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Qualitative Analysis of an Interdisciplinary Team's Treatment of Velocardiofacial Syndrome

Marissa Meredith
mmm376@zips.uakron.edu

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“Qualitative Analysis of an Interdisciplinary Team’s Treatment of 22q11.2 Deletion Syndrome”

Author: Marissa Meredith, Class of 2021

Sponsor: Dr. Scott Palasik

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Abstract

The purpose of this University of Akron honor's project research project is to evaluate the interdisciplinary care approach taken by Nationwide Children's Hospital Craniofacial Clinic when treating Velocardiofacial Syndrome. Velocardiofacial Syndrome is also known as 22q11.2 Deletion Syndrome (22q). 22q. This is a developmental disorder with a wide variety of symptoms requiring the care of several professionals. It has been determined that the most common needs are related to congenital heart disease, immune deficiency, palate defects affecting feeding and speech, learning difficulties, feeding disorders, early growth faltering, gut dysmotility, psychiatric, behavioral and neurological conditions, structural (renal, skeletal, brain, gastrointestinal, eye and dental) abnormalities, hearing impairment, hypocalcaemia, haematological and autoimmune disorders (Habel, Herriot, Kumararatne, Allgrove, Baker, Baxendale, Bu'Lock, Firth, Gennery, Holland, Illingworth, Mercer, Pannebakker, Parry, Roberts, & Tsai-Goodman, 2014). Research that has taken place in treatment clinics across the country shows that an interdisciplinary care is the most time effective and produces the best results in patients with 22q. However, the majority of 22q patients are still not getting this type of care due to the lack of interdisciplinary care facilities available. Therefore, this research brings relevant and important information because no other studies have been found that assess the operation of interdisciplinary clinics like that of Nationwide Children's directly to determine the advantages and disadvantages of this style of treatment.

The methodology of research for this project was a survey of the directors of the 22q Clinic at Nationwide Children's Hospital in Columbus, Ohio. The results were then analyzed for patterns and correlations between the two respondents. Both professionals surveyed are experts in their field with unique specializations and both indicated that they believe that the treatment

approach used in their clinic is the best model for patient care in patients with 22q11.2 deletion and related disorders. Both professionals also indicated that this treatment model is the most effective treatment model due to the unique needs of each individual patient and the range of body systems that can be affected by 22q.

Introduction

22q11.2 Deletion Syndrome is a genetic condition that can cause a variety of other conditions in several body systems. In fact, nearly any part of the body can be affected and even affected members of the same family may experience different symptoms and conditions (22q11.2 deletion syndrome, n.d.). Due to this variety within the developmental disorder, a multitude of professionals is often required to treat patients with 22q for all symptoms. The more that the treatment of patients with 22q is researched, the more symptoms related to the condition are found, which makes this area of research one that is becoming increasingly complex and relevant. To build on the research of treatment models for patients with 22q, this study will analyze the treatment model used at Nationwide Children's Hospital Craniofacial Clinic in Columbus, Ohio.

At Nationwide Children's and interdisciplinary care team treats patients individually based on their needs. The core specialties of the 22q clinic at Nationwide Children's includes a geneticist, genetic counselor, pediatric nurse practitioner, speech-language pathologist, plastic surgeon, ENT, orthodontist, social worker, audiologist, and psychologist or neuropsychologist, with other professionals available in several other areas depending on the unique needs of the patient. This treatment methodology benefits patients and is aligned with the philosophy of care of the clinic, which is stated on their website, Nationwide Children's, "22q11.2 deletion syndrome (22q) can affect any system of the body, however most children with 22q have heart, immune, learning, speech, and/or behavior difficulties." Each person with 22q has their own unique needs at varying levels of severity, and interdisciplinary team care is the best management approach. The 22q Center at Nationwide Children's Hospital offers comprehensive and coordinated care for children and adults with 22q. The hospital's website describes the care

provided by stating, “the 22q Team helps families manage medical, developmental, mental health, and other needs,” (About, n.d.).

This study will further expand on the ways that families are helped through the interdisciplinary care of professionals from several different fields of study at Nationwide Children’s Hospital. This study addresses the following questions specifically:

1. How many patients are seen per year and per day at the clinic?
2. What does a regular appointment look like at Nationwide Children’s Hospital in the 22q clinic?
3. Which types of professionals make up the team that treats patients at Nationwide Children’s Hospital in the 22q clinic?
4. How does the team approach affect the way that the coordinators do their jobs?
5. How does the multidisciplinary team benefit patients and staff?
6. What about the nature of 22q makes a team approach beneficial?
7. What are the possible disadvantages to this style of team approach?
8. What research is being done at the clinic and how is it being implemented into treatment plans?
9. What are the ideas of the coordinators moving forward to help the clinic evolve?
10. What motivates the coordinators to help this group of individuals with 22q?

Included in this study is a report of the answers to the questions above as well as an extensive analysis of the answers provided. The purpose of this study is to increase awareness of 22q11.2 Deletion Syndrome as the research and treatment of this condition is a growing need, and to determine the possible advantages and disadvantages of the team approach used at Nationwide Children’s Hospital 22q clinic.

Literature Review

According to Genetic and Rare Diseases Information Center (GARD), 22q11.2 (22q) Deletion Syndrome affects 1 in 4,000 to 1 in 6,395 individuals and can affect several different body systems while varying greatly in severity among individuals with the condition (22q11.2 Deletion Syndrome, n.d.). Some of the typical clinical manifestations of 22q include congenital heart disease, palatal abnormalities (velopharyngeal incompetence, submucosal cleft palate, bifid uvula, and cleft palate), immune deficiency, characteristic facial features, learning difficulties, hearing loss can (sensorineural and/or conductive), laryngotracheoesophageal, gastrointestinal, ophthalmologic, central nervous system, skeletal, and genitourinary anomalies also occur. Psychiatric illness and autoimmune disorders are more common in individuals with this condition (McDonald-McGinn, D. M., Hain, H. S., Emanuel, B. S., & Zackai, E. H., 2020). Due to the wide range of clinical manifestations and the varying severities among individuals with 22q even in the same families, a multidisciplinary approach is necessary to the treatment of 22q.

Individuals with 22q may receive treatment for their conditions associated with the chromosomal disorder, however, rarely do medical professionals work together in the same location as an interdisciplinary team. This interdisciplinary approach is beneficial because it gives medical professionals with several different specializations the opportunity to hone their focus on the same condition and communicate with each other to learn more about their patients' unique needs and how to treat them best.

