Assessment of Doctors’ Awareness about Rare Diseases and their Management Protocols in Karachi

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ABSTRACT

Health is the basic human right of every individual. Increasing number of preventable deaths in Pakistan however seeks attention of responsible bodies towards Primary Health concerns for majority natives (Pakistan Demographics and Health Survey, 2012-2013). This creates a situation where discussion of Rare Diseases and their treatment would never come on surface due to the existing economical constrains. Although, rare diseases affect 1 in every 15 but it becomes 400 million for same disease worldwide (Vrueh, 2013). Rare Disease patients face many problems including whom should they consult for treatment (Knight AW, 2006). This study aims to find the doctors’ awareness about Rare Diseases and their management protocols in Karachi. Cross-sectional study to evaluate the subjective awareness of doctors about rare diseases and their management protocols was done via questionnaire which was adopted from an article of CDC( Center for Disease Control)(Moore H, 2005)(Laurvick CL, 2006). A sample size of 382 was calculated. The study showed that there is considerable unawareness towards rare diseases (i.e. awareness level of 62.7% of the doctors was average or below average) particularly on part of General Physicians (p-Value=0.042) who are the first touch point in any treatment cycle. The results depict that doctors consider problems with diagnosis being the real killer for a patient of rare- disease in local setting and they require some continuous source of awareness to manage such patients effectively. Strategic action plan should be devised in tiers starting from developing statistical analysis of prevalence of rare diseases in Pakistan up to the endorsement of awareness among doctors and general public and engaging other health stake holders like NGOs, Support groups and Pharmaceuticals.

Keywords: Rare Diseases, Orphan Drugs, Doctors’ Awareness, Support Groups