myAURA: a personalized health library for epilepsy management via knowledge graph sparsification and visualization

Keywords: epilepsy, sparsification, semantic web, systems analysis, social media data

Extended Abstract

The chronic health disorder epilepsy affects more than 3.4 million people in America and 65 million worldwide. People with epilepsy (PWE) are at risk for lower quality of life, social isolation, depression, anxiety, medication-related symptoms, and premature death [1]. Exacerbating these risks, PWE can wait up to 9 months to see a neurologist and much longer to see an epileptologist, so many PWE are treated by general practitioners while they wait [1,2]. Thus, to achieve desirable health outcomes, self-management by PWE and their caregivers (PWEC) becomes essential and they seek information online. While much recent research has aimed to help patients retrieve health information online, the sheer abundance from heterogeneous data sources makes it difficult for PWEC to distinguish the best treatment options available or even the relevance of information to an individual case. They are challenged by a daunting array of options about treatments, drugs, drug interactions and side effects, diet, lifestyle, and stigma.

Indeed, any chronic health condition unfolds as a complex interplay among all these biological, psychological, and societal factors that change over time. A personal health library with integrated and individualized information retrieval has a clear role to play in improving health outcomes for PWE and anyone with a chronic health condition. Qualitative and quantitative studies show a clear need for visually engaging, easy-to-use online tools for two key purposes: first, to extract, classify, organize, and personalize information; and second, to provide automated recommendations in support of evidence-based decisions about treatment and self-management [3,4].

Here, we present milestones of the ongoing *myAURA* interdisciplinary project that aims to address this problem directly with data- and network-science methods to integrate multiple resources into a personalized easy-to-use web service for PWEC. To design this service according to their needs, our interdisciplinary team of experts in biomedical informatics, text and social media mining, visualization, user interface design, and epilepsy self-management works with patients, caregivers, and their advocates. We also leverage an exclusive use agreement with the Epilepsy Foundation of America (EFA) both to obtain PWEC data from their website, discussion groups, and social media presence, and to recruit PWEC for our user study group. All of this goes into computing a large-scale, multi-layer epilepsy *knowledge graph* (KG) that comprises a set of networks of associated data from heterogeneous data sources relevant to PWEC.

We compute the metric backbone, a network sparsification method based on removing edges that are redundant for shortest path computation [5] of the epilepsy KG and discuss it as a powerful way to infer, identify, visualize, and recommend personalized, relevant information for PWEC. We also summarize our patient-centered methodology for designing a myAURA application. Per stakeholder needs and human-centered design specifications, when fully deployed, *myAURA* will integrate practical, location- and patient-specific health care information with targeted scientific literature, biomedical databases, social media

platforms, and epilepsy-related websites with information about specialists, clinical trials, medications, community resources, and chat rooms.

The data- and network-science methods that underpin *myAURA* drive 3 research aims:

1. Produce a multilayer epilepsy KG of relevant terminology by federating heterogeneous sources of large-scale data and exemplify its value in the study of drug-drug interaction.
2. Develop recommendation and visualization algorithms by automatically extracting the epilepsy KG's metric backbone.
3. Design and pilot test *myAURA* using focus group studies that survey PWEC regarding their desired *myAURA* content and its format.

Our immediate goal is to produce and visualize an epilepsy KG representation of heterogeneous resources in support of a user-friendly web service to facilitate PWEC self-management. We report on the interface design based on PWEC focus group input and the design requirements for other similar applications. Our long-term goal is to generate a personal health library for PWEC and in so doing create a suite of methods that can be generalized to support self-management of other chronic diseases.

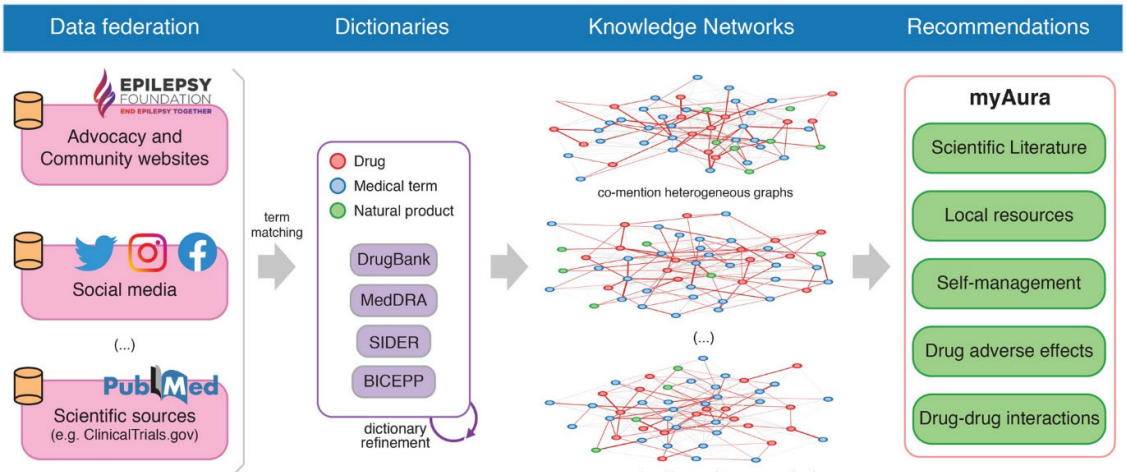

Figure 1: Diagram of the overall myAURA project: federated heterogeneous data; biomedical dictionary built from various scientific resources; the constructed multilayer epilepsy knowledge graph with its computed backbone; and the myAURA application features (local resources include, eg, epilepsy centers and clinical trials)..

References

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