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The Dysphagia Research Society Accelerating A Priority Research Agenda

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Abstract

The DRS was established 25 years ago with the intention of bringing together a variety of disciplines involved with research into mechanisms, diagnosis, and management of swallowing disorders (dysphagia). With a rapidly growing membership and committee structure within the DRS, as well as in other similar societies throughout the world pursuing the same agenda (i.e. sharing research findings and putting it into practice), the global importance of this type of interdisciplinary development of research has become increasingly apparent. The DRS has reached out to other dysphagia societies across the globe, including the Japanese society, European society, and Latin American society. Research is now crossing the globe as well as crossing the age span from pediatrics to geriatrics. Interest in swallowing and swallowing disorders is reaching an all-time high. With this much attention and diversity, variability in the quality and direction of research can occur. Therefore, it is increasingly important to develop an all-inclusive research agenda for the DRS to serve as a guide for developing further work in this field that is well designed, functional, and impactful.

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Development of the Research Agenda

This agenda comes from the Society's key stakeholders that include officers of the board and past presidents. It can be seen as an endorsement of the Society's support for investigators to advocate for accelerating new technologies and strategies to recognize and improve swallowing and feeding safety and efficiency along with quality of life among the population with dysphagia across the age spectrum. Furthermore, this document can guide funding organizations, including, but not limited to, the National Institutes of Health, Patient-Centered Outcomes Research Institute, World Health Organization, United Nations, scientific foundations, pharmaceutical industry, nutritional industry, philanthropic organizations, and hospitals, in supporting dysphagia research that is impactful. Finally, as the survival rates are increasing in infants and individuals are living to increasingly older ages, morbidity related to neurological, aerodigestive, and respiratory pathologies is increasing. This document can serve as a guide to policy and planning for regional societies around the world to develop services for dysphagic patients. The proposed agenda is by no means an exhaustive list of all the conditions associated with disorders of swallowing across the lifespan, but rather is intended to serve as an overview of areas of emphasis for further research considerations.

Preamble to Research Agenda

Swallowing is the most complex function needed for survival with quality and is the first physiological function developed during early fetal life with pharyngoesophageal swallowing of amniotic fluid. Safe swallowing involves control and regulation of bolus movement from lips to stomach, and encompasses the oral-, pharyngeal-, esophageal-, and gastric phases. In parallel, this act requires precise regulation of airway functions, particularly so when airway function can be compromised during pharyngeal or esophageal phases of swallowing or during gastroesophageal reflux events. Therefore, pathologies of the aerodigestive anatomical and neuroregulatory structures or of surrounding structures can upset the homeostasis, and contribute to dysphagia in its various manifestations. Such diseases range from maturational pathologies, inflammatory, neurological, cancers, degenerative, and aging to trauma-induced malfunctions. Thus, the root cause of the

problem can be different, yet the abnormal function can be dysphagia. Therefore, several disciplines have evolved over time specializing in local pathologies and therapies. The concept of deglutition has emerged and that it integrates the functions of all components of the swallowing. The DRS is a transdisciplinary organization composed of speech-language pathologists, otolaryngologists, gastroenterologists, radiologists, neurologists, pediatricians, gerontologists, physiologists, translational and basic scientists whose mission is to advance evidence-based practice in the evaluation and treatment of individuals with dysphagia.

Given the critical need for advancement of science related to these debilitating disorders, the strong anatomical and physiological connections among communication disorders and dysphagia, and the common scope of practice among those performing research and clinical practice in dysphagia and communication disorders, this society is a home for like-minded researchers. We, therefore, provide a broad research agenda to encompass all aspects of swallowing and swallowing disorders research.

1. *Definition and burden of deglutition disorders*

Dysphagia affects individuals across the lifespan, from premature infants to geriatric adults. Research indicates that one in 25 adults in the United States have dysphagia, and 25–45% of developing children demonstrate feeding, swallowing, and aerodigestive disorders. This may be an underestimation when considering global prevalence. Dysphagia is associated with multiple diseases and disorders, hence the transdisciplinary nature of the professions treating the disorder and conducting the research. Dysphagia represents a critical healthcare burden often leading to aspiration pneumonia and death. In addition, dysphagia limits nutrition and hydration, negatively impacts rehabilitative potential for communication impairments, and reduces quality of life. Areas with potential for further research are:

- (a) Definition of normal and abnormal swallowing based on regional anatomical origins.
- (b) Classification of disorders of deglutition based on age (neonatal to geriatric patient), anatomical sites, pathophysiological mechanisms, and functions.
- (c) Characterization of severity of deglutition disorders.
- (d) Epidemiology, incidence, prevalence of deglutition of disorders across the age spectrum.
- (e) Pharmacoepidemiology of medications used in the management.
- (f) Economic burden of managing individuals with dysphagia or a given condition relevant to dysphagia.

