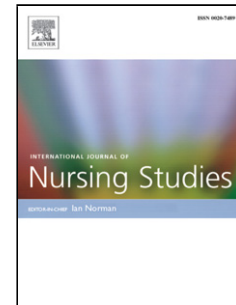
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Authors: Samantha E. Shune, Deanna Linville

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Understanding the dining experience of individuals with dysphagia living in care facilities: A grounded theory analysis

Samantha E. Shune, PhD, CCC-SLP<sup>a,\*</sup> sshune@uoregon.edu, Deanna Linville, PhD, LMFT<sup>b</sup> linville@uoregon.edu

<sup>a</sup>Communication Disorders and Sciences, University of Oregon

<sup>b</sup>Couples and Family Therapy, University of Oregon

\*Corresponding author information: Assistant Professor, 249 HEDCO Education Building, 5284 University of Oregon, Eugene, OR 97403-5284, Phone: (541) 346-7494

### Abstract

**Background and Objectives:** Person-directed care in nursing homes, also known as the ‘culture-change movement’, aims to enhance dining-related quality of life. However, for residents with dysphagia, it is unclear how to best support this enhancement while balancing eating-related safety/risks. Thus, the purpose of this study was to explore the experience of and to define successful, person-centered dining for residents with dysphagia. **Research Design and Methods:** Grounded theory methodology guided twenty-one 60-90 minute semi-structured interviews with participants across 7 stakeholder groups including residents, family members, and nursing, dietary, and therapy staff. We used a systematic and iterative approach for all data collection, analysis, and generation of theory. **Results, Discussion, and Implications:** A theory emerged from the data that highlighted how individualization and socialization are the central tenants for improving residents’ dining experiences and success, or ‘focusing on the person: individualization and socialization during mealtimes’. We identified multiple facilitators and barriers to successful dining for residents with dysphagia such as the importance of positive social connections and invested, knowledgeable, and aware care team members. The focus of

care was a salient theme suggesting that individualization of care that promotes residents' quality of life is a key facilitator of successful dining experiences. A social-ecological model for successful dining with dysphagia is ultimately proposed: optimizing health and well-being for these residents through successful dining experiences requires collaborative and coordinated care to address a variety of interrelated individual-, interpersonal-, and organizational-level facilitators and barriers.

**Keywords:** culture-change movement; dysphagia; ecological models; mealtimes; nursing homes; person-centered care; qualitative research

### **Contribution of the Paper**

#### **What is already known about the topic?**

- Important contributors to person-centered mealtime practices in nursing homes include increasing resident choice and independence, decreasing dining-related restrictiveness, and promoting positive social interaction.
- Dysphagia is common among nursing home residents.
- For residents with dysphagia, it is unclear how to best support person-centered dining enhancements while balancing eating-related safety/risks.

#### **What this paper adds**

- Across all stakeholder groups, there is a consensus that individualization and socialization are at the heart of mealtime care, even for residents with dysphagia.
- Many factors can facilitate and/or impede successful dining with dysphagia including fostering social connection, individualizing versus medicalizing care, and increasing care team investment.
- A social-ecological model for successful dining with dysphagia highlights the need for coordinated dysphagia care in order to optimize health and well-being.

## Introduction

In 2014, nearly 1.4 million residents were living in nursing homes in the United States; approximately 85% of these residents were over the age of 65 (Harris-Kojetin et al., 2016). While the incidence of institutionalization varies worldwide (e.g., Verbeek et al., 2015), it is estimated that 2-8% of people over the age of 65 reside in nursing homes in industrialized countries (Alders et al., 2017, Katz, 2011, Ribbe et al., 1997). This number is expected to grow. Nursing home admission is a major life event, requiring the modification of well-established personal habits, physical and social environments, and autonomy (Bergland and Kirkevold, 2006, Hvalvik and Reiersen, 2011). Residents may perceive a loss of agency, often related to efforts to prioritize safety and health (Bangerter et al., 2017). The traditional care facility structure emphasizes institutionalization based on illness and dependency. In response, recent research and public policy has begun to emphasize person-directed care (termed the culture-change movement in the United States; see Rahman and Schnelle, 2008, Zimmerman et al., 2014).

This culture-change movement has compelled the enhancement of dining-related practices, particularly in light of the crucial role mealtimes play for meeting biological (e.g., nutrition/hydration) and psychosocial needs. Improving nutrition and quality of life are key research priorities for the nursing home setting worldwide (Morley et al., 2014). As many as 50-65% of residents experience unintended weight loss and under-nutrition (American Dietetic Association, 2005, Beck, 2015). Advanced age alone is a risk factor for malnutrition (Favaro-Moreira et al., 2016, Forster and Gariballa, 2005, Tamura et al., 2013). Malnutrition is common among long-term care and nursing home residents and associated with poorer psychological well-being (Muurinen et al., 2015, Soini et al., 2011). In general, malnutrition is associated with

increased mortality and morbidity. Malnutrition is linked to decreased survival, function, and quality of life, higher rates of hospital readmission, healthcare-associated infections, and depression, worse health outcomes, and higher healthcare costs (Barker et al., 2011). Eating and food-related activities are also intricately tied to individual identity and the quality of social relationships (Mintz and Du Bois, 2002, Plastow et al., 2015). When an individual is experiencing illness, eating-related activity is viewed as an integral marker of a continued “sense of normalcy” while eating difficulties can increase the impact of disease by further isolating them from their social networks and norms (Klinke et al., 2013, Perry and McLaren, 2003). This sense of normalcy is a desired functional outcome for individuals with chronic illness, such as dementia (Horton-Deutsch et al., 2007), whereas isolation and a lack of companionship is a predictor of functional decline, particularly among older adults (Perissinotto et al., 2012). Ultimately, successful mealtimes are vital for residents’ health and well-being, spurring the emphasis on improved dining-related practices.

Person-centered mealtime practices are multifaceted, thought to require elements of: (a) increasing resident choice and independence; (b) decreasing dining-related restrictiveness; and (c) promoting positive social interactions (e.g., Milte et al., 2017, Pioneer Network, 2011, Reimer and Keller, 2009, Watkins et al., 2017, Watkins et al., 2017). However, it is challenging to balance the aspects that promote resident-specific autonomy, health, and quality of life in a highly communal, medical environment. Additionally, organizational and policy barriers often negatively influence important mealtime culture and enjoyment, as well as impede efforts toward fostering resident agency (Watkins et al., 2017).

