

Designing Survey-Based Mobile Interfaces for Rural Cancer Patients Using Apple's ResearchKit and CareKit: Usability Study

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Abstract

Background: Despite the increased accessibility and availability of technology in recent years, equality and access to health-related technology remain limited to certain demographics. In particular, patients who are older or from rural communities represent a large segment of people who are currently underutilizing mHealth solutions and are considered medically underserved. Rural communities commonly have a higher rate of chronic disease and reduced access to providers; therefore, rural patients could benefit from adopting digital solutions such as mHealth apps. However, system usability continues to be a barrier to mHealth adoption among users with non-traditional digital literacy.

Objective: This study investigated if state-of-the-art mobile app interfaces from open-source libraries provide sufficient usability for rural cancer patients with minimal design changes and forgoing the co-design process.

Methods: We developed the Assuage app to serve as a research platform for any mHealth study. We conducted a pilot study using Assuage to assess the usability of four (4) mobile user interfaces (UIs) based on open-source libraries from Apple's ResearchKit and CareKit that all had varying complexity in reporting distress symptoms with cancer patients. Cancer patients were recruited to complete the distress assessment using a randomly selected UI. Data was collected on participants': ages, location, mobile app usage, and familiarity with mobile health apps. Participants rated usability with the System Usability Scale (SUS), and usability issues were documented and compared. A one-way ANOVA was used to compare the effect of the UIs on the SUS scores.

Results: Thirty (30) current and/or post-surgery cancer patients participated in this pilot study. Most participants were over 50 (24/30, 80%), from rural areas (25/30, 83%), had up to a high school education (19/30, 63%), and were unfamiliar with mobile apps for health (21/30, 70%). General mobile app use was split with (14/30, 43%) not regularly using mobile apps. The mean SUS score across the UIs was 75.8 (SD 22.2), with two of the UIs achieving an SUS score >=80, meeting the industry standard of 80. Critical usability issues were related to data input and navigation with touch devices, such as scale-format questions, vertical scrolling, and traversing multiple screens.

Conclusions: The findings from this study show that most cancer patients (20/30, 67%) who participated in this study rated the different interfaces of Assuage as above average (68). This suggests that with minimal interface alterations, Apple's ResearchKit and CareKit libraries can provide usable UIs for older and rural users. When resources are limited, the design stage can be simplified by omitting the codesign process, while still preserving suitable usability for users with non-traditional technical proficiency. Usability comparable to industry standards can be achieved by considering heuristics for both interface and electronic survey design, specifically: how to segment and navigate surveys, present important interface elements, and signal

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gestural interactions.

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Abstract

Background: Despite the increased accessibility and availability of technology in recent years, equality and access to health-related technology remain limited to some demographics. In particular, patients who are older or from rural communities represent a large segment of people who are currently underutilizing mobile health (mHealth) solutions and are considered medically underserved. Rural communities commonly have a higher rate of chronic disease and reduced access to providers; therefore, rural patients could benefit from adopting digital solutions such as mHealth apps. However, system usability continues to hinder mHealth adoption among users with nontraditional digital literacy.

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Results: We recruited 30 current and/or post-surgery cancer patients for this pilot study. Most participants were over age 50 (24/30, 80%), from rural areas (25/30, 83%), had up to a high school education (19/30, 63%), and were unfamiliar with mobile health apps (21/30, 70%). General mobile app use was split with (14/30, 43%) not regularly using mobile apps. The mean SUS score across the UIs was 75.8 (SD 22.2), with UI 3 and UI 4 achieving an SUS score >=80, meeting the industry

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standard for good usability of 80. Critical usability issues were related to data input and navigation with touch devices, such as scale-format questions, vertical scrolling, and traversing multiple screens.

Conclusions: The findings from this study show that most cancer patients (20/30, 67%) who participated in this study rated the different interfaces of Assuage as above average usability (68). This suggests that Apple's ResearchKit and CareKit libraries can provide usable UIs for older and rural users with minimal interface alterations. When resources are limited, the design stage can be simplified by omitting the co-design process while preserving suitable usability for users with non-traditional technical proficiency. Usability comparable to industry standards can be achieved by considering heuristics for interface and electronic survey design, specifically, how to segment and navigate surveys, present important interface elements, and signal gestural interactions.

