

Exploring a Mechanism Toward Automated Feedback for Cancer Patient Self-Reporting

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Abstract. "Infobuttons" spearheaded electronic health records (EHR) based decision support by offering automated knowledge resources to physicians. However, how such a mechanism could be leveraged to provide optimal resources to patients remains unanswered. Informatics approaches are expected to utilize more relevant information beyond EHR, such as patient-reported outcomes, to support clinical decisions. This pilot study is intended to explore how patient-reported outcomes version of the common terminology criteria for adverse events (PRO-CTCAE) in EHR can be incorporated and how to recommend tailored content to cancer patients via automated feedback.

Keywords. Automated feedback; PRO-CTCAE; cancer patients; recommended content

1. Introduction

Electronic Health Record (EHR) is a valuable tool for healthcare professionals to gain a patient's health-related data and to support healthcare professionals in making accurate decisions. EHR presently encompasses a range of patient clinical data, including health concerns and comorbidities, test and procedure results, medication, allergies, and so on [1]. However, as patients' histories become complex, there is a growing interest in providing healthcare professionals with tailored feedback to help with clinical decisions. In 2012, "Infobuttons" a clinical decision support tool to provide context resource information, was introduced into the EHR to provide resources to healthcare professionals [1]. However, evidence has shown that such automated knowledge resources lack the ability to provide individualized information for patients' various health conditions [1]. Also, evidence has shown that current EHR systems lack the ability to provide proper information about self-management and adequate communication with healthcare professionals [2]. Therefore, there is an imminent need for a summary and feedback mechanism for patients and physicians to utilize, such as patient-reported outcomes (PROs). PROs, referring to health status outcomes coming directly from a patient, have begun to play an increasing role in healthcare with the advent of more ways

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of patient-centered healthcare [3]. PROs can be utilized to quantify patients' health-related subjective experiences. The quantified outcomes reported by patients can be used to generate prioritized tasks based on patients' reports and tailored feedback to each patient. Inspired by the idea from the Infobuttons, the purpose of this paper was to explore oral anticancer agents (OAA) management using PRO-CTCAE and how PROs can be incorporated into EHR systems to enhance value-aligned decision-making.

The Infobuttons are designed for providers to offer pertinent resources based on patient data in EHR [1] by retrieving relevant resources such as patients' test results or procedure schedules and results, medication, comorbidities, and allergies. Although the Infobuttons are helpful in reducing encounter time, there is a lack of evidence about how it helps healthcare professionals improve patients' health-related outcomes [1]. Furthermore, the use rate of Infobuttons has been lower than anticipated, indicating that the user's perception may not perfectly match up with the designer's intention and barriers in maximizing its potential benefits for interpreting health outcomes during encounters [1].

Patient portals, an indispensable module in EHR, currently contain basic information accessible to the patient, such as immunization records, lab test results, prescription information, physician notes, and allergies [1]. Despite the basic information, patient portals do not offer individualized information based on patient-reported health-related concerns. Current EHR systems still need to demonstrate the effectiveness of incorporated PROs [3].

Integrating PROs into patient portals would enhance patient feedback and effective communication between providers and patients. Furthermore, PRO dashboards can be leveraged to improve the utility of patient portals, facilitating patient engagement and informed decisions [4].

2. Methods

A literature search was conducted in PubMed, Web of Science, Scopus, and Cochrane to identify articles relevant to the objectives of this study. Sixty-four articles were included in this study, among which 14 articles were evaluated on patient perception of automated feedback, approaches for measuring, aggregating, and calculating a set of triggers for automated recommendations [5].

Tableau, a data visualization tool, was considered for developing a dashboard visualization for patients taking OAA, which is expected to give an overview of side effects measured by PRO-CTCAE.

SWAY, a new app from Microsoft Office facilitating the creation and sharing of interactive reports, personal stories, presentations, and more, magazine-style webpages were explored to create tailored content between PROs and Tableau URLs and redirect to patient education webpages. Once certain PROs are calculated by a severity score, a SWAY webpage that contains useful information related to certain PROs will become available for the patient. The SWAY webpages containing content for managing OAA agents' symptoms can be accessed via web browsers on smartphones, tablets, and personal computers.

