Down Syndrome outreach during the COVID-19 pandemic – An interprofessional Zoom® WhatsApp® collaboration in Syria

Margaret H. Wolf MS, OTR/L, Kerry Haugh PT, DPT, Asma A. Taha PhD, CPNP-PC/AC, FAAN

PII: S0891-5245(22)00305-4
DOI: https://doi.org/10.1016/j.pedhc.2022.10.003
Reference: YMPH 2037

To appear in: Journal of Pediatric Health Care

Please cite this article as: Margaret H. Wolf MS, OTR/L, Kerry Haugh PT, DPT, Asma A. Taha PhD, CPNP-PC/AC, FAAN, Down Syndrome outreach during the COVID-19 pandemic – An interprofessional Zoom® WhatsApp® collaboration in Syria, Journal of Pediatric Health Care (2022), doi: https://doi.org/10.1016/j.pedhc.2022.10.003

This is a PDF file of an article that has undergone enhancements after acceptance, such as the addition of a cover page and metadata, and formatting for readability, but it is not yet the definitive version of record. This version will undergo additional copyediting, typesetting and review before it is published in its final form, but we are providing this version to give early visibility of the article. Please note that, during the production process, errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Copyright © 2022 Published by Elsevier Inc. on behalf of National Association of Pediatric Nurse Practitioners.
Running Head: COVID 19 GLOBAL IMPACT ON CHILDREN WITH DOWN SYNDROME
Down Syndrome outreach during the COVID-19 pandemic – An interprofessional Zoom®
WhatsApp® collaboration in Syria

Authors
Margaret H. Wolf, MS, OTR/L¹; Kerry Haugh, PT, DPT¹; Asma A. Taha, PhD, CPNP-PC/AC, FAAN¹,²

¹ CDRC, Oregon Health & Science University, 3181 SW Sam Jackson Park Rd, Portland, OR 97239, USA
² School of Nursing, Oregon Health & Science University, 3455 SW US Veterans Hospital Rd, Portland, OR 97239, USA

Author Note
Correspondence concerning this article should be addressed to Margaret H. Wolf, CDRC, Oregon Health & Science University, Portland, OR, 97239. Email: wolfma@ohsu.edu, Phone # 503 494 6118

Conflicts of Interest: None

Acknowledgement: We would like to thank the Down Syndrome Clinic team at Oregon Health and Science University, including Dr. Joseph Pinter, Dr. Amy Costanza-Smith, Dr. Katherine Breithaupt, Ms. Erin Cochran, for creating and presenting educational materials, the Syrian American Medical Society for providing written translation of lectures, Mr. Abdullah Mohamed Almohamed, Idlib Center director, for collaborating with us, and Mr. Jim Seidl, Friends of Idlib Center for connecting our groups.

Ethical Conduct of Research: This was an outreach project with approval from both organizations (Oregon Health and Science University and Idlib Center in Syria), no Institutional Review Board approval was required for this project.

Down Syndrome outreach during the COVID-19 pandemic - An interprofessional Zoom®
WhatsApp® collaboration in Syria

The COVID-19 pandemic has strained healthcare systems globally, resulting in limited access to health care for the vast majority of patients, including children (Buser & Taha, 2022).
Global pandemic restrictions have temporarily discontinued or reduced vital child healthcare services including immunization, nutrition services, community-based welfare, and early child development programs (Kyeremateng et al., 2020). For example, Bhattacharyya and colleagues (2022) found that more than 68 countries had disruptions in immunization programs, leaving an estimated 80 million children unvaccinated against preventable diseases (e.g., measles, mumps, and rubella). Reduced access to nutritional programs and food shortages due to supply chain disruptions are deleterious to the health and wellbeing of children. Equally alarming, amidst decreased community surveillance, is the increased risk for child abuse, sex trafficking, and militant recruitment (Loperfido & Burgess, 2020). Healthcare systems have been forced to prioritize pandemic responses over pediatric care; the resultant restrictions have had grim implications for the global health and wellbeing of children.

Reduced access to healthcare services induced by global pandemic restrictions is estimated to contribute to more than 6,000 child deaths per day from otherwise preventable causes. Globally families have reported closures of local healthcare centers, medication and provider shortages, excessive wait times, and delayed treatments (Kyeremateng et al., 2020). The deleterious effects of these pandemic restrictions are more apparent among children who experience vulnerabilities such as poverty or developmental disabilities (World Bank, 2020).

Children living in poverty and low-income countries often experience disproportionate effects of pandemic restrictions such as reduced access to healthcare services. According to the Centers for Disease Control and Prevention (2021), children with developmental disabilities are one group experiencing the deleterious effects of the pandemic.

Reduced access to healthcare services places stringent demands on families and caregivers of children with developmental disabilities (Prime et al., 2020). With minimal or no
professional support, these caregivers and families now must fulfill additional roles (e.g., special education provider, social skills coach, speech language pathologist, behaviorist, mental health therapists) to maintain their child’s health and wellbeing (Eshraghi et al., 2020). These roles are immensely challenging for those without specialized training, and the transition into these roles can drastically increase caregiver burnout and fatigue (Meguid et al., 2020). Complicating these additional stressors is poverty. While 10% of the world’s children experience developmental disabilities, yet, 80% of these children live in developing countries (UNICEF, 2021b), creating the perfect storm for negative health outcomes relative to their counterparts without developmental disabilities or those who are socio-economically advantaged.