No other studies were found that focused specifically on the interdisciplinary care of individuals with 22q the way that this project does. However, there was research conducted and published in 2019 that was similar because it was collecting qualitative data about the perceived benefits and challenges of interdisciplinary ward rounds. Walten, Hogden, Long, Johnson, and

Greenfield, D (2019) found that there were 3 main categories of benefits: being on the same page, focusing on patients, and holistic care planning; there were also 3 main categories of challenges: time, workforce and team coordination, and care planning (Walten, Hogden, Long, Johnson, & Greenfield, D, 2019).

The benefits and challenges found in the qualitative research of 2019 were categorized into major themes, but the data was collected by survey and there were several responses. In the benefits category of being on the same page, all of the answers were centered around effective communication and efficient workflow, including direct communication between team members, developing a more cohesive healthcare team, medical officers being more accessible to other clinicians, and improved teamwork (Walten, Hogden, Long, Johnson, & Greenfield, D, 2019). The results of this study show that teamwork and effective communication of the team is very important to delivering the highest level of care to the patients and offering specialized care in a way that freestanding clinics practicing one discipline cannot always do (Walten, Hogden, Long, Johnson, & Greenfield, D, 2019).

In the category of focusing on patients, all of the responses were related to patient satisfaction and access to information for the patients which the experts felt enabled patients and families to be more informed of their care, created individualized care, and allowed patients to gain confidence when they saw the team working together (Walten, Hogden, Long, Johnson, & Greenfield, D, 2019). This patient-centric approach is vital to providing patients with the highest level of care and creating rapport with the patients (Walten, Hogden, Long, Johnson, & Greenfield, D, 2019).

The final category of benefits was holistic care planning and the responses in that category were focused on patient flow, care planning clarity, and shared contribution to care

planning in regard to all plans that are currently relevant, discharge planning, and focusing on interdisciplinary information rather than strictly medical information (Walten, Hogden, Long, Johnson, & Greenfield, D, 2019). The responses recorded in this study show that an interdisciplinary approach is crucial when planning treatment and determining prognosis of the patient so that all factors can be considered (Walten, Hogden, Long, Johnson, & Greenfield, D, 2019).

The challenges described by the participants of this 2019 study were also categorized into 3 major themes. The primary challenge indicated by the participants in regards to working on an interdisciplinary team was the factor of time required to balance working clinically and caring for the patients' needs with multiple clinicians. Also involved with time requirements is case conferences and the journey board process that their team has in place. (Walten, Hogden, Long, Johnson, & Greenfield, D, 2019). The time required is a challenge that shouldn't be ignored due to the value of the time of so many clinicians focusing on the same patients. The second category of challenges was the workforce and the team coordination of different health professional team structures as well as perception of respect which manifested itself in difficulty selecting times to meet, team structures not being uniform, and a power imbalance between disciplines (Walten, Hogden, Long, Johnson, & Greenfield, D, 2019). These workforce related challenges pose an important concept because in order for interdisciplinary teams to function effectively, the team must be able to operate as a cohesive unit. A successful interdisciplinary approach involves leadership, communication, and teamwork to allow all disciplines to work collaboratively with common purpose so that they can effectively set goals and make decisions to treat patients with the highest level of care and share resources while delegating responsibility (An interdisciplinary approach to caring, n.d.). The third category of challenges determined was care planning when it

comes to patient and environmental factors because of the setting of the team and the way that care routine was disrupted; the participants also felt that the amount of professionals on the team was uncomfortable for patients due to having too many people around the bed space and the feeling that of competing priorities when caring for patients (Walten, Hogden, Long, Johnson, & Greenfield, D, 2019). These responses highlight that it is necessary to evaluate the challenges associated with the staff of medical professionals who will be working together to ensure that the energy and attitudes of the team are in alignment so that everyone can continue to work cohesively and productively.

There was also a study done by Habel, Herriot, Kumararatne, Allgrove, Baker, Baxendale, Bu'Lock, Firth, Gennery, Holland, Illingworth, Mercer, Pannebakker, Parry, Roberts, and Tsai-Goodman in 2014 to determine the amount of care needed to treat patients with 22q in 2014. The study used evidence-based practice guidelines and protocols to assess the needs of individuals with 22q and those needs were assessed by both age and body systems affected. The researchers concluded that there was a wide variety of needs that varied from patient to patient and that holistic care by a multidisciplinary team was the best approach for determining needs and detecting onset of conditions when possible (Habel, Herriot, Kumararatne, Allgrove, Baker, Baxendale, Bu'Lock, Firth, Gennery, Holland, Illingworth, Mercer, Pannebakker, Parry, Roberts, & Tsai-Goodman, 2014, para. 5). The study also found the needs of patients with 22q to require several different types of medical professionals due to the different categories of needs present in most patients. "The major conditions occurring in approximately 70 % or more are congenital heart disease, immune deficiency, palate defects affecting feeding and speech, and learning difficulties. Those found in 25–50 % include feeding disorders, early growth faltering, gut dysmotility, psychiatric, behavioural and neurological conditions, structural (renal, skeletal,

brain, gastrointestinal, eye and dental) abnormalities, hearing impairment, hypocalcaemia, haematological and autoimmune disorders,” (Habel, Herriot, Kumararatne, Allgrove, Baker, Baxendale, Bu'Lock, Firth, Gennery, Holland, Illingworth, Mercer, Pannebakker, Parry, Roberts, & Tsai-Goodman, 2014).

Due to the wide range of conditions requiring treatment present in patients with 22q, it can be concluded that an interdisciplinary approach is the most effective way to treat patients with this chromosomal deletion and the related conditions caused by it. Despite the challenges and extra effort required by the team to maintain an interdisciplinary treatment model, it is worth the benefits for the patients with 22q who are seeking expertise to treat an assortment of different symptoms and conditions related to 22q. These assorted symptoms and conditions are related to differences in physical conditions pertaining to several different body systems and the psychological conditions as well such as mental health and behavioral challenges associated with the chromosomal deletion.

The purpose of this study was to develop a baseline understanding of the daily operations of the 22q center at Nationwide Children's Hospital and to analyze the team approach treatment model used and its impact on the individual jobs of professionals within the clinic. Additionally, this study was conducted to connect current data to the findings of everyday clinical practice to suggest the best method of treating patients with 22q and their varying symptoms and severities.

Methodology

The purpose of this research was to observe the responses to a questionnaire of two experts in the field of developmental disabilities, with a focus on 22q11.2 Deletion Syndrome, and analyze their responses to take away possible advantages and disadvantages of the interdisciplinary team approach used at Nationwide Children's Hospital 22q Center.