Further complicating the dining-related culture-change shift is the frequent presence of dysphagia, or swallowing impairments, leading to particularly poor mealtime experiences (Milde

et al., 2017). Dysphagia occurs in up to 55% of nursing home residents (Park et al., 2013). The reconciliation of person-centered mealtime practices involving agency and flexibility with the eating-related safety needs for these individuals presents a unique challenge. This important area of inquiry has been mostly neglected by researchers and, therefore, it is also not entirely clear what the specific needs are for these residents.

There is growing recognition that mealtime management involves multiple stakeholders. Beyond the residents, multiple disciplinary perspectives are involved, such as nursing, dietary, and therapy staff. It is not appropriate or feasible to implement dining-related changes that improves aspects of dining for one stakeholder group at the expense of another. Insufficient recognition of all team members' opinions and professional responsibilities during the design of education and program initiatives can lead to policy and practice change failures (e.g., Yoon and Steele, 2012). Previous research highlights the need for change at both management and service-provision levels, in order to improve organization and staff support (Bennett et al., 2015, Watkins et al., 2017). Thus, it is crucial to account for the interdisciplinary nature of dining and to develop dining improvement programs that are shaped by joint perspectives regarding barriers and facilitators. There is a paucity of research pertaining to the *shared* views across stakeholders, particularly when focusing on the unique challenges for individuals with dysphagia (Watkins et al., 2017). For researchers and service providers to effectively target dining-related improvements, from development to implementation and sustainability, it is necessary to take into account the complexity of mealtimes according to all stakeholders.

The purpose of the current study was to identify the shared viewpoints regarding the experience and definition of successful, person-centered dining for residents with dysphagia as reported across primary stakeholder groups. Further, we aimed to conceptualize the data themes

as part of an emerging theory that can help us elucidate the multifaceted nature of mealtime practices for future intervention design.

## **Design and Methods**

### **Design**

For this preliminary study, we broadly explored the dining-related experiences of care facility residents with dysphagia and their formal and informal caregivers. We employed a qualitative design guided by grounded theory to contribute to our theoretical understanding of ‘successful dining’, particularly for individuals with dysphagia (Charmaz, 2014, Glaser and Strauss, 1967). Therefore, we used a systematic and iterative approach to data collection/analysis and theory development. One goal of our broad work is to identify the most malleable and salient factors that positively and negatively influence dining success for this population in order to improve clinical care. Generating a theory of the shared definition of successful mealtime directly from participants’ accounts can help inform clinical intervention programs and target outcomes. Thus, we concentrated on the ecological validity of the study findings in order to ensure that our findings could translate well to real world settings and so that subsequent interventions are grounded in the theoretical and empirical conceptualization of the dining process. The Institutional Review Board at the participating institution approved all study procedures.

### **Participants**

The research team recruited 21 participants across seven stakeholder groups, using purposive sampling techniques. We recruited all participants via posted flyers and word-of-mouth. The majority ( $n = 18$ ) of participants were affiliated with a single, Pacific Northwest care



facility while the remaining participants ( $n = 3$ ) were affiliated with three different facilities in the same region. Interview participants received \$40 compensation.

All participants self-identified with one of the following groups: care facility residents with dysphagia, family of residents with dysphagia, nursing staff (nurses, certified nursing assistants), dietary staff, and therapy staff (occupational therapists/therapy assistants, speech-language pathologists). While not exhaustive, these groups represent the primary individuals involved and/or invested in the resident dining process. To best capture a variety of opinions, inclusion criteria were broad. Residents with dysphagia needed to be: (a) over the age of 60, (b) participating in the dining process (i.e., not receiving complete enteral nutrition), and (c) living at the facility for at least two weeks. Given the goals of the study and the need to obtain reliably descriptive information from participants, residents with severe language or cognitive difficulties were ineligible. Remaining participants needed to be over the age of 18. Staff participants could have any number years of experience. Table 1 presents participant demographic information. We broadly recruited participants until we reached theoretical sufficiency in the data analysis process (Dey, 1999; see further details below). However, as the current study aimed to explore the shared commonalities *across* groups regarding opinions on mealtimes for individuals with dysphagia, we sampled equally from all stakeholder groups in order to pool all data. Thus, once theoretical sufficiency was reached, we continued recruiting only from those groups that had fewer participants; our final sample contained 3 participants from each group.

## Data Collection

The principal researcher and one research assistant collected the data. The researcher, a certified and licensed speech-language pathologist and doctoral-level faculty member at the local university, and the research assistant, a post-baccalaureate student, had no affiliation with the care facility sites. As of data collection, the researcher had over eight years of experience working as a speech-language pathologist across healthcare settings including skilled nursing and long-term care facilities, primarily in dysphagia management. The researcher and 20 participants did not know each other prior to the study. The researcher did know one of the speech-language pathologist participants professionally; however, based on feedback from the research assistant, who did not know any of the participants, this interview was no different than the others.

The researcher conducted 60-90 minute semi-structured, in-depth interviews that were video recorded. The interviewer asked generative questions about dining-related behaviors, needs, goals, and barriers that may influence the behaviors. Interview guides were specific to each stakeholder group and served as the framework for the conversations (Table 2). For example, the interviewer asked residents about their dining-related changes since admission and whether these changes aligned with their personal preferences. The interviewer asked nursing staff about a time they were required to or elected to change dining behaviors and whether this change was successful. Questions were purposefully open-ended to allow for a wide range of responses and the interviewer used tailored probes as needed.

The research team met with participants in locations preferred by them, such as in a private room in the facility or in participants' homes. Only the participant, researcher, and

research assistant were present during interviews. Consistent with grounded theory methods, we used concurrent data collection and analysis. The research assistant took detailed field notes; the interviews and field notes were both considered primary sources of data. In addition, analytic memos were written by the researcher and research assistant throughout the data collection process, in order to further capture new theoretical insights, unanswered questions, or ideas that needed more exploration (Saldaña, 2016). Thus, interview questions were recursively modified based on emerging themes at different stages of data collection and partially derived from field notes and analytic memos.

