Motivating Adherence to Symptom Reporting Among Patients with Cancer: Pilot Study

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***Abstract*—Incorporating mobile health (mHealth) into cancer care holds growing promise for improving quality and access, especially in rural and disadvantaged populations, who continue to face disparities in distress prevalence and healthcare engagement. Regardless, sustained engagement with mHealth solutions remains challenging due to motivational, technical, and usability barriers. We developed and piloted a HIPAA-compliant mHealth app, Assuage, in a 45-day longitudinal study with seven cancer patients, the majority from rural backgrounds. Participants alternated between daily and every-other-day symptom reporting. Our findings reflect adherence trends across reporting frequencies, stable and favorable system usability measures before and after the study, and qualitative insights about participants' willingness to use mHealth for symptom self-reporting.**

***Index Terms*—mobile health, mHealth, cancer patients, adherence, symptom-reporting, patient-reported outcomes, user studies**

I. Introduction

The National Comprehensive Cancer Network (NCCN) defines distress as "a multifactorial unpleasant experience of a psychological (ie, cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with one's ability to cope effectively with cancer, its physical symptoms, and its treatment [1]." Distress is highly prevalent among cancer patients in the United States, with rural populations disproportionately affected due to limited access to providers and long travel distances to care [2]–[4]. Untreated distress reduces treatment adherence, satisfaction with care, quality of life, and survival rates [3]. The NCCN developed the Distress Thermometer (DT) as a validated tool to screen for distress [5], typically administered during in-person visits approximately every 45 days [4].

The ubiquity of mobile devices makes mobile health (mHealth) systems particularly attractive, especially for reaching rural populations [6]. A promising use of mHealth is remote patient monitoring (RPM), which can include objective data collected via sensor devices or subjective data gathered from patient-reported outcomes (PROs). This approach results in a better understanding of a patient's overall health and symptom tracking between visits, potentially overcoming barriers related to geography and provider availability. Incorporating mHealth into cancer care can reduce the need for frequent in-person visits, lowering costs for patients and providers.

While patients generally accept mHealth for RPM and PRO [7]–[10], sustained engagement and adherence remain challenges [11]. Inconsistent use of mHealth is often attributed to a lack of motivation, poor engagement strategies, and poor usability [12]–[14], which directly relates to adoption and engagement with an app, affecting a patient's willingness to adhere [15]. Notifications and prompting are important for increasing and maintaining adherence to PROs with mHealth [7]. However, encouraging PROs at too high a rate can be counterproductive, contributing to patient distress and burnout [16]–[18], indicating that a proper balance must be struck to maximize compliance.

This paper introduces Assuage, a HIPAA-compliant mHealth app, and presents preliminary results from a within-subjects 45-day longitudinal study with seven cancer patients, majority rural, that investigates adherence to distress symptom reporting at varying frequencies. We approached this study with the following research questions.

- How frequently are patients with cancer willing to self-report symptoms?
- How can patients with cancer be effectively motivated to engage with mHealth and adhere to symptom-reporting?

We report on participant adherence to reporting symptoms at different frequencies, usability of the system, and participant feedback concerning using mHealth and adhering to self-reporting symptoms.

II. Methods

A. Study Tool

Assuage is a HIPAA-compliant iOS mobile app designed as a research testbed for conducting mHealth studies. It leverages Apple's open-source ResearchKit and CareKit frameworks and integrates quality-of-life surveys seamlessly. Additionally,

