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Running head: UNDERSTANDING DYSPHAGIA

Understanding Dysphagia: The Social and Emotional Impact

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Abstract

The purpose of this study was to explore the social and emotional impact of dysphagia on the lives of adults with dysphagia and their caregivers. Four adults participated in this study. Five narratives were elicited, two from adult caregivers for children, two from an adult who assisted with family members, and one from an adult who experienced dysphagia. The semi-structured interviews conducted with these adults were audio taped and transcribed word for word. They were then member checked for accuracy. Themes were abstracted from the data set using narrative analysis. Emotional issues associated with dysphagia were the most common themes across all participants, followed by social themes. While fewer in number, all narratives included reports of changes in physical aspects of feeding and swallowing.

Understanding Dysphagia: The Social and Emotional Impact

In virtually every culture around the world, the main means of gathering and interacting in a meaningful way is around food. Food brings people together. It enables the growth of generations physically, of course, but also socially and emotionally. Food nourishes the body; heals it; prepares it for the days ahead. Similarly, gathering around food allows social traditions to be spread and emotions to be shared. A family gathering around a table and eating together is worth much more than the sake of simply consuming food. It is a time where things slow down, allowing for a deeper understanding of each other. There are connections forged, memories made, and traditions kept by the act of breaking bread.

The importance of gathering and eating together for sustenance and companionship having been established, it is easy to see how, if a person has difficulty or the inability to swallow, he or she would often experience negative outcomes from not being able to participate normally. First and foremost, the individual would be at a much higher risk of choking, developing pneumonia, or malnutrition. The physical dangers and complications of feeding and swallowing problems have been well documented; however, that is not the only side of the issue. There are major social and emotional implications faced by individuals and their families due to feeding and swallowing difficulties, i.e., dysphagia. It is of the utmost importance that the social and emotional impact of feeding and swallowing problems upon individuals and their families be recognized as a serious issue, studied, and accounted for through research. The goal of this study was to investigate the social and emotional impact of dysphagia upon individuals as well as their families.

Review of the Literature

Dysphagia, or difficulty swallowing, “means it takes more time and effort to move food or liquid from your mouth to your stomach. Difficulty swallowing may also be associated with pain. In some cases, you may not be able to swallow at all” (<http://www.mayoclinic.com>). Swallowing is made up of three different stages; the oral, pharyngeal, and esophageal stages. Therefore, problems feeding and swallowing can happen anywhere along the line of these three stages. In the oral phase, a person sucks and chews food and drink in order to move it to the back of the mouth and into the throat. Then, the pharyngeal stage takes over, in which the swallowing reflex squeezes the bolus, or clump of food, down the throat. During this stage, the airway is also sealed to prevent aspiration of the bolus. Finally, in the esophageal stage, the esophagus squeezes the bolus into the stomach through rhythmic muscular movements (<http://www.asha.org>).

Dysphagia is a condition comorbid to many others, whether they are acquired or developmental. These include stroke, traumatic brain injury, brain tumors, Parkinson’s disease, multiple sclerosis, cerebral palsy, and mouth, laryngeal, or esophageal cancers. All ages of people may be affected by the various conditions that play a part in feeding and swallowing, however; according to the National Health Service in England, “as you get older, the muscles that are used to swallow can become weaker. This may explain why dysphagia is relatively common in elderly people” (<http://www.nhs.uk>).

ASHA lists four consequences of feeding and swallowing problems many patients may experience. These are dehydration and lack of adequate nutrition, a risk of aspirating materials into the lungs which can cause pneumonia and even death, a decrease in enjoyment of eating or drinking, and embarrassment in social situations involving eating or drinking which may lead to feelings of isolation in the patient (<http://www.asha.org>).

In reference to what is stated by ASHA above, the focus of this study was primarily on the social and emotional consequences of dysphagia, what patients with this condition and their caregivers experienced on a daily basis, as well as their perceptions surrounding the condition. This review of the literature will cover the range of issues concerning the impact of dysphagia on patients as well as their caregivers, such as changes in roles and activities, emotional and social implications of the condition, and the role food plays in everyday social rituals and traditions.

Diagnosing Dysphagia

Before diagnosing dysphagia, a speech-language pathologist will first assess a patient's muscle strength and coordination, their posture, oral movements, and behaviors during feeding. If there is difficulty or inability to swallow, or aspiration of materials into the airway, the SLP will refer the patient for more in depth studies. These are the modified barium swallow and an endoscopic assessment (<http://www.asha.org>).

Being correctly and affirmatively diagnosed with dysphagia is of the utmost importance in order for patients to receive the proper care they need. A study was conducted in Europe in which “[36%] of patients acknowledged receiving a confirmed diagnosis of dysphagia [but] only 32% acknowledged receiving professional treatment for it. Most people with dysphagia believe their condition to be untreatable [and] only 39% of the sufferers believed that their swallowing difficulties could be treated” (Ekberg, Hamdy, Woisard, Wuttge-Hannig, Ortega, 2002, p. 1).

Another important factor is an early diagnosis. Miller, Noble, Jones, and Burn (2006) emphasized the importance of early detection of dysphagia and the changes associated with it for the patient's optimal health and quality of life. In another study, Altman, Yu, and Schaefer (2010) found that dysphagia has a significant impact on hospital length of stay and is a bad prognostic indicator. Early recognition of dysphagia and intervention in the hospitalized patient

is advised to reduce morbidity and length of hospital stay. These researchers also found that in patients hospitalized with stroke, only 14% of those without dysphagia required more than 7 days of hospitalization. When a patient was hospitalized with stroke and comorbid dysphagia, their likelihood of hospitalization longer than 7 days went up to 73.9% (Altman et al., 2010). Don, a man interviewed during “Swallow: A Documentary” gave his views pertaining to the importance of early diagnosis and treatment: “That’s one thing that’s frustrating to me...this happened way back in November and I’m just now starting the therapy on swallowing. It seems like it could’ve started a lot earlier...that’s what I would’ve really liked to put the pressure on...to start the therapy on swallowing [earlier]” (Belafsky & Blue, 2011).