Interviews were transcribed verbatim using a three-stage process (Duff et al., 2008). First, audio portions of the interviews were transcribed. Next, the transcriber added gestures that contributed unique content (e.g., facial expressions indicating displeasure) and made any corrections to the audio content of the transcript. Lastly, a second transcriber watched the video to generate a final transcript that reflected any corrections. Discussion between the two occurred as needed. Through memo writing, the transcribers wrote their thoughts and emerging theoretical connections (Saldaña, 2016). Data collection continued until theoretical sufficiency was reached (Dey, 1999). Given the focus on shared views, rather than individual or group differences, we aimed to reach theoretical sufficiency instead of theoretical saturation, since we cannot provide evidence that we have reached true theoretical saturation across all groups (Charmaz, 2014). In other words, we determined that we had met our goal of theoretical sufficiency, or a sufficient depth of understanding to allow for theory development, when there were no new suggested themes emerging from the data.

### **Data Analysis**

The researcher and team of four research assistants comprised the data analysis team. We analyzed the data using constant comparative methods outlined by Glaser and Strauss (1967), which allowed us to make comparisons during each stage of analysis. First, we manually analyzed the written data line-by-line to develop an initial set of open codes (Charmaz, 2014). Throughout the first two stages of the analysis, we used axial coding processes to identify relationships among the open codes, merging related concepts into categories and iteratively adapting our coding scheme. One of the main strategies we used during this phase of data analysis was to write analytic memo narratives, which afforded us a more practical method of putting the theoretical puzzle pieces together (Saldaña, 2016). We reanalyzed transcripts, analytic memos, and field notes during each stage to further explore the emerging ideas that related to the definition, facilitators, and barriers of successful dining for residents with dysphagia. In the final stage of analysis, we used theoretical coding techniques and consistently examined how emerging themes made sense across transcripts, which allowed team members to weave together ideas and experiences across stakeholder groups. The final central core category and grounded theory emerged during this final stage of analysis. Throughout the process, we identified relevant quotations from the transcripts that exemplified the emerging theory and its associated categories; we present these quotations to illustrate the results below.

The research team ensured data fidelity by completing multiple steps. For example, to promote dependability and trustworthiness of the findings, we engaged in weekly peer debriefings, and the creation of an audit trail, or a step-by-step process of data collection and analysis procedures (Creswell, 2008). Further, to increase trustworthiness of the findings, the data analysis team coordinated and harmonized ideas throughout the coding process, allowing for the creation of a shared interpretation of the data (Weston et al., 2001). Likewise, we used

reflective listening and summarizing techniques throughout the interviews to ensure data accuracy.

## Results

The central theory that emerged across all of the participants' accounts was that individualization and socialization are at the heart of mealtime care, or 'focusing on the person: individualization and socialization during mealtimes' (Figure 1). Successful dining for residents with dysphagia is reliant upon residents being valued as individuals with their own individual needs. As one participant noted:

Everyone's special in their own way, and everyone needs some sort of special care. Regardless if it's barely anything or all of it...I kind of judge how to work with a resident by the resident themselves...and make them comfortable. Instead of working with everyone in a similar way, I try to adapt to each person (Participant 6, nursing assistant).

Likewise, residents do not want to be viewed as their diagnosis and want mealtimes to be recognized as an intimately social experience, in and of itself. This sentiment was also shared among facility staff. One speech-language pathologist described her relatively "idealistic" and "naïve" views upon graduation that approached dysphagia as "purely a medical issue" (Participant 12). However, she quickly learned that it is not "just a medical issue, it's a social issue". Similarly, one nursing assistant noted that social interactions are a huge part of mealtimes and that taking the time to talk to residents while feeding is "wonderful for the recovery, mental health and all" (Participant 7). Ultimately, the "patient as person" as the center of care emerged as most crucial:

That's always my goal. I always want to focus on the patient, all of their needs. Not just their medical needs, but, you know, as a whole (Participant 14, nurse).

Four interrelated categorical themes emerged from the data that highlight the factors that define, facilitate, and/or impede such individualization and socialization (Figure 1): (a) focus of

care matters; (b) dining success requires positive social connections; (c) team members need to be invested, aware, and knowledgeable; and (d) despite positive intentions, structural and organizational barriers exist. Notably, team member investment, awareness, and knowledge can directly influence the ability, or willingness, to individualize care and provide desired social opportunities during mealtimes. It therefore is likely a strong contributor to successful person-focused mealtime care. Further, a number of structural and organizational barriers exist external to this process that unfortunately limit the ability to focus on the individual. We will describe these four themes and their associated subthemes underpinning the theory below, illustrated by the participants' words.

### **Focus of Care Matters**

Overall, participants emphasized that the focus of care mattered: when team members focused on individualizing resident care, it led to more successful dining experiences and the promotion of quality of life. It was clear that despite having dysphagia, this diagnosis did not define these residents. Notably, participants rarely discussed dysphagia treatment itself; rather than focusing on the optimization of swallowing abilities, dining success was more often defined in terms of improved activity/participation in the mealtime process through the realization of individualized care. Staff discussed the need to tailor their interventions and approach. This was important for not only building a therapeutic alliance, but also for setting realistic mealtime-related goals that took patient preference into account as illustrated by the following quotes:

...if you don't have that therapeutic relationship with them I don't think they're going to get very far. Whether being able to joke with them or just having that very professional boundary, depending on the person (Participant 19, occupational therapist).

I feel like in general, dietitians are more patient-centered people anyway. I mean, obviously we have the clinical and the medical background, and we know these things.

But if the person's not going to do it, they're not going to do it. So you really have to tailor your interventions to each person (Participant 16, dietitian).

Crucially, participants recognized the need to incorporate resident choice into the mealtime decision-making process. For most participants, such choice was ultimately what defined individualized care. In other words, the participants viewed successful dining as being reliant on honoring resident choice. Yet, conflict was identified between realizing oneself as an autonomous being and the limitations associated with institutional care settings:

...resident choice is pretty much the most important part of our job. Or the residents' comfort. Where we would be going outside, going and doing stuff, a lot of these people are spending literally 100% of their time in here...it is important that you let them have their choices and let them feel like they're still in control of their life, because nobody wants to feel like they're caged up and not allowed to be themselves (Participant 6, nursing assistant).

Participants acknowledged that resident choice related to dining was more difficult for individuals with dysphagia. One participant identified the challenge of creating a system where patients with dysphagia get the same type and amount of choices as those without since frequently, regardless of the meal chosen, staff is "pureeing whatever is easiest to puree" (Participant 10, speech-language pathologist). Similarly, there were times when the meals selected were clearly not chosen by the residents themselves. For example, one dietary aide described an experience where she questioned the order she was filling because "I know [she] hates cream of wheat, but it was circled" (Participant 5). Awareness of food preferences was valued as both residents and staff noted that negative meaning was associated with receipt of food that was not requested and/or generally eaten. This was especially important in light of the negativity associated with modified-textured foods themselves (as further described below).