The first step was to reach out to the Craniofacial clinic at Nationwide Children's hospital in Columbus, Ohio to describe the desired study and obtain written informed consent (attached in Appendix A). Then, a proposal was submitted and approved by The University of Akron's Institutional Research Board. Following the approval of the project proposal, it was then sent to the experts of the 22q clinic who were being surveyed as well as a general list of themes that represented the questions that would be asked on the questionnaire. The questionnaire was then created to address demographic information that the experts wished to share about their own career histories as well as clinic related questions including the amount of patients seen, the types of professionals on the care team, the impact it has on the job of the directors, and the perceived advantages and disadvantages to the approach used, as well as the professional opinions regarding clinic operations.

The goals of the questions presented were to develop a baseline understanding of the daily operations of the 22q center at Nationwide Children's Hospital and to analyze the team approach treatment model used and its impact on the individual jobs of professionals within the clinic. These goals were executed by asking each expert to describe their perspective of daily operations of the 22q center, list the professionals who make up the team in the clinic, describe what it is about 22q that makes a team approach beneficial, and list the possible advantages and disadvantages of the team approach used. Both experts have spent approximately 10 years

working for Nationwide Children's Hospital but have been in the field for even longer than that

The questionnaire was available to the experts from September 24, 2020 to November 1, 2020. The questionnaire was 12 questions and was estimated to take around 30 minutes to complete. Once the questionnaire was completed by both experts, the responses were then read through and analyzed by the researcher and the project sponsor for patterns and details that could be reported.

Findings

Two experts in the field of 22q11.2 Deletion Syndrome research and treatment participated in the online questionnaire. The knowledge and experience of the professionals interviewed is highly valuable to the field of speech language pathology, craniofacial biology, plastic surgery, and many other fields due to their experience and specialization. The questionnaire successfully collected qualitative data to be reported so that related fields could understand the treatment model used at Nationwide Children's 22q center.

The first question included quantitative information about the professionals being surveyed, their job titles, how long they have worked in the field, how long they have worked at the clinic, and what they do at the clinic on a day-to-day basis. It was up to the discretion of the professionals being surveyed how much information they wanted to include in their response and all information has been removed apart from their daily tasks at the clinic in order to remove personal information such as titles.

Question 1: Please provide some information about yourself. Consider including your job title, how long you have been involved in the field, how long you have worked at the clinic, and what you do day-to-day at the clinic.

Expert 1: "...I see patients in the clinic for diagnostic speech evaluations and imaging about 2-3 days per week, supervise a speech fellow to train them in speech evaluation/therapy approaches for children with craniofacial anomalies and 22q, and conduct research and administrative duties the remaining days of the week."

Expert 2: "...my primary clinical role in the Center is the evaluation and management of velopharyngeal dysfunction."

The second and third questions focused on attaining a clear understanding of the amount

of patients seen at the 22q center in Nationwide Children's Hospital in Columbus, Ohio. It is important to see how many patients are seen in the clinic to understand the dynamic of the team approach that the treatment model uses when treating patients.

Question 2: Approximately how many patients are seen in an average year?

Expert 1: "200"

Expert 2: "200"

Question 3: Approximately how many patients are seen per day under normal circumstances?

Expert 1: "About 4-5 22q patients per clinic, 4 clinics per month"

Expert 2: "5"

The fourth question focused on the style of appointment that patients actually receive when visiting the 22q center. It is important to understand how an appointment is scheduled for each patient considering the needs of each patient and their families can be so vastly different from patient to patient.

Question 4: Please describe what a regular appointment looks like.

Expert 1: "Full day of visits with multiple team members (noted in next question) lasting from 3-6 hours depending on the patient's needs; some patients also get labs drawn or other imaging studies done as part of their visit; each visit plan is customized to each patient's needs but they still all see the same "core" of professionals and then add other specialists to their visit as needed based on their medical/developmental needs. Each visit is preplanned to ensure that the right specialists see each child - not a cookie cutter approach but rather truly individualized care."

Expert 2: "Appointments are customized to each patient's needs. Patients will see multiple providers from different specialties depending upon their clinical needs. Many of these appointments are grouped on a single day; however, some patients may see other providers on

adjacent days.”

The fifth question focused on determining the types of care providers that make up the team at the 22q center at Nationwide Children’s Hospital in Columbus, Ohio. It is the team approach and the treatment model used by such a large team that makes the clinic unique, so it was crucial to develop a baseline understanding of exactly the spread of disciplines that make up the interdisciplinary team at the clinic.

Question 5: Can you describe the team of professionals at the clinic? What types of professionals are on your team?

Expert 1: “Core specialties include - Geneticist, genetic counselor, pediatric nurse practitioner, speech-language pathologist, plastic surgeon, ENT, orthodontist, social worker, audiologist, psychologist or neuropsychologist. Additional specialists seen based on each patient's clinical needs include cardiologist, pulmonologist, feeding specialist, sleep medicine specialist, endocrinologist, immunologist, psychiatrist, hematologist, developmental pediatrician, neurologist, and others as indicated”

Expert 2 “•Cardiology

•Dentistry

•Developmental Pediatrics

•Endocrinology

•Gastroenterology

•Genetics

•Hematology

•Immunology

•Neuropsychology

- Nursing
- Orthodontics
- Otolaryngology (ENT)
- Plastic Surgery
- Psychiatry
- Psychology
- Rheumatology
- Speech-Language Pathology
- Social Work”

The sixth question gained professional insight into the way that the team operates and how the directors are affected by having so many professionals with so many different areas of expertise on one team. The ability to operate smoothly and cohesively is very important to any treatment model, so getting the opinion of the experts as far as the team’s influence on their personal jobs was part of the foundation of this study. The dynamic of the team couldn’t be assessed without seeing the influence that the large team has on individual members’ workloads and attitudes towards their work.

Question 6: How does the team approach at the 22q center influence how you do your job?

Expert 1: “I greatly enjoy working in a team environment where all team member's perspectives are valued and care plans are coordinated and integrated for each patient. Communication amongst professionals is strong, and is key to the best care for the child. The 22q center team members are responsive and committed to their roles on the team.”

Expert 2: “The team approach requires that all clinical decision making is carried out with the input of professionals from other disciplines and requires that each provider gather information

from and share information with the other providers.”

