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Dental & Craniofacial Research

The FACIAL network as a model of craniofacial team science

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Abstract

The Facial Asymmetry Collaborative for Interdisciplinary Assessment and Learning (FACIAL) network applies key principles of established team science while using equity-based approaches that advance career development and accelerating collaborative research in craniofacial microsomia. Team science is an effort to leverage a challenge in science by using professionals of different backgrounds and expertise.

Introduction

The concept of multidisciplinary clinical care is intuitive among healthcare professionals who care for individuals with congenital or acquired conditions that affect the head and face. To optimize care, patients need diverse professional perspectives. Craniofacial teams in the US have existed for over a century and the national organization of cleft and craniofacial care, the American Cleft Palate-Craniofacial Association, celebrated its 75th anniversary in 2018 [1]. Despite leadership in clinical team development in the field of craniofacial care, the application of team science is relatively new to craniofacial research.

In 2010, the National Institutes of Health (NIH) published a "field guide" to explain the idea of team science, including examples of what constitutes effective functioning of teams [2]. We describe an ongoing team-based approach to study of the congenital condition of craniofacial microsomia. The goal of this paper is to present the process of building and developing a research network among clinicians and scientists focused on craniofacial conditions. As compared to many existing networks, the FACIAL network has a highly diverse group of specialties, including genetics, psychology, pediatrics, epidemiology/biostatistics, plastic surgery, otolaryngology, and dentistry. As each specialist has a unique background and skillset, each feels ownership of his/her area of expertise. This individual ownership helps develop a collaborative, synergistic approach.

Background

Craniofacial microsomia (CFM) is a complex congenital condition associated with orbital, mandibular, ear, nerve and soft tissue facial anomalies. Individuals with CFM can also have extracranial malformations, which may include central nervous system (CNS), skeletal, renal, and cardiac anomalies [3]. CFM is the second most common craniofacial birth defect after cleft lip and palate [4] and occurs in 1 in 3000 to 1 in 6000 live births [5]. The etiology of CFM is unknown and its phenotypic variability is significant [6].

Children with CFM often undergo multiple interventions throughout childhood and recommendations include longitudinal care by an interdisciplinary team. Although there are guidelines about the role of each provider in team care, relatively few outcome studies have been performed in this population [7] and consensus on standards of care does not exist. Despite variability in treatment planning, many children obtain their health care through craniofacial centers to coordinate specialties and procedures. Teams also track longitudinal growth assessments and often try to limit exposure to imaging studies to those deemed necessary. Craniofacial centers typically have a formulaic group of members that includes speech language pathologists, a surgeon, orthodontist, and psychologist, as a minimum, in order to achieve approval of their team [8]. Most teams meet regularly, either in person or virtually, in order to develop integrated treatment plans. The established culture of interactions among different healthcare providers coupled with providers interested in promoting better care to patients with CFM created the environment that allowed the FACIAL (Facial Asymmetry Collaborative for Interdisciplinary Assessment and Learning) network to be formed in 2009.

FACIAL is a multicenter, interdisciplinary network to advance research in CFM that was initially funded by the NIH (NIDCR Grant # RC1DE020270) in order to establish the research infrastructure. Investigators with a variety of areas of expertise were selected based on their experience caring for individuals with CFM, commitment to collaboration, and participation on multidisciplinary teams with an established research infrastructure to support the project with a patient population that could facilitate enrollment of at least 10 individuals with CFM each year. The study sites are the following four craniofacial centers: Seattle Children's Hospital (SCH), Children's Hospital of Los Angeles (CHLA), Children's Hospital of Philadelphia (CHOP), and University of North Carolina at Chapel Hill (UNC).

Methods

The primary goal of the initial FACIAL study was to develop consensus on CFM research eligibility criteria, demonstrate feasibility of identifying individuals with CFM from geographically diverse craniofacial centers, and establish reliable methods to study a variety of aspects of the patient population.

Team members have has been mostly stable and the network has slowly grown over time. The research infrastructure established by the FACIAL network was used for the subsequent NIH-funded CLOCK (Craniofacial microsomia: Longitudinal Outcomes in Children Pre-Kindergarten) study (NIDCR Grant # R01 DE022438-01 R01), which began in 2012. The CLOCK study focuses on early neurobehavioral outcomes in children with CFM and explores possible causal pathways for neurodevelopmental delays. The CLOCK study expanded the FACIAL network to include co-investigators from audiology, psychology, and speech and language pathology. The additional study sites of University of Illinois at Chicago (UIC) and Shriner's Hospitals for Children, Chicago (SHC) allowed the network to expand the geographic diversity.