Keywords: human-computer interaction; usability testing; mobile health; mHealth; cancer patients; distress; survey design

Introduction

Background

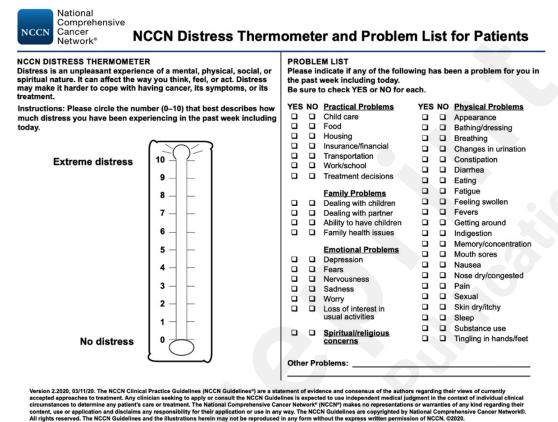
Mobile health (mHealth) technologies have been around for over a decade, yet the percentage of adult patients actively using these mHealth technologies is lower than desired [1,2]. The demographics of adults not utilizing mHealth solutions are consistent with patients from rural populations, racial and ethnic minority groups, and older individuals, which overlaps with persons categorized as medically underserved [3]. According to the Health Resources & Services Administration, medically underserved populations have been designated as having too few primary care providers, a high infant mortality rate, prevalent poverty, or a high elderly population [4,5]. Specifically, rural communities, like those of the Southeastern United States or Appalachia, commonly have higher rates of chronic disease, reduced access to providers, and lack the same medical resources as their urban counterparts [6–10]. The ubiquity of mobile devices makes mHealth particularly attractive for reaching disadvantaged populations [11–14]. A promising use of mHealth is remote patient monitoring, which can include objective data, such as biometrics, via sensor devices or subjective data, such as quality of life surveys, via patient-reported outcomes, resulting in a better understanding of a patient's overall health and symptom tracking between visits [15,16].

As of 2023, 90% of people in the United States own a smartphone. In addition, it was reported that while 27% of people who lived in rural areas did not have broadband at home, 87% owned a smartphone [17,18]. In particular, adopting innovations in rural communities is essential because the disparities between advantaged and disadvantaged communities continue to grow for digital literacy [16,19,20], also known as the digital divide [20–22]. Factors in the divide between advantaged and disadvantaged groups are health literacy, knowledge of technology, and comfort of use [20,23,24]. Designers should ensure system user interfaces (UIs) are universally acceptable, particularly concerning users with limited technical proficiency [20]. Ensuring the usability of a system is essential for accurate data collection and reducing attrition rates [25–27].

Simply digitizing a paper-based survey may present complexities that render the digitized counterpart unusable and discourage the required frequency and accuracy to encourage adherence [28–30]. For example, patients may accidentally submit their responses prematurely or not at all. Not to mention the role that usability can play in the eventual penetration of an innovative technology, which has been explored through the Technology Acceptance Model [31–33] and research focused on mHealth adoption [27,34–36]. A participant's age has been shown to significantly affect the ease of navigation and learnability, especially as cognition and motor control decline [37]. However,

proper interface design can minimize user error and allow a smooth user experience [38]. To address the aforementioned concerns, researchers and developers can co-design the UI to ensure digitization is tailored to the respective demographic [39,40].

Figure 1. National Comprehensive Cancer Network's Distress Thermometer and Problem list. The version shown here was the version used for this study. The newest version can be found here [41].



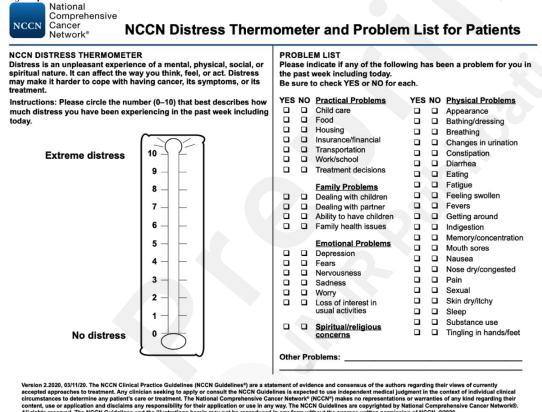
Distress Screening

According to the National Cancer Institute, distress is an "emotional, social, spiritual, or physical pain or suffering that may cause a person to feel sad, afraid, depressed, anxious, or lonely" [42]. Distress is prevalent in cancer patients regardless of disease stage or modality [8,43–46], and untreated distress has been shown to lead to greater pain, reduced physical function, increased medical costs, and longer stays in the hospital [8,43,47]. The National Comprehensive Cancer Network (NCCN) created the Distress Thermometer and Problem List, hereafter referred to as the NCCN assessment, for use as a screening tool for recognizing distress in cancer patients (Figure 1) [41,48], and has since been shown to indicate distress accurately [43,49]. The NCCN assessment was designed to improve patient care and increase patient quality of life. Furthermore, studies have shown that distress screening can improve health outcomes, including reduced morbidity and mortality [8,43].

