



Serving Underserved Patients with Primary Immune Deficiency Disorders: A Pilot Educational Program for Clinical Fellows

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To the Editor,

Despite increasing awareness of barriers to health care and the role of social determinants of health in human disease, disparity in the care of children and adults with primary immune deficiency disorders, including inborn errors of immunity (IEI) with identified causative genetic variants, is a reality in the USA. Early diagnosis and treatment are lifesaving in severe forms of immune deficiency. Although newborn screening for severe combined immune deficiency is now established in all 50 states in the USA, awareness of clinical signs of primary immune deficiency disorders among primary providers is lacking, and even when identified, locating a nearby center with expertise can prove to be difficult. Advanced immunologic diagnostic testing, genetic sequencing technology, culturally aware premarital and pre-conception interventions, and genetic counseling are not widely available [1]. Specialized hematopoietic stem cell transplantation (HSCT) centers with experience in IEIs are not available in many states, and donor availability is limited for patients of minority or mixed ethnic backgrounds [2].

Even in places where diagnostic tools are available, disparity remains. In an analysis of patients with primary antibody deficiency (PAD) at Boston Medical Center (BMC), which has higher proportions of patients with PAD identifying as black/African American or Hispanic/Latinx than in the USIDNET registry, 30.1% of PAD patients at BMC were prescribed immunoglobulin replacement (IGRT) compared to 86.8% in the USIDNET registry [3]. Pneumonia

and bronchiectasis occurred significantly more frequently in PAD patients identifying as black/African compared to all others, 75% vs 33% and 75% vs 11%, respectively. Bronchiectasis also occurred more frequently in PAD patients from an urban county with lower median income.

An important step in addressing these disparities is to formalize education as it relates to the care of underserved patients with immune deficiencies. We designed a pilot educational program entitled ASCEND: Addressing Socio-economic and Cultural Education in immunoDeficiency in which allergy/immunology fellows (4 pediatric and 6 adult fellows) met twice monthly for didactic and workshop-based sessions. All fellows were included from a single institution that prioritizes the recruitment of diverse applicants to its training program. This pilot group included men, women, Caucasians, South Asian-Americans, and one Latin-American. The length of each session was four continuous hours, and the total duration of the program was 3 months. The curriculum incorporated the perspectives of many members of the care team including nurses, psychologists, care coordinators, laboratory scientists, and patient/families (Fig. 1A) to emphasize the interdisciplinary nature of caring for patients with primary immune deficiencies.

In our first session of the program, a care coordinator discussed how factors such as occupation, insurance coverage, citizen status, home support, number of children/siblings, and transportation to infusion centers each play a role in healthcare delivery and efficacy. An infusion nurse then discussed her experience with intravenous immune globulin replacement (IVIG) in underserved patients, discussing scheduling flexibility, the identification and treatment of reactions, and sensitivity at the bedside to the different cultural and language needs of patients and families.

During the second session, a child psychologist reviewed the emotional challenges faced by patients with immune deficiencies including navigating chronic illness, frequent doctor's visits, and social isolation, comparing themselves to their peers, and searching for normalcy. She also discussed