Further detracting from the individualization and normalcy of the shared dining experience, medicalizing resident care was viewed as a key barrier:

...I know sometimes [nursing assistants] will feed both residents and, if you can multitask, that's cool, but it kinda does take away from the personal experience. So I try to feed people one-on-one, give them my attention (Participant 6, nursing assistant).

They come in and put your medicine down at the table, and I do not like that at all. Then they might say, 'Did you have a BM today?' Well that's- that's embarrassing to me. That's terrible...and I don't think pills are [appropriate] either. We all stop eating and watch them take them (Participant 3, resident).

As one nursing assistant eloquently stated, taking “purely a medical standpoint, kind of takes the heart out of it” (Participant 7). Across interviews, it became clear that all participants valued individualized care that not only acknowledges each resident as a unique person, but that also recognizes that the purpose of the care is not always medical. In other words, the focus of the mealtime to the individual, and ultimately the focus of mealtime care, is not simply about getting a job done (e.g., passing medications, quickly getting nutrition in), but rather experiencing the meal. Participants also made clear that, while not the direct focus, medical improvements would still be expected because “when you feel better as a person, your whole body is just going to be better” (Participant 16, dietitian).

### **Dining Success Requires Social Connections**

Related to the focus of care and definition of a successful dining experience, study participants noted how important positive social connections are for residents with dysphagia. Given the fundamental role mealtimes play in facilitating social relationships, it was not surprising that social connection being central to successful dining emerged during theory development across all participant groups. Subthemes included the need to cultivate a community and supporting resident happiness, particularly through mealtimes. Residents desired to eat in good company and be among friends, rather than be restricted to sitting by “diagnosis”. In fact, residents viewed the social aspects of mealtime, rather than the safety, as critical for overall well-being:



We established our table... We just make stories up. You know, that's what works. [Staff member] came over and I said, 'This is the greatest table in this whole area.' 'Yeah,' he said, 'The laughing table.' He said, 'Every time I look over there you all- somebody's laughing.' And we're all laughing... We love [our tablemates]. We look forward to them... very good friends... if you want to have a happy place, you've got to have happy friends who enjoy it (Participant 3, resident).

Community cultivation also extended beyond the residents themselves. Residents and family members described that those staff who were more invested seemed to care more about the residents, which in turn helped to nurture the sense of shared community. As related to dysphagia and feeding, the more engaged staff were with the residents, the more they knew about the residents' mealtime preferences. Similarly, family members could play an important role in enhancing the social aspects of dining through small acts of individualization:

I think just treating everybody like they're family up here. I always make a point of knowing people's names that I see all the time [during mealtimes] and then I use their name. I think that makes 'em feel good. And just make it their home (Participant 17, daughter).

Emphasizing differences between residents was identified as a clear barrier to successful dining. Given the high value placed on the social experience of mealtimes and resident autonomy, it was not surprising that participants viewed an emphasis on individual differences negatively. Residents wanted to feel included and aspects of their care that highlighted differences, such as receiving different or unappealing foods, left them feeling alienated from their friends. Elements specific to dysphagia (e.g., modified-texture foods) negatively influenced not only the food, but, perhaps more importantly according to participants, also the social experiences of mealtimes:

[Modified food] makes them feel less normal. Like they're different or they're... almost like childish... And then they feel self-conscious or like, 'Why me? Why do I have to eat this?'... That would obviously make somebody emotional cause, like, you're kinda getting pointed out of the group, and nobody likes that (Participant 6, nursing assistant).

### **Team Member Investment, Awareness, and Knowledge**

Another overarching theme that emerged from the data was that when team members were invested, aware, and knowledgeable, residents seemed to have more individualized and, ultimately, successful experiences. Staff investment and demonstration of care was a crucial facilitator of successful dining. As one resident indicated, “You want to know that they’re really caring for you and they have a person in their heart” (Participant 11). Increased staff investment, particularly those who are “more compassionate, responsible, and communicative” (Participant 8, occupational therapy assistant) as compared to those who “kinda do this job just to, you know, make the money and get out of here” (Participant 6, nursing assistant), was a commonly described facilitator of positive mealtime experiences. Staff members being able to see and interact with a resident as a person, rather than an individual with dysphagia requiring care, was highly valued. For example:

[Residents] respond better to people who care about them and what they’re doing... a lot of these people don’t have a lot of family with them here and... people who work here are their family... if you treat them like that they’re going to treat you like that (Participant 6, nursing assistant).

As described above, participants noted that increased staff investment was directly associated with greater caring, which helped to cultivate a sense of shared community. Not surprisingly, greater investment also appeared to relate to increased job satisfaction and enjoyment, particularly in a field known for higher levels of staff turnover (e.g., nursing assistants).

Investment and caring on the part of staff directly linked to increasing meal-related individualization. Resident preferences surrounding mealtimes, as well as dysphagia safety strategies, could be more easily realized when staff took the time to observe and communicate. Both care providers and residents indicated the importance of staff consistently recognizing the types of food that residents enjoyed or disliked, preferred portion sizes, and the typical dining location. Yet, learning and disseminating this information required work. Communication

emerged as another key component for successful dining as illustrated by the contrasting quotes below from one participant:

We made up this, like, buddy huddle system to make [dietary staff] communicate...it's just been working wonderfully, and everything's improved. Just- attitudes...the food that goes out is even more awesome because, I mean, obviously if the cooks are in a good mood, they're going to put out a better meal (Participant 15, assistant dietary manager).

There's nothing worse than being upgraded and it not going into effect that next meal [because of poor communication] (Participant 15, assistant dietary manager).

It was important for all team members (residents and family included) to be aware of dietary restrictions and changes. Dietitians, speech-language pathologists, and nursing staff were just some of the team members identified as making these types of decisions. Thus, participants described how crucial it was for there to be an efficient and effective information sharing process – both within a single unit and across the entire facility.