Unfortunately, due to factors like staff burnout or emotional fatigue, signs of distress in patients may go unnoticed [43,44]. In addition, there can also be variations across different cancer centers regarding when patients should be screened [43]. This raises the need for a more effective and efficient process related to distress screening [44]. The implementation of digitizing the NCCN

assessment as a mobile app poses many advantages, such as real-time identification of distress factors and triage to the proper provider, generating insightful data around common issues during the cancer experience, and providing insight into potential resource allocation [14,15,50].

Conversely, there are barriers to the implementation of new tools in healthcare. For example, modifying any clinical practice can be challenging, and providers hesitate to make drastic changes without enough evidence of substantial benefit and patient-driven motivation [51–53]. Additionally, digital implementations of distress screening that are considered complex or not user-friendly by target users can lead to reduced effectiveness. Effective distress screening requires patient adherence and accurate information input to enable providers to devise proper interventions and follow-ups [14]. Despite the challenges, technology poses a great solution to address the needs of patient distress monitoring when resources and access to care are limited [54,55]. In particular, the prevalence and ubiquity of mobile devices present opportunities for patients in remote and rural areas to utilize mHealth apps to enhance their care. By reducing the time between distress screenings, providers and researchers can better understand a patient's overall distress and causes of distress and track symptoms between visits.



Open-source Frameworks

In 2014, Apple launched HealthKit, a central repository for health and fitness data that is automatically available on all iOS devices, and subsequently launched an open-sourced ResearchKit in 2015. Three major modules make up ResearchKit: informed consent, surveys, and active tasks [56,57]. Institutions like Duke and Stanford have launched research-based mobile apps using ResearchKit [58]. Mobile apps developed using ResearchKit have already begun to be integrated into standard hospital software systems such as Epic Systems [59]. The ResearchKit framework has been used in various mHealth apps, including those focused on asthma, autism, Parkinson's, type 2 diabetes, cancer, cardiovascular, mental health, pregnancy, postpartum, hepatitis, and epilepsy [56].

In 2016, Apple released and open-sourced a complementary framework to HealthKit and ResearchKit, called CareKit, which supports personalized healthcare with customized care plans, adherence tracking, and visualization of trends in user data [60]. CareKit consists of three independent modules: CareKitUI, CareKitStore, and CareKitFHIR. CareKitUI provides a set of health, fitness, and medical views that can be customized to create mobile apps. CareKitStore provides local storage of patient data on personal devices using CoreData, which is Apple's implementation of an SQLite database. Data generated using the CareKitStore framework is securely stored and encrypted on the device [61]. CareKitFHIR enables seamless conversion between CareKitStore objects and HL7 FHIR [62] resources to integrate with FHIR-based electronic health records and applications. Combining HealthKit, CareKit, and ResearchKit allows for the development of mHealth apps with many desired features for remote patient monitoring and self-management of health by users [26,63] with reduced effort from developers [60]. Together, these iOS and iPadOS frameworks enable the collection and sharing of user-generated health data and streamline the process of building survey-based mobile apps for research [64].

Survey Design Heuristics

The following heuristics from previous research can be followed to provide an optimal user experience for respondents in digital surveys. Surveys should be aesthetically pleasing and easy to navigate [28,30] with an explicit visual flow [65]. Although some researchers [66] have found that scrolling layouts can sometimes have faster completion times, designers should still be strategic in deciding between paging versus scrolling along with the grouping and sequencing of questions. Furthermore, when considering answer choices, potential options should include some variation of "do not know" [67,68]. In addition, surveys should be succinct [30,65,69] and maintain a standardized format, as variations in format can lead to decreased usability [28]. Surveys should always be easy to understand with clear directions for answering questions [28,65,69]. Moreover, survey language should mimic verbal dialogue whenever possible [28]. Additional features to consider implementing are showing participants their progress towards completion, a "thank you" page, and an overview of results at the end [28].

A set of usability heuristics often used as a baseline for designing systems is Nielsen's 10 principles for interaction design which consist of the following guidelines: (1) visibility of system status, (2) match between system and real world, (3) user control and freedom, (4) consistency and standards, (5) error prevention, (6) recognition rather than recall, (7) flexibility and efficiency of use, (8) aesthetic and minimalist design, (9) recognize, diagnose, and recover from errors, (10) help and documentation [70]. Lastly, incorporating Nielsen's 10 general principles for interaction design will make UIs more accessible, user-friendly, and intuitive [70,71].

This Study

Ensuring the interface usability of an mHealth system is essential to its effectiveness, which often requires patient adherence and accurate information input to enable providers to devise proper interventions and follow-ups and prevent attrition [27,72]. Previous research suggests that codesigning for users with limited digital literacy, such as older or rural users, may be required to build suitable usable interfaces, but it often requires considerable time and resources [73–75]. Designers often co-design the UI to address the concerns and ensure digitization is tailored to the respective demographic [40]. This pilot study assesses the usability of multiple UI implementations of the NCCN assessment (Figure 1). In particular, for understudied populations, such as Appalachian and rural cancer patients who are underserved and vulnerable [76,77]. The different UIs were designed

without co-design to assess whether or not usable UIs could be achieved for this demographic when resources for the design stage are limited.