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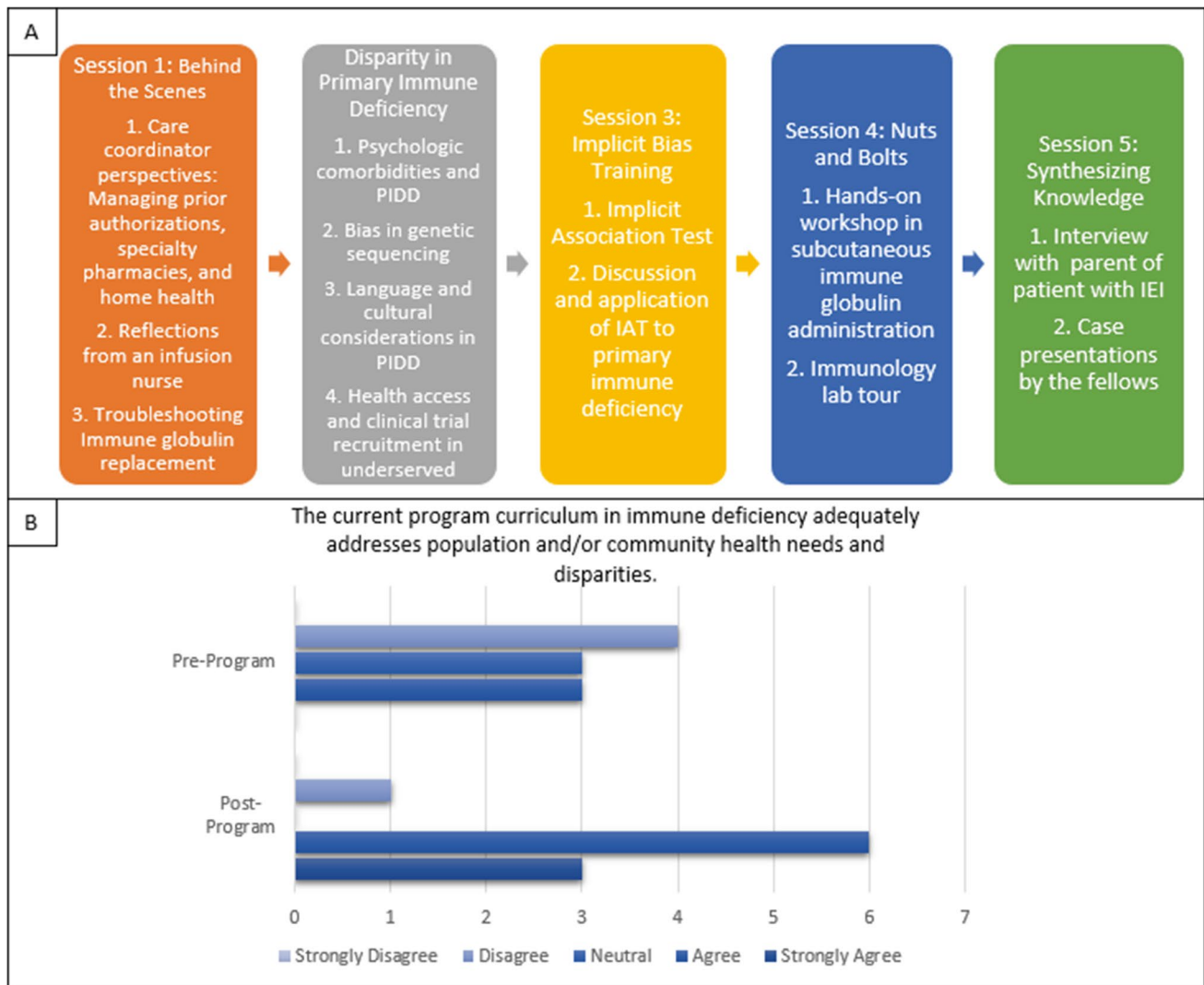


Fig. 1 Addressing primary immune deficiencies within minority and underserved populations

the importance of early recognition of psychologic comorbidities including anxiety and depression. Additionally, she discussed the needs of teens transitioning to adulthood who may be entering the workforce or college for the first time and are taking greater ownership of their health.

Next, the fellows heard from two physician-scientists in clinical immunology. The speakers outlined healthcare disparities as they relate to immune deficiency care. The first speaker discussed disparity in genetic testing. Although gene sequencing in the USA is more accessible and affordable than ever before, clinical immunologists with expertise in interpreting and acting on the results are located in academic medical centers in major cities. Additionally, current referenced genetic databases for classifying variants involved in immunologic disorders are incomplete in their inclusivity of diverse populations, although this is improving. Patient and family concerns about the potential misuse of genetic

information and distrust of healthcare systems may also play a role in genetic testing disparity, and further research is needed to understand this relationship. The second speaker discussed the importance of including diverse participants in clinical trials and barriers to recruiting underserved patients especially when moving a family for advanced therapy may be recommended.

