Mapping PD-1 inhibitors’ side effects using patient reported outcomes (PRO) generated by a digital patient-powered network (PPN)

INTRODUCTION

Checkpoint inhibitors such as programmed cell death receptor 1 (PD-1) antibodies have significantly improved the prognosis in several malignancies. While treatment with the PD-1 targeting antibodies, pembrolizumab and nivolumab, has substantial clinical benefit, it is associated with a spectrum of side effects different from most chemotherapy drugs. Most evidence on adverse events (AE) from anti PD-1 drugs was collected in clinical trials controlled environment and now there is a need for insights on the treatment patterns and AE in daily practice. Belong PPN is a social network for cancer patients and caregivers, providing them with access to patients, healthcare professionals and disease management tools. In this study, we explored the immunotherapy treatment patterns among Belong’s users and evaluated immunotherapies’ associated AE using PRO.

METHODS

Patients treated with either pembrolizumab or nivolumab were identified in the Belong PPN and their data researched. Data included patient-generated treatment data and medical records provided voluntarily and anonymously. Validation of data was done by algorithms and manually by the research team to assure accuracy.

RESULTS

Treatment with PD-1 inhibitors was validated and confirmed for 51 patients, showing 57% used pembrolizumab and 43% nivolumab. PD-1 treatment was detected in patients diagnosed with 7 different malignancies (Figure 1), mainly lung cancer (68%), melanoma (16%) and colorectal cancer (6%). Patients reported 23 different adverse events (AEs) covering clinically documented gastrointestinal, dermatologic, pulmonary and other toxicities (Figure 2). The three most frequent AEs were fatigue/tiredness (23%), nausea (8%) and diarrhea (8%). Comparing the two drugs distinctly showed fatigue/tiredness as a hallmark AE of pembrolizumab (Figure 3), which was even more prominent among lung cancer patients (Figure 4).

CONCLUSIONS

Data from the Belong PPN successfully captured the spectrum of PD-1 inhibitors’ reported AEs. Analyzing PRO of post approval treatments could provide deeper understanding of treatment patterns, expose limiting AE that bear implications on cost of treatment, indicate patients’ quality of life (QOL), improve management recommendations and provide a comprehensive outlook of patients’ outcomes.