Methods

Ethics Approval

The University of Kentucky's Institutional Review Board approved all research activities (#64149).

Recruitment

Cancer patients were recruited in person from the University of Kentucky's Markey Cancer Center to participate in this study between July and August 2021. Two medical oncologists at the cancer center permitted us to interact with willing patients at their clinics. The doctors asked if patients would be willing to speak to a researcher about the study during their visits. If patients agreed, we went to the respective waiting room, informed the patients about the purpose of the study, gauged interest, and, if applicable, proceeded with the study tasks. If patients were not interested in the study, we thanked them for their time, and they were not entered into the pilot study. We recruited 30 patients to participate in this study. Participants did not need to have a certain level of digital literacy, as we were interested in participants who were not very familiar with mobile devices and apps to assess whether Assuage would be usable for people with limited digital literacy. Participants were not offered payment to participate in this study.

Procedure

This pilot study used between-subjects A/B testing to compare the usability of 4 different UI designs for completing a distress survey in a mobile app. A/B testing, or split testing, is a randomized experiment where users are shown two or more versions of a system, website, or app to determine which version performs better based on specific metrics [78]. A/B testing protocols are commonly used in industry, and different system versions are randomly assigned to users for comparative analysis [78,79]. All research procedures were conducted in person at the Markey Cancer Center. Assuage was pre-installed onto an iPad for participants to use. After we went over informed consent information with the patient, the procedure went as follows: we asked patients the following demographic questions: age range, gender identity, ethnicity and race, education, residence, familiarity with the paper form of the NCCN assessment, mobile application use frequency, and mobile applications for health and medical use frequency.

We then introduced Assuage to the patient, which re-iterated consent via an in-app onboarding process and study information and re-verified that the patient was still interested in participating. Assuage was programmed to randomly select one of the UIs to display to users following in-app onboarding. This was done by assigning a number from 0 to 3 to the different UIs and randomly selecting an integer in that range. Therefore, we did not have direct control over which UI group participants were assigned. Participants were presented with the randomly selected UI and instructed to follow the app prompts to complete the distress assessment. If a participant went through the NCCN assessment with a companion, the participant did all the physical interaction with the interface. It was appropriate for 2 of the patients (2/30, 7%) to enlist the help of their accompanying caregiver, as this mimics assistance needed naturally in the clinical or at-home setting.

While participants were completing the NCCN assessment in the app, we observed and collected notes on any usability issues, software bugs, and other noteworthy information. If a participant got

stuck or confused using the app, we gently nudged them on how to proceed and documented the usability issue. After participants finished using Assuage to complete the assessment, they completed a usability assessment. Afterward, participants were asked to provide additional comments regarding the study and their use of Assuage. We also inquired about each participant's specific set of mobile devices. No identifiable participant information was collected through the Assuage app. No video or audio recordings took place. Notes about the participants' actions, usability issues, and responses were also collected, and usability issues were organized into related themes.

Outcomes Measured

This study measured perceived usability by participants after completing the distress assessment with Assuage. Scores from the System Usability Scale (SUS) [80] were compared between the UI design variations within Assuage. The SUS is a validated tool with a reputation for providing swift and reliable results [81,82]. The SUS consists of 10 statements, or items, with a five-point Likert scale from 1 (strongly disagree) to 5 (strongly agree). A negative response is considered a score less than 3 for positively worded statements and greater than 3 for negatively worded statements. While the SUS is not a diagnostic tool, it can effectively determine whether the tested system would be generally usable even when used to evaluate small sample sizes with as few as five (5) users [80–86]. The SUS has been used in industry and academic research and is sufficient for pilot studies of mHealth applications [25,27,40,83,87–89]. Individual SUS Items can be seen in Multimedia Appendix 1.

The SUS scores from participants (N=30) were grouped by the respective user interfaces tested by the participants, and results were analyzed using the SciPy Python3 package in iPython Notebooks [90]. A one-way ANOVA was performed to compare the effect of the different UIs on usability, represented by the SUS score. Lewis and Sauro assessed data from 241 usability studies to create a curved grading scale where the SUS score of 68 is a "C" grade and considered acceptable usability [81]. However, industry targets an SUS score of 80 to represent an above-average user experience [17, 62, 94]. We used a content analysis approach to analyze qualitative data, such as observed usability issues and participant comments. Content analysis is a method used to systematically classify data, usually written, into segments with codes (labels) to make inferences about the content and underlying themes [91]. Data was coded using Taguette [92].