As noted previously, participants made surprisingly few comments about optimizing swallowing ability (impairment-level) as the conduit for improving dining, while optimizing the emotional response to mealtimes (activity/participation-level) was frequently discussed. Discussion of swallowing ability itself more often occurred, though, as related to staff awareness and training. Participants identified a lack of training, knowledge, and “interfering” prior beliefs as barriers to successful dining experiences for the residents. Importantly, more extensive training and knowledge related to dysphagia emerged as being required to better individualize care. There was a need to balance recognizing the increased safety risks and common signs associated with dysphagia while acknowledging that each individual has unique needs and presentations. As two providers stated:

Even like our [nursing assistants], the nursing staff here, I don't think they necessarily know what to look for. I've seen a lot of people that start choking and they start \*pats back\* 'You ok?' And pat them on the back sort of thing and it's like maybe it was just an

accident, but maybe just based on the population we're working with it's not? (Participant 19, occupational therapist).

I just try to find what's going to work best for the patient. That's what I'm going to be pushing. Not kind of the general chin tuck for everybody! And that's something else I've had to do a lot of education about, too, cause, you know, I find the PTs in the hall, 'Tuck your chin when you're swallowing!' \*shakes finger\* I'm like, 'That's not the appropriate strategy for that patient' (Participant 10, speech-language pathologist).

Ultimately, all participants indicated that team members play a crucial role in laying the foundation for positive mealtime experiences, fostering individualization and socialization as the focus of care. Providers who demonstrated investment and care, maintained good communication, and possessed appropriate knowledge and training, were able to put the "resident-as-individual" rather than "dysphagia-as-diagnosis" as the center of care.

### **Structural and Organizational Barriers**

Despite recognizing that care teams often have good intentions, external structural and organizational barriers were identified by the majority of participants that threatened the ability of mealtimes and dysphagia-related activities to be focused on individualization and socialization. These thematic barriers included: care facilities being under-resourced, food appearance and taste being undesirable, and restrictions being forced on care facilities by regulating bodies. The following quotes exemplify some of these barriers:

...when I first started working here we had dry erase boards above every patient's bed. All disciplines used it and the nursing staff used it too, so when PT decided somebody was [mod assist] they would go up, erase it, mod I, they'd go to the nurse, they'd fill out their paperwork and do all of that. The next aide that came on for the next shift could see, 'Ok, oh, there's a change.' So right, immediate, there was a change... Same thing for speech. This was the diet texture they were on and now, I've downgraded them. They're having a really hard time with this texture: change it. That's all changed. That system I felt was better... and of course because of [the Health Insurance Portability and Accountability Act] we can't do those things anymore (Participant 10, speech-language pathologist).

...just because you have problems with swallowing, doesn't mean you have problems with taste. My taste buds are still active and some of the food that I get served is like

blech \*sticks out tongue\* beige newspaper with a touch of green (Participant 20, resident).

So yes, I do think that changes in insurance and what their payer source is affects greatly...the patient you're going to see next, he's Medicaid. He's one that- his progress may have been slowed a little bit because he saw speech only twice a week instead of five times a week which initially would have been beneficial for him (Participant 10, speech-language pathologist).

These barriers acted in direct opposition to the "focus on the person" that emerged as being crucial for successful mealtime experiences. Participants, particularly staff, grappled with the need to balance resident desires and their individualized needs with such regulatory demands and policies implemented to protect the business side of nursing homes. Almost ironically, one speech-language pathologist mused that such policies take away from "the ability to treat each patient individually" and yet there is "a push for us to treat each patient individual" (Participant 12).

In response, many of the care team participants identified how increased resources and collaboration could aid in more successful dining:

...it would be great if I could rely on everybody having a part of this. It's almost to the point where...if you had a heavy caseload, and heavy dysphagia, it might be neat to have a dysphagia team. Just like we had stroke teams (Participant 12, speech-language pathologist).

I would like to have more staff to help people that need help. Because I feel like some of the problem with being able to meet nutrition needs is people need help and they can't get it. And not because we don't want to give it. We literally do not have enough time and people to give it. Especially when you're taking more high acuity people or you have a lot of long-term people that are declining and need help (Participant 16, dietitian).

The majority of staff desired to be able to do more than the "bare minimum", acknowledging that having more than what is legally mandated (e.g., caregivers) would benefit patient care overall.

Unfortunately, many reported feeling as though more responsibilities are given with fewer resources provided. Staff have needed to get more creative, stemming the suggestion of a

focused interdisciplinary dining team. Through such a team approach, communication could be facilitated, changes could be made more rapidly, and disciplines could better assist each other. Importantly, such an approach would ensure that all team members are supported and decisions are not made that negatively impact any of the team (e.g., increased burden), allowing for better patient-focused care.

### **Discussion and Implications**

Through study participants' accounts, the concepts of individualization and socialization emerged as being at the heart of mealtimes for individuals with dysphagia. Salient facilitators emerged for helping care facility residents with dysphagia have more fulfilling and successful dining experiences such as altering the focus of care, cultivating community, and increasing staff investment. Study participants also identified barriers such as inadequate training/knowledge and biased beliefs that impeded caregivers from providing competent and nurturing care. The main theory and categories encompass the *shared* perspectives of the multiple stakeholder groups invested in dining. Thus, while other factors exist that may define, facilitate, or impede successful dining for individuals with dysphagia, those identified in the current study represent, arguably, the most pervasive and ultimately relevant considerations for sustainable change.

Focusing care on the person through individualization and socialization arose as an incredibly complex activity, influenced by factors across multiple levels. Effectively changing dining practices for residents with dysphagia to emphasize individualization and socialization requires a more comprehensive approach that systematically targets mechanisms of change across these various levels. We interpreted the emergent theory and the important role mealtimes play for health and well-being within a *social-ecological model for successful dining with dysphagia* (Figure 2). Ecological models are multi-level frameworks that draw attention to

individual and environmental determinants of behavior and behavior change (e.g., McLeroy et al., 1988). They aim to inform comprehensive intervention approaches that systematically target mechanisms of change at several levels of influence. As applied to dining for individuals with dysphagia in light of our emergent theory, the context of care ultimately influences outcomes.

Drawing from McLeroy and colleagues' (1988) ecological model for health promotion, the current model portrays that optimizing health and well-being for residents with dysphagia via successful dining requires exploration of individual-, interpersonal-, and organizational-level facilitators and barriers, and the relationships among them. Through this model, we also highlight the various stakeholders involved in dining management. That is, the facilitators and barriers do not narrowly focus on the residents with dysphagia and their impairments. Rather, individual-level factors related to both staff and residents, interpersonal-level factors related to communication between staff and residents, and organizational-level factors related to regulations, policies, and the environmental context within which dining occurs are all included.

