

Overcoming Barriers: Bioethics for Equity in Rare Diseases and Neurooncologist in Latin America and the Caribbean

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Rare diseases and nervous system cancer pose distinctive and intricate challenges for patients, healthcare professionals, and government entities. These complex medical conditions demand specialized and personalized attention; however, regrettably, significant disparities persist in accessing medical care, clinical trials, and treatments. Notably, Mateus et al's registry in Colombia reported that over 13,000 people were grappling with rare diseases in the country in 2017 alone.

In this editorial, we delve into the imperative to address these disparities, emphasizing the crucial role of clinical trial participation, access to healthcare, respect for autonomy, and the fundamental impact of bioethics on healthcare improvement in Latin America and globally. We issue a call to action for standardization, regional collaborations, improved access to clinical trials, and the pursuit of fair healthcare for all.

Disparities in Medical Treatment

Rare diseases, particularly in oncology, present ongoing challenge in diagnosis and treatment due to their intricate nature and underreported rates. It is disconcerting to observe how these

medical conditions disproportionately affect vulnerable populations. Disparities in healthcare access and clinical trial opportunities are especially evident in developing countries like Colombia. It is imperative and urgent that concerted efforts are made to mitigate these disparities, ensuring equitable access to medical care and innovative treatment options that all patients, regardless of their location or socioeconomic status.

The Importance of Clinical Trials

Clinical trials play a fundamental role in developing effective treatments for rare diseases and brain tumors. Rigorous scientific studies enable the assessment of the effectiveness and safety of new therapies, aiming to enhance the quality of life for those afflicted with these diseases. Nevertheless, it is a matter of concern that many patients with rare diseases and cancer lack access to clinical trials due to institutional, economic, geographic, and informational barriers.

As healthcare professionals and advocates for comprehensive biopsychosocial care, it is our responsibility to collaborate with health authorities, academic institutions, and non-profit organizations. This collaboration is vital to ensure

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that clinical trials are accessible to all patients who stand to benefit from them.

Access to Healthcare

Access to quality healthcare is a fundamental right for every human being, regardless of their socioeconomic level, religion, preferences, gender, or sexual orientation. Nonetheless, many patients dealing with rare diseases and oncological pathologies encounter significant barriers in accessing specialized medical services. These barriers may encompass a shortage of specialized care centers in rural areas, inadequate financial resources to cover healthcare costs, and challenges in securing appropriate referrals. It is imperative that we collaborate closely with policymakers and healthcare providers to enhance access to specialized healthcare. This ensures that all patients receive the necessary care, irrespective of their geographic location or socioeconomic status.

Respect for Autonomy as the Pillar of Medical Care

Respecting the autonomy of each individual is a fundamental bioethical principle in medical practice. Every patient possesses the right to make informed decisions about their medical care. In the context of rare diseases and brain tumors, individuals often encounter difficult and complex decisions. Providing early, consistent, clear, and understandable information about treatment options, risks, and benefits is essential. This allows patients and their families to make informed decisions and actively participate in their care. Respecting autonomy not only strengthens the doctor-patient relationship but also, empowers patients, ensuring that their individual rights and wishes are honored.

The Importance of Clinical Bioethics in Oncology

Bioethics plays a pivotal role in improving healthcare and ensuring equitable and accessible care for all patients. Through the principle

of autonomy, patients are granted the right to informed decision-making, irrespective of their race, disease, geographical location, among other factors. Respecting autonomy facilitates early decision-making in the context of rare diseases. Bioethics calls on us to consider the fundamental principles of beneficence, non-maleficence, justice, and autonomy. Applying these principles to the care of patients with rare diseases and cancer helps address disparities in access to healthcare and clinical trials. Bioethics underscores the importance of treating each patient as a unique individual, considering their values, preferences, and personal circumstances. Furthermore, bioethics challenges us to scrutinize biases and stigmas that may influence healthcare. It is essential to address structural and social barriers hindering equitable access to healthcare and unbiased decision-making for each individual.

In general, developing clinical bioethics involves collaborative efforts with policymakers, healthcare systems, and communities. This ensures that health resources and services are available and accessible to all patients, regardless of their ethnic origin, gender, sexual orientation, socioeconomic level, or geographic location, for unbiased decision-making. Bioethics, also emphasizes the importance of responsible research and continuous informed consent, without prejudice or barriers.

Clinical Trials and Bioethics

Clinical trials and scientific research must adhere to ethical principles to safeguard participants' rights and well-being. Promoting transparency, equity, and inclusion in research is crucial, avoiding the exploitation of individuals and vulnerable communities. The effective implementation of bioethics in medical practice necessitates multidisciplinary collaboration.

Physicians, scientists, ethicists, patients, and health advocates must collaborate to dismantle barriers to disparities in access to healthcare and clinical trials. This requires the establishment of policies and programs that promote equity and

accessibility. Additionally, it involves education and training healthcare professionals in the fundamentals of bioethics, fostering patient participation in decision-making about their care.

In conclusion, courageously addressing disparities in the treatment of rare diseases in neurooncology, demands a comprehensive and ethical approach. A call for standardization is sounded, aiming to eliminate discrepancies in research and development partnerships, funding opportunities, and access for all communities.

Crucially, fostering regional alliances for scientific and clinical collaboration is imperative. Latin American countries should unite to facilitate clinical research and enhance access to orphan drugs. For instance, government could exempt orphan drugs from import tariffs, stimulate collaborations in Latin America and

the Caribbean by facilitating access to clinical trials, drawing lessons from collaborations developed amid the COVID-19 pandemic. Governments could also provide tax exemptions to pharmaceutical companies, setting prices below a certain range. Other effective incentives include regulatory fee waivers, 50% tax credits on clinical expenses, significant grants for clinical research, and a ten-year market exclusivity.

Promoting research on rare diseases is crucial, as it can enhance scientists' understanding of all diseases in the future. By working collaboratively in Latin America, the Caribbean, and the United States, we can surmount the barriers and challenges faced by patients with rare diseases, providing them with the care they deserve. Bioethics will guide us on this challenging path toward better healthcare for all.