System Design and Development

Assuage is a HIPAA-compliant mobile iOS, iPadOS, and watchOS platform developed using Apple's HealthKit [93], CareKit [60], and ResearchKit [56]. Assuage is a research testbed for assessing and improving patient care through health-related studies. Remote patient monitoring can be accomplished through Assuage by adding various quality-of-life surveys, such as the NCCN assessment in Figure 1. Additional frameworks like ParseCareKit [94] synchronize ResearchKit and CareKit data with a HIPAA-compliant server [95]. Assuage offers multiple UIs for patient input of subjective information such as their distress symptoms. The decision to provide multiple UIs is based on the knowledge that some demographics, like rural cancer patients, have not heavily adopted mHealth but are also not completely removed from modern everyday technologies, like mobile devices or smartphones [17,18,96]. Conversely, the number of rural-dwelling adults who own a smartphone continues to rise [18], creating avenues for mHealth to have a larger impact on this population. Therefore, we wanted to gauge if standard UI elements common in mobile interfaces provide acceptable usability for a mHealth use case, such as symptom reporting, without expending extra resources on co-design.

Figure 12. User interface 1.

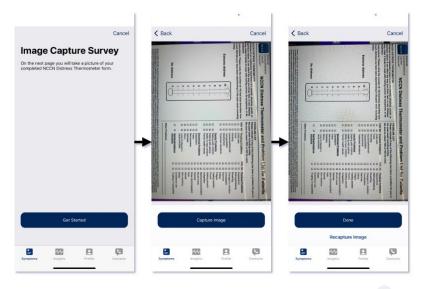


Figure 23. User interface 2.

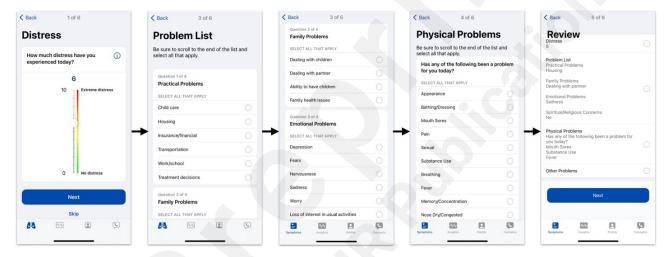


Figure 34. User interface 3.

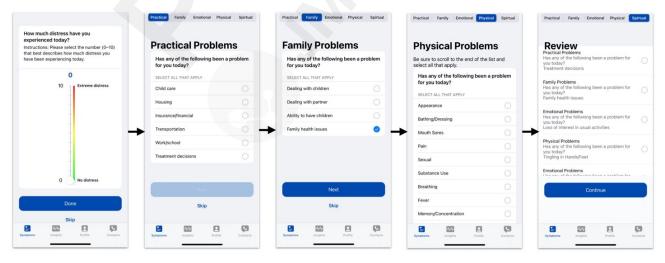
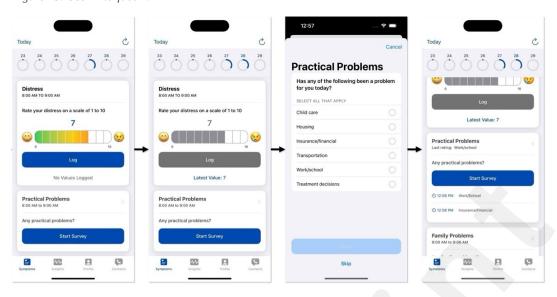


Figure 45. User interface 4.



Four user interfaces were implemented in Assuage for the pilot. All the UIs were designed with Apple's ResearchKit and one with CareKit, which leverages Apple's Human Interface Guidelines [97]. ResearchKit and CareKit provide out-of-the-box UI views and elements for developers to build health and medical mobile apps, which have been used in various research studies [34,64,98–101]. Screenshots of the different UIs are shown (Figure 2-5). In particular, the UIs differ in how the NCCN assessment components are displayed and navigated. When gauging a patient's distress using the NCCN assessment, the reported number value of the distress thermometer component typically correlates to the immediate actions taken by the care team regarding the patient. With this in mind, the entirely digitized interfaces (UIs 2-4) present the distress thermometer first, but patients can still choose to skip any question in all UI versions. Descriptions of the different UIs are as follows.

