Empowering Cancer Patients for Self-Tracking Medication Safety During Transitions of Care

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Abstract. This demo introduces a patient-facing platform that aims to improve the self-tracking and management of medication-related issues for patients with cancer during transitions of care. Patient-reported data are collected and stored using the Research Electronic Data Capture (REDCap), a key platform component. Individual dashboards are integrated with REDCap to visualize medication or symptom-related data and generate customized report summaries, which can be shared with their healthcare providers. Moreover, the platform's overview dashboard provides healthcare professionals with documented details of patients' medication self-tracking to support effective patient care management.

Keywords. Patient-facing technology, medication safety, REDCap, visualization

1. Introduction

Patient-facing technology (PFT) is crucial for chronic disease management, especially for patients with cancer, to manage their medications and symptoms during transitions of care [1]. Despite patients' needs and willingness to report medication-related safety concerns, current systems fail to provide a user-centered platform for easy reporting and receiving personalized feedback [2,3]. Our platform is designed to empower and engage patients in reporting, tracking, and managing medication-related safety concerns after transitioning back home. We aimed to ensure a user-friendly reporting experience for patients. Features such as easy navigation, instant feedback, and education materials customized to the patient's concern are included in the design of the reporting interface. In addition to the reporting mechanisms, we implemented an individual dashboard using Google Looker Studio for the patients to track the trajectories and summaries of their reported medication concerns and symptoms. Furthermore, this platform maintains a record of medication concerns and related symptoms reported by the patient, thus supporting evidence-based communication about their concerns.

REDCap, a HIPAA-compliant web-based application, is employed to develop our platform because it can build and manage online surveys, offer cloud-based data

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management, and provide out-of-the-box data collection tools [4]. Utilizing the native tools of REDCap, such as branching logic or field embeddings, enables a streamlined medication and symptom-tracking experience. The branching logic mechanism allows data fields to be conditionally revealed based on patients' selections regarding medication or symptoms. The field embedding feature is utilized to insert audio clips of curated scenarios of medication events to help patients understand and report their medication concerns. These interactive elements are key to our PFT design, equipping patients with knowledge and engaging them in medication self-management. However, REDCap lacks customized visual elements, such as charts and graphs, for summarizing the reported data. Thus, we integrated Google Looker Studio with REDCap to demonstrate the collected data by creating personalized dashboards for each patient. We have also developed alert mechanisms and an overview dashboard for the staff to monitor the reports and provide timely intervention, ensuring a user-centered loop.

2. Contents of demonstration

Patients report their medication-related concerns and symptoms through our platform using any preferred mobile, tablet, or desktop device compatible with popular operating systems. Branching logic is applied to help patients easily navigate to the appropriate location without excessive steps. Upon report submission, reported data will trigger an email containing customized educational materials. The email also includes a link to an updated individual dashboard, which summarizes the patient's history of reported medication concerns and symptoms. A staff member reviews patient-reported data through the report summaries and overview dashboard, where critical events are highlighted, such as severe symptoms reported by the patients. (Figure 1)
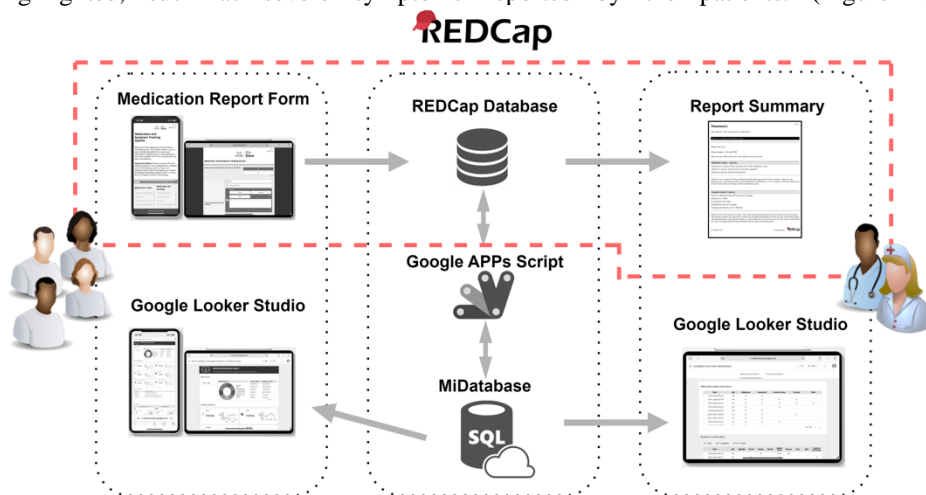

Figure 1 A diagram of the medication safety self-tracking platform.

During the presentation, the speaker will first introduce the architecture of the proposed PFT. Then, the speaker will discuss the advantages and disadvantages of different user-centered designs, such as challenges in reporting and data display interface

design, balancing sign and symptom categories and text-entry fields, and considering workload in the context of timely reporting and reviewer burden [3].

With cutting-edge tools like automated text analysis, natural language processing, and conversational agents available, generative AI has the potential to revolutionize PFT platforms. Incorporating human-in-the-loop workflows can further refine these tools to understand patients' needs and concerns better. However, to achieve optimal results, it is crucial to have access to more free text and to gain a deeper understanding of the issues that patients face.

To fully utilize the potential of advanced healthcare tools, it is crucial to involve, educate, and inform patients during transitions of care. This can be achieved by bridging the gap between current healthcare information systems and patient-reported outcomes in a sustainable manner. In simpler terms, it means creating a smooth flow of information between healthcare providers, patients, and their caregivers. By doing so, patients can be actively engaged in their own care, leading to better outcomes and higher quality healthcare. For instance, PFTs can be an indispensable component in patient portals and electronic health records, allowing patients to access their health information and communicate with their providers based on self-reported signs, symptoms, and adverse events to inform their care plan and improve overall healthcare quality. By empowering patients to take an active role in their care, healthcare providers can enhance patient safety and satisfaction while improving healthcare outcomes.

3.   Brief CVs of presenter

Dr. Yang Gong is a clinical informatician at McWilliams School of Biomedical Informatics, University of Texas. He is a past Chair of the AMIA Clinical Decision Support Working Group. Dr. Gong's research focuses on the design, implementation, and evaluation of informatics tools for reporting and analyzing patient safety events, and empowering patients and families toward shared decision-making.

4.   References

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