Impact of Dysphagia on the Patient

According to Miller et al. (2006), the psychosocial impact of dysphagia is one of two main themes shared by the participants with dysphagia in his study. This entails that, apart from the physical struggles a person with dysphagia experiences, there are self-esteem, socialization, and quality of life issues that coincide with them (Ekberg et al., 2002). Ed Steger, president of the National Foundation of Swallowing Disorders and a person with dysphagia said, “...dysphagia takes a tremendous physical and emotional toll. At times it feels like you're stuck outside looking through a porch window at a gathering you can't really attend” (as cited in Casey, 2012). (Balandin, Hemsley, Hanley, & Sheppard, 2009, p. 201) cite two main impacts from the changes that dysphagia causes for the individual. These are “reduced social interaction during meals” and “loss of independence.” Feeding and swallowing problems have the ability to change a person’s life. A person with dysphagia must alter his or her everyday routine, often in the blink of an eye, in order to accommodate a partial or complete inability to swallow. Sonia is a woman living with dysphagia as a result of a brain tumor. When interviewed in “Swallow: A

Documentary,” she highlights having to adjust to her inability to swallow: “I didn’t eat anything by mouth for six years. I could eat then I couldn’t eat and I had to learn how to be in the world and not eat. So you go from...grabbing an apple, a salad...you’re just eating...and one day it just stops” (Belafsky & Blue, 2011). Terry, a man also living with dysphagia as the result of a brain tumor, explains how his life has changed in regard to using a feeding tube: “this is what the new normal was, you know you get up every morning and you’re on a tube...and you’ve got to keep it clean, which is kind of unspeakable amongst people...but it becomes a lifeline” (Belafsky & Blue, 2011).

Impact of Dysphagia on the Family

Dysphagia can also have an effect on the family members of someone with feeding and swallowing problems, especially if a significant other or relative is the primary caregiver for that person. ASHA suggests a few ways in which family members may be of assistance to their loved one during or after the time of diagnosis. These are “asking questions to understand the problem and the recommended treatment and assisting in following the treatment plan by helping with exercises, preparing the recommended textures of food and liquid, making sure that recommendations for eating safely are followed, and keeping track of how much food or liquid is consumed” (<http://www.asha.org>). In a study conducted to understand the changes in mealtimes caused by dysphagia in aging adults with cerebral palsy, “10 [participants] noted they were more reliant on others to support them in these changes by providing appropriate food choices” (Balandin et al., 2009, pg. 200). These authors also “highlight the importance of ensuring that there is always someone available who is capable of providing assistance if a person chokes, pg 200.” It is very important to explore the perceptions of adults who act as caregivers for close family members who have feeding or swallowing problems because of these special demands

placed on them. In many cases of dysphagia, a caregiver's role is invaluable to the health and well-being of the individual with dysphagia. Miller et al. (2006) explain how "coping strategies could aid swallowing problems but often to the detriment of others in the family through altered demands on preparation and organization, pg. 614." To illustrate this, in "Swallow: A Documentary," the mother of a three year old boy with hypotonic cerebral palsy and comorbid dysphagia speaks to her role as his primary caregiver: "I would say it's half of my day, half of my waking hours, are spent making sure he's fed properly, making sure his food is prepared properly, making sure he's swallowing properly, and making sure he's sitting in the correct position...at least half of my waking hours are spent being concerned about his swallow safety." She continues to describe the experience of being in a restaurant and how the public perceives her son's special feeding needs. "People do still kinda stare, like 'why are you giving a child baby food?' I get those looks all the time and...I'm okay with it; I'm really used to it by this point." (Belafsky & Blue, 2011).

Food as Ritual and Social Cohesion

In most cultures around the world, food holds a pivotal and sacred place. Food, no matter how grand or meager a spread, has the ability to bring people together. It allows them to share, for a time, a common bond, as people socializing and eating together. However, for people with dysphagia, this simple yet cherished act of breaking bread with one another often becomes unattainable and a source of anxiety and isolation. Dr. Belafsky, the director of the Voice and Swallowing Center at University of California Davis, shares that "for people who cannot eat, the pain and suffering that [holidays bring] is immeasurable. The inability to eat and drink leaves those whom we care most about alone and isolated because they cannot commune with family and friends over a shared meal" (as cited in Casey, 2012). As a person living with severe

dysphagia, Steger testifies that "that shared experience of preparing traditional recipes and enjoying plates of food is lost upon those who cannot enjoy it" (as cited in Casey, 2012). Ekberg et al. (2002) reported that 84% of patients interviewed with dysphagia felt that eating should be an enjoyable experience but only roughly half of those people (45%) actually admitted that it was. In the same study, 41% of patients with feeding and swallowing problems reported that they experienced some form of anxiety or panic during mealtimes. Further still, 36% of these patients stated that they avoided eating with other people altogether. "Not only are you not eating, but you're not going out for coffee, you're not making breakfast, you're not shopping, you're not preparing food; it's over, it stops," says Sonia, in "Swallow: A Documentary" (Belafsky & Blue, 2011).

Summary and Questions of the Study

The physical aspects aside; there are major social and emotional attachments people have to food and eating with others that go hand in hand with tradition and routine. Not being able to swallow properly or at all poses a great risk not only to an individual's health, but also his or her social or emotional well-being as well as that of the individual's family. The purpose of this study was to explore the social and emotional impact of dysphagia. This leads to the specific questions of this study:

1. Are there perceived differences in the social and emotional impact of adults that have dysphagia themselves versus adult caregivers?
2. Are there perceived differences in the social and emotional impact of dysphagia whether it is acquired versus developmental?

Methodology

Participants

Ten adult participants who have or had personally experienced feeding or swallowing problems or who have parented a child or cared for an adult with feeding or swallowing problems were sought through nomination for this study. There was no control for age, gender, or socioeconomic status.

Materials

The semi-structured interview questions were developed from the literature. They include a brief history of the interviewee and their experience with feeding and swallowing difficulties, which can refer to their own difficulties or that of a family member. A digital audio recorder was used during the interviews.

Procedures

Data was collected through a semi-structured interview process and was conducted at the location of choice for the participants, such as the in home, place of work, nursing home, etc. The interviews lasted approximately 30 minutes and were audio recorded. Field notes on the interview were also hand documented as part of the data gathering process. A member-checking procedure after the abstraction of the themes required an additional 30 minutes of participation in the study. This member-checking could take place in person, via telephone, or email depending on the preferences of the participant.

Analysis

The audio record was transcribed and analyzed for the purpose of gathering themes in the study. This analysis of themes was on-going. In other words, the transcription of each interview and its member-checking immediately followed the data collection. When the narratives of social and emotional impact associated with dysphagia did not change the study was considered complete as was consistent with narrative research methodology.