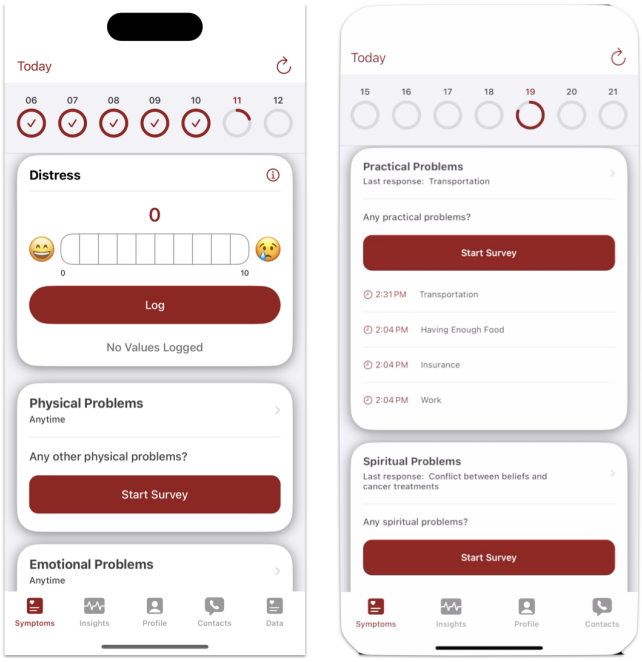

Fig. 1. Screenshots of the symptom reporting page in Assuage.

Assuage uses Apple's HealthKit to collect sensor-based health data from wearable devices such as Apple Watch or Fitbit, if available.

All data collected by Assuage is securely stored on the user's device, with transmission and storage protected by HIPAA-compliant encryption. Each participant is assigned a random identifier within the app and database to safeguard patient privacy. Key features of Assuage at the time of this study included symptom reporting (Figure 1), local notifications to encourage adherence, alerts prompting users to contact the cancer center if distress levels were rated medium or high, and pre-loaded contact information for the cancer center, the research team, and each participant's oncologist.

B. Study Procedures

This mixed-methods study comprised three parts and was approved by the University of Kentucky's Institutional Review Board (protocol 70590). Participants were recruited in person from the Markey Cancer Center between July and December 2023 and required access to an iOS or iPadOS device. Employing a within-subjects design, each participant alternated weekly between two symptom-reporting frequencies: daily and every-other-day. Reporting schedules were pragmatically aligned with participants' most recent or upcoming medical appointments.

At enrollment, participants met individually with a research team member for approximately one hour to complete preliminary questionnaires covering demographic information, cancer diagnosis, mobile device usage, attitudes toward electronic symptom reporting, and an initial usability assessment. They were informed that reporting frequency would vary weekly. After the 45-day study period, participants met again individually for about an hour to answer post-study questions and complete an additional usability assessment. All interactions occurred either in person at the cancer center or via Zoom.

C. Data Collection and Analysis

We collected data through the Assuage app, questionnaires, and semi-structured interviews. Variables collected included demographics, system usability scores, patient-reported distress, reporting timestamps, notification interactions, app usage metrics, and qualitative responses to post-study questions. Quantitative data from Assuage and usability assessments were analyzed descriptively using Python in Jupyter notebooks. Semi-structured interview transcripts were analyzed using thematic analysis [19]. System usability was measured using the Post-Study System Usability Questionnaire (PSSUQ) [20], which assesses overall usability and three subcategories: System Usability, Information Quality, and Interface Quality. Although not diagnostic, the PSSUQ is effective for evaluating usability in small samples [21].

Adherence was defined as logging distress on required reporting days. To assess long-term compliance, we employed the Loyalty Index (LI), a component of the Engagement Index [22]. The LI calculation is as follows:

$$L = 1 - \frac{1}{N} \tag{1}$$

where N is the number of expected visits during a specified interval [23]. For daily reporting weeks, the expected LI is:

$$L_{DE} = 1 - \frac{1}{7} = 0.85 \tag{2}$$

For every-other-day reporting weeks, the expected LI is:

$$L_{AE} = 1 - \frac{1}{4} = 0.75 \tag{3}$$

We evaluated adherence by comparing each participant's observed LI against these expected values.

III. Results and Discussion

Descriptive statistics for usability and adherence are presented alongside participant feedback.

