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Down Syndrome Outreach During the COVID-19 Pandemic: An Interprofessional Zoom WhatsApp Collaboration in Syria

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KEY WORDS

Down syndrome, global outreach, provider education, Syria
The COVID-19 pandemic has strained health care 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 health care services, including immunization, nutrition services, community-based welfare, and early

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

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child development programs (Kyeremateng et al., 2022). 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 because of supply chain disruptions are deleterious to the health and well-being of children. Equally alarming, amidst decreased community surveillance, is the increased risk for child abuse, sex trafficking, and militant recruitment (Loperfido & Burgess, 2020). Health care systems have been forced to prioritize pandemic responses over pediatric care; the resultant restrictions have had grim implications for the global health and well-being of children. Reduced access to health care 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 health care centers, medication and provider shortages, excessive wait times, and delayed treatments (Kyeremateng et al., 2022). 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 health care 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 health care

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, behavioralist, and mental health therapist) to maintain their child's health and well-being (Eshraghi et al., 2020). These roles are immensely challenging for those without specialized training, and transitioning into these roles can drastically increase caregiver burnout and fatigue (Meguid et al., 2022). Complicating these additional stressors is poverty. Although 10% of the world's children experience developmental disabilities, 80% live in developing countries (United Nations International Children's Emergency Fund, 2021), creating the perfect storm for negative health outcomes relative to their counterparts without developmental disabilities or those who are socioeconomically 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 (World Health Organization, 2021). Down syndrome is a common chromosomal disorder with an estimated prevalence of one case per 1,000 global births (United Nations, 2022). According to the National Institute of Child Health and Human Development (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 health care services while hindering families' ability to engage in health behaviors and social distancing (Meguid et al., 2022). Children with Down syndrome also experience immunologic 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 U.S. team at an academic medical center in the Pacific Northwest collaborated with the Syrian Idlib Center for children with Down syndrome. We learned of the center, 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 aged 3–15 years with Down syndrome. The staff are volunteers 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 (Zoom Video Communications, Inc., San Jose, CA) and messages via email and WhatsApp (Meta Platforms, Inc., Menlo Park, CA). Our Down Syndrome Clinic team developed five training sessions tailored specifically for the Syrian staff and population on the basis of identified needs. Topics included the following: (1) Down syndrome: A clinical overview, (2) Down syndrome and physical therapy, (3) Communication assessment and treatment in Down syndrome, (4) Vision, motor, and self-care skills in children with Down syndrome, and (5) Feeding for children with Down syndrome.

The written lectures were translated into Arabic with the help of the Syrian American Medical Society and shared with Idlib Center staff over Google Drive (Google LLC, Mountain View, CA). They were presented synchronously over Zoom on Sunday evenings in Syria in the fall of 2021, with the real-time interpretation of Arabic by a multilingual health care provider on our team. Syrian providers were able to ask questions and share experiences with our United States-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 the program. They noted they could immediately implement new strategies and change treatment plans on the basis of 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 because of 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 among 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 health care services. However, the health and well-being of these children and their families may be improved by providing pediatric health care providers with specialized training to improve health care and access to health care 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 well-being of these children and future generations.

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