Results

Demographics – Those Who Told the Story

The participants sought for this study were adults aged eighteen years or older, who had either experienced feeding or swallowing problems themselves or who had been care providers for other adults or children that had. There was no control for age, gender, or socioeconomic status. Four adults who wished to participate contacted the principal researcher through a nominative process. A total of four individuals participated in this study, which yielded five narratives as one participant shared two separate experiences dealing with feeding and swallowing problems.

The demographic makeup of this study is as follows: one participant acted as a caregiver to two separate individuals within her family who experienced feeding and swallowing problems. Two other participants were mothers who cared for their children with these issues, and one participant spoke about his own difficulties in this area.

Protagonists - Who the Story was About

Each of the interviews resulted in a narrative about a particular person who had or was experiencing feeding or swallowing problems. What follows is a description of each of the ‘protagonists’.

Thomas was a man who developed amyotrophic lateral sclerosis later in life. He worked as a farmer and a real estate agent so talking and socializing were important parts of his life. His niece, who reported his story for this study, travelled to his home for a week or two at a time to provide respite for her aunt who was his primary caregiver. She acted as a temporary caregiver to her uncle during these times.

Mary was a woman who developed Parkinson's disease later in life. She was never evaluated for or diagnosed with dysphagia. She lived alone until the late stages of her disease process made it unsafe for her to do so any longer. Her story was reported by her daughter-in-law who interacted with her socially during mealtimes as part of their family tradition.

John was a man who worked with people with disabilities in the nonprofit business. John's work had a large social component in which food played a part as well. John had never been formally or professionally diagnosed with feeding or swallowing problems. He said that he had experienced what he self-diagnosed as "esophageal spasms" intermittently during mealtimes since he was around forty years of age. He nominated himself for this study.

Sarah and Leah were both children who experienced feeding and swallowing difficulties. Sarah's story was reported by her mother, her primary caregiver. Sarah was born with Down's syndrome and a heart defect. She also required tube feeding until the age of six. Sarah's mother worked in the non-profit industry assisting children and families with special needs.

Leah's mother reported her daughter's story for this study as well. Leah was born three months premature and suffered from feeding and swallowing issues associated with that. She aspirated easily on liquids and dealt with extreme acid reflux. She also had trouble triggering a swallow response. Leah's caregiver was a single mother who had been a teacher before having to take time off to devote to her young daughter.

Description of Coding Procedures

The process that was used to gather data was a semi-structured interview process. The researcher then transcribed each interview word for word. Next, the researcher read each transcript for themes one category at a time. For example, an entire transcript was read and highlighted for social themes. It was then read and highlighted for emotional themes. During this

process, any specific themes solely related to the physical mechanism or other issues were highlighted. After each interview was transcribed and analyzed for social and emotional themes, a member checking procedure took place with each participant either in person, via email, or over the phone. The researcher presented the main themes from the interview transcription to the participant to allow them to verify their accuracy. The participant had the opportunity at that time to make any comments or corrections to the themes gathered by the researcher. The verified themes were then entered into a spreadsheet where any similar or repeating themes were consolidated. The density of themes within and across stories was assessed at that time. The themes that appeared across three or more stories suggested that they held some importance socially or emotionally for the participants. The themes that appeared many times within one story but perhaps in none of the others were noted as well, as they seemed to be very significant to that one participant's experience. Table 1 (see below) summarizes the frequency of these themes across narratives.

Table 1

Frequency of Themes Across Narratives

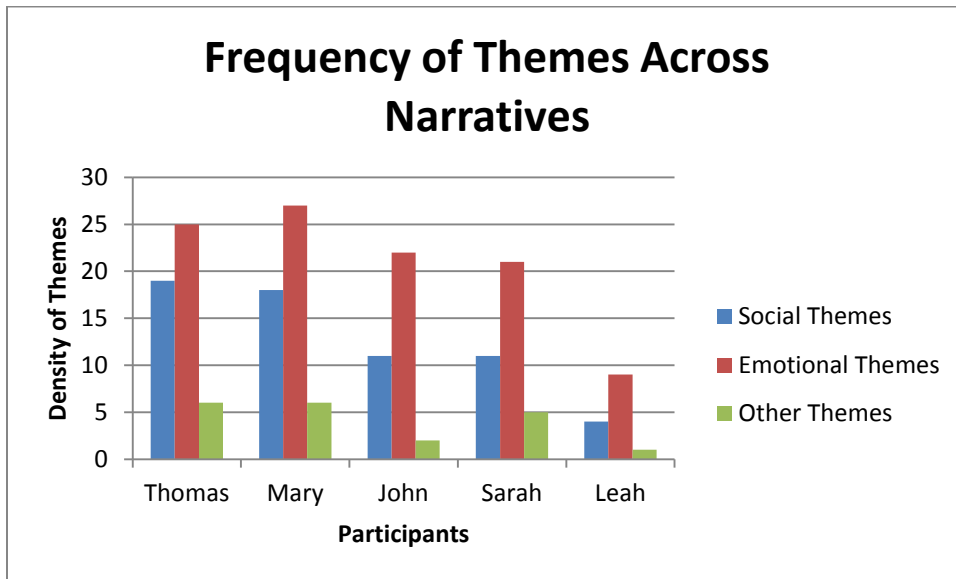


Table 1 illustrates the density of the themes. Narrative examples will be used to answer the specific questions of the study.

Question One

The first question of this study evaluated the perceived differences in the social and emotional impact of feeding and swallowing problems on the lives of adults who had dysphagia themselves versus adult caregivers. In essence, whether there were differences between what John self-reported versus what the caregiver of Thomas and Mary reported.

Overall, there were not many striking differences between what John self-reported and what the narrator of the stories of Thomas and Mary reported. John, the only self-reporter in this study, felt like he was impacted very minimally socially and emotionally by his experiences with dysphagia. The main emotional impact he described was for his wife who constantly worried about his safety. According to the reporter of Thomas' story, both he and his primary caregiver, his wife, felt deeply emotionally impacted by their experiences. They cherished the food routines they had, which kept them together through a difficult disease process. Mary's reporter felt that

Mary was not emotionally impacted because she lived around her dysphagia, although maintaining the social traditions around food were highly important to her. Her family members were impacted emotionally, according to her caregiver, especially by her unexpected death related to complications with aspiration pneumonia.