The seventh question, again, to gain the insight of the experts due to their expertise in the field. The way that the patients and staff are benefited by the model used at the 22q center is crucial to evaluating whether or not said model should be used by other clinics to treat 22q or to treat other developmental disabilities. The opinions of the experts on the effect of the interdisciplinary approach to treatment used at the clinic are crucial because it offers perspective to how the team operates as a whole.

Question 7: How does having a multidisciplinary team benefit patients and staff?

Expert 1: “We use an interdisciplinary team approach for the 22q center/clinic, which is the same model we follow for all other craniofacial, cleft lip/palate, and VPD patient populations. This is the best care model for comprehensive, accurate, efficient, patient centered care and helps facilitate the best outcomes for each child and family. Our team members also thrive with this model as there is high mutual respect and strong communication amongst the group.”

Expert 2: “Children with 22q11.2 deletion syndrome (22q) and related disorders, such as 22q11.2 duplication syndrome, have unique medical, developmental, and behavioral health needs that must be addressed by a variety of specialists beyond the traditional medical care model. Each person is affected by different features of the syndrome and needs to have personalized care. Because each child is unique and because this diagnosis can affect so many body systems, care is best provided by a team of specialists who are familiar with 22q.

Coordinated care provided by an interdisciplinary center can facilitate ease of scheduling appointments and enhance provider communication, increase support and access to resources for families, enhance standardization of care, as well as improve outcomes and family satisfaction. A team approach to management of 22q aims to bring together specialists with experience and

expertise at a single medical center to treat the whole child, from birth to adulthood. In order to provide truly coordinated high quality care, the center should have a centralized intake and care coordination process with dedicated staff to help families navigate their child's care journey and follow up needs. In some settings, this may be a nurse, genetic counselor, or other designated healthcare professional. Team care can offer the following benefits:

- Expert coordinated care across specialties where patients are seen by multiple specialists on the same day or within the same week, and the providers meet face-to-face to discuss care coordination and follow-up needs
- Syndrome-specific care including guidance on routine bloodwork, screening exams and medical/developmental monitoring for children and adults
- Coordination of referrals
- Communication with the patient's primary care doctor follow-up recommendations
- Education and coordination of care with local primary care providers, therapists, school personnel, and other local programs about the unique needs of persons with 22q
- Easier appointment scheduling for families wanting to see numerous specialists in one trip and assistance with insurance needs
- Assistance with transition care for individuals and their families as they approach adulthood – to identify appropriate medical and mental health specialists, primary care providers, insurance/financial assistance, and psychosocial resources
- Linking families to educational events, social activities and family support programs

The 22q Center at NCH provides all of the above benefits and includes 30 team members from over 20 different specialties dedicated to caring for individuals with 22q. The NCH 22q Center works with each family to individualize a visit plan based on each patient's needs and concerns.

Following a team visit, we work with families to guide them on the treatment plan with the overall goal of ensuring best outcomes for all children with 22q.”

While the seventh question focused on the benefit of the team approach to the actual patients and staff, the eighth question focused directly on the varying phenotypes within 22q and the nature of the condition that requires a team of so many different skilled professionals. Not all conditions require so many fields of focus to treat individual patients, so the nature of 22q11.2 Deletion Syndrome needed to be questioned to gather the qualitative data that the experts could offer from their experience and understanding of the condition.

Question 8: What about the nature of 22q makes a team approach to treatment beneficial?

Expert 1: “Team care prioritizes the needs of the patient, true coordination of care, and strong communication amongst team members. Since 22q is a multisystem, lifelong condition, with changing needs over time, the team model allows for us to be dynamic as we manage each patient's needs.”

Expert 2: “There is significant phenotypic variability amongst patients with 22q, but nearly all present with abnormalities in multiple developmental and physical systems. In many cases, abnormalities in one system (or the treatment thereof) significantly impact those of another. As a result, a multidisciplinary team approach with excellent interdisciplinary communication is essential to achieving best outcomes.”

The ninth question focused on attaining any disadvantages of the treatment model used at the 22q center. There are no perfect treatment models, so it is pertinent to also view the potential negatives to having such a large staff that specializes in so many different fields all treating patients with the same condition.

Question 9: What are the possible disadvantages to this style of team approach?

Expert 1: “It takes time and resources from the institution to ensure team members can dedicate time to see 22q patients and to have team members specifically dedicated to care coordination and follow up such as our nursing team, nurse practitioner, and social workers who help families execute their care plans.”

Expert 2: “The team approach requires the participation of a large number of knowledgeable and experienced providers within a single institution. This may not be possible in all centers. The team approach requires strong and consistent communication as well as the commitment of a significant amount of time, coordination, and resources.”

The tenth and eleventh questions transitioned into the evolution of the treatment model, the future of the clinic, and the implementation of research done at the clinic. Constant evaluation and implementation of new findings is important to a working treatment model and the experts expressed clear intent of improvement over time. The tenth question specifically addresses research being conducted currently at Nationwide Children’s in Columbus, Ohio.

Question 10: What research is being conducted at the clinic and how is it being implemented into treatment?

Expert 1: “Research on speech development and outcomes in children with 22q, research on variation genetic variations and how they impact the clinical presentation of patients with 22q, research on how team care improves clinical outcomes and adherence to care guidelines for patients with 22q.”

Expert 2: “Research is being carried out in a number of disciplines within the 22q Center. Each of these is aimed at establishing best practices and achieving best outcomes.”

The eleventh question is more related to the experts’ professional opinions with regard to the future of the clinic. Their expertise is valuable for analyzing the current methods of operation

and transitioning to new innovations in treatment and research.

Question 11: What are your ideas moving forward to help the clinic evolve?

Expert 1: “Continue to grow to help more families from all over the US and world; continue to collaborate with other centers on research initiatives; develop more resources and educational materials for families.”

Expert 2: “We continue to do more to develop and provide educational materials to professionals and families. Efforts continue to improve ease of scheduling and care navigation, particularly for out-of-state patients.”

The twelfth and final question strays from the expertise of the experts and taps into the motivation behind the implementation of such an involved treatment model. As the experts expressed, the benefits of such a large-scale interdisciplinary approach are numerous but there are definitely challenges associated with such a task as coordinating a team so large and a clinic responsible for the treatment of so many body systems and providing support in so many areas for families of patients with 22q.

Question 12: What motivates you to help this group of individuals who have 22q?

Expert 1: “22q is a fascinating medical condition in which most patients share a few common features, yet also have unique profiles and presentations which also illustrates the variability of this syndrome; there is still so much we do not know or understand about 22q and the need for research is still great; the patients and families are so resilient and it is rewarding to see so many of the patients do well with their clinical and personal/quality of life outcomes over time.”

