The grander challenge of pediatric oncology: disparities in access to care

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The excellent survival of children with cancer in the United States (US) is a grand achievement that has been accomplished mainly through five decades of translating biomedical discoveries to the bedside. However, it obscures the significantly inferior survival of racial-ethnic minorities in the US^{1, 2}, and highlights the unconscionably abysmal survival of children with cancer globally³. Intrinsic differences in epidemiology of prognostically relevant tumor and host biological factors contribute to these survival disparities. However, as demonstrated by the fact that the widest survival disparities occur among children with the most curable cancers and risk-groups^{2,4}, the primary driver of inferior survival among minorities and children globally is*lack of access* to effective pediatric cancer care. Discovery of efficacious therapies was/is the grand challenge to pediatric oncology; ensuring access to effective care for all children in the US and globally is the *grander* challenge of pediatric oncology.

Access to health services is a complex construct that includes⁵: (1) availability of the services to a specific population, (2) adequate supply of the services to the population, (3) ability to utilize the health services, which includes requisite financial (e.g., medical insurance coverage) and social (e.g., flexibility of work schedule to attend medical appointments) resources, and (4) suitability of the services to the socio-cultural context of all demographic groups in the population. For the majority of the world's children that develop cancer ($^{80\%}$) and live in low/middle income countries, infrastructure and expertise for evidence-based pediatric oncology services are simply unavailable or are extremely scanty. On the other hand, racial-ethnic minorities in the US also suffer from lack of access to adequate pediatric oncology care despite the apparent abundance of services – suggesting barriers to utilization and/or suitability of services.

In this issue of *Pediatric Blood & Cancer*, Zheng D.J. et al present an evaluation of access to a psychiatry service that is integrated into a children's cancer center – the Dana-Farber/Boston Children's Cancer and

Blood Disorders Center (DF/BCH) from 2013 to 2017. The authors examined the relationship between *utilization* of this psychiatry service and patients' socio-demographic characteristics. Among a sample of 394 children with cancer that were evaluated, racial/ethnic minorities had 52% lower odds of using the psychiatry service. Household material hardship and household income, two indicators of financial deprivation that may be considered the most obvious determinants of service utilization, did not influence utilization of this psychiatry service. For children who utilized the psychiatry service, 88% were diagnosed with a psychiatric disorder, 76% were given a pharmacological therapy and 62% were given a behavioral intervention for their diagnosis. The high occurrence of a specific diagnosis and therapeutic interventions for the children that used the psychiatry service suggest that this is a highly valuable service for children that are referred.

Zheng D.J. et al's findings demonstrate that availability of services does not equate to access, and that it is often difficult to pin-point the underlying reasons. Although racial-ethnic minorities in the US are associated with financial deprivation, financial indicators did not explain the disparity in utilization of psychiatry services at DF/BCH⁶. This suggests other utilization or suitability factors were at play. Such factors may include stereotypical beliefs, attitudes, or practices in the interactions between minorities and health providers that negatively influence clinical decision-making and effectiveness⁷. In this case such stereotypes may influence minority children's or parents' rapport with their oncology providers and willingness of parents to report mental or behavior symptoms, and oncologists' suspicion and threshold to make a psychiatric referral. Other practical social-cultural factors such as language barriers can influence utilization of services even when foreign language translators are used, particularly in the culturally sensitive realm of mental illness and behavioral disorders⁸.

Research to identify and quantify these disparities and their underlying mechanisms is critical to devise effective strategies that will overcome the systemic dynamics that deter minority children from accessing optimal cancer care. In the case of Zheng D.J. et al's findings, it would be very informative to determine the exact nature of the disparity by evaluating whether, (1) minorities were genuinely less likely to require a psychiatric consultation – a potential difference in disease epidemiology, (2) minorities needed psychiatric services but were not referred – suggesting inferior quality of care, (3) minorities were referred but never followed through on the psychiatric referral – a utilization problem. Mixed methods study designs that complement quantitative data with qualitative insights and involving key players (e.g., providers and minority patients in this case), can unveil critical issues around usability and acceptability that often underly under-utilization of services.

Global and US disparities in pediatric cancer care and outcomes epitomize the public health adage that discovery of efficacious biomedical interventions does not automatically translate into improved health services and outcomes for those that need them. Whereas many pediatric oncology researchers are acutely aware of the difficulty to translate research innovations into bedside interventions (aka, "the valley of death")⁹, most children/families affected by cancer globally are on the wrong side of a pediatric oncology "death canyon" – a complex milieu of financial, social-cultural, business interests, and health systems barriers that lie between them and the bedside (Figure 1). Enough scientific technologies have made it to the bedside to cure them, but only a few children can make it to the bed.

Research that bridges efficacious interventions and their delivery to children with cancer is critically needed. In addition to dedicated *disparities research*, hybrid designs that build disparity questions in translational, clinical trials, and epidemiology research are likely to be efficient and even more informative. This requires broadening the scope of research teams and meticulous recruitment of appropriate socio-demographic strata of research participants. For global settings where the landscape of health systems infrastructure and organization and social-cultural norms are very different, *implementation research* is urgently needed to innovate strategies that will enhance the adoption of pediatric cancer best practices that suit the local context.

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Legends

Figure 1 Minorities and children with cancer globally face enormous challenges to access already proven pediatric cancer interventions (Illustration credit: Maria Mbasooka)