A. Participant Demographics

All seven participants were non-Hispanic White. Most (n=5) held a college degree, while two completed some college. Participant ages ranged widely: over 65 (n=1), 55–64 (n=3), 45–54 (n=1), 35–44 (n=1), and 25–34 (n=1). Diagnoses included breast cancer (n=2) and melanoma (n=5), with participants at various treatment stages. The majority (n=5) resided in rural areas. Participants had varying levels of mobile app experience. Notably, for one participant (P5), a caregiver used and logged symptoms on their behalf, reflecting common real-world practice.

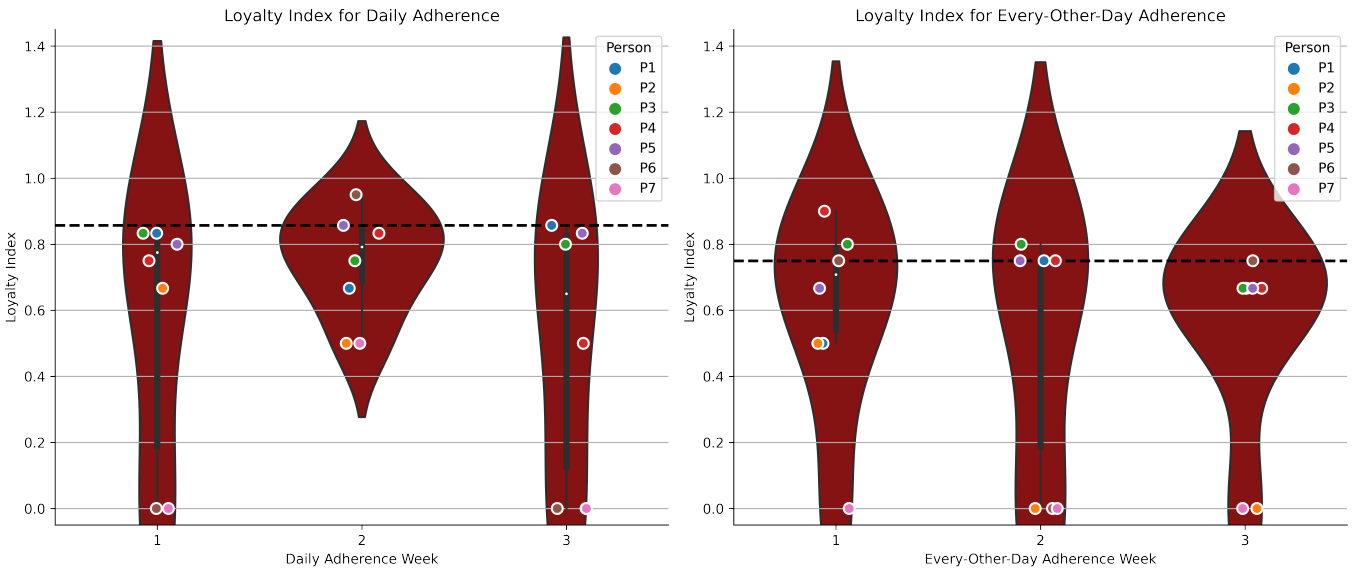

Fig. 2. Violin plots depicting the *Loyalty Index* of each participant grouped by daily reporting schedules and every-other-day reporting schedules. The horizontal dashed line represents ideal adherence. *Due to P2 dropping out of the study midway, their loyalty index was not included in the computation of the plots.

TABLE I
AVERAGE PSSUQ RATINGS BEFORE AND AFTER THE STUDY.

Usability	**Mean (SD)**	
	Pre	***Post***
Overall	1.2 (0.7)	1.4 (0.4)
System Usability	1.4 (0.8)	1.3 (0.3)
Information Quality	1.4 (0.7)	1.6 (0.4)
Interface Quality	1.4 (0.9)	1.2 (0.4)

TABLE II
MEDIAN (IQR) VALUES OF THE *Loyalty Index* FOR A PARTICIPANT'S RESPECTIVE REQUIRED ADHERENCE WEEK DURING THE STUDY.

