Opinion

The United States Food and drugs administration defines a rare disease as any disorder that affects fewer than 200,000 Americans. The European definition is when a disease affects less than 1 in 2,000. These rare diseases poses lot of challenges in treatment decision making [1-3]. In particular Oncological disorders caused multitude of dilemma in clinical decision making. These rare cancers maybe difficult to characterize or define, the recruitment into clinical trials maybe difficult with lack of high quality evidence with very few centers with necessary expertise to manage and do research in these disorders [4-6]. Rare Oncological disorders may cause chronic illness, disability, and often premature death. They are complex with lack of adequate treatment with a very high health care spending. They have a huge tendency to get misdiagnosed or get wrongly diagnosed. Very few drug companies tend to invest into such rare diseases since it may be difficult to cover cost for developing therapeutics for such small and geographically diverse populations [7-10].

To advance medical research on rare diseases, a research network facilitates collaboration, enrollment in studies and trials, and sharing of data. National Institutes of Health (NIH) established the Rare Diseases Clinical Research Network (RDCRN I) to cater to the needs of these rare diseases. In addition certain toxicities and therapeutics to treat certain common malignancies maybe rarely used and these don’t find common utility in clinical settings [11-14]. Conducting a systematic review on rare oncological disorders, their distinctive features may help in an accurate assessment of prevalence of the condition; allow to find trends and similarities comparisons between countries; and, highlights areas of high or low prevalence [15-18]. Streamlines targeting of resources, planning and prioritization of future research. The cardinal points while doing a rare cancer systematic review is to define the research question, extraction of information appropriate screening of data, with data extraction and data synthesis. Similarities exist between SRs of prevalence of rare diseases but individual conditions present unique challenges. A good knowledge of disease classification and historical nomenclature is essential for effective searching and screening [9-10,19]. Whether diagnosis is simple or complex, it should be clearly and fully reported, data extracted and compared with other studies reporting the same outcome. Definitions of prevalence should be clearly extracted and compared to similar studies. Limitations surrounding individual studies and their effect on prevalence should be carefully considered.

References