Expert 2: “They are great kids that need a comprehensive team approach to their care in order to reach their full potential.”

Discussion

Literature review has shown that studies have been conducted on the needs of patients with 22q and there is research with qualitative data about interdisciplinary teams treating other patients. However, there has not been research found evaluating a specific care team of a 22q center, like that of Nationwide Children's, to collect qualitative data on the treatment model used to treat patients with this condition. Therefore, this study is valuable to several medical fields that may treat 22q11.2 Deletion Syndrome and it is also relevant as it raises awareness of 22q to students and medical professionals who may be able to contribute to the treatment of individuals with 22q.

According to the 22q Family Foundation, there are 11 nonprofit organizations in the world that seek to benefit individuals with 22q and their families (22q Organizations, n.d.). Research studies that raise awareness and assess the treatment of 22q patients can help to contribute qualitative information to encourage more support for individuals with 22q and their families. The 22q center at Nationwide Children's Hospital in Columbus, Ohio focuses on assisting patients with 22q and their families with the highest level of care in a facility that staffs professionals from several different disciplines who can help the patients in many different areas.

Studies have been done to assess the needs of patients with 22q and it was determined that the most common needs are related to congenital heart disease, immune deficiency, palate defects affecting feeding and speech, learning difficulties, feeding disorders, early growth faltering, gut dysmotility, psychiatric, behavioral and neurological conditions, structural (renal, skeletal, brain, gastrointestinal, eye and dental) abnormalities, hearing impairment, hypocalcaemia, haematological and autoimmune disorders (Habel, Herriot, Kumararatne, Allgrove, Baker, Baxendale, Bu'Lock, Firth, Gennery, Holland, Illingworth, Mercer,

Pannebakker, Parry, Roberts, & Tsai-Goodman, 2014). Studies have also been done to collect qualitative data on the dynamic of interdisciplinary healthcare teams like the 2019 study of Walten, Hogden, Long, Johnson, and Greenfield.

Collaborative holistic care is beneficial to patients because it offers higher level care due to the delegated specializations of each team member in their respective disciplines. An interdisciplinary care team has the ability to offer a treatment model to patients that is a more convenient access to the majority of medical health professionals related to the focused condition of the patient and the symptoms of that condition as well. Nationwide Children's Hospital in Columbus, Ohio is one of 23 clinics in the United States, according to the 22q Family Foundation website (List of 22q Clinics, n.d.). The treatment model used at the 22q center in Nationwide Children's Hospital is relevant because 22q centers that specialize specifically in the care of patients with 22q in an interdisciplinary holistic care setting is uncommon.

The two experts of this study from Nationwide Children's 22q center indicated that they see approximately 200 patients per year (question 2) and their staff consists of 30 team members from over 20 different specialties (question 7). The experts also indicated that appointments typically last 3-6 hours depending on the unique needs of the client and that many patients will see every specialist on the same day (question 4). One expert actually described the treatment model as being the opposite of a cookie-cutter approach, but rather true individualized care (question 4). When asked how the team approach affects how they do their jobs, both experts referred to communication across specialists when making decisions and treating patients (question 6). This is important because the previous study mentioned from 2019 by Walten, Hogden, Long, Johnson, and Greenfield mentioned that communication and the social dynamic of the team was one of the most inhibiting challenges due to the importance of this characteristic

of the team and the way that it was missing on the team studied due to lack of respect and communication between disciplines. Without cooperative and effective communication, it is difficult to make a treatment plan, effectively implement research, or communicate informatively with patients. One expert from Nationwide Children's 22q center even indicated that staff also benefited from this model, as well as patients, due to the "high mutual respect and strong communication amongst the group," (question 7).

When asked about the disadvantages of the team approach used at Nationwide Children's 22q center, both experts indicated that time and resources were large factors that kept other smaller clinics from being able to provide the same treatment model, as well as the coordination required to get so many skilled experts in their field to join the same institution (question 9). This is an important concept because interdisciplinary teams cannot always be implemented to every patient care facility due to the amount of resources required to create collaboration among so many healthcare providers of different specialties.

However, when it is possible to have so many specialists of different disciplines in the same institution, research like that of the 22q center in Nationwide Children's is very valuable to the field as well as to treatment of patients. One expert indicated that research was currently being done on possible speech development and outcomes for patients with 22q, genetic variations and how they can be observed in clinical manifestations, and how team care improves clinical outcomes when guidelines are followed (question 10). This research is so valuable because it is being done in a place where every staff member specializes in 22q and is the expert of their own discipline in regards to patients with 22q. The 22q center at Nationwide Children's shows that they continually use the advantage of having so many different professionals to further the research of 22q.

The final two questions of the survey were focused on the professional opinions of the experts. Question 11 addressed the ideas of the experts to evolve and grow the clinic and both experts mentioned reaching new patients. One expert indicated that they would like to see scheduling and planning made easier for out-of-state patients, while the other mentioned that they would like to see patients from all over the United States and from other countries to be able to assist and educate more families.

The final question addressed the purpose or motivation of each of the experts in regards to what motivates them to bring their expertise specifically to patients with 22q. One expert described their understanding of 22q and the clinical manifestations possible and their understanding of interdisciplinary teamwork and the benefits that it could bring to these patients with such varying conditions. The other expert described the way that each individual has a unique profile and requires unique care. They also described a feeling of seeing an improving prognosis and quality of life as a patient receives treatment over time for both them and their families. These questions are important to evaluate because it is crucial that the experts tackling such cardinal tasks in this field have strong reasons as to why they continue to do their jobs to the best of their abilities. It is also notable when the care providers are also connected emotionally to the improving states of their patients and are pursuing research to help future families as well.

Conclusions

The qualitative data collected through this study shows that an interdisciplinary team approach to treating 22q11.2 Deletion Syndrome has the potential to offer a significant amount of benefits that cater to the unique needs of individuals with this condition, as the professionals at Nationwide Children's in Columbus, Ohio seek to do. Although this treatment model may not be possible for every clinic due to the amount of time, resources, and staff needed to operate with such a large team (see question 9), it greatly benefits the patients seeking care to have all of their care providers working together and specializing in the condition of the patients.

