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June is Dysphagia Awareness Month

Passed by congress in 2008, June is recognized as National Dysphagia Awareness Month.

We honor all persons living with swallowing disorders, caregivers supporting those with dysphagia, and healthcare providers seeking to improve the health, well-being and quality of life for people living with swallowing disorders.

Dr. Catriona Steele's Swallowing Rehabilitation Research Lab has shared the following statistics:

- 1 in 2 adults will encounter swallowing challenges in themselves or a loved one.
- Swallowing disorders (dysphagia) are 10 times more common than epilepsy.
- Swallowing disorders are more common than diabetes

We have a special E2D for you!

Here are the contents:
One Person's Journey
Dysphagia during COVID-19
CEU: Pediatric Grand Rounds
ABSSD CEU Opportunities

The ABSSD encourages SLPs to share during this month using hashtags of #DysphagiaAwareness & #dysphagia to continue to raise awareness this month.

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One Person's Journey

Mark Kimmell, a head and neck cancer survivor, shares his brave and resilient story with ABSSD to inspire us and the people we serve.

My Journey with Dysphagia by Mark Kimmell

My experience with dysphagia began as I was being treated for head and neck cancer, specifically squamous cell carcinoma at the base of tongue, left oropharynx. Radiation and chemotherapy treatments necessitated use of a PEG (percutaneous endoscopic gastrostomy) tube for several months and my ability to swallow diminished over time. A year after my initial treatment completed, I was making progress regaining my ability to swallow when my cancer recurred. I had to have extensive surgery to remove the tumor and had a free reconstruction. The cancer was removed successfully but I was unable to talk or swallow at all for several weeks and was completely dependent on the feeding tube. With the help of a terrific Speech and Language Pathologist (Thank You, Tanya Duke!), I began working once more to regain my ability to speak and swallow. While I made some good progress, my esophagus had narrowed. I had several surgical procedures to dilate the esophagus but ultimately the surgeon could not detect an opening at the top of my esophagus. It had been completely closed by scar tissue. I weighed my options regarding a surgical procedure to attempt to re-open my esophagus and decided that the risk of serious complications from that surgery coupled with the lack of assurance that my esophagus would remain open even if it could be opened, led me to decide not to pursue that surgery. I received some good guidance from my SLP and my ENT that helped me in this decision. They encouraged me to not discount the good quality of life I had achieved after recovery from extensive cancer treatment.

Impact of Tube Feeding

After I regained my strength and stamina, I was able to travel and be physically active with no problem. If I go on an extended trip, I just ship my formula enteral to mν destination, take a supply with me, or arrange to purchase a substitute there. Although I use a very calorie and protein dense formula, I found a suitable one easily available at local

pharmacies all over France during a three week vacation a couple of years ago. I have fed myself on airplanes, at picnics, and in countless restaurants. Being reliant on a feeding tube truly does not figure into my social schedule. I use a low profile (Mic-Key) gastrostomy tube and carry an extra one when I travel. While I miss eating and drinking by mouth (A LOT!), my experience has been that this change in my life does not have to be a constant source of anguish or anxiety. As is the case with many who have had significant medical challenges, I have learned that the experience can be an opportunity to open myself up

#DysphagiaAwareness Month Celebrate Quality of Life

- My experience with dysphagia began as I was being treated for cancer at the base of tongue & throat.
- I needed a feeding tube, as radiation & chemotherapy caused my swallow to diminish over time, but I made progress in regaining my ability to swallow.
- However, my cancer came back. I had to have extensive surgery to remove the tumor and had a free flap reconstruction.
- With the help of a terrific Speech-Language Pathologist, I started to regain my ability to speak and swallow.
- Then, my esophagus narrowed & completely closed. My SLP & ENT helped me weigh my options!



 They encouraged me to not discount the good quality of life I had achieved after recovery from extensive cancer treatment.



to unrecognized sources of fulfillment. For example, I find that I enjoy the smell of food, more than I ever did. I am not tortured by being around food or others who are eating. The option of eating by mouth has somehow just been "set aside" for me. I did not do anything special to adopt this attitude, it just seemed to happen organically.

During a recent discussion about eating with fellow members in my SPOHNC (Support for People with Oral and Head and Neck Cancer) support group, it dawned on me that I was actually in a better place, in many ways, than my peers who could swallow but had challenges with dry mouth, sensitivity to spices, difficulty chewing meat, etc. For them, eating in a restaurant could present problems I didn't have. For example, it took them a very long time to eat a meal or they couldn't tolerate most of the typical menu offerings. For me, all I do is bring my formula and I'm good. And if I want a glass of wine, down the tube it goes! This is not to say that losing my ability to eat and drink by mouth is trivial or unimportant. I would love to be able to swallow, but I can't and I accept that. I have had to reassure my friends that I still want to go to dinner with them. It has had an impact on my spouse, who is a great cook. Preparing meals together and enjoying the results is something we have lost, and we have worked to recognize and mitigate that loss.



