

Dashboard of Data Visualization Concepts for Patients with Metastatic Adrenocortical Carcinoma

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Abstract

Adrenocortical carcinoma (ACC) is an aggressive and rare endocrine malignancy. 60% of ACC are functional and most commonly secrete cortisol. They have characteristics of both tumors and endocrine disorders with many time-series parameters. Therefore, making treatment decisions is often challenging. Data visualization methods have recently been developed to visualize time series, single or multiple pieces of information, and complex patient information. We summarized the clinical issues and dashboard concepts for patients with metastatic ACC.

CCS Concepts

• *Human-centered computing* → *Scientific visualization*; • *Applied computing* → *Medicine*;

1. Introduction

With increasing biomedical parameters and therapeutic advances in cancer, data visualization of patient trajectories and cohorts has become complex. Methods for visualizing a single patient timeline and multiple patient cohorts have recently been developed [BSM*15, BSKR18].

Adrenocortical carcinoma (ACC) is an extremely rare endocrine malignancy, often aggressive cancer with an overall 5-year survival rate of 13% in cases of stage IV. Many patients with ACC have clinical hormone excess, and hypercortisolism is the most common hormone-secreting ACC. Patients with hypercortisolism cause hypertension, immunosuppression, muscle weakness, and weight gain, leading to deteriorating quality of life or fatal conditions. Physicians must consider oncological and endocrinological perspectives, that is, not only the symptoms due to the tumor burden but also organ damage and complications caused by hormone excess.

Regarding treatment for metastatic ACC, systemic chemotherapy is an option. When symptoms caused by excessive cortisol levels are severe, management of hypercortisolism, such as debulking surgery or cortisol synthesis inhibitors, is considered [UTK*21]. In contrast, when the focal symptom caused by the tumor mass is severe, local therapy with radiation or medication for symptom palliation may be performed. Thus, a multidisciplinary team for ACC patients should ideally consist of endocrinologists, surgeons, medical oncologists, pathologists, radiologists, and genetic counselors. Still, effective sharing of patient data during meetings is a challenging task.

Finally, because ACC is extremely rare, with a reported incidence of about two cases per million per year, the number of patients a physician may have encountered is limited. Therefore, it is necessary to simulate the clinical trajectory of patients with ACC in subgroups predicted to have similar disease behaviors.

2. Clinical Needs for Data Visualization

Insights into Oncology and Endocrinology. An important point in determining the therapeutic strategy for patients with metastatic ACC is the cause of the symptoms and complications of tumor mass and hormone excess, which contribute to a decreased quality of life (QOL). Therefore, it is necessary to visualize tumor size, hormone excess and complications, QOL-related information, and treatments (Figure 2). Bar charts represented tumor mass sizes to grasp the time-series changes for each lesion in multiple organs. Metastatic lesions are often present in various organs, so bar charts were chosen to grasp the tumor size at each time point by area. On the other hand, hormone levels were represented by a line chart to contrast with the changes in tumor mass. The severity of symptoms due to hormone excess and tumor mass, respectively, is indicated by the box thickness around each point. These thickness representations allow the viewer to determine whether the presence of tumors and hormone excess affects the patient's QOL or does not harm it at each time point.

Time-Series Data. The natural course of the tumor, including diagnosis, surgery, metastatic recurrence, systemic therapy, tumor progression, and death, should be represented in chronological order using specific colors and icons (Figure 1). The choice of color for clinical events was based on previous studies [BSM*15,

