Design and Use of Patient-facing ePRO and Sensor Data Visualizations During Outpatient Chemotherapy

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Submitted to: Journal of Medical Internet Research
on: May 31, 2024

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Abstract

Background: Symptoms and side effects change frequently during outpatient cancer treatment. As electronic patient-reported outcome (ePRO) systems used in oncology have become more common, they have been primarily designed to collect symptoms from patients and shared with providers without making the data collected available to patients. The goal of this study was to develop and evaluate ePRO and sensor data visualizations that patients could access online during chemotherapy.

Objective: The goal of this study was to develop and evaluate patient-facing ePRO and sensor data visualizations that patients could access online during chemotherapy.

Methods: As part of an ongoing NCI-funded study to develop a remote symptom monitoring system, we created mobile-friendly web visualizations of daily symptom ratings, wearable data and self-management resources, available to patients undergoing chemotherapy. At the end of the three month study, 141 patients completed a survey.

Results: Survey respondents were heterogenous in age (M 61 years old, range 29- 92 years old), race (80%, 113/141 white, 20%, 28/141 other) and cancer stage (56%, 75/135 Stage IV). About half (54%, 76/141) of participants accessed the link to their data visualizations. There were no significant differences between the participants who did and did not click the link during the study in terms of average age (P =.74), gender (P =.66), race (P =.50) or cancer stage (P =.31) . Of those who accessed the platform, most (54%, 41/76) viewed it a few times, while 13% (10/76) used it daily. Most (77%, 58/75) believed it was “Somewhat” or “Very Helpful/Informative.” All ten daily users joined the study within three months of starting chemotherapy for the first time.

Conclusions: Findings suggest that patients new to chemotherapy may be most interested in viewing visualizations of daily symptom and sensor data and that the web application is widely accessible for patients of different ages, races, and cancer stages.

(JMIR Preprints 31/05/2024:62711)
DOI: https://doi.org/10.2196/preprints.62711

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Introduction

Cancer patients undergoing outpatient chemotherapy experience a range of symptoms that fluctuate during treatment and impact quality of life [1]. As electronic patient-reported outcome (ePRO) systems to collect symptom ratings from patients have become more common in oncology care, they have been primarily designed to share data with or trigger alerts for clinicians with less than half sharing data visualizations back to patients providing the data [2-3]. Sharing visualizations of ePRO data along with other patient-generated health data (e.g., data from wearable devices) may help patients undergoing cancer treatment find patterns that help them prepare for future treatment cycles, manage side effects, and have productive conversations with their clinicians [4-5].

Objective

The purpose of this study was to describe initial efforts to design and develop personalized patient-facing visualizations of daily ePRO symptoms along with wearable device data and to describe patterns of use in the context of a prospective longitudinal study of patients undergoing chemotherapy.

Methods

Overview

As part of an ongoing NCI-funded study to develop a remote symptom monitoring system during chemotherapy for any solid tumor, we created mobile-friendly web visualizations of daily symptom ratings and wearable device data along with dynamic evidence-based self-management resources (Figure 1). We provided each patient with a personalized link to their real-time visualizations at the time of enrollment, but patients were not given instructions about how often to view the visualizations or reminded to use it during the study. At the end of the three-month study, 141 patients completed a survey assessing whether they used the visualizations, frequency of use, what information was helpful, and suggestions for improvement. Data were collected between February 2022 and April 2024.

Ethics Approval

This study was conducted at a National Cancer Institute-Designated Comprehensive Cancer Center. The Institutional Review Board of the University of Pittsburgh approved all study activities (STUDY 19070011).

Results

Characteristics of our sample can be found in Figure 2. Survey respondents were heterogenous in age (M 61 years old, range 29-92 years old), race (80%, 113/141 white, 20%, 28/141 other) and cancer stage (56%, 75/135 Stage IV). About half (54%, 76/141) of participants accessed the link to their data visualizations. There were no significant differences between the participants who did and did not click the link during the study in terms of average age (P =.74), gender (P =.66), race (P =.50) or

cancer stage (*P* =.31). Of those who accessed the platform, most (54%, 41/76) viewed it a few times, while 13% (10/76) used it daily. Most (77%, 58/75) believed it was “Somewhat” or “Very Helpful/Informative.” All ten daily users joined the study within three months of starting chemotherapy for the first time.

Discussion

Principle Findings

Providing patients with real-time visualizations of their ePRO and activity data throughout chemotherapy could help them anticipate and manage symptoms more effectively and potentially find patterns between activity or other sensor data and symptoms. Findings from this preliminary work suggest that patients are motivated to view their own data visualizations and that these initial visualizations were accessible to patients of different ages, races, and cancer stages. Patients who viewed the visualizations daily tended to be patients new to chemotherapy, who may be experiencing higher levels of anxiety and need for health information [6]. Future research should investigate the potential benefit of patient-facing visualizations for patients beginning chemotherapy treatment.

Limitations

The visualizations and other website content described here were developed during an ongoing research study as an ancillary project, and participants received no instructions or reminders about how or when to interact with the website.

Conclusion

This report describes initial efforts to share real-time ePRO and wearable device data visualizations

with patients undergoing chemotherapy. More research is needed to assess and improve the usability of data visualizations and to examine the impact of visualizations on symptom management self-efficacy and other outcomes.

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Supplementary Files

Figures

Visualizations of daily symptom ratings and wearable data with self-care resources.

Participant characteristics.

Characteristic	Overall, N = 141[1]	Did you click on this link during the study?		Test statistic and p-value[2]
		No, N = 65[1]	Yes, N = 76[1]	
Age, years	61 (12)	61 (13)	60 (11)	$t(130.1)=0.68$, $p=0.74$
Gender				$X^2(1)=0.2$, $p=0.66$[3]
Female	94 (67%)	45 (70%)	49 (64%)	
Male	45 (32%)	19 (30%)	26 (34%)	
Non-binary	1 (0.7%)	0 (0%)	1 (1.3%)	
Unknown	1	1	0	
Race				$X^2(1)=0.45$, $p=0.5$
White/Caucasian	113 (80%)	50 (77%)	63 (83%)	
Other	28 (20%)	15 (23%)	13 (17%)	
Stage IV cancer				$X^2(1)=1.04$, $p=0.31$[4]
Yes	75 (56%)	39 (61%)	36 (51%)	
No	60 (44%)	25 (39%)	35 (49%)	
Unknown	6	1	5	

[1]Mean (SD); n (%)

[2]Welch two sample t-test; Pearson's Chi-squared test

[3]Participants with non-binary or unknown gender excluded

[4]Participants with unknown cancer stage excluded