John did, however, report behaviors such as managing his social environment a certain way and modifying his food intake in order to accommodate for his changes in feeding and swallowing. Thomas and his wife also exhibited these behaviors, by changing his feeding style and adapting where they sat in restaurants. Mary and the reporter of her story also modified their feeding behaviors to accommodate changes in Mary's feeding mechanism. The presence of social management and modification of food management across all three of these narratives shows the similarities between them.

John's story. John was the only participant in this study that reported on his own feeding and swallowing problems. It should be noted, however, that John felt his esophageal spasms affected his social experiences "very minimally," if at all. Even so, he did discuss certain modifications in his behavior that may suggest that his spasms affected him at least to some extent socially. When in certain social situations, such as meetings or luncheons associated with his work, John talked about demonstrating social management of his food situation. He said that often his spasms would cause him to throw up so he made sure that he was always aware of the nearest exit or restroom in case he experienced spasms during the meal. John also discussed different ways he modified his food intake so as to avoid embarrassing situations in public. At the time of his interview, John was not exactly aware of which foods caused or exacerbated his esophageal spasms during mealtimes. He admitted that during meetings with meals involved, he

would often choose food alternatives that he thought were less likely to cause him spasms such as salads. Sometimes he would skip meals altogether.

“It’s just something that is in the back of my mind...sometimes in those situations I don’t eat...but I do know that I seem to be able to eat salads without any problems so I’ll sometimes just skip the other part...”

He also mentioned that he loved going to his favorite local barbeque joint and getting ribs, but he was rarely able to go there because he felt like that type of food was more likely to cause him to experience spasms. The fact that John had to stop eating at his favorite restaurant is yet more evidence of John modifying his behavior socially to accommodate for his feeding and swallowing problems.

Just as John did not feel that his social experiences were affected by his feeding and swallowing problems, he did not feel that his emotional experiences were very much affected by them either. He referred to them as an “inconvenience” and that the only real concern he had was that if they happened in public they might cause him embarrassment.

“I guess I just don’t think about it very much as being something that hampers me in any way...I just don’t consider it to be a huge deal, it’s just something that I deal with...I feel even odd thinking of it as a problem because people that I work with every day have problems. And what I have is...an inconvenience...”

Even though John admitted that his feeding and swallowing problems did not affect him emotionally to a great extent, he did discuss a heavy emotional toll they took on his wife. He said that his issues during mealtimes were much more of a problem for his wife than for himself. John rarely went to the doctor and his wife was adamant that he should seek professional attention for his esophageal spasms. John’s wife was the only person at the time of the interview that knew

about John's issues during mealtimes and he spoke about her being genuinely worried about him. When asked how his wife had adapted to his feeding and swallowing issues at mealtimes he replied,

“She...has not really adapted...it always worries her...and then I always downplay it...this is like this cycle that we have. If it happens, you know, I try to just...stand up quietly and walk away...but it doesn't fool her and so...then she'll say something and I'll say 'it's really not a big deal...'And then she quickly tells me...letting me know that, to her, it is a big deal.”

The stories of Thomas and Mary were both reported by their caregiver, which happened to be the same person. This person was Thomas' niece and Mary's daughter-in-law. She reported a perceived social impact that dysphagia had on both of the lives of Thomas and Mary as well as herself as their caregiver. Similar to John, both Thomas and Mary modified their behaviors to accommodate their changing feeding and swallowing mechanism while in public.

Thomas' story. Thomas, who developed ALS later in life, experienced a severe deterioration of his feeding and swallowing abilities. He began to eat much more slowly over the course of a few years and then began aspirating easily and losing saliva as his disease process progressed. Eventually, Thomas required the use of a feeding tube for nutrition. For Thomas and his wife, eating and the social traditions associated with that were very important. One of the main social themes present in the Story of Thomas was that, even as his physical condition deteriorated, he would continue to entertain at home and participate socially in public in a food context. He was determined to maintain that social aspect of food in his life but since he was experiencing such rapid deterioration in his feeding and swallowing abilities, Thomas modified

the way that he ate. He could no longer eat in a conventional sense, but his caregiver reported that,

“He would actually put [the food] in his mouth and when he could still chew he would chew it up but he wouldn’t be able to swallow it, so he would stick his fingers in his mouth and push it to the back of his throat so he could swallow it. And he was able to do that kind of maneuver because the tongue wasn’t working very well anymore and the jaws...He’d still lose a lot out of his mouth and he would be wiping that down...”

Maintaining the social aspect of food was so important to Thomas and his wife that they manipulated their social environment in order to accommodate the new way in which Thomas ate. When Thomas and his wife entertained at home, he still participated socially by being present during the food preparation and at the table while others ate but he waited until his guests had left the table before he ate his own meal. During this time Thomas and his wife also continued to eat at their favorite restaurants. They would make sure that they chose a table in the back and that Thomas sat with his back to the other guests so they would not be able to see him pushing the food down his throat. They modified their behavior and surroundings in a way that accommodated Thomas’ feeding and swallowing difficulties while still allowing them to enjoy food socially.

A theme that was reported by Thomas’ caregiver as being important but was not reported by John was the importance of social support in a food context. She said that throughout his disease process, his family and friends surrounded him.

“There was more laughter at the table, more joking, more camaraderie to fill in the blank times when he couldn’t talk and to act like you weren’t seeing the

food and liquid come out the mouth. And I think that that was a real extension of love. Nobody turned away, they were right there. And maybe the biggest [thing] that I saw that was so impressive was that he belonged to a men's club. He was quite active in that men's club and those guys would always invite him to lunch even when he wasn't eating and they made sure they stopped by the house many times at a time when he would be eating and it's like they were cherishing that...for all of them those were important things.”