- (g) Recognition and prevention of swallowing abnormalities.
 - (h) Burden on caregivers and extended community.
2. *Dysphagia-related quality of life (DRQL)* Dealing with abnormalities of swallowing alone has a limited scope in the absence of consideration for reasons of co-morbidities and complications related to feeding. The concept of swallowing disorders is increasingly emerging in many centers, particularly the interdisciplinary nature of science and practice.
 - (a) Define symptom occurrence (screening test) as a consequence of abnormal function.
 - (b) Develop appropriate tests to evaluate relevant conditions.
 - (c) Develop algorithms for defining DRQL specific to age and or primary diagnosis.
 - (d) Determine and reduce the impact of dysphagia on the caregiver.
 - (e) Swallowing and feeding difficulties are inherently associated with emotional, social, recreational, educational, and vocational aspects of life. Therefore, the interrelationship among swallowing and communication disorders is an area of emphasis.
 - (f) Develop age- and disease-appropriate quality improvement feeding and eating strategies.
 3. *Development of new technologies* The era of modernization and nanotechnologies have offered multiple technologies to explore the scientific frontiers to aid in precision medicine at the point of care. This aspect can be applied to enhancing the accuracy of diagnosis and management approaches.
 - (a) Develop tests that aid in recognizing the accuracy of dysfunctional targeted site, that may be contributing to dysphagia.
 - (b) Develop combination or a battery of tests to assess the neurological, airway, and digestive aspects of dysphagia that may have a better prediction of diagnosis.
 - (c) Develop precision tools to monitor progress at the point of care.
 - (d) Develop non-invasive instruments to monitor progress at the point of care.
 - (e) Develop apparatus to facilitate airway protection and maintain luminal bolus flow from oropharynx via esophagus into stomach. Such devices may include, but not limited to maintaining the integrity of upper and lower esophageal sphincter, esophageal luminal patency, and preventing gastroesophageal reflux.
 4. *Organs system-based research* As said in the introductory paragraphs, swallowing phases involve attention to oral phase, pharyngeal phase, esophageal phase, and gastric phase, in addition to airway protection. Pathologies of structures related to these phases or organs surrounding this specific apparatus can affect swallowing. Integrating the physiology between key regulatory and effector systems involved with normal and abnormal deglutition is needed.
 - (a) Increase understanding of the command and control systems at the crucial level of central and enteric neurons to peripheral level of effector muscle cells (skeletal or smooth muscles).
 - (b) Increase understanding of the mechanisms of normal and abnormal motility pertinent to safe and efficient swallowing.
 - (c) Develop the importance of aerodigestive protective mechanisms, markers to assess (dys-)function, quantify the objective evidence to assess therapies.
 - (d) Develop biomarkers for aspiration, abnormal peristalsis, abnormal sphincteric functions, esophageal disorders, glottal, and airway disorders.
 - (e) Characterize the phenotype and mechanisms of deglutition disorders in the context of individual disease, for example, neuropathology, chronic lung disease, gastroesophageal reflux disease, and supra-esophageal and extra-esophageal diseases.
 - (f) Characterize the phenotype and mechanisms of swallowing disorders in the context of age-related diseases, for example, in those affected by conditions seen in premature birth, developmental disorders, congenital anomalies, acquired degenerative diseases, stroke, cancers related to head and neck or aerodigestive apparatus, and Parkinson's disease.
 - (g) Increase diagnostic specificity in order to identify neuromuscular pathologies such as spasticity or ataxia.
 - (h) Neurogastroenterology of oro-pharyngo-esophago-gastric motility and regulatory mechanisms can be advanced with the use of novel manometry approaches.
 5. *Development of therapeutics* Disorders of swallowing do not have a single target to treat or a single etiological factor that can be modified. Thus, a combination of innovative strategies is needed.

- (a) Develop non-pharmacological approaches to manage swallowing disorders. This may include, but is not limited to, nutritional rehabilitation approaches, postural therapies, behavioral therapies, muscle strengthening exercises, skill-based training, neuromodulator therapies, non-nutritive oral therapy, and nutritive oral therapy.
 - (b) Develop pharmacological approaches to modify neuromuscular functions, sensory modification, and modulation of muscle function ranging from facilitation of relaxation as in spasticity to strengthening as in weak and hypotonicity, regulation of central enteric functions.
 - (c) Develop new technologies that will aid in facilitating feeding and swallowing by targeting specific task or nerve–muscle interactions.
 - (d) New technologies such as endoscopic interventions on the esophagus like stenting for benign and malignant dysphagia, POEM for achalasia, endoscopic resection or ablation for early cancer, treating leaks and perforation, and scope for novel therapies with regenerative medicine may be explored.
6. *Development of experimental models of dysphagia* It is important to recognize that both translational and reverse translational research is critical in developing better tools for diagnosis, therapies, and rehabilitation.
- (a) Develop age-related, disease, and condition-specific models for acute and chronic dysphagia.
 - (b) Understand novel mechanisms that define neuromuscular and regulatory pathways and functional neural connectivity related to normal and abnormal swallowing.
 - (c) Understanding the role of esophageal inflammation and pathologies.
 - (d) Clarify swallowing-specific neural lesions in the recognition of biomarkers of disease so as to define opportunities for rehabilitation.
7. *Disseminating knowledge and enhancing team science* This is a critical barrier to progress in delivering the benefits of research to bedside or homecare settings.
- (a) Educating the providers of feeding and swallowing therapies with cutting edge research.
 - (b) Developing high-impact feeding and swallowing rehabilitation teams with a common goal.
 - (c) Educating individuals with dysphagia and their caregivers to facilitate compliance and advocacy.
 - (d) Health maintenance programs to facilitate safe swallowing are needed with dysphagia rehabilitation.

Summary

A new optimism that dysphagia across the age spectrum can be defeated is energizing the research community and patient advocates. Understanding the importance, mechanisms, and opportunities for modifying and halting the progression of dysfunctional feeding and swallowing milestones is crucial to improve patient quality of life. Restoring lost function or even preventing swallowing dysfunction, particularly in vulnerable populations (premature infants and geriatric adults) are all realistic goals. This hope is fueled by the accelerating pace of discovery and technological innovations in neuroscience research, aerodigestive science research, and deglutology research. In providing this research agenda, we hope to have highlighted areas of research emphasis in transdisciplines managing dysphagia and disorders of deglutition. This document may support investigators' research endeavors in seeking funding from agencies and advocate groups for enhancing nutrition, feeding, swallowing, and rehabilitation across the age range.

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