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www.SwallowingDisorders.org @BCSSwallowing on Social Media

Unexpected Impact on Others

While working with a personal trainer to build my strength and stamina, she mentioned that I had had an impact on her home life. Her mother's brother, a man with developmental challenges, had developed swallowing problems. His medical team suggested a feeding tube on a temporary basis while he underwent therapy to swallow safely and effectively. My trainer's mother was the man's guardian and she had resisted the feeding tube. She viewed it as a prelude to death. My trainer explained to her that she worked with a client who had a feeding tube for years, came to the gym

regularly, and worked out vigorously. She was able to convince her mother to allow the

tube, the therapy was successful, and after her uncle had regained the ability to swallow safely again the tube was removed.

Thank you to our BCS-S affiliate, Tanya Duke, for sharing Mark's story with us!

Dysphagia Management During the COVID-19 Pandemic

by Karen Sheffler, MS, CCC-SLP, BCS-S

It has been well over one year since the start of the COVID-19 pandemic that changed practice patterns and staffing so urgently. We had terrific guidance from many experts around the world to help guide SLPs through the fog. Special thanks goes out to the DRS COVID-19 Task Force: https://www.dysphagiaresearch.org/page/COVID-19Resources).

Now we will start to see more research publications based on months of gathering and analyzing data regarding outcomes of people who had COVID-19 and required prolonged hospitalizations. For examples: How many needed to be intubated? How many people suffered from post-extubation dysphagia? How many people required an SLP evaluation? How many needed to be held NPO? Did the long lengths of intubation correlate with how long people took to restart oral intake? Were people started on modified diets and thickened liquids more often than regular diets? Were people with dysphagia readmitted with aspiration pneumonias?

During #DysphagiaAwareness month (June), the ABSSD wants to encourage all to ask and discuss these issues with their colleagues. Too often dysphagia goes under-referred, under-evaluated, and under-treated. How did practitioners within the field of dysphagia do during the height of the COVID-19 surge and beyond?

Dr. Camilla Dawson, DClinP, BSc(hons) MRCSLT, MHCPC, an SLP/SLT from the Queen Elizabeth Hospital in Birmingham, UK, started answering these questions -- along with her huge team of authors/researchers (See Dawson, et al., 2020, in The Journal of Laryngology & Otology; Link: https://pubmed.ncbi.nlm.nih.gov/33168109/). Their article titled: "Dysphagia Presentation and Management Following Coronavirus disease 2019: An Acute Care Tertiary Centre Experience," was first published online in November 2020.

Dawson shared with ABSSD: "Unfortunately our hospital Trust saw over 13,000 patients from March 2020 to March 2021, the most patients in a single centre in the UK. Whilst a sobering number, this has allowed us to analyse our data and practice to hopefully help other teams reflect and plan interventions as the pandemic pressures develop across the globe," (personal Twitter communication on May 26, 2021).

During the surge from March to May 2020, these researchers analyzed the 720 people who were admitted for more than 3 days (out of an approximate total of 1700 total admissions). Please see some of the interesting percentages listed in this infographic and discussed below:

LET'S TALK DYSPHAGIA & COVID-19 #DysphagiaAwareness Month 50% 28.3% 80% Needed SLP Eval of those needing SLP eval, required a trach. Admitted to ICU **lean** for ventilator 33% Age: On a modified diet or liquids on 1st ICU eval. 29% Only 1/58 on Level 7. # of days intubated 67% correlated with time Required NPO based from intubation to of total were referred on initial ICU eval. to Speech Pathology oral intake - for ETT & (SLP/SLT) Trach groups. All data based on a study from the UK, analyzing 720 people in 1 hospital who were admitted for >3 days. See Dawson, C., et merican Board of al. (2020). Dysphagia presentation & management following coronavirus disease 2019, Journal of Laryngology & Otology.

About 42% of people (N=720 out of the approximately 1700 total people admitted to this hospital from March to May 2020) required admission greater than 3 days. Those 720 people were who this team of researchers analyzed.

- **28.9%** (208 out of 720 people) were referred for**SLP** evaluations and received targeted therapy as appropriate.
- Referrals were from staff and were based on overt clinical signs, such as: coughing, pain, difficulty swallowing, reduced oral intake, and presumed aspiration events with chest x-ray results.
- Certainly, there may have been dysphagia that was un-recognized and underreferred.
- **28.3%** (204 out of 720) required **ICU admission** for endotracheal intubation and ventilator needs.
- 50% of those in the ICU required SLP evaluation. Based on the initial assessments:
- 33% were started on a modified diet or liquid (with only one person on an IDDSI Level 7 Easy to Chew diet), while
- 67% had recommendations for NPO.