Adherence	**Median (IQR)**
Daily week 1	0.78 (0.19-0.23)
Daily week 2	0.79 (0.69-0.85)
Daily week 3	0.65 (0.13-0.83)
Every-other-day week 1	0.71 (0.54-0.79)
Every-other-day week 2	0.75 (0.19-0.75)
Every-other-day week 3	0.67 (0)

B. Usability

Usability was assessed using the Post-Study System Usability Questionnaire (PSSUQ), which employs a 7-point Likert scale where 1 indicates strong agreement and 7 strong disagreement. Table I summarizes average scores pre- and post-study across overall usability and subcategories. Overall, usability ratings remained stable and favorable throughout the 45-day period.

C. Adherence

Figure 2 depicts violin plots illustrating participants' Loyalty Index (LI) grouped by daily and every-other-day reporting weeks. Participant P2's LI was excluded from median and interquartile range calculations due to early dropout. Table II reports weekly median LI values. The expected ideal LI for daily and every-other-day reporting is 0.85 and 0.75, respectively.

D. Participant Feedback

Most participants found the app highly intuitive and easy to use, though several required initial orientation before independently navigating its features. Once familiar, nearly all agreed that completing assessments demanded minimal extra effort. Many successfully incorporated symptom logging into their daily routines, while others reported more sporadically as memory permitted. Notably, most participants relied on self-motivation rather than local notifications, using the app primarily at home but sometimes during work or between appointments.

A strong preference emerged for daily or even multiple daily reporting, particularly during periods of heightened symptom severity. However, participants also recognized that sustained daily reporting could become overwhelming when faced with significant distress or life stressors. Reminders were consistently viewed as valuable, helping counteract cognitive lapses and facilitating engagement amidst the "chaos" of cancer management.

Self-reporting fostered greater self-awareness, prompting regular "self-checks" and facilitating more informed communication with healthcare providers. Participants described sharing logged symptom histories with their clinicians, which enhanced the quality and efficiency of medical consultations. Several expressed intent to continue routine self-reporting beyond the study, either with the app or personal journals.

E. Discussion

Participant feedback underscored the app's strength as a supportive tool for self-monitoring and symptom trend tracking. Routine symptom logging empowered patients to reflect on their physical and emotional wellbeing, creating a sense of control and active involvement in their care. This self-awareness, paired with the ability to efficiently share assessment histories with providers, helped facilitate higher quality care interactions. Despite these benefits, some barriers persisted. Providers lacked direct access to patient logs, potentially limiting engagement. Many patients and clinicians preferred integrating symptom tracking with existing platforms—particularly MyChart—highlighting the need for interoperability with electronic health records to streamline communication and workflow.

Notifications were broadly considered helpful and unobtrusive; however, participants emphasized the importance of flexibility in reporting schedules, as strict daily tracking could exacerbate distress during challenging periods. These insights point toward designing mHealth interventions that balance structured engagement with patient autonomy, integrating seamlessly into diverse clinical environments and supporting ongoing behavioral change.

IV. Conclusion

This 45-day pilot study demonstrated the feasibility and usability of Assuage, a HIPAA-compliant mHealth app, for distress symptom reporting among seven cancer patients. Adherence to varying symptom-reporting schedules and notification strategies was assessed, with participants consistently describing Assuage as intuitive, empowering, and non-burdensome. Routine use increased patient awareness and facilitated symptom tracking and communication with care teams. Participant feedback highlighted desires for enhanced connectivity with existing health systems and responsiveness to individual reporting needs. Ongoing recruitment aims to validate these findings in a broader population. Future development will prioritize integration with electronic health records, support bilateral provider engagement, and explore machine learning approaches to proactively identify patients at risk for deterioration.

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