- (1) UI 1: (Figure 2) Enables patients to sequentially step through three (3) screens to capture a picture of the paper-based NCCN assessment. UI 1 depends solely on ResearchKit's standard survey design with no alterations. Navigation is limited to the *next* and *back* buttons. Patients familiar with the NCCN assessment survey may benefit from UI 1 since it requires completing the paper-based survey as normal. Conversely, if a patient is unfamiliar with mobile devices or has ailments that prevent them from holding the camera steady, UI 1 could be less usable.
- (2) UI 2: (Figure 3) Patients navigate the NCCN survey components sequentially. UI 2 depends solely on ResearchKit's standard survey design, with no alterations. Navigation is limited to the *next* and *back* buttons. Patients unfamiliar with the NCCN survey may benefit from UI 2 since all the NCCN survey questions must be viewed before completing the survey. Conversely, the sequential requirement of UI 2's design does not allow the user to quickly navigate different survey sections compared to the paper NCCN assessment or UI 3 and UI 4. This may require more time to be spent on the survey and could burden patients already familiar with the NCCN survey question set, who prefer to skip sections that do not apply to their current distress. When a patient reaches the end of UI 2, they can review their answers before submission and are allowed to change previously entered questions.
- (3) UI 3: (Figure 4) Patients can navigate the NCCN survey sequentially and non-sequentially with a horizontal navigation segment, allowing patients to skip around to different sections. UI 3 is designed by retrofitting ResearchKit's survey design with a horizontal navigation segment that enables patients to skip around to different sections of the NCCN survey, providing improved navigation. In addition, UI 3 requires minimal vertical scrolling by the patient compared to UI 2. Like the paper-based NCCN assessment, UI 3 allows patients to

quickly see all relevant distress categories. However, unlike the paper-based survey, patients are not overwhelmed by having to step through all the questions and are only presented with questions associated with the respective section of interest. Patients familiar with the NCCN assessment may benefit from UI 3's design as it allows quicker survey completion times since they can navigate to sections and questions of interest. On the contrary, if a patient is unfamiliar with the NCCN assessment or a familiar patient forgets a relevant question to their distress belonging to a particular segment label, skipping around may cause questions to be missed, reducing the ability of the care team to provide the best care. When patients reach the end of UI 3, they can review answers before submission and change previously entered questions.

(4) UI 4: (Figure 5) Implements a modern and modularized view of the NCCN assessment highly dependent on vertical scrolling. Patients can select *cards* corresponding to surveys, allowing for the most fluid navigation between sections. The navigation and card layout in UI 4 leverages both ResearchKit and CareKit and takes advantage of the latest iOS design principles. The distress thermometer in UI 4 keeps the thermometer aesthetic of the paper-based NCCN assessment but deviates by being horizontally placed instead of vertically. In addition to the temperature and number values that UIs 1-3 have on the distress thermometer, UI 4 also has emojis representing extreme distress points. UI 4 allows patients to scroll through survey sections vertically, while answers provided on previous days can be viewed by swiping the screen horizontally. Individual survey cards display the answers entered for the respective survey section. An adherence circle is also shown at the top of UI 4 to represent survey completion. Limitations to UI 4 are similar to those of UI 3, concerning patients unfamiliar with the NCCN assessment who may miss recording relevant answers. In addition, if a patient is not comfortable with the latest UI design principles of iOS, patients could be deterred from UI 4.

To reiterate, the most significant change in design between the different UIs is the navigation style and how a user will traverse through the application/survey. Regarding mHealth tracking apps for users with chronic illness, the design should be simple, self-explanatory, visually appealing, and intuitive to navigate [16].

Figure 6. Nielsen's 10 usability heuristics and the different heuristics covered in Assuage's 4 UIs.

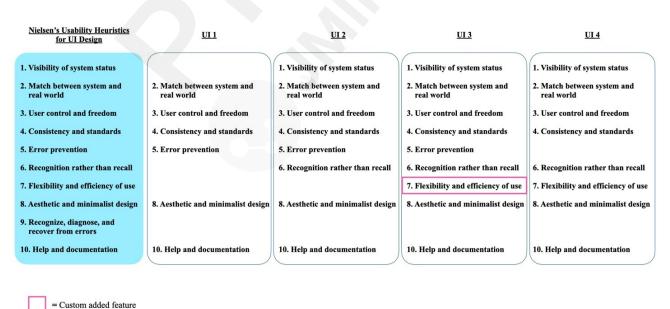


Figure 6 highlights which of Nielsen's principles were present in the different UI variations. Note that 3 out of 4 of the UIs were using out-of-the-box interface elements while we customized the

navigation elements of UI 3 to include a flexible way to navigate the surveys, correlating with Nielsen's guideline for flexibility and efficiency of use (#7) and suggested from prior research on electronic survey navigation design [28,30]. Further description of how the different UIs in Assuage satisfied Nielsen's usability heuristics can be found in Table S1 in Multimedia Appendix 2.

(1)

Results

This section presents the findings of this pilot study regarding the 4 UIs. Descriptive statistics are reported (Table 1). Thirty (N=30) usability surveys were completed across Assuage's 4 UIs. This study was not designed or powered to detect the differences between the UIs; therefore, the comparative results reported should be considered preliminary evidence [40].