Within the model, individual level themes incorporated aspects of staff investment, training, and knowledge and residents' emotional state. Most foundationally, staff investment and training greatly influenced dining experiences for individuals with dysphagia as they directly impacted staffs' ability and/or willingness to individualize care and promote shared community, or 'focusing on the person'. Previous research has suggested that higher levels of organizational commitment are associated with more favorable perceptions of organizational culture and greater job satisfaction, which is then significantly linked to decreased nursing home staff turnover ( Karsh et al., 2005; Sikorska-Simmons, 2005). Decreased staff education and training has also been associated with under-diagnosis and recognition of dysphagia and its symptoms, leading to

more negative mealtime experiences (Kayser-Jones and Schell, 1997). More comprehensive education for nursing assistants related to dysphagia, beyond basic feeding skills, has been previously recommended (Pelletier, 2004), but is clearly still a relevant issue as demonstrated here. Further, staff attitudes and beliefs intertwine with decreased awareness. For example, staff may focus on “nutrition/hydration” as primary mealtime-related goals, de-emphasizing the social aspects of sharing “food/drink” (Pelletier, 2005, Wu and Barker, 2008). Feeding beliefs and knowledge have been found to impact staff compliance with dysphagia-related recommendations (Rosenvinge and Starke, 2005). Conversely, staff training can promote more positive, patient-centered attitudes and knowledge related to mealtimes (Chang and Lin, 2005).

Happiness and/or subjective well-being represent a fundamental human need. Therefore, it is of no surprise that happiness as related to mealtimes was also identified as a facilitator of successful dining for residents with dysphagia. Older adults generally report higher levels of happiness (George, 2010). Yet, poor health and decreased social support and perceived decision-making choice – often associated with nursing home residency – relate to decreased sense of subjective well-being. Thus, while happiness during mealtimes emerged as an individual-level factor, a multitude of interpersonal- and organizational-level factors related to emotional state, social relationships, and resident autonomy are likely interrelated.

Interpersonal level themes relating to communication, caring, and community cultivation, provide clarity about how effective social relationships and efficient communication are essential to the dining process as reflected in our theory construction. Breakdowns in communication are a major healthcare concern since adverse events often occur as a result of ineffective communication (Manias et al., 2016). Communication is essential for managing dysphagia – for safety, individualized care, and quality of life. Further, social relationships among and between



nursing home residents and staff are crucial, associated with improvements in quality of life and survival (Bergland and Kirkevold, 2006, Bowers et al., 2001, Haugan, 2014). Positive social relationships aid residents in the creation of an enjoyable environment (Roberts and Bowers, 2015). Mealtimes are a key time for social interaction, therefore promoting positive social interactions during mealtimes for nursing home residents should be a priority. The results of the current study confirm that social interaction is equally valued for residents with dysphagia. Also consistent with previous literature, social interaction was highly valued among the community as a whole, between residents as well as with staff.

Organizational level themes highlighted the contrast between individualized and medicalized care and current – often limiting – food, resource, and regulatory options. The shift toward, or goal of, more person-directed care was clearly reflected in the participant interviews and emerged as a key variable in theory construction. Yet, this suggestion is not new: previous research has supported creating individualized mealtime plans at assessment (Kayser-Jones, 1996). Clearly barriers remain toward the implementation of individualized medical care. Factors reflected in the current study and in the previous literature include feeding practices that continue to emphasize more “task-oriented” institutionalized norms rather than “resident-oriented” approaches, lack of resources, lack of organizational and staff support, and policy barriers such as concerns over citations (Bennett et al., 2015, Reimer and Keller, 2009, Rosenvinge and Starke, 2005, Watkins et al., 2017). Specific to residents with dysphagia, components of individualized care, such as increased dining choice, may appear incompatible with what is deemed medically “safe” for a resident.

Ultimately, the key themes that emerged from participant interviews emphasize the importance of individualization and socialization in mealtimes for individuals with dysphagia –

consistent with the contributors to person-directed mealtime practices for nursing home residents most broadly. A growing body of literature supports that individualization and belonging, or elements that target the core of any individual's personhood, are central to mealtime care for nursing home residents (e.g., Milte et al., 2017, Reimer and Keller, 2009, Watkins et al., 2017, Watkins et al., 2017). As Reimer and Keller (2009) summarize, person-centered mealtime care requires maintaining choice and individual preference, supporting independence, promoting social interaction, and respecting the individual. Together, these create a mealtime culture that represents a shared understanding of mealtime values and traditions while promoting resident agency. Yet, organizational and staff support remains a profoundly influential factor on the entire mealtime process (e.g., Watkins et al., 2017). Ultimately, implementation of person-centered mealtime practices requires better support for staff, including increased training on the provision of mealtime care, the importance of the social side of mealtimes, and how to communicate with residents (such as relationship building communication) as well as the presence of more staff (Reimer and Keller, 2009). Such findings directly map onto the central tenants for improving the mealtime experience for individuals with dysphagia illustrated in our current theory (Figure 1) and incorporate the multiple facilitators and barriers described in our social-ecological model (Figure 2).

The culture-change movement necessitates a concerted effort to improve mealtimes for these individuals. Yet, maximal and sustainable change requires a team effort from the resident up through administration. Most of the salient themes identified here incorporated a component of joint or shared responsibility, investment, and active participation. Together, this supports a need to approach dining from a more interdisciplinary approach, one suggestion that emerged in the current study. Interprofessional care offers great value for older adults. Such collaborative

care leads to reductions in healthcare utilization, costs, and severity of symptoms, while improving communication and efficiency in service delivery (Mion et al., 2006). Rather than partitioning out the elements of dining by discipline as is the current model of care (e.g., dietitian focuses on nutrition, speech-language pathologist focuses on swallowing, nursing assistant focuses on feeding), a dining team could address goals that are more globally meaningful. This approach would allow for a more streamlined process (e.g., communication, training), create more of a sense of community, and ultimately focus attention on the overall dining experience. In turn, this could help to de-medicalize the mealtime and improve quality of life. The development and implementation of such an interdisciplinary approach should be prioritized in future research.