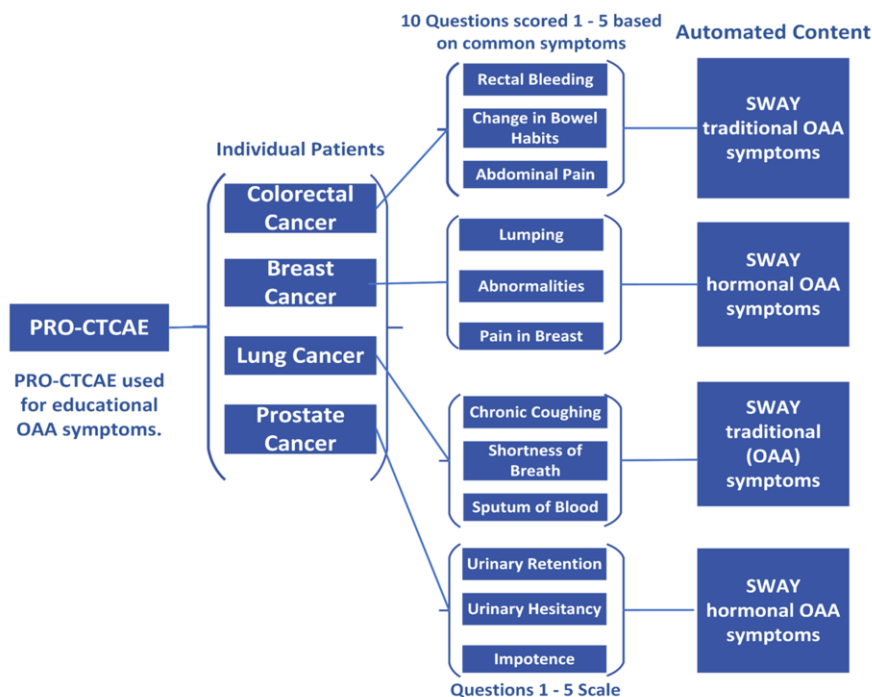


Figure 1. PRO-CTCAE automated flow

Figure 1 shows the flow from capturing patients' health-related concerns using PRO-CTCAE to delivery of magazine-style educational materials. PRO-CTCAE is used to measure the frequency and severity of symptoms based on a 1-5 rubric on an ordinal scale. The 1-5 rubric is utilized for self-management of cancer-related adverse events or concerns, which is evidenced by the articles as feasible and effective in representing different opinions. Proper scaling of PRO-CTCAE is an essential component of accurately representing the patient's symptoms based on their perspectives. Since PRO-CTCAE is designed to capture generic symptomatic adverse events reported by patients with cancer, the questions can be more specific per cancer type. To individualize questions by cancer type, the most common symptoms of each cancer type should use to promote the individualized experience, such as breast lumps, which are exclusive and specific symptoms of breast cancer. Lastly, ten questions are needed for each cancer type, i.e., lung, breast, colorectal, and prostate cancer. The scores based on the ten questions can be used to determine the overall health status of a patient. Meanwhile, the questions limited to 10 help reduce redundancy and increase patient engagement by addressing their specific needs. A score threshold is set for 10. Any PRO scored ≥ 10 will trigger an alert and follow-up SWAY web pages.

3. Results

Using the selected studies that demonstrated the most common symptoms for cancer type, specific symptoms for breast, lung, prostate, and colorectal cancer were explored [6,7,8,9]. The most common symptoms by frequency of reported symptoms via survey. An overall mechanism toward automated feedback was explored in reference to the

selected methods of automating education concepts to patients. Firstly, by using PRO-CTCAE, a patient can answer a subject of common symptoms of cancer type. Once the patient answers these questions, those answers can be scored. This mechanism can offer the benefit of giving patients the ability to quantify their symptoms, tailor information directly from patients, help with self-management, and get individualized content automated. This automated content is intended to increase self-management and patient engagement and facilitate provider-patient communication, evidenced by PROs.

4. Discussion

Using the URL action function of Tableau to support this automated function was developed to increase the accuracy of resources to empower patients and enhance healthcare quality. Utilization of the patient's perspective has not been well incorporated in patient portals for clinicians and patients to make value-aligned decisions. With this PRO consideration, individualizing each patient's health record will be more viable.

In multiple studies that included symptom management and incorporating automated patient feedback, symptom management was achieved by measuring questions using a 1-5 rubric with varying amounts of questions. Furthermore, most symptom management uses an automated feedback response to focus on the efforts of reducing cognitive stress, providing quantified evaluation, and increasing patient engagement. Most studies that we have reviewed revolve around a survey-type response for patients to navigate overall health and wellness in their daily lives. However, the studies have yet to attempt to use PROs to create automated feedback. Furthermore, only a few studies have attempted to analyze symptoms to deploy resources to patients. This brings to the question that, overall, PROs have yet to be utilized in many areas, including but not limited to mobile apps, desktop apps, or patient-facing technologies for patient symptom management. Also, there is a lack of evidence regarding if EHR has effectively incorporated any PROs. Therefore, Infobuttons hold the potential to support providers' work routines, yet their impact on the design and development of patient-facing technologies remains indistinct.

Capturing PROs continues to be an essential component within healthcare to give the full potential for offering 360-degree individualized patient care. Healthcare systems are incredibly complex environments where multiple factors need to be considered to make the best decision possible for both patients and clinicians. Furthermore, both the patients and clinicians need to understand the basis of cancer to utilize self-management fully. By leveraging PROs, it is reasonable to expect individualized care for cancer patients, particularly during transitions of care when the patients are in imminent need of managing their signs, symptoms, or adverse events in a timely manner. Ultimately, informatics approaches can offer patient-facing technology platforms to support PROs with patient burden consideration, timely alerts and reminders, automated and individualized feedback, and provider-patient communication evidenced by PROs.

It is important to ensure that the automated mechanism is not only evidence-based but also takes into account individualization. The OAA treatments can have varying effects on different individuals, so it is crucial to personalize the care to each patient's needs. This can be done by incorporating PROs into the automated system, which can provide information on how the patient is responding to treatment, their symptoms, and overall quality of life. In addition to PROs, the relationship between medication adherence, symptoms, and expected outcomes should also be considered. Adherence to

medication is vital in cancer treatment, and automated feedback can help remind patients to take their medications as prescribed. However, it is also essential to monitor the patient's symptoms and adjust the treatment plan accordingly to ensure that the expected outcomes are being achieved. Overall, patient-centered care should be specific to each individual's needs and preferences. By incorporating individualization, PROs, and medication adherence, the automated mechanism can provide personalized care and improve patient outcomes. Further discussion and research in this area are necessary to ensure that patients receive the best possible care.

5. Conclusions

To promote medication adherence and self-management for patients taking OAA, a patient-facing technology platform is expected to offer automated and individualized patient feedback. This pilot project introduced the ideas to advance PROs for cancer patients to benefit from self-reporting and enhance care quality.

Acknowledgment

This project is funded under grant number R01HS027846 from the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services (HHS).

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