One of the main emotional themes highlighted by the reporter of the Story of Thomas was the importance of food routines for Thomas and his wife. His caregiver reported that Thomas loved food. Not just eating it, but the other sensory aspects of it as well, such as the smell of it being prepared. Every morning for years and years Thomas' wife would cook him bacon, eggs, and toast. That was their special routine as husband and wife. Even when Thomas' feeding mechanism was deteriorating, he would push the food down his throat. When Thomas required a feeding tube his wife would cook his breakfast, puree it, and put it through his tube. His caregiver emphasized the importance of this because he was still getting the smell of the food and the time spent with his wife during its preparation, even when he could no longer taste the food. This morning routine was not only important to Thomas, but for his wife as well. His caregiver reported that,

“...I think that there was a real, kind of emotional thing on her part because it was just as important for her to continue to be that wife who was doing that kind of cooking and giving him those kinds of experiences and I think that that was...a really important kind of thing...until the very end including the day he died she cooked his eggs and bacon and toast and pureed it and put real food through that

tube...for them it was a bonding about that food and that food experience that kept them together in a very difficult process, even though it was a very broken system for swallowing and even speaking but still it was the legacy or the history of this that was so important that was a lynchpin in the good times and the bad. The physical gave out but that social and that emotional food bonding survived all seven years.”

As Thomas’ disease progressed the emotional impact that those changes had affected those around him. The reporter of his story felt like it was hard on his family members to see the deterioration of his feeding and swallowing abilities at family gatherings, but she said that the main emotional impact was on his wife. She then highlighted the importance of emotional support for Thomas’ wife since she was his primary caregiver. When the reporter of Thomas’ story visited her aunt and uncle to provide respite for her aunt, her aunt confided in her about how hard she thought the whole situation was. The reporter discussed how important she thought it was not only to provide respite, but to provide emotional support for her aunt in such trying times.

“...I was the moral support for her...so we could really talk, one, about how difficult it was, because she never wanted [her husband] to recognize how absolutely difficult it was and so it was really being that support person. I think that that’s really important.”

Mary’s story. Mary was a woman who developed Parkinson’s disease later in life. According to her caregiver and reporter for this study, she lived independently but was surrounded by a large Italian community made up of her close friends and relatives. The reporter of Mary’s story discussed how she and her husband, Mary’s son, would go out with Mary once

or twice a month to socialize over a meal. That tradition was very important to them all. As her Parkinson's progressed, she began to experience the gross motor impairments associated with the disease but she maintained the tradition of eating and socializing with her family at restaurants. Eventually, Mary's caregiver reported noticing subtle changes in Mary during mealtimes.

“I began to notice that whenever we were going out and eating she would never finish her food...so she was eating more slowly and she was eating less at any particular mealtime...what I notice is that she would slow down, and I began to notice that pretty consistently...she was really slowing down and not getting fed...”

These changes in how Mary approached food in public led her caregiver to believe that she may have been having problems with feeding and swallowing. Mary was modifying her food management in a way that compensated for the changes in her feeding and swallowing mechanism.

The role Mary's caregiver took during this time was more of a social companion during mealtimes rather than a person who provided assistance in daily living. As she began noticing the changes in Mary's eating habits when they were at restaurants or at family dinners, she began modifying the way that she ate as well. She recognized what Mary was doing and why she was doing it and felt it was important that she match her eating with Mary's in order to maintain their social experience.

“...I would pace myself to match up with [her] because a big part of mealtimes, the reason we were having dinner with her is for the social thing...I changed what I did socially with her and that's even with family dinners. So other people would be jumping up and getting things and passing bowls around and I deliberately ate

slower and slower. And I usually made sure that I would sit close to her, whether it was right next to her or sometimes I would sit across the table from her, but where I could maintain that eye contact and where I could facilitate being part of a social group with her. And also if I need to Heimlich I could be able to do that. So that...changed...how I dealt with food on my part, being around her and a lot of times I would order the same thing that she did, you know.”

Another social theme Mary’s caregiver reported was how Mary’s other family members managed the changes she exhibited during mealtimes. As Mary began eating less and more slowly, the rest of the family maintained the same pace during meals as they always had. At first they did not notice the subtle changes. When they finally did, Mary’s caregiver said that they thought Mary was just slowing down to make their time together last longer. Mary’s caregiver reported that Mary’s family members would urge her to eat faster in restaurants and family gatherings. These comments to ‘hurry up’ illustrate how Mary’s family members socially managed the changes in her feeding and swallowing mechanism in a way that was familiar to them.

“...my brother in law used to make kind of, remarks, you know, ‘hurry up, we wanna get outa here,’ I mean you know, ‘we’d like dessert now’ at the Thanksgiving table, ‘how are we doing on this’ and those kinds of things...confrontive kind of things...”

While Mary was slowing down during mealtimes and her caregiver was matching her pace, neither of them spoke aloud of the situation. Her caregiver knew that Mary did not want to openly admit that she had a problem with feeding and swallowing and continued to say,

“I think that she always denied that she had any problems in that area. That she didn’t wanna be seen as having even Parkinson’s...that was part of her personality...she never requested help, she just, she didn’t wanna go there...”

Since Mary chose to live around her issues with feeding and swallowing, her caregiver did not think that they impacted her emotionally to a large extent. Her caregiver was sure that Mary was aware of the changes within herself but that she preferred to manage her issues quietly so as to maintain normalcy.

The reporter of Mary’s story did discuss a large emotional impact on Mary’s other family members, particularly her son and daughter. Mary’s children did not recognize her slowing down at mealtimes to be an issue even remotely related to her having problems in that area in the beginning. Even after Mary’s caregiver alerted them to the issue, they continued to overlook its severity. Mary managed her food situation quietly while she lived independently and even after she went into assisted living. She never made it an issue for herself, which never gave her children real cause for alarm. She was never assessed for dysphagia in the assisted living facility. No real attention was drawn to her feeding and swallowing issues until she died of aspiration pneumonia in assisted living. The reporter of her story shared how she felt Mary’s children were impacted by her death,

“...I think the emotional impact then is in a sense...wasn’t for [Mary] because she was living around it...I think where the emotional impact was for both my husband and I know for his older sister, that they missed it. That they should’ve pursued it...that this is what took their mother’s life. Maybe...she could’ve had a better quality of life and a longer one...but for them that was a difficult thing because with aspiration pneumonia, I mean when it built up and it was identified,

I mean...she had a problem. And you know, even with antibiotics and everything else it just was too far gone. So I think her death was a very difficult death for them because of the circumstances.”

Question Two

The second question of this study evaluated the perceived social and emotional differences in the impact of the lives of the participants whether feeding and swallowing issues were acquired versus developmental. Adults could report on children for whom they acted as caregivers. However, this study assessed the adult caregiver’s perspectives, not specifically those of the children themselves. Children were not sought in this study to report on their own situations. In this study, two mothers reported the stories of their daughters and these children happened to have developmental issues with feeding and swallowing. To clarify, these narratives will be highlighted in relation to having developmental attributes first. The fact that they are about children, while significant to the social and emotional impact on their mothers, will be noted second.

