STEM CELLS TRANSLATIONAL MEDICINE®

LETTERS TO THE EDITOR

Inequality Issues in Stem Cell Medicine

With the recent opening of the world's largest publicly funded and accessible human stem cell bank [1], there is renewed focus on the potential of stem cells to be an important part of precision medicine. But every advance also brings us closer to the reality that this could potentially widen disparities in health care. Social justice is a concept borne of recognition that socioeconomic conditions and their distribution within the population can impact health outcomes. It implies that unequal parties may have different needs, and measures to correct inequalities and meet the individual needs of those parties must be in place to achieve common outcomes regardless of socioeconomic situation. A large portion of this overlaps with distributive justice, which requires the fair allocation and access of resources, and equitable representation that includes both genetic, ethnic, and socioeconomic representation, as well as a wide spectrum of different health and disease conditions. However, this equation is also affected by health awareness and literacy, which tie in closely with a patient's ability to access and make informed decisions about their treatment, and with religious and cultural sensitivity, which influences how patients and their families choose and accept their treatment. These issues can often be magnified in newer technologies such as stem cell medicine, and addressing this is a complex challenge.

A biological treatment that needs to be tailored to each individual entails significant costs, with specialized logistics and infrastructure. This will relegate treatment availability to either large academic centers with adequate funding and strong industry support, or commercial, for-profit entities that may solicit direct funding from patients. Such facilities are usually in a metropolitan setting. These factors highlight the issue of cost and geographical isolation impacting on accessibility, but these are not unique issues to stem cell medicine. Personalized oncology, for example, with increasingly tailored biological agents and multidisciplinary treatments, has incorporated some creative solutions. These include telemedicine, multidisciplinary teams involving rural members, decentralization of services such as radiotherapy, increasing data collection and research on disadvantaged patient cohorts, and specific government schemes involving development of models of rural/regional oncology aimed at improving patient access and outcomes. There are many lessons that stem cell medicine will learn from this trail.

With regard to cost, there are reasonable arguments that this eventually may be driven down with increasing adoption and evolution of technology leading to more efficient systems, although observing parallels in hematopoietic stem cell and cord blood transplantation suggests this may be somewhat hopeful. However, it is likely insurance coverage (both public and private) will recognize the cost savings from using these treatments to cure chronic conditions, which may improve accessibility.

What will remain a major shortcoming, however, is genomic inequality. Because stem cells will also treat rare diseases and be influenced by individual patient biology, we will become increasingly dependent on "one-person trials" [2]. Data pooled from such research and cells from repositories will be used to guide future treatment choices, forecast and prognosticate treatment responses, and produce treatments to matched recipients. However, an obvious challenge is ensuring we account for genetic diversity, which is associated with different age, ethnicity, and socioeconomic backgrounds (patient factors), as well as different disease states, including severity of disease and interaction with comorbidities (disease factors). This will ensure the resultant treatments cater to the genetic diversity of the population. Recently, efforts have been made to develop stem cell banks based on diverse demographic and immunogenetic characteristics (human leukocyte antigen [HLA] haplotyping) [3, 4]. Furthermore, it has been proposed that immune rejection of transplanted cells may be reduced if donors who are homozygous at major HLA loci are used [5, 6]. This suggests that there may be some reprieve from trying to cater to every exhaustive permutation of genetic diversity and that some concerns may be allayed regarding the limited availability of donor cells from certain patient groups. It may also present some cost savings if we access already established databases of HLA-typed individuals to identify and contact donors from bone marrow and blood registries [7]. However, this does not necessarily help with disease modeling or drug testing, which are other important aspects of stem cell medicine.

Organizations such as the International Society for Stem Cell Research have touched on this issue of fair access and allocation of resources in their policy recommendations, and have highlighted the need to develop alternative models to the current research development and clinical translation pipeline. Clearly, government input at a national and international level is necessary to mobilize infrastructure, public funding, and legislation for this purpose, but academic institutions and commercial entities also need to be involved in this initiative. Examples of such a collaboration would be government incentives for commercially sponsored clinical trials to be conducted in resource-poor areas, and mandatory inclusion of minorities in all clinical trials, including commercially sponsored trials. Bio-networking programs partnering scientists from emerging economies and developed research hubs will also facilitate the cross-pollination of expertise and specimens. Crowd-sourcing initiatives also enable pooling of resources such as cell repositories [8]. Encouraging donor registering programs is another important strategy to widen the availability of biological specimens. An example of an innovative solution is the program run by DATRI, a nonprofit organization in India [9]. With industry support, DATRI has set up a growing genetic registry, from simple cheek swabs, that can be harnessed through future database searches to match donors to potential recipients for bone marrow transplants. Part of this success has been the ability to mobilize grassroots awareness campaigns sensitive to local cultural norms, which has extended to rural communities. This example also highlights the importance of awareness, education, and advocacy in improving social justice.

Science frequently distances itself from politics and social concerns, and there can be a reluctance to deal with all issues at once when "someone else can worry about it when the time comes." But in a field such as stem cell research, with extensive implications for society and medicine, it is difficult to compartmentalize such perspectives. All stem cell researchers should aspire to a notion of social justice, and their research should derive from and strive to cater to the genetic and socioeconomic diversity that is inherent in our population. Accomplishing this while, at the same time,

developing an affordable therapy will no doubt be a tough challenge, but we need to recognize this and begin this important dialogue early to plan the steps ahead.

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Disclosure of Potential Conflicts of Interest

The author indicated no potential conflicts of interest.

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