Results

The multi-institutional research team has enrolled over 300 study participants into studies of CFM. All 5 sites enrolled cases and controls, with larger centers such as SCH and CHLA usually enrolling more participants. As part of the ongoing work from members of the network, 9 Institutional Review Board (IRB) applications were approved at the 5 sites by the local review agencies. The coordinating center (SCH) and monitoring agencies (i.e. Rho, contract research organization) conducted individual site visits. Discussion and planning were improved by weekly meetings at the sites and monthly teleconferences, with minutes recorded and distributed. Study data were kept on REDCap databases as the study progressed. An ongoing prospective study requires continued shared recognition in terms of authorship and scholarship. (Figure 1) We are in the process of publishing manuscripts based on data collected on the study cohorts and have demonstrated the ability to facilitate multidisciplinary co-authorship in other research efforts to further our understanding of optimal care for CFM.

The key elements of team science were applied in carrying out our research [2]. Specifically, different networks and systems were successfully navigated, communication occurred on a routine basis, and team members were queried about and included in submissions of scientific abstracts, talks, and papers.

In order to continue to expand the expertise of the network and ensure that our research is relevant to an international population, the FACIAL research US network has partnered with colleagues from the South American collaboration for the study of the genetic causes of microtia to facilitate the Craniofacial microsomia: Accelerating Understanding of the Significance and Etiology (CAUSE) study, which will start enrollment in 2018 (NIDCR Grant # U01 DE025862). Genetic samples from participants in FACIAL and CLOCK are also included in the 2017 X01-Kids First Initiative, which is an NIH initiative that allows for leveraging the capacity for data sharing, learning from other large cohorts, and raising awareness about CFM.

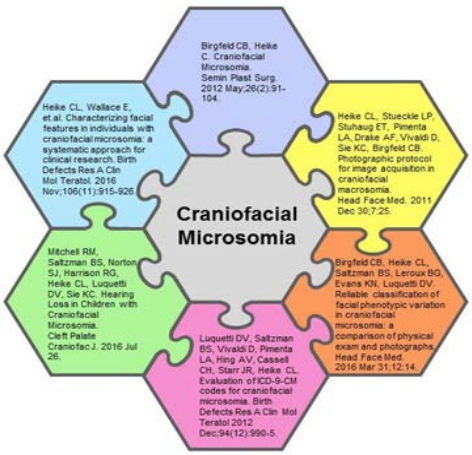

Figure 1. *An example of cross-fertilization through publications.*

Team science is critical in order to accelerate translational science and advance multi-disciplinary research in healthcare.

In an era of increasing complexity in healthcare delivery, further sub-specialization, and increasing clinical demands, it is essential that we put equal energy into facilitating true team science. Not surprisingly, providers likely to have the most clinical insight into opportunities to advance knowledge are not easily able to participate in multidisciplinary, multicenter science usually because of high clinical volumes and absence of protected time. Although this is not within the scope of this paper, it should be noted that not every clinician has the interest or the drive to participate in clinical research. Some are overcommitted to clinical care, while others have other interests outside of research, such as teaching, administration, or global outreach.

Whereas team dynamics, including social networking, teleconferencing, and mentoring, all contribute in major ways to the success of team science, it is also clear that there are also challenges. For example, institutional requirements for advancement, which may only recognize first and last place authorship for advancement or promotion, can make decisions about authorship order more difficulty in large groups. Despite these challenges and academic barriers, we present an example of cross-fertilization through hypothesis development, data analysis, and publications, in which authorship is varied throughout the group.

Conclusions

The concept of team science is an ongoing and relevant force with the potential to significantly advance understanding of complex health conditions across the lifespan. The FACIAL network provides a model for team research, i.e. team science with marked diversity in team composition, based in a multidisciplinary and multi-site collaborative brought together by the common goal to better understand and improve care for patients with CFM. Though not identified often in craniofacial research, this model can enhance our study of relatively rare yet complex health conditions

with wide variability in both clinical outcomes and healthcare delivery. Future study in the area of team science and its relevance to craniofacial research is anticipated.

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