In answering this question, the researcher will focus on comparing the stories of Thomas and Mary versus the stories of Sarah and Leah. John will be excluded in this examination because he was the only participant who self-reported. To maintain clarity and consistency, only those narratives reported by caregivers will be compared in this section.

The main social and emotional differences between the stories of Thomas and Mary, who had acquired dysphagia, and Sarah and Leah, who had developmental dysphagia, was the impact on their caregivers. The reporters for all four narratives reported an emotional impact for themselves to an extent but in the narratives where mothers reported, the emotional impact associated with dysphagia seemed to be greater. Incidentally, not only did Thomas and Mary

have acquired issues, but they were also adults. They had lived a normal life well into late adulthood before their feeding issues began, so they were more independent in their narratives, even when they did depend on caregivers for support. Sarah and Leah were born with feeding and swallowing issues, so from the very beginning they depended completely on their mothers for their feeding needs. The social and emotional burden the caregivers of Sarah and Leah reported was much heavier than what the caregivers of Thomas and Mary reported which may suggest inherent differences in the emotional impact of dysphagia and whether it is acquired or developmental. This could also be due to the fact that the primary caregivers of Sarah and Leah were their mothers, whereas those of Thomas and Mary were not as direct in family relation. The story of Thomas was reported by his niece who acted only as a temporary caregiver, and the story of Mary was reported by her daughter-in-law who was more of a social companion during mealtimes than a true caregiver. The reporters for the stories of Thomas and Mary did discuss, however, a heavier emotional impact for closer family members within these two stories; Thomas' wife and Mary's son and daughter.

All four narratives contained instances of social management of food situations and/or food modification in social spaces yet there were specific differences in how individuals and caregivers dealt with these issues. Both Thomas and Mary, who had acquired feeding and swallowing problems later in life, accommodated for the changes that they experienced, as did their caregivers to an extent. Sarah and Leah, perhaps due to the fact that they had developmental dysphagia along with the fact that they were children, did not accommodate for their own difficulties with feeding and swallowing. Their primary caregivers took full responsibility in those areas and reported heavier emotional burdens placed on them.

Sarah's story. The narrative of Sarah was reported by her mother. Sarah was born with Down's syndrome and a heart defect as well as problems with feeding and swallowing because, as her mother later found out, her throat had not developed correctly. At the time of this study Sarah was ten years old. Sarah had to be on a feeding tube for the first six years of her life.

Her mother and primary caregiver discussed the different social aspects that went along with having to tube feed her daughter for such an extended period of time. One of the main social themes Sarah's mother discussed was managing their social environment while they were in public to accommodate for Sarah's special feeding needs. She reported that she had to prepare in advance to feed Sarah if they were going to be away from home because feeding her was such a process. She also admitted that when she first began tube feeding her daughter she was not comfortable doing it in plain view of the public. If they were in the mall, for example, she would tube feed her daughter in the sitting area of a restroom so that no one would see.

“When I first started tube feeding her...it was kind of an awkward...situation because I knew people didn't understand what was going on and so I guess for about two years...if we were at the mall, the Dillard's restroom has a sitting area so we would do it there and I fought with it because I thought I hate feeding her in a bathroom ...”

Eventually, Sarah's mother adapted to her daughter's special feeding needs and no longer felt like she had to feed her privately when they were in social spaces. Sarah's mother fed her anywhere and anytime their family sat down for a meal.

Sarah not being able to eat by mouth had a major emotional impact on her mother. Sarah tube fed for six years and her mother worried that she would have to do that for the rest of her

life. She reported that the main reason it bothered her was because she knew just how much Sarah wanted to taste and eat food.

“...if she would have not wanted to [eat by mouth] that would have been one thing, but she begged when we would eat food. She always wanted what was on our plates...And her not being able to [eat it] was hard for me. If she didn't want to like I know some kids who tube feed, they don't ever want anything near their mouth, that would be one thing but she wanted to and so I think that was the hardest thing, knowing that she was trying but just couldn't.”

Sarah's mother also reported the emotional importance of the food routine that she and her daughter shared. She said that her husband fed their daughter occasionally and that other members of their family were trained to feed her and sometimes did, but that she always wanted to be the one to feed her daughter. She discussed the time when she tube fed her daughter as being a special bonding experience that she cherished.

“...[feeding her] brought us closer, just because that was something that I did with her...my husband did it some, but I kind of wanted to always do it...that was our time, my job...”

Even though Sarah's mother preferred to feed her daughter herself for emotional reasons, she also cited the importance of having strong emotional support. She felt supported by her family, who adapted well to her daughter's special feeding needs. She also belonged to a Down's syndrome support group and had made friends who understood what she was going through as a parent of a child with special needs.

Leah's story. At the time of this study, Leah had just turned one year old. Her mother and primary caregiver reported her experiences with her daughter's feeding and swallowing issues.

Leah was born three months premature and required nutrition through a nasogastric tube for the first two months of her life. After the tube was removed, doctors realized that she had further feeding and swallowing problems. She experienced severe acid reflux, frequent aspiration of liquids, and a delayed swallow response.

During her interview, Leah's mother expressed that she felt limited in her social experiences and opportunities because it was difficult to take her daughter to public places during mealtimes and otherwise. She said that feeding Leah in public was always a fight. Leah would scream and cry and her mother felt it was almost impossible to feed her in public. This naturally caused Leah's mother to modify her social experiences in a food context, even to the point of not going out at mealtimes at all. She also had to constantly be on guard that no one fed her daughter anything because she was at such a high risk for aspiration. This further limited her social opportunities. She reported that,

“I have had to stay at home because I can't put her in a typical daycare 'cause they're not trained to deal with all the issues...I'm pretty much stuck at home constantly 'cause people aren't trained to feed her to have a babysitter...so, as far as social experiences, it's hard to take her places, like even church because the daycare workers aren't trained...to handle her and she can't eat food that regular one year olds can eat so, it's pretty much just me and her...'cause they'll try to give her food and stuff and you have to stop 'em...”

Even at family gatherings, Leah's caregiver said she had to constantly be alert so that no one gave her daughter food. She felt that her family did not appreciate the severity of Leah's issues with feeding and swallowing.