The team dynamic of the 22q center at Nationwide Children's Hospital in Columbus, Ohio is able to benefit 200 families per year (per question 3), but the research they carry out will benefit so many more in the future. The interdisciplinary team approach allows patients and their families to have access to a team that communicates cohesively and effectively to offer the best care possible. Additionally, the team of professionals at the 22q center is exposed to varying phenotypic characteristics of 22q which gives them a perspective that single care providers in other freestanding clinics may not have the same expertise in. Making a shift towards more interdisciplinary care could benefit patients of several different conditions all around the world.

This study adds value to several fields because not many studies have been done to collect qualitative data from experts in the field who are actively seeking new innovative methods of treatment, especially in specialized clinics like the 22q center at Nationwide Children's. It is important to bring attention to the things that clinics like this 22q center are doing because they are paving the way for future clinics that will specialize in 22q and other developmental disabilities.

The objective of this research project was to raise awareness of 22q11.2 Deletion

Syndrome so that more students will choose to observe other 22q clinics in their regions and potentially become motivated to do research and/or work in one. Another objective was that professors and medical professionals would be impacted by the research collected and want to learn more about 22q so that more minds can be set on possible treatment options and care for the individuals living every day with 22q11.2 Deletion Syndrome and their friends and family members who are also impacted by the condition.

The work being done at the 22q center in Nationwide Children's Hospital of Columbus, Ohio is very important to the development of treatment models and the building of interdisciplinary teams treating unique conditions like 22q. The data collected suggests the potential benefits and the challenges to this approach, but offers a way to continue treating patients with the most expertise possible. By observing this qualitative research, further research can be done on the effectiveness of interdisciplinary approaches and how to implement them in more facilities around the world to treat more patients more effectively with unique and varying conditions.

Some limitations of this study are that only 2 professional opinions were included in the findings and only qualitative data was collected. Future research studies could examine the qualitative data provided by directors of several clinics or the other experts of specialized fields within the clinics. Additionally, future studies could examine quantitative data about the retention of patients and the growth of patients and families over time. Quantitative data could show the direct effect that the treatment model used at Nationwide Children's Hospital and similar clinics has on patients and families treated by this clinic. Further research could also be done to collect qualitative data from patients and families about how practical and beneficial treatment at specialized clinics is for tasks of daily living. In addition to qualitative data collected

from families, quantitative data could also be collected to show financial impact on families and overall medical need of patients with 22q. There is much research to be done on 22q11.2 Deletion Syndrome, the symptomatology of the condition, the effects on tasks of daily living, and the clinics that specialize in treating the condition. This condition affects many patients worldwide and there is huge potential for research and specialization with this condition.

Acknowledgements

I would like to take a moment to acknowledge those who helped make this project happen. Beginning with my project advisor, Dr. Scott Palasik, who encouraged me to pursue research that I was passionate about and taught me how to conduct research like this, I cannot thank you enough for teaching me to fall in love with research and learning. Dr. Palasik has been an amazing professor and mentor who has inspired me all throughout my time at the University of Akron because of his passion and dedication to the work that he does. I am among many other students who have been personally affected by Dr. Palasik and he has helped me so much to solidify my vision for this project and for my future and shown me the steps to take to make that a reality.

I would also like to thank my readers, Dr. James Steiger and Dr. Todd Houston, for agreeing to assist me with a project that means so much to me. I feel so fortunate to have had them both as professors and their willingness to refine my project and guide me through the process is very appreciated. Having such an experienced and talented staff of professors agree to mentor and guide me through this project has been so valuable to my developing understanding of research conduction and I feel very blessed that they were willing to offer so much time and effort to something so important to me.

Additionally, I would like to thank Theresa Duff for her mentorship and friendship throughout the entire project from start to finish. Without her I would've never had the confidence to pursue this project the way that I did or know where to begin with structuring my project as a whole. There aren't words to express my appreciation for her being there for me through every step of the process during this research.

I am thankful for the University of Akron Institutional Review Board for approving my

proposal and giving me the opportunity to pursue this project. Without their training and procedures, this experience would not have been as beneficial to me as it was. I learned so much about research through the conduction of this project that I never would've learned without the standards that they had set.

Furthermore, I would also like to acknowledge the Williams Honors College and my honors advisor for my last semester, Ms. Kimberly Roy. I am so grateful that the Honors College has built this project into the curriculum because it has been such an opportunity for learning and growth for me. Without this project, I never would have considered pursuing a PhD or potentially working in a research facility after graduation. And to Ms. Roy, I am thankful for her diligence in the area of academic advising so that I could receive credit for this project that so many people have spent so much time on.

And finally I would like to acknowledge Nationwide Children's Hospitals's Craniofacial clinic and the experts of this study who sacrificed so much of their valuable time to make this research possible. Over the course of several months, I was able to communicate with the experts despite their busy schedules and the complications with communication due to COVID-19. But they never hesitated to offer their expertise for the sake of growing their field and spreading awareness of 22q11.2 Deletion Syndrome and clinics like theirs across the country. I am so grateful that they choose to pour themselves into their profession everyday to benefit families all over the world and they were able to make time for this study as well. Without them, this project would not have been possible.

References

An interdisciplinary approach to caring. (n.d.). Victoria State Government.

<https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/older-people/resources/improving-access/ia-interdisciplinary>

About. (n.d.). Nationwide Children's. <https://www.nationwidechildrens.org/specialties/22q-center>

Habel, A., Herriot, R., Kumararatne, D., Allgrove, J., Baker, K., Baxendale, H., Bu'Lock, F., Firth, H., Gennery, A., Holland, A., Illingworth, C., Mercer, N., Pannebakker, M., Parry, A., Roberts, A., & Tsai-Goodman, B. (2014, January 3). *Towards a safety net for management of 22q11.2 deletion syndrome: guidelines for our times.* <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4032642/>

Kobrynski, L. J., & Sullivan, K. E. (2007, October 18). *Velocardiofacial syndrome, DiGeorge syndrome: the chromosome 22q11.2 deletion syndromes.* The Lancet. <https://www.sciencedirect.com/science/article/pii/S0140673607616018>

List of 22q clinics. (n.d.). 22q Family Foundation. <https://22qfamilyfoundation.org/living-with-22q/22q-clinics?page=4>

McDonald-McGinn, D. M., Hain, H. S., Emanuel, B. S., & Zackai, E. H. (2020, February 27). *22q11.2 Deletion Syndrome.* <https://www.ncbi.nlm.nih.gov/books/NBK1523/>

Walten, V., Hogden, A., Long, J. C., Johnson, J. K., & Greenfield, D. (2019, December 11). *How do interprofessional healthcare teams perceive the benefits and challenges of interdisciplinary ward rounds.* <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6912018/>