### **Limitations**

A few limitations are worth noting. First, this study excluded residents who did not have the cognitive-linguistic capacity to participate in interviews. While this exclusion criterion was necessary to allow use of in-depth interviews, it is possible that the views of this subpopulation were represented with less trustworthiness. However, this population was not excluded from discussion and staff participants did discuss the needs of residents with more advanced dementia. Thus, it is expected that the needs of this population are, at least partially, reflected in study findings. Further, a small number of individuals from each stakeholder group participated, despite the theoretical sufficiency of the pooled analyses completed across groups. Finally, the majority of participants were from the same general community in the United States and there was a lack of racial and ethnic variation in the sample; future research would benefit from recruiting a more diverse sample.

### **Conclusions and Practice Implications**

The constructed theory, ‘focusing on the person: individualization and socialization during mealtimes,’ highlights the need for more concerted efforts to be made toward improving the mealtime experience for residents with dysphagia. Framing mealtimes for individuals with dysphagia within an ecological perspective allows for better identification of the personal and environmental leverage points for effective, sustainable interventions targeting such improvements. Importantly, such a framework emphasizes the interrelatedness of these factors. This suggests that interventions must be comprehensive, requiring the joint efforts of service providers, administrators, and care recipients themselves.

The current theory and model need further testing. Future work should vet the identified themes, building on this model in order to develop new dining practices that will receive buy-in, get implemented, and, ultimately, be effective at improving health and well-being. The current model highlights the value of coordinated dysphagia care given the multiple, interrelated levels that influence outcomes. Dysphagia is clearly not just about swallowing; in fact, very few participants discussed this aspect. Rather, dysphagia also encompasses the context within which swallowing occurs. From eating and nutrition to social interaction and community building, mealtimes are crucial for human functioning. Dysphagia’s impact on the individual thus extends well beyond the impairment itself and interventions need to be comprehensive. This is precisely the driving force behind the culture-change movement: residents are more than just their medical impairment(s) and our clinical practices need to acknowledge, and center on, the individual.

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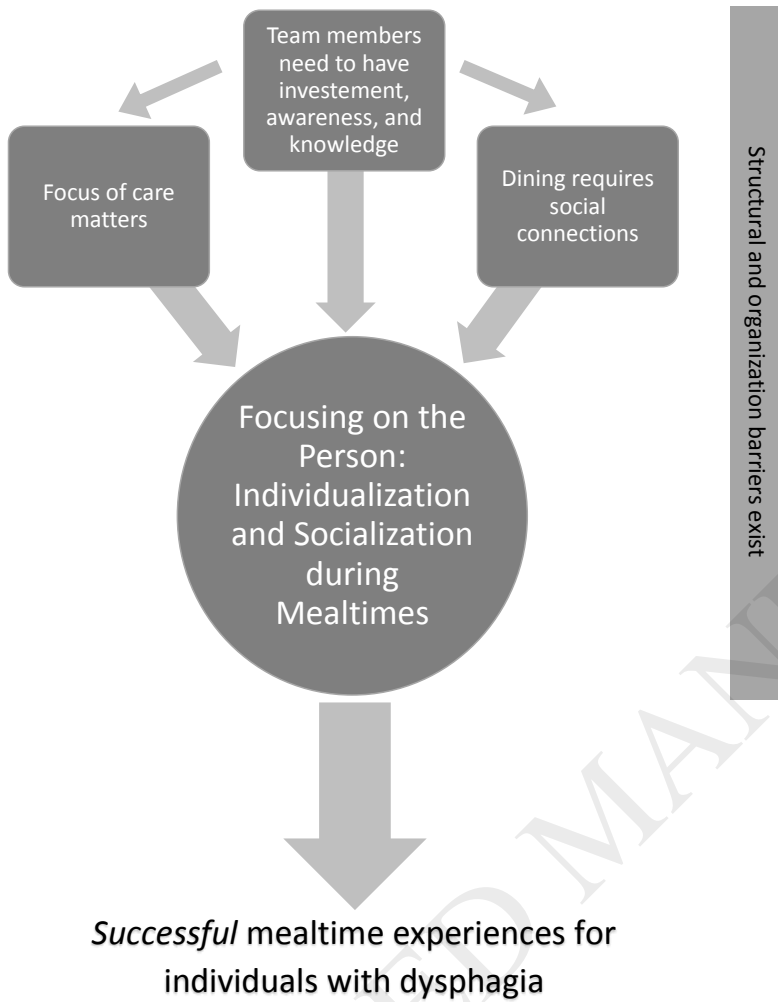
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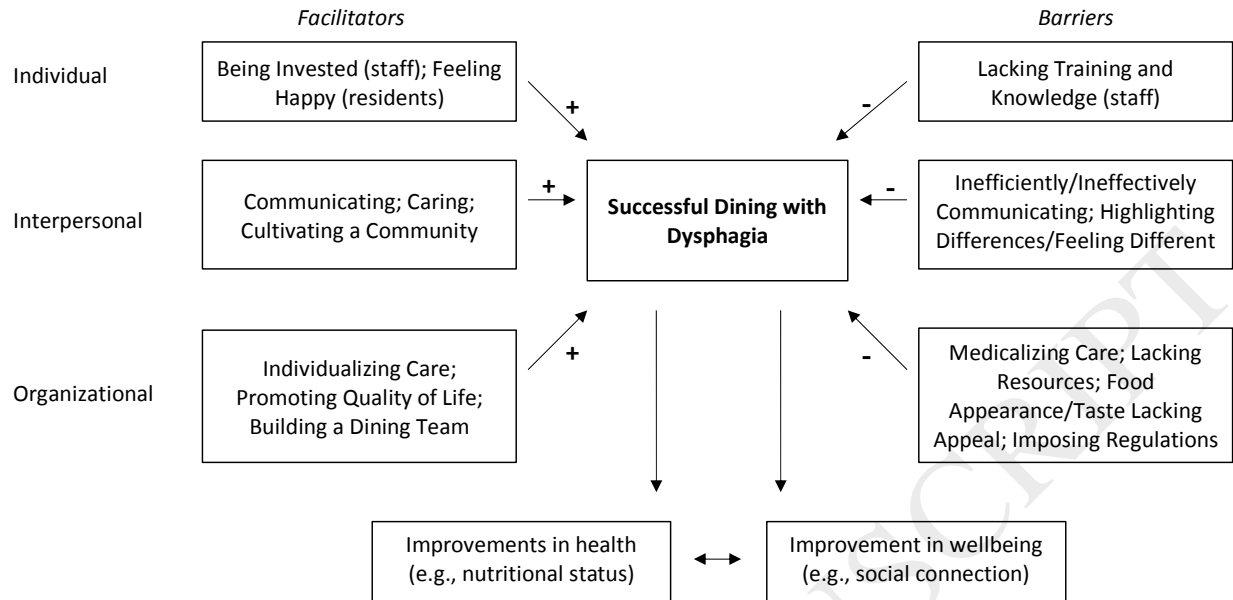
**Figure Titles**

