Equity as a Method: Diversity in Teams and Justice in Clinical Research and Cancer Care

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Equidade como Método: Diversidade nas Equipes e Justiça na Pesquisa Clínica e na Assistência Oncológica

La Equidad como Método: Diversidad en los Equipos y Justicia en la Investigación Clínica y la Atención del Cáncer

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Contemporaneous oncology stands on top of two inseparable promises: produce robust evidences and translate these evidences into effective, timely and human care. However, when clinical research and assistance are organized over socially uneven bases, the universality of knowledge starts to be a hypothesis and not a data. It is estimated that nearly 70% of deaths by cancer occur in low- and middle-income countries reflecting structural disparities of access to diagnosis, treatment and innovation[1]. Even though, the production of biomedical knowledge remains strongly concentrated in high income countries, directly impacting the external validity of findings and health distributive justice in health care.

Analyzes of international databases of clinical trials registries show that the majority of oncologic clinical research sites is located in high-income countries and residual participation of low- and middle-income countries[2]. The geographic concentration is added to systematic sub-representation of minority racial and ethnical groups, of socioeconomic vulnerable populations, LGBTQIA+, disabled individuals and individuals living in other than large urban centers, perpetuating a cycle where the most affected by cancer burden remain underrepresented in the production of clinical practice-driven evidences.

Scientific literature consistently demonstrates that diversity is not a mere ethical imperative but a methodological requirement. Clinical trials with ample populational diversity present better potential of generalizability, improved safe evaluation of effectiveness and toxicity and better social legitimacy[3]. Accepting this scenario, regulatory bodies and editorials are consistently requiring transparency and inclusion as the NIH Revitalization Act, the recent guidelines of the US Food and Drug Administration on diversity plans and the recommendations of the International Committee of Medical Journal Editors (ICMJE) in accountable reporting of social variables[4-6].

However, the expansion of diversity of participants is unfeasible without structural transformation of research teams and assistance. Evidences indicate that more diversified teams are associated with improved enrollment of underrepresented populations, stronger reliability of the research process and better communication among patients and health professionals[7]. In oncologic assistance diversified multiprofessional teams contribute to reduce implicit biases, improved decision-making and better adherence to treatment.

The Brazilian context is marked by profound populational diversity and persistent regional inequalities that are central and urgent. Qualitative studies reveal that race, territory and socioeconomic condition influence the experience in oncologic care and health outcomes[8]. Irrespective of institutional advances, the participation of Brazil in global clinical research remains unchanged, reinforcing the necessity of decentralization strategies, strengthening of public sites and formation of diversified scientific leadership.

Promoting equity in clinical research and oncologic assistance requires intentional actions based on sustainable evidences as teams diversification, continuous training in diversity and inclusion for the whole team, revision of exceedingly restrictive eligibility criteria and systematic collection and analysis of disaggregated data that allow the identification and correction of disparities of access and results of the treatments[9]. In addition, it is paramount to have substantial financial investment from institutions targeted to ensure enough resources for patients' navigation and strengthening of community engagement, fundamental to overcome barriers that restrain the participation of historically underrepresented groups[10]. More than a discursive engagement, equity should be incorporated as operational principle of scientific and assistance excellence.

Inequities in clinical research and oncologic assistance are not only an ethical challenge, but a structural limitation for the production of valid evidences and quality of care. Low diversity in clinical trials compromises external validation of the results while poor representative assistance hinder access, communication and adherence to treatment. In contrast, diversified multiprofessional teams qualify care, widen access to guidelines-based protocol and can positively impact health outcomes. Incorporate equity as institutional principle is a required condition for a scientifically robust oncology, socially legitimate and responsive to the population demands.

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