“They’ve accepted it but I don’t think that they really acknowledge how serious it is...her great grandparents still think she can take cookies and that kinda stuff. And so, people just don’t understand the severity of it...it’s just been a little bit hard to make sure that you catch people before...they do stuff that they shouldn’t.”

The overarching emotional theme Leah’s mother discussed during her interview was the emotional impact on her as the primary caregiver for her daughter. Regarding the different social limitations and hardships she experienced, Leah’s mother explained that it was very difficult for her. She spoke about a particular time when her daughter choked so badly that she had to be resuscitated. Having to constantly be on guard against others giving food to her child and watching her to ensure her safety was probably the hardest thing about her daughter having dysphagia for her emotionally.

In relation to this emotional impact on her as Leah’s primary caregiver, she expresses a desire for emotional support and why she thought that would be important for her and others in her situation. She confided that she felt very lonely and that it would be helpful to have other people to talk to who could understand her emotional struggles.

“...it takes a lot of patience...it’s hard because you don’t really have people out there who understand and...it doesn’t seem to be so common...I wish there was a way we could communicate [with other people]...just sharing experiences...if people are struggling and just worried about getting the nutrition that they need...if they could just communicate and...get some comfort in knowing that it’ll be ok.”

Discussion

The purpose of this study was to examine the ways in which feeding and swallowing problems have had an impact on the social and emotional experiences of adults and adult caregivers. Of course, as with any issue as central to humanity as eating, every person will experience it in a very unique and personal way. Emotional issues associated with dysphagia were the most common themes across all participants, followed by social themes. While fewer in number, all narratives included reports of changes in the physical aspects of feeding and swallowing. There were two major themes that appeared across all stories to varying degrees, which suggests that these were very important in assessing the social and emotional impact feeding and swallowing problems had on the lives of the participants of the study.

The discussion that follows shows the relation between the social and emotional aspects of feeding and swallowing issues addressed in the literature review and the findings that this study revealed. According to Miller et al. (2006), the psychosocial impact of dysphagia is one of two main themes shared by the participants with dysphagia in his study. This entails that, apart from the physical struggles a person with dysphagia experiences, there are self-esteem, socialization, and quality of life issues that coincide with them (Ekberg et al., 2002). These findings from the literature were also present in the results of this study. The physical aspects of feeding and swallowing were reported in every story to an extent, but every participant reported the importance of the social and emotional aspect of feeding and swallowing problems.

The main social theme that appeared in some way across every narrative, no matter if the person self-reported or reported as a caregiver, whether the etiology of dysphagia was acquired or developmental, was the social management of the food situation. This occurred when an individual, it could have been the person with dysphagia, their caregiver, or other family members, manipulated his or her social environment in order to accommodate for special feeding

needs. Balandin et al. 2009, cite two main impacts from the changes that dysphagia causes for the individual. These are “reduced social interaction during meals” and “loss of independence.” p. 201. Even though the participants of this study dealt with special feeding needs, most of them developed a way of adapting in order to minimize these negative outcomes. Thomas demonstrated this in his persistence to continue to eat in restaurants even when he had to physically force food down his throat. He and his wife chose seats near the back of the restaurant and faced away from the other guests so that they would not be able to see him eating. John, who reported his own experiences with dysphagia, also managed his social situation to fit his feeding needs. Whenever he entered the room where a meeting with food involved was taking place, he would make sure to locate the nearest exits to prepare himself if he had to make a quick getaway to the bathroom. In the Story of Sarah, Sarah’s caregiver demonstrated social management of her daughter’s food situation. At first, she always made sure that she was in a semi-private area before tube feeding her daughter in public. She manipulated her social environment to facilitate privacy because she did not feel comfortable doing it in plain sight. As she learned and became more comfortable, she began to tube feed Sarah in plain view of the public when the rest of the family sat down for a meal.

Leah’s mother also reported having to manage her social environment in such a way that would enable her to feed her daughter with ease. In her case, she preferred not feeding her in public in general because it was such an ordeal for her. For Leah’s mother, staying home to feed her daughter seemed like the most feasible option. In this sense, Leah’s mother did seem to experience the negative outcomes associated with dysphagia described by Ekberg et al.

Another theme that often went hand in hand with social management was the modification of food management in social spaces. This theme was categorized as ‘other’

because it was more based around the physical mechanism, but these two themes often coincided. What this theme depicted was a person actually modifying the way that they ate in social environments in order to match their changing feeding and swallowing mechanism. In the Story of Mary, Mary ate slower and took smaller bites in restaurants in order to accommodate for her mechanism becoming less efficient. Even her caregiver and reporter of her story began to modify the way that she ate in restaurants and family gatherings to match up with Mary's pace. John also modified his food management in social situations in order to avoid uncomfortable episodes of esophageal spasms. He said that he would avoid certain foods, even his favorite foods, if he thought there might be a chance of them causing him problems. During meetings that provided a set meal, he said he would often opt out of the regular meal in favor of eating just a salad or even nothing at all.

Overall, the emotional themes abstracted from this study were more numerous than the social themes. This suggests that the emotional aspect of food played a larger role in the lives of the participants and their families. The emotional theme that appeared in some form or another across all narratives was the emotional impact associated with feeding and swallowing problems. In some stories the emotional impact was on the individual with the issues themselves, in others it was on their caregivers. Still others showed an emotional impact on the family members of these individuals who did not serve as direct caregivers.

According to the literature, being correctly and affirmatively diagnosed with dysphagia is of the utmost importance in order for patients to receive the proper care they need. This also coincides with the emotional impact of dysphagia. According to Ekberg et al., many people living with dysphagia are never diagnosed. Many other people do not believe their feeding and swallowing issues can be helped or treated. John was never diagnosed and he reported managing

his feeding and swallowing problems relatively well. They did not seem to affect him negatively to a great extent. Mary was also never diagnosed with dysphagia. According to her caregiver, she was aware that she was having trouble with eating, but she did not see it as an issue. That only led to a minimization of her problems. She managed her food intake but she eventually died of aspiration pneumonia which could possibly have been avoided had she been evaluated for dysphagia. This outlines the importance of an affirmative diagnosis of dysphagia and the likely emotional impact that overlooking feeding and swallowing problems may have.