As members of an inequitable health system, the fellows were then asked to confront their own potential biases in the third session, which involved formal implicit bias training. Implicit biases are learned stereotypes that are automatic, unconscious, and able to influence behavior. The fellows were first asked to take an implicit association test (IAT). The IAT is a computer-based test in which measuring the speed of association of images and words can suggest automatic discriminatory patterns of thinking. For example, if a participant is slower to associate the word “delightful”

or a photo of an African American man to the category entitled “good or African American” than she is to associate the same word with the category “good or European American”, then this may reflect an automatic preference for white over black individuals. Besides race, there are other demographic elements that can be assessed such as religion, gender, sexuality, disability, socioeconomic status, and age. Following the IAT, the fellows were led through a discussion of immune deficiency cases that were representative of some of the issues discussed. Thus, in this very personal session, the fellows were asked to acknowledge their own potential biases and were guided through the practice of perspective taking in order to work toward equality of care in their current and future practices. From an ethical perspective, taking the IAT was an optional part of the curriculum, and the results were confidential to the participant unless they chose to share with the group.

The fourth session involved hands-on training in subcutaneous immune globulin (SCIG) dosing, preparation, and administration. Underserved patients may find barriers to the use of SCIG including out-of-pocket expenses, delivery of supplies to a consistent address, and concerns with self-injection. However, with greater understanding of the logistical considerations involved in SCIG, we hope that our fellows will be able to discuss with their patients in need of IGRT the available options and use shared decision-making to choose the route of delivery that is best for the patient.

The final session was an opportunity for the fellows to synthesize their learning in the context of real patients. The first part consisted of an interview with a parent with a child with IEL. The second part consisted of each fellow presenting an immune deficiency case from his or her panel, discussing the ways in which the patient was underserved, and brainstorming how to support the patient more completely.

Prior to the program, the majority of the fellows described that the curriculum in immune deficiency did not adequately cover health disparities and community health needs (Fig. 1B). However, following the program, the majority of the fellows felt that the curriculum addressed these issues. The fellows were also more comfortable with discussing the direct and indirect costs of immune globulin replacement therapy, troubleshooting subcutaneous immune globulin replacement, accessing resources for non-English-speaking patients, and discussing genetic testing (Supplementary Figure 1).

Starting with this pilot, the program will be offered every 2 years, such that each fellow will experience the curriculum at least once during his or her training. Future installments will be updated to include additional patient testimonies, increased number and diversity of fellow participants, and outreach efforts to health systems and hospitals in the area to spread awareness of primary immune deficiency disorders.

By launching this educational program, we join efforts already in progress to address these disparities including identifying undiagnosed immune deficiency and improving IGRT prescribing practices. For example, Cunningham-Rundles et al. used computer-generated algorithms to identify undiagnosed minority patients with immune deficiency [4]. Among all hospitalized patients 60 years or less in one health system who had been given a diagnosis of two or more ICD-9-coded complications associated with immunodeficiency, but no primary diagnosis ($N = 533$), 86% were Hispanic or African American. Of the 59 randomly selected to undergo further evaluation, 29% were found to have a primary immune deficiency disorder. Therefore, machine learning may be helpful to remove bias if carefully designed and could be automatically employed for individuals who meet certain clinical criteria, such as frequent hospitalizations for infection.

Other proposals to reduce disparity include promoting broader awareness of the signs and symptoms of immune deficiency in communities serving minority populations, empowering primary care providers and hospitalists to screen with quantitative immunoglobulins for children and adults who have had more than 1 hospitalization for infection within any given year, and improving outreach from clinical immunologists to hospital systems to solidify the referral network for patients with dysregulated immunity. Further research will be needed to measure the impact of implementing these efforts.

The COVID-19 pandemic has illuminated the importance of serving underserved immune deficiency patients [5]. Economic inequality has contributed to poorer outcomes among minority patients who are more likely to be without health insurance and living in communities hit hardest by local outbreaks. Vaccine administration has been hindered by lack of access and concerns about efficacy and safety among patients with primary immune deficiency disorders. As well, monoclonal antibody therapies for both acute infection and prophylaxis have been limited in supply.

A multifaceted approach is critical to addressing issues of healthcare disparity in primary immune deficiency care, including advocating for national policy changes, broadening healthcare delivery networks, addressing institutional and systemic racism, expanding the recruitment of diverse medical school applicants, improving patient engagement and education, and strengthening research programs to focus on mechanisms and outcomes in underserved groups. A formalized educational curriculum is one component of this larger goal, training the next generation of clinical immunologists to be advocates for their patients of all backgrounds. We plan to expand this curriculum and hope that it can serve as a model in the future.

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