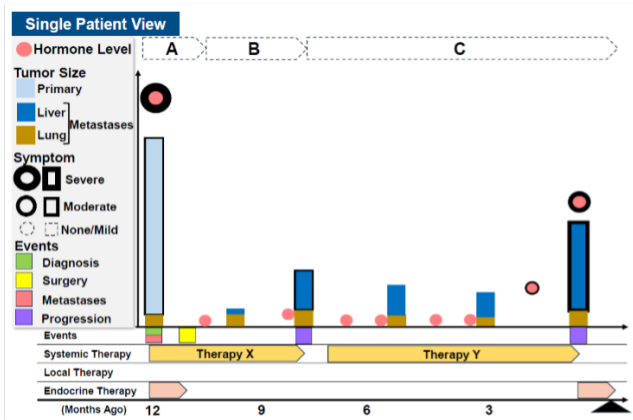


Figure 1: Visualization of a patient trajectory with a metastatic hormone-secreting ACC. (A) Although the patient had pulmonary metastatic lesions from diagnosis, the patient’s QOL was significantly impaired due to hormonal excess, so the primary tumor was removed surgically. Hormone synthesis inhibitors were used until surgery. (B) After surgery, the patient was treated with therapy X, but the lung metastases were slightly enlarged, and the newly emerged liver metastases were also enlarged. (C) Therapy Y was initiated. Initially, tumor reduction was observed, but tumor growth progressed during the treatment, so the treatment was discontinued. With tumor growth, symptoms of hormone excess reappeared, and endocrine therapy was restarted.

[BSKR18]. We can gain insight into the impact of each treatment on cancer progression and QOL by comparing the treatments listed at the bottom of the dashboard and clinical courses.

Subgroup Classifications. ACC has recently been classified into clusters based on hormonal excess, genetic mutations, and prognostic speculations, and therapeutic agents are being explored for each group [MLFH19]. Therefore, classification using these markers should be implemented in future research and development (Figure 2). These parameters can be selected from a pull-down menu at the top of the dashboard to analyze patient cohorts. While large databases may lack detailed information on the progress of individual patients, this display allows the details of individual trajectories to be reviewed and used to predict prognosis and treatment response.

3. Usage Scenario

Support of Decision-Making. Dashboards are used in two scenarios: a physician-patient conversation and a multidisciplinary meeting. The single-patient view provides an endocrine and oncological view of the patient’s historical progress and current condition for the treatment strategy. The multiple-patient view clarifies the clinical course of patients with similar characteristics and analyzes subgroup classification.

Therapeutic Development and Research. The multiple-patient view allows the evaluation of how hormone excess status or genomic mutation affects the therapeutic response and prognosis. The

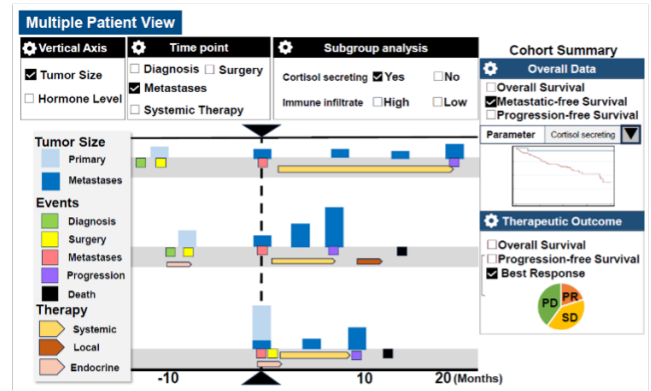


Figure 2: Visualization of multiple ACC patients’ trajectories. Users can choose the tumor parameter, time-point, and subgroup. Statistical data on overall data and therapeutic outcomes for the selected subgroup are also displayed.

timeline of the horizontal axis depends on the purpose of the analysis. When analyzing treatment response, treatment initiation or metastasis diagnosis is often used, whereas when predicting prognosis, the time of diagnosis or surgery is usually chosen. By setting the time points from the top tab, we can compare the chronological progress of each patient for analysis.

4. Conclusion

We summarized the clinical requirements of metastatic ACC compared with those of typical solid tumors for practical data visualization tools. Because ACC is very rare, it is necessary to build a multinational connected database; thus, this type of user-centered service might trigger further data gathering. We can retrospectively use patient data from the National Center as a data source. However, developing an infrastructure for collecting prospective information, including QOL data, is a major challenge for this project.

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