An Exemplar - Children with Down Syndrome

It has been estimated that nearly half of all children with Down syndrome experience poverty in low-income countries (WHO, 2021). Down syndrome is a common chromosomal disorder with an estimated prevalence of 1 case per 1,000 global births (United Nations, 2022). According to the National Institute of Child Health and Human Development (NICHD; 2017), Down syndrome is often comorbid with other pediatric health issues (e.g., congenital heart disease, vitiligo, hypothyroidism, obesity, hypotonia, sensory disorders, blood disorders, atlantoaxial instability, sleep disorders, dental disorders, epilepsy, digestive problems, celiac disease, and mental health disorders). These comorbidities may exacerbate the impact of reduced access to healthcare services while also hindering family ability to engage in health behaviors and social distancing (Meguid, et al., 2022). Children with Down syndrome also experience immunological dysregulation (Espinosa, 2020), which increases their risk of severe outcomes (e.g., respiratory symptoms, fever, and several medical complications) from coronavirus infections (Emes et al., 2021). Of note, Down syndrome has been associated with greater
functional deficits among children relative to other developmental disabilities (Fidler et al., 2005), placing additional stressors on their families experiencing the restrictions from the pandemic.

**Boots on the ‘virtual’ ground – An interprofessional Zoom® WhatsApp® collaboration in Syria**

In response to the global need for increased support for children, families, and providers involved with Down syndrome, our experienced and well-supported interprofessional US team at an academic medical center in the Pacific Northwest (PNW) collaborated with the Syrian Idlib Center for children with Down syndrome. We learned of the center, which is located in an area of Syria heavily impacted by civil war, through a featured news story (Damon, 2021). This news story sparked a fundraising campaign by another organization, who contacted our Down Syndrome Clinic team with a request for assistance. The Down Syndrome Clinic team includes a pediatric neurologist, occupational therapist, speech language pathologist, physical therapist and pediatric nurse practitioner. Our team reached out and began by assessing the learning needs of the Idlib Center staff, who serve approximately 40 children and youth ages 3 years to 15 years with Down syndrome. The staff are volunteer, but committed therapists, nurses, and teachers, with little specialty training related to pediatrics or Down syndrome. They provide services in a school-like environment.

Learning needs and objectives for the Idlib Center staff were assessed and clarified through a series of meetings over Zoom® and messages via email and WhatsApp®. Based on identified needs, our Down Syndrome Clinic team developed five training sessions, tailored specifically for the Syrian staff and population. Topics included the following:

- *Down Syndrome: A Clinical Overview*
• Down Syndrome and Physical Therapy
• Communication Assessment and Treatment in Down Syndrome
• Vision, Motor and Self-Care Skills in Children with Down Syndrome
• Feeding for Children with Down Syndrome

The written lectures were translated to Arabic with the help of the Syrian American Medical Society, and shared with Idlib Center staff over Google Drive. They were presented synchronously over Zoom on Sunday evening in Syria in Fall 2021, with real time interpretation to Arabic by a multilingual healthcare provider on our team. Syrian providers were able to ask questions and share experiences with our US-based providers during these meetings for even more tailored learning and support.

The project was beneficial for both parties. Syrian staff gave positive feedback in a formal evaluation of each training session and of the program as a whole. They noted they could immediately implement new strategies and change treatment plans based on what they learned. For example, they could use more evidence-based strategies and techniques to support feeding, communication, and integration of care. Our participating team identified many benefits, including professional development, the opportunity to learn more about Syrian culture, and the connection with others across the globe in a shared mission of supporting children with Down syndrome. In a time of significant isolation for humankind due to the COVID-19 pandemic, this project created a bridge between health care providers from two very different countries and allowed for education, connection and collaboration that may not have been possible before. As virtual education formats have become acceptable and accessible, collaboration amongst providers across the globe is possible and allows for better care of children with developmental disabilities, no matter where they live.
In conclusion, in the context of crises such as pandemics, military conflicts, climate change, forced displacement, and food insecurities, children with Down syndrome who live in poverty or low-income countries are at extreme risk for negative health outcomes issued through increased stress exposure and reduced access to healthcare services. However, the health and well-being of these children and their families may be improved through providing pediatric healthcare providers with specialized training to improve healthcare and access to healthcare services in light of these prevalent crises in low-income countries. The time to act is now as these trends will only worsen without intervention, holding grave implications for the health and wellbeing of these children and future generations.

References


https://dds.cepal.org/redesoc/publication?id=5336


National Institute of Child Health and Human Development. (2017, January). *What conditions or disorders are commonly associated with Down syndrome?*
https://www.nichd.nih.gov/health/topics/down/conditioninfo/associated


day#:~:text=The%20estimated%20incidence%20of%20Down,born%20with%20this%20chromosome%20disorder.


https://www.who.int/news-room/fact-sheets/detail/disability-and-health