**Figure 1.** Central tenants for improving the mealtime experience as represented by the emerging theory: ‘Focusing on the person: Individualization and socialization during mealtimes’

**Figure 2.** Social-ecological model for successful dining with dysphagia



**Figure 1.** Central tenants for improving the mealtime experience as represented by the emerging theory: 'Focusing on the person: Individualization and socialization during mealtimes'



**Figure 2.** Social-ecological model for successful dining with dysphagia

## Table Titles

**Table 1.** Participant demographic information

**Table 2.** Semi-structured interview guide

**Table 1.** Participant demographics

<b>Group</b>	<b>N</b>	<b>Mean Age, years (SD)</b>	<b>Female Sex, N (%)</b>	<b>Caucasian Race, N (%)<sup>a</sup></b>	<b>Hispanic Ethnicity, N (%)<sup>a</sup></b>	<b>Mean Years in Profession (SD)</b>
<b>Residents with Dysphagia<sup>b</sup></b>	3	72.3 (8.1)	2 (67%)			N/A
<b>Family Members</b>	3	62.7 (8.0)	3 (100%)			N/A
<b>Nursing Staff</b>						
<b>Nurses</b>	3	41.0 (4.0)	2 (67%)			5.3 (3.1)
<b>Nursing Aides</b>	3	25.0 (1.0)	1 (33%)			2.3 (1.8)
<b>Dietary Staff</b>	3	27.3 (3.2)	3 (100%)			4.7 (3.0)
<b>Therapy Staff</b>						
<b>OT</b>	3	36.7 (7.6)	3 (100%)			2.9 (3.6)
<b>SLP</b>	3	37.0 (8.5)	3 (100%)			12.2 (8.9)
<b>Total</b>	21	43.1 (17.7) Range 24-81	17 (80.9%)	19 (90.5%)	2 (9.5%)	5.4 (5.6)

*Note.* <sup>a</sup>To help maintain participant anonymity, race/ethnicity information is only presented for the entire sample of participants. <sup>b</sup>All participating residents had been residing at the facility for at least 1 month at the time of their interview. *N* = number; *N/A* = not applicable; *OT* = occupational therapy; *SD* = standard deviation; *SLP* = speech-language pathology

**Table 2.** Semi-structured interview guide

<b>Main Focus</b>	<b>Probe for</b>
<b><i>Residents and Family Members</i></b>	
Every individual has different eating and mealtime habits. Could you please describe to me a typical meal in your home setting? Now can you describe a typical meal in this facility? Have you/your family member enjoyed mealtimes since admission here?	-Specific examples and comparisons
What dining-related changes have you/your family member experienced since admission here? Have these changes been in line with your or your family's own personal preferences about eating and dining? In light of these changes, would you consider your mealtimes here to be successful, not successful, or neutral?	-Specific examples and comparisons
What is the impact of dysphagia on your/your family member's eating and drinking? Do you feel that you understand what dysphagia is and how it needs to be managed? If not, what additional information would be helpful? How does your/your family member's dysphagia impact interactions with facility and therapy staff?	-Specific examples
Who do you feel should be involved in managing dysphagia in the nursing home setting? Who should be involved in setting dysphagia-related goals?	
If no limitations existed, how might you improve the nursing home dining process for all residents and for residents with dysphagia? What are some potential barriers that you might anticipate, if any?	-Specific examples
Are there any other subjects you would like to discuss concerning dysphagia, mealtimes, or other related areas?	
<b><i>Nursing and Dietary Staff</i></b>	
Every facility works in a slightly different way. Could you please describe what your role is here during mealtimes? How does dysphagia impact your typical role or duties, if at all? What is your role in managing care or treating residents with dysphagia? What would a typical mealtime interaction with these residents look like?	-Specific examples and reasons why
Please describe at least one situation in which you were asked to or chose to change a dining-related behavior. For example, this could relate to how you were interacting with a particular resident during meals or how you were to perform your mealtime duties. Would you consider the outcomes of this behavior change to be successful, not successful, or neutral?	-Specific examples and reasons why

Are you familiar with the new shifts toward patient-centered care in nursing homes, also termed the culture-change movement? Has your work been impacted (positively/negatively) at all by this shift?	-Specific examples -[Can provide background]
Who do you feel should be involved in managing dysphagia? Who should be involved in setting dysphagia-related goals? What are your goals related to eating and dining for residents with dysphagia? What barriers exist or might you encounter in reaching these goals?	-Specific examples -Barriers of different types
If no limitations existed, how would you improve the nursing home dining process for all residents and for residents with dysphagia? What are the barriers to such a change?	-Specific examples -How barriers could be addressed
Are there any other subjects you would like to discuss concerning dysphagia, mealtimes, or other related areas?	
<b>Therapy Staff</b>	
Every facility works in a slightly different way. Could you please describe what your role is here during mealtimes, if any?	-Specific examples
Please describe at least one situation in which you were asked to or chose to change a dining-related behavior. For example, this could relate to how you were interacting with a particular resident during meals or how you were to perform your mealtime duties. Would you consider the outcomes of this behavior change to be successful, not successful, or neutral?	-Specific examples and reasons why
Are you familiar with the new shifts toward patient-centered care in nursing homes, also termed the culture-change movement? Has your work been impacted (positively/negatively) at all by this shift?	-Specific examples -[Can provide background]
How often do you work with residents with dysphagia? What would a typical treatment session look like? What do your goals look like for these residents? What barriers have you encountered in working with residents with dysphagia and/or what barriers might you encounter in trying to reach these goals?	-Rehabilitation vs management -Swallowing and eating goals -Barriers of different types
How is dysphagia managed in general in your facility? Who do you feel should be involved in managing dysphagia? Who should be involved in setting dysphagia-related goals?	Specific examples
If no limitations existed, how would you improve the nursing home dining process for all residents and for residents with dysphagia? What are the barriers to such a change?	-Specific examples -How barriers could be addressed
Are there any other subjects you would like to discuss concerning dysphagia, mealtimes, or other related areas?	