22q organizations. (n.d.). 22q Family Foundations. <https://22qfamilyfoundation.org/living-with-22q/22q-resources/22q-organizations>

22q11.2 deletion syndrome. (n.d.). Genetic and Rare Diseases Information Center. Retrieved

December 23, 2020, from <https://rarediseases.info.nih.gov/diseases/10299/22q112-deletion-syndrome>

22q11.2 Deletion Syndrome. (n.d.). Medline Plus. Retrieved December 22, 2020, from <http://medlineplus.gov/genetics/condition/22q112-deletion-syndrome/#synonyms>

Appendix

Appendix A



School of Speech-Language Pathology and Audiology

Qualitative Analysis of an Interdisciplinary Team's Treatment of Velocardiofacial Syndrome

INFORMED CONSENT

Introduction: You are being invited to participate in a survey questionnaire pertaining to the collaborative team approach used at Nationwide Children's Hospital to treat clients with Velocardiofacial Syndrome. The study will be conducted by undergraduate student, Marissa Meredith, under the advising of Dr. Scott Palasik during this fall 2020 semester and spring 2021 semester in the Department of Speech-Language Pathology and Audiology at The University of Akron. The goal of this study is to examine the unique team approach utilized at the 22q Center in order to discover possible advantages and disadvantages, to examine and define each professional's role as a member of the care team, and to determine how the team collaborates as a unit.

Participants: The co-directors of the 22q Center at Nationwide Children's Hospital

Exclusionary Criteria: Those who are not the co-directors will not be able to participate in this study.

Procedures: This study will involve filling out a survey questionnaire that asks questions about one's professional demographics, the team approach utilized at the 22q Center, and the individual role each professional contributes to the care team. **If you choose to participate, please print and sign this form below, scan or take a photo of the document, and email it to mmm376@zips.uakron.edu. You will then receive an email with the link to a google form that will include the qualitative survey. Once you complete the survey, click "submit" and it will be submitted to Marissa Meredith and Scott Palasik for review and data collection.**

The questionnaire should take no more than 30 minutes.

Contact: For any questions or concerns regarding this survey questionnaire, please e-mail Scott Palasik at: spalasik@uakron.edu or Marissa Meredith at: mmm376@zips.uakron.edu

Risks and Benefits: There are no anticipated risks to this study. You can benefit by adding to our research pertaining to the collaborative team approach to treating clients with Velocardiofacial Syndrome and increasing awareness of the condition within the professional and academic fields.

Payment / Costs: Participation in this study is voluntary; there will be no financial payment for participating.

Confidentiality: Your personal information will be kept confidential. Results will be reported and the name and location of the clinic will be reported, but your names will not be included in the report.



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Questions: If you have any more questions you can contact **Scott Palasik** at 330-972-8185 (spalasik@uakron.edu). This project has been reviewed and approved by The University of Akron Institutional Review Board. If you have any questions about your rights as a research participant, you may call the IRB at (330) 972-7666.

Consent: I understand that this study is being conducted for the purpose of undergraduate research at the University of Akron. Through this document the researcher has explained how the study will be completed, what I will have to do, and how long my participation is required. I am aware that my full participation in this study is voluntary. I am fully aware that my name will not be released or used in any manner. I am aware that no compensation will be provided for completing this questionnaire. By signing this form I consent my participation in the study and will fill out the questionnaire to the best of my ability.

Participant Signature (Consent to Participate)

Date

Research Survey - Google Forms

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Demographic information:

Please provide some information about yourself. Consider including your job title, how long you have been involved in the field, how long you have worked at the clinic, and what you do day-to-day at the clinic.

2 responses

Speech Scientist/Director of Velopharyngeal Dysfunction Program; Speech Language Pathologist for approximately 15 years; Associate Professor for OSU; Worked at NCH for approximately 10 years; I see patients in the clinic for diagnostic speech evaluations and imaging about 2-3 days per week, supervise a speech fellow to train them in speech evaluation/therapy approaches for children with craniofacial anomalies and 22q, and conduct research and administrative duties the remaining days of the week

I am the chief of the department of Plastic and Reconstructive Surgery (since 2010) and Co-Director of the 22q Center at NCH. As a plastic surgeon, my primary clinical role in the Center is the evaluation and management of velopharyngeal dysfunction.

Details about the 22q Center at Nationwide Children's:

Approximately how many patients are seen in an average year?

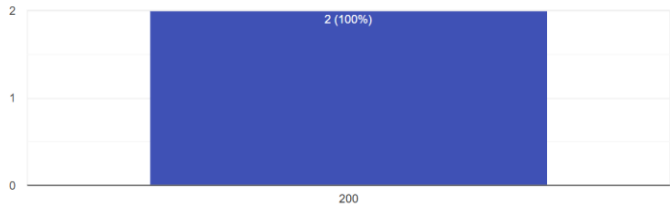
Research Survey - Google Forms

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Details about the 22q Center at Nationwide Children's:

Approximately how many patients are seen in an average year?

2 responses



2 (100%)

200

Approximately how many patients are seen per day under normal circumstances?

2 responses

About 4-5 22q patients per clinic, 4 clinics per month

5

Research Survey - Google Forms

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Please describe what a regular appointment looks like.

2 responses

Full day of visits with multiple team members (noted in next question) lasting from 3-6 hours depending on the patient's needs; some patients also get labs drawn or other imaging studies done as part of their visit; each visit plan is customized to each patient's needs but they still all see the same "core" of professionals and then add other specialists to their visit as needed based on their medical/developmental needs. Each visit is preplanned to ensure that the right specialists see each child - not a cookie cutter approach but rather truly individualized care.

Appointments are customized to each patient's needs. Patients will see multiple providers from different specialties depending upon their clinical needs. MANY of these appointments are grouped on a single day; however, some patients may see other providers on adjacent days.

Can you describe the team of professionals at the clinic? What types of professionals are on your team?

2 responses

Core specialties include - Geneticist, genetic counselor, pediatric nurse practitioner, speech-language pathologist, plastic surgeon, ENT, orthodontist, social worker, audiologist, psychologist or neuropsychologist. Additional specialists seen based on each patient's clinical needs include cardiologist, pulmonologist, feeding specialist, sleep medicine specialist, endocrinologist, immunologist, psychiatrist, hematologist, developmental pediatrician, neurologist, and others as indicated

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Can you describe the team of professionals at the clinic? What types of professionals are on your team?