Participant Demographics

The demographics of participants are summarized in Table 1. The majority of participants were older than 50 years old (24/30, 80%), had up to a high school education (19/30, 63%), lived in a rural area (25/30, 83%), and were unfamiliar with mHealth apps (21/30, 70%). Participant gender and general mobile app use were split with slightly more females (16/30, 53%) and users of mobile apps with a frequency of at least sometimes or more (17/30, 57%). About half the participants (16/30, 53%) used Assuage in light mode, and the rest (14/30, 47%) used Assuage in dark mode. While we did not gather specific data on each participant's cancer type and mode of treatment, the two oncologists who were a part of this study specialize in the following: (1) all forms of lung, head, and neck cancers; and (2) bone and soft tissue sarcomas, colectoral, pancreatic, and hepatobiliary cancers. Of the participants, 83% (25/30) were patients of the first oncologist, and 17% (5/30) were patients of the second oncologist. Most of the participants (29/30, 97%) resided in Kentucky, and the remainder (1/30, 3%) resided in West Virginia.

Table 1. Participant demographics. Some percentages may not total 100 due to rounding.

Variable		UI 1 n=6	UI 2 n=8	UI 3 n=7	UI 4 n=9	Total N=30
Gender, n (%)						
	Female	3 (50)	4 (50)	3 (43)	6 (67)	16 (53)
	Male	3 (50)	4 (50)	4 (57)	3 (33)	14 (47)
Age, n (%)						
	> 50	5 (83)	6 (75)	7 (100)	9 (100)	24 (80)
	< 50	1 (17)	2 (25)	-	3 (33)	6 (20)
Race & Ethnicity, n (%)						
	Non-Hispanic White	5 (83)	6 (75)	7 (100)	9 (100)	27 (90)
	Non-Hispanic	1 (17)	2 (25)	-	-	3 (10)

	Black					
Education, n (%)						
	Did not complete high school	-	-	3 (43)	1 (11)	4 (13)
	High school	3 (50)	5 (63)	2 (29)	5 (56)	15 (50)
	Some college	1 (17)	2 (25)	1 (14)	2 (22)	6 (20)
	College degree	2 (33)	1 (13)	1 (14)	1 (11)	5 (17)
Mobile Apps, n (%)						
	Never/Rarely	3 (50)	3 (38)	4 (57)	3 (33)	13 (43)
	Sometimes or more	3 (50)	5 (63)	3 (43)	6 (67)	17 (57)
Health Apps, n (%)						
	Familiar	2 (33)	3 (38)	1 (14)	3 (33)	9 (30)
	Unfamiliar	4 (67)	5 (63)	6 (86)	6 (67)	21 (70)
Residence, n (%)						
	Rural	4 (67)	6 (75)	7 (100)	8 (89)	25 (83)
	Urban	2 (33)	2 (25)	-	1 (11)	5 (17)
NCCN, n (%)						
	Yes	2 (33)	2 (25)	2 (29)	3 (33)	9 (30)
	No/Unsure	3 (50)	3 (38)	5 (71)	6 (67)	17 (57)
	N/A	1 (17)	3 (38)	-	-	4 (13)
Display mode, n (%)						
	Light	2 (33)	3 (38)	4 (57)	7 (78)	16 (53)
	Dark	4 (67)	5 (63)	3 (43)	2 (22)	14 (47)
Mobile, n (%)						
	No mobile device	3 (50)	4 (50)	5 (71)	6 (67)	18 (60)
	Basic phone	-	-	-	1 (11)	1 (3)
	Android	2 (33)	2 (25)	-	-	4 (13)
	Apple	1 (17)	2 (25)	2 (29)	2 (22)	7 (23)
Oncologist, n (%)						
	Lung, head, and neck	6 (100)	6 (75)	6 (86)	7 (78)	25 (83)

	and soft	-	2 (25)	1 (14)	2 (22)	5 (17)
tissue	sarcomas,					
colecto	ral,					
pancrea	atic, and					
hepatol	oiliary					

System Usability Scores

The mean SUS score across the UIs was 75.8 (SD 22.2). Participants were randomly distributed across the 4 UIs. Among the 30 participants, 6 (20%) assessed UI 1 with a mean SUS score of 70.4 (SD 25.3), 8 (27%) assessed UI 2 with a mean SUS score of 67.2 (SD 31.2), 7 (23%) assessed UI 3 with a mean SUS score of 80.0 (SD 14.1), and 9 (30%) assessed UI 4 with a mean SUS score of 80.3 (SD 16.1). The SUS scores for each UI are reported in Table 2. Figure 7 shows the distribution of SUS scores for the different UI groups in relation to different target SUS scores. The dashed line represents an acceptable usability rating of 68 or above [81]. The dash-dotted line represents the industry target score of 80 to determine good usability [81]. Of the 4 UIs, 3 (UI 1, UI 3, UI 4) had an average SUS score above the acceptable threshold of at least 68, and 2 (UI 3, UI 4) met the industry threshold of at least 80. The average SUS score of UI 2 was just below what can be considered acceptable usability by 0.8 points. A one-way ANOVA was done to compare the effect of the UIs on the SUS scores. However, the results were not statistically significant ($F_{3.26} = 0.68$, P=.57). Figure 8 depicts the SUS scores across the UIs grouped by participant age. Additional figures depicting the SUS scores across the different UIs grouped by participant mobile use and light mode versus dark mode are shown in Figure S1-S2 in Multimedia Appendix 2. The averages of these groupings are shown in Table S2 in Multimedia Appendix 2. The average score for each item on the SUS (Multimedia Appendix 1) is also reported in Table S3 in Multimedia Appendix 2. Of the participants who rated the UIs in Assuage as having less-than-acceptable usability, all were over 50 and unfamiliar with health applications (10/30), and (2/30) did not regularly use mobile apps.

