

Disease Burden of Rare Cancers in Korea

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Background/Aims: Rare cancer is generally defined as incidence by less than 6 per 100,000 person per year. Because of low incidence, there have been no interest in rare cancer and the research was sporadic, limiting in diagnosis and treatment. Until now, there are few studies on effective treatment in rare cancer, nor basic epidemiological studies in Korea. The aim of this study is to investigate the incidence of rare cancer and estimate the disease burden in Korea. **Methods:** We extracted all newly diagnosed cancer patients from 2009 to 2017 using nationwide claim data from National Health Insurance (NHI) database. We confirmed the cancer registration time using the classified code C00 to C97 in the Korean Classification of Disease (KCD) and special code to V193 and V194. Rare cancers were defined as incidence of less than 6 per 100,000 person per year. **Results:** We classified by KCD-6 codes that 50 types of cancer were rare cancers and 12 cancers were common cancers. Rare cancers accounted for about 15.8% of total cancer incidence in Korea, and showed increasing trends every year. The most common anatomic location was digestive system (21.7%) followed by female reproductive organ (14.8%). According to age group, the incidence rate was the highest in younger age groups, presenting 71% of less than 20 years old, and 30% in 30 years old. In overall survival, rare cancers showed poorer survival than common cancers. Five year survival rate were 62.9% for rare cancers and 72.3% for common cancers. The survival rates of rare cancers decreased with age, and poorer in all age groups than in common cancers. In terms of average per capita medical costs, the expenditure was higher in rare cancers than in common cancers. **Conclusions:** In this study, we investigated the incidence, survival and disease burden of rare cancers in Korea using nationwide databases. Rare cancers account for 16% of all newly diagnosed cancer and the types were varied. Compared with common cancers, overall survival was poorer and costs of disease management was also higher. There were various survival rate and distribution of medical costs even in rare cancers. Further study is needed to investigate the detail of rare cancers.