2 responses

- Cardiology
- Dentistry
- Developmental Pediatrics
- Endocrinology
- Gastroenterology
- Genetics
- Hematology
- Immunology
- Neuropsychology
- Nursing
- Orthodontics
- Otolaryngology (ENT)
- Plastic Surgery
- Psychiatry
- Psychology
- Rheumatology
- Speech-Language Pathology
- Social Work

How does the team approach at the 22q center influence how you do your job?

2 responses

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How does the team approach at the 22q center influence how you do your job?

2 responses

I greatly enjoy working in a team environment where all team member's perspectives are valued and care plans are coordinated and integrated for each patient. Communication amongst professionals is strong, and is key to the best care for the child. The 22q center team members are responsive and committed to their roles on the team.

The team approach requires that all clinical decision making is carried out with the input of professionals from other disciplines and requires that each provider gather information from and share information with the other providers.

How does having a multidisciplinary team benefit patients and staff?

2 responses

We use an interdisciplinary team approach for the 22q center/clinic, which is the same model we follow for all other craniofacial, cleft lip/palate, and VPD patient populations. This is the best care model for comprehensive, accurate, efficient, patient centered care and helps facilitate the best outcomes for each child and family. Our team members also thrive with this model as there is high mutual respect and strong communication amongst the group.

Children with 22q11.2 deletion syndrome (22q) and related disorders, such as 22q11.2 duplication syndrome, have unique medical, developmental, and behavioral health needs that must be addressed by a variety of specialists beyond the traditional medical care model. Each person is affected by different features of the syndrome and needs to have personalized care. Because each child is unique and because

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How does having a multidisciplinary team benefit patients and staff?

2 responses

A team approach to management of 22q aims to bring together specialists with experience and expertise at a single medical center to treat the whole child, from birth to adulthood. In order to provide truly coordinated high quality care, the center should have a centralized intake and care coordination process with dedicated staff to help families navigate their child's care journey and follow up needs. In some settings, this may be a nurse, genetic counselor, or other designated healthcare professional. Team care can offer the following benefits:

- Expert coordinated care across specialties where patients are seen by multiple specialists on the same day or within the same week, and the providers meet face-to-face to discuss care coordination and follow-up needs
- Syndrome-specific care including guidance on routine bloodwork, screening exams and medical/developmental monitoring for children and adults
- Coordination of referrals
- Communication with the patient's primary care doctor follow-up recommendations
- Education and coordination of care with local primary care providers, therapists, school personnel, and other local programs about the unique needs of persons with 22q
- Easier appointment scheduling for families wanting to see numerous specialists in one trip and assistance with insurance needs
- Assistance with transition care for individuals and their families as they approach adulthood – to identify appropriate medical and mental health specialists, primary care providers, insurance/financial assistance

What about the nature of 22q makes a team approach to treatment beneficial?

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How does having a multidisciplinary team benefit patients and staff?

2 responses

day of within the same week, and the providers meet face-to-face to discuss care coordination and follow-up needs

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- Communication with the patient's primary care doctor follow-up recommendations
- Education and coordination of care with local primary care providers, therapists, school personnel, and other local programs about the unique needs of persons with 22q
- Easier appointment scheduling for families wanting to see numerous specialists in one trip and assistance with insurance needs
- Assistance with transition care for individuals and their families as they approach adulthood – to identify appropriate medical and mental health specialists, primary care providers, insurance/financial assistance, and psychosocial resources
- Linking families to educational events, social activities and family support programs

The 22q Center at NCH provides all of the above benefits and includes 30 team members from over 20 different specialties dedicated to caring for individuals with 22q. The NCH 22q Center works with each family to individualize a visit plan based on each patient's needs and concerns. Following a team visit, we work with families to guide them on the treatment plan with the overall goal of ensuring best outcomes for all children with 22q.

What about the nature of 22q makes a team approach to treatment beneficial?

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Research Survey - Google Forms

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What about the nature of 22q makes a team approach to treatment beneficial?

2 responses

Team care prioritizes the needs of the patient, true coordination of care, and strong communication amongst team members. Since 22q is a multisystem, lifelong condition, with changing needs over time, the team model allows for us to be dynamic as we manage each patients needs.

There is significant phenotypic variability amongst patients with 22q, but nearly all present with abnormalities in multiple developmental and physical systems. In many cases, abnormalities in one system (or the treatment thereof) significantly impact those of another. As a result, a multidisciplinary team approach with excellent interdisciplinary communication is essential to achieving best outcomes.

What are the possible disadvantages to this style of team approach?

2 responses

It takes time and resources from the institution to ensure team members can dedicate time to see 22q patients and to have team members specifically dedicated to care coordination and follow up such as our nursing team, nurse practitioner, and social workers who help families execute their care plans.

The team approach requires the participation of a large number of knowledgeable and experienced providers within a single institution. This may not be possible in all centers. The team approach requires strong and consistent communication as well as the commitment of a significant amount of time, coordination, and resources.

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Research Survey - Google Forms

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What research is being conducted at the clinic and how is it being implemented into treatment?
2 responses

Research on speech development and outcomes in children with 22q, research on variation genetic variations and how they impact the clinical presentation of patients with 22q, research on how team care improves clinical outcomes and adherence to care guidelines for patients with 22q

Research is being carries out in a number of discipline within the 22q Center. Each of these is aimed at establishing best practices and achieving best outcomes.

Professional opinions in regard to clinical operations:

What are your ideas moving forward to help the clinic evolve?
2 responses

Continue to grow to help more families from all over the US and world; continue to collaborate with other centers on research initiatives; develop more resources and educational materials for families

We continue to do more to develop and provide educational materials to professionals and families. Efforts continue to improve ease of scheduling and care navigation, particularly for out-of-state patients.

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Research Survey - Google Forms

docs.google.com/forms/d/1fGKiFp6CQlhpqag09Ho0ZjsfvIX25gn-oCDJBScrjU/edit#responses

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We continue to do more to develop and provide educational materials to professionals and families. Efforts continue to improve ease of scheduling and care navigation, particularly for out-of-state patients.

What motivates you to help this group of individuals who have 22q?
2 responses

22q is a fascinating medical condition in which most patients share a few common features, yet also have unique profiles and presentations which also illustrates the variability of this syndrome; there is still so much we do not know or understand about 22q and the need for research is still great; the patients and families are so resilient and it is rewarding to see so many of the patients do well with their clinical and personal/quality of life outcomes over time

The are great kids that need a comprehensive team approach to their care in order to reach their full potential.

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