The IDDSI Framework

Providing a common terminology for describing food textures and drink thicknesses to improve safety for individuals with swallowing difficulties.



© The International Dysphagia Diet Standardisation Initiative 2019 @ https://iddsi.org/framework/ Licensed under the CreativeCommon Ambiation Sharealise 4.0 License trops://prestrecommons.org/ficense.try-sa/4.0/legistode Dentalities works ethnology benedil engages to breaktion are NOT PERFETTIO.

- 51% of the total SLP evaluations were for people on the wards (non-ICU).
- 29% (31 out of 106) were started immediately on a Regular diet/IDDSI Level 7. By discharge, the majority of these people on the wards were advanced to an IDDSI Level 6 or 7 diet.
- 22% (23 out of 106) had recommendations for NPO.
- 193 people (out of the initial 208 people who were referred to SLP) survived to resume oral intake. (93%)
- 20% were taking thickened liquids (39/193). The researchers stated: "thickener is not frequently used in our institution, with postural advice and exercise therapy being preferred," (page 984).
- 75% were eating a modified diet (145/193).
- 87% of those with tracheostomies required a modified diet versus 59% who were
 extubated and did not require a tracheostomy. These people with trachs also
 required more therapy time, including cuff deflation, downsizing trach tubes, and
 the use of speaking valves to support sensation, cough, and expectoration. They
 noted: Support through saline nebulizers kept secretions thinned and able to be
 mobilized, and this worked better than secretion-drying agents.
- 18% of those who were intubated/extubated were recommended for thickened liquids, versus only 4% of the people with tracheostomies. As opposed to the higher number of 36% of people were on thickened liquids in the ward cohort. In addition to their tendency to not use thickened liquids, I also wonder if this was due to less close monitoring and more conservative recommendations per the SLP on the wards versus in the ICUs. It may have been also due to the use of more definitive testing (FEES) on some more complex ICU patients.

How quickly were people able to start oral intake?

- Mean time from extubation to starting oral intake: 5.3 days (SD = 2.3 days).
- Mean time from tracheostomy placement to oral intake:14.8 days (SD = 6.6 days).
- Mean time for the tracheostomy group from cessation of sedation to oral intake:
 13.0 days (SD = 6.0 days).
- Mean time from *intubation*, through tracheostomy, to oral intake: 28.0 days (SD = 8.5 days).
- Mean time from intubation to extubation to oral intake: 15.8 days (SD = 6.2 days).
- Statistically significant positive correlation only seen in the following groups regarding when oral intake was started:
- For the endotracheal tube (ETT) group: Number of days from intubation to the start

of oral intake.

For the tracheostomy group: Number of **days from intubation** to the start of oral intake. This shows that it was the amount of time intubated that was the most significant factor in delay to oral intake, rather than sedation or time post-extubation, or even time post-tracheostomy insertion. That is consistent with anecdotal reports during COVID-19 of extremely long intubations and the potential for post-extubation dysphagia.

How much therapy did they require on average?

- 8.6 days for those who were not intubated or trached.
- People in the ICU required significantly more days than people in the ward.
- 11.3 days for those who had ETT.
- 12.9 days for those with trachs.
- These numbers did not include the extensive indirect therapy time, consulting with and communicating with the multidisciplinary team.

It is important to highlight and **document** concomitant factors that are noted during our comprehensive bedside evaluations. Researchers noted: "**dysphagia was complicated by**:

- Delirium [hyperactive or hypoactive],
- Use of sedation,
- · Frequent expectoration of high-volume secretions, and
- Significant fatigue." (page 983)

They also questioned the effects of:

- Proning,
- Trauma of prolonged critical illness and critical care,
- Reduced translation/interpreter services within infectious areas, causing a significant communication barrier to people for whom English was not their first language,
- · Inability to see family members/friends,
- Providing care with PPE, and
- Restrictions placed on aerosol-generating procedures.

The researchers also noted the following **barriers** to oral intake:

- Neurological compromise
- Respiratory swallow coordination
- Post-extubation issues: Vocal cord palsy, Laryngeal edema, Pain
- Pervasive laryngeal issues / pervasive voice changes (when these were in conjunction with persistent dysphagia without perceived improvement, the clinicians used fiberoptic endoscopic evaluations of swallowing (FEES) - thereby reducing the use of FEES to only these complex cases).

Per these researchers and clinicians, often the "holistic symptom burden" contributed to recommendations for NPO more so than the suspected overt signs/symptoms of dysphagia and aspiration (page 983).

The dysphagia was multifactorial, per this research, which is typical in critical care. It is so important for SLPs to:

- look at the big picture,
- communicate with the whole team (which has the person and their goals and wishes as the driver of the team), and
- **document** how these complicating factors/barriers provide the rationale behind the team's clinical decision-making and recommendations for oral intake options.