Thomas never really felt an emotional impact associated with his dysphagia even though he had an emotional attachment to food. He loved food and was determined to keep that as a part of his life, but the real emotional impact discussed by the reporter of his story was on his wife, his primary caregiver. The reporter, whose role in the story was to provide respite for her aunt, talked about how difficult it was for her aunt to see her husband go through such a disease process. Similarly, the emotional impact associated with Mary's feeding and swallowing problems was not that immense for her personally. The real emotional impact, according to the reporter of Mary's narrative, fell on her children, especially after she died from a cause they had brushed under the rug so many years ago.

The only emotional impact John reported of his own dysphagia was that he was concerned at times when he would have to eat in public. Other than that, he really did not feel like it bothered him emotionally. He reported that his wife, however, was very emotionally impacted by his esophageal spasms. She was very concerned about his safety and would become angry with him because he played them off as not being important or dangerous in any way.

Dr. Belafsky said, "...the inability to eat and drink leaves those whom we care most about alone and isolated because they cannot commune with family and friends over a shared

meal” (as cited in Casey, 2012). This is evident in the Story of Sarah. Sarah had to be on a feeding tube for the first six years of her life, but her mother said that she always wanted to taste and eat food. Sarah’s mother discussed that as an emotional hardship for her because she knew just how badly her daughter wanted to participate in mealtimes and eat food like the rest of her family could.

In Sarah’s story, her mother felt as though she shouldered the emotional weight of caring for her daughter and her special feeding needs. Miller et al. (2006) explain how “coping strategies could aid swallowing problems but often to the detriment of others in the family through altered demands on preparation and organization, pg. 614.” Sarah’s mother described her hardships as she learned to adapt to her daughter’s special feeding needs, especially while in social situations. Leah’s mother also reported bearing the full burden of the emotional impact related to her daughter’s feeding and swallowing issues. She admitted that she often felt alone because it was hard for her to take her daughter anywhere during mealtimes. She also reported that she did not feel like she had anyone to talk to about what she was going through with her daughter. Leah’s mother reported that it was emotionally demanding for her to monitor her daughter around her family and others for fear that they would give her a piece of food that she could choke on.

Limitations

The main limitation of this study was that, since participants were sought through a nominative process, the researcher had no way of controlling how many participants would have feeding and swallowing issues themselves and how many would be caregivers of those that had. Likewise, there was no way to control how many participants would have been caregivers of adults versus children, or if the cause of feeding and swallowing problems were acquired versus

developmental. The questions of the study were so broad that they really invited anyone who had experience with these issues to participate, without being able to set a cap for how many of each category would be sufficient for a decent sample. The participants that volunteered did make for a varied sample as far as assessing themes was concerned, but there were not the same number of participants to represent each category.

Future Directions

This study yielded varied and informative results on the social and emotional aspects of dysphagia on the lives of adults and adult caregivers. There were five stories from four participants which were analyzed for social and emotional themes. Certain themes did present themselves as being more central to the lives of the participants than others as they either showed up across stories, or several times within the same story. One issue that should be taken into account, however, is that for all five stories, only one was from an individual who experienced feeding and swallowing problems himself. Most of the data in this study was reported by caregivers of adults or children. For future research efforts, a more distinct focus should be placed on gathering data from individuals who deal with these issues themselves. It would be extremely valuable to explore more primary source perspectives on the impact that dysphagia has socially and emotionally. Firsthand reports may provide insight into different nuances of feeding and swallowing problems that this study simply could not capture when so many of the participants served as caregivers who did not experience these issues in themselves.

Another valuable avenue to explore would be the social and emotional impact of dysphagia of adults who have developmental issues. For this study, the only narratives about adults were of acquired problems with feeding and swallowing. The time of onset for these acquired conditions combined with age of the individuals most likely had an effect on the social

and emotional impact for those individuals as well as their caregivers. To look at a population of people who were born with developmental dysphagia who have grown into adulthood would provide more valuable insight into the social and emotional affect dysphagia has on the lives of these individuals as well as their caregivers.

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Semi-Structured Interview

1. Tell me a little about yourself.
2. Have you or a family member had feeding and/or swallowing problems?
3. What was the most difficult thing about having this condition?
4. How did dysphagia impact your social experiences?
5. How did dysphagia impact your emotional experiences?
6. If you could let others know something about yourself and your experiences with dysphagia, what would it be?
7. How have your relatives adapted to your special feeding needs at family gatherings?
8. If you or your family member's feeding and/or swallowing problems were acquired, how is your life different now than it was before?
9. How has your relationship to others been affected by your or a family member's feeding and/or swallowing problems?
10. How has your relationship to food been affected by your or a family member's feeding and/or swallowing problems?

Appendix B

October 30, 2013

MEMORANDUM

TO: Savannah Learned
Fran Hagstrom

FROM: Ro Windwalker
IRB Coordinator

RE: New Protocol Approval

IRB Protocol #: 13-10-156

Protocol Title: *Understanding Dysphagia: The Social and Emotional Impact*

Review Type: EXEMPT EXPEDITED FULL IRB

Approved Project Period: Start Date: 10/30/2013 Expiration Date: 10/20/2014

Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (<http://vpred.uark.edu/210.php>). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

This protocol has been approved for 20 participants. If you wish to make *any* modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior to* implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 210 Administration Building, 5-2208, or irb@uark.edu

Appendix C

Coding for Themes

- Adult participants volunteered for study through nominative process
- Researcher met with participants for semi-structured interview at participant's location of choice
- Interview was audio recorded and field notes were taken by researcher
- Interviews were transcribed word for word by researcher
- Transcriptions were read for social themes associated with feeding and swallowing problems
- Transcriptions were read for emotional themes associated with feeding and swallowing problems
- Transcriptions were read for other pertinent themes associated with feeding and swallowing problems
- Themes were highlighted and given names to capture their essential meaning
- Member checking procedure required approximately an additional thirty minutes of participation for individuals who participated in the study
- Social, emotional, and other themes extracted from their interview were presented to each participant. They had the opportunity at that time to make comments or address concerns with the themes presented. They were asked to verify the accuracy of the researcher's understanding of what they had said in their interview.
- Once verified, social, emotional, and other themes were assembled into an Excel spreadsheet with theme title on the Y-axis and participant names on the X-axis
- Overlapping or redundant themes were condensed

- Themes were tallied by density within and across stories
- A theme was considered significant when it showed up multiple times within the same story or when it showed up across three out of the five stories from different participants
- These themes were considered significant for the study as they suggested importance to one participant specifically or importance to multiple participants