Per Dr. Luis Riquelme, PhD, CCC-SLP, BCS-S (at our ABSSD - Meet The Masters, 2020), people with COVID-19 were "fluctuating hour to hour and day to day." He emphasized that there was significant variability within one person in their ability to breath, stay alert, and take oral intake from one minute to the next and one day to the next. (Please see his session on how COVID-19 affected our clinical swallowing evaluation in Meet The Masters 2020: COVID, It's Hard to Swallow: Managing Patients with Dysphagia during the Pandemic:

https://www.swallowingdisorders.org/page/MTM 2020 COVID.)

Despite this multifactorial nature and significant variability within the individual, some patterns did emerge, per Dawson and colleagues (2020). **Oral dysphagia** was commonly seen, causing most people to need a modified diet. Some people required thickened liquids for their more overt issues of delirium, fatigue and poor lip closure. They were using Slightly thick / IDDSI Level 1 more often than other thicker levels and found it to be effective for a small number of individuals at the start of their oral intake (page 984).

Another unifying issue was that these people required a significantinvestment in appropriate skilled therapy. This attention and therapy must have worked for this research cohort, as no one was readmitted with a new aspiration pneumonia after they were discharged to the next level of care. They noted that intensive and "targeted and sustained swallow therapy" was what helped people "regain near normal swallow function prior to discharge" (page 984). The therapy techniques listed in the article were at the level of our professional standard of practice (not extraordinary or novel), as seen on page 982, but a facility does require enough staff to carry them out fully. Additionally, the SLP department had to use a "whole systems approach," (page 985) incorporating "medical, surgical, nursing, therapy, and education teams." They used a person-centered care approach, although they did not label it as such, as their targeted treatment reflected that and had good outcomes.

Dr. Camilla Dawson concluded:

"For me the most important finding was prevalence of dysphagia for approximately 30% of people admitted to our hospital for over 3 days with COVID.

Appropriate funding, infrastructure and recognition of the fundamental role of SLP/SLT in acute services is a core message in our data, and is highlighted by the clinical presentations we describe.

Collaboration of clinical teams created strength and developed our clinical acumen during this complex time, the importance of working together and supporting one another can't be overlooked."

(personal communication May 26, 2021).

Hopefully, this research will encourage others to analyze their outcomes. We look forward to hearing from our affiliates; please share your experiences and other research articles that address similar COVID-19 dysphagia evaluation, management and outcomes data.

Here is the Dysphagia Research Society's link again: https://www.dysphagiaresearch.org/page/COVID-19Resources

Continuing Education Opportunity



Interdisciplinary Management of Complex Dysphagia in the ICU Infant: SIMPLE Solutions!

June 15, 2021 11:00 am - 12:00 pm, CST (Chicago)

Description:

Management of dysphagia within the medically complex ICU infant requires an interdisciplinary approach in which an infant's functional and physiologic deficits are considered within the context of their systemic health. However, in what often seems a dysphagia world of grey, deciding on the best management option can pose a tremendous hurdle for even the best clinical team. In this presentation Neonatologist Dr. Sudarshan Jadcherla and Speech-Language Pathologist Dr. Katlyn McGrattan will dissect some of these real-life clinical conundrums within a patient case from their practice. Research elucidating the mechanisms most commonly at the source for infants who grunt and bear down with feeds will be discussed, with discrete plans of care and associated rationales for when allowing aspiration may be permissible reviewed. Effective translations of care bundles for the management of complex aerodigestive and feeding difficulties in the ICU setting are possible when we switch from multidisciplinary, fragmented, isolated care model to transdisciplinary, integrated, all-inclusive care model based on objective evidence. The approaches discussed can be applicable across the age-spectrum.

For more information on this Pediatric Grand Rounds & to Register, GO TO: https://www.dysphagiaresearch.org/page/CE Webinars Interdisciplinary management.

ABSSD CEU Opportunities



New CEUs coming soon! Keep an eye out for these exciting new offerings!

We have four new, on-demand continuing education courses planned for this year, two on pediatric topics and two on adult topics including:

- Esophageal dysphagia in adults: Joy Gaziano, MA and Joel Richter, MD
- Dysphagia in individuals with airway and respiratory disorders: Jo Puntil, MS and Marc Moss, MD
- Dysphagia in Pediatrics Patients with Cardiac Conditions: Hema Desai, MS and Nita Doshi, MD
- Dysphagia in Pediatric Patients with Airway Disorders: Christina Rappazzo, MA and Deepak Mehta, MD
- We are also happy to announce our continued partnership with Bracco in planning the Meet the Master's Symposium. This year's presentation will be on-demand as well for those unable to travel to the ASHA convention. More details coming soon!

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