Though our findings depict differences in scores between participant groups, they are not as significant. For example, UI 3 had a difference of ~19%, and UI 4 had a difference of ~1.3% when comparing mobile app users to non-users (Table S2 in Multimedia Appendix 2). Similarly, when looking at participants over the age of 50, UI 3 and UI 4 have a smaller variance in usability score, and UI 3 had the tightest distribution with only one (1) user rating below acceptable usability. Another interesting finding was the difference in usability scores between interfaces in dark mode and light mode. Aside from UI 1, the UIs in dark mode received significantly lower average usability scores, about 20-30 points, when compared to light mode.

Figure 7. Boxplots depicting the distribution of SUS scores grouped by the user interface.

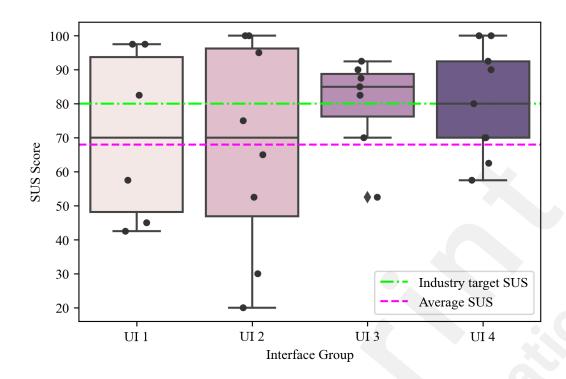
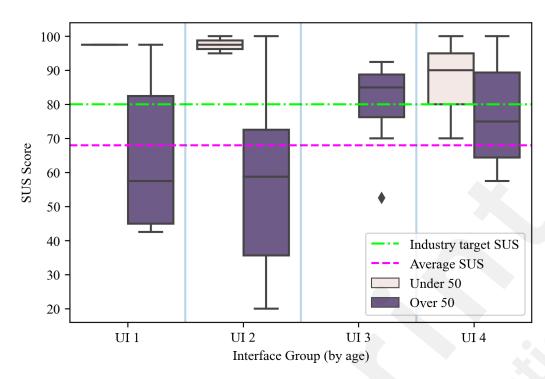


Table 2. An overview of the usability for each UI group is presented. Number of participants per group, the mean and median SUS scores per group, how many participants rated a UI with a less-than-acceptable usability score, and how many usability issues occurred with each UI group.

Interface	Users, n	SUS score, mean (SD)	SUS score, median (IQR)	Unacceptable usability, n (%)	Usability issues, n
UI 1	6	70.4 (25.3)	70.0 (48.1-93.8)	3 (50)	1
UI 2	8	67.2 (31.2)	70.0 (46.9-96.3)	4 (50)	11
UI 3	7	80.0 (14.1)	85.0 (76.3-88.8)	1 (14)	14
UI 4	9	80.3 (16.1)	80.0 (70.0-92.5)	2 (22)	10
Total	30	74.8 (22.2)	81.3 (58.8-92.5)	10 (33)	36

Figure 8. Boxplots depicting the distribution of SUS scores grouped by interface and age.



Usability Issues

Although all UIs were considered usable for patients, there were quite a few usability issues that could correlate with users' lack of digital literacy. About half of the participants (16/30, 53%) encountered usability issues when using Assuage. Most participants who experienced issues were over 50 years old (13/16) and did not regularly use mobile apps (12/16). A total of 16 usability problems were identified during the study. The usability issues experienced were divided into the following themes: data input and collection (15 issues), navigation (12 issues), instructions (3 issues), NCCN (4 issues), and color and interaction (2 issues). Table 5 presents the usability issues and the frequency of occurrence. Data input and collection are issues that could affect the user's accuracy and input of distress data. Navigation issues are related to how the user navigates the assessments within the app. Instructions are issues where clearer instruction is needed. NCCN are issues related to the NCCN questionnaire. Color and interaction are usability issues that did not fit well in the previous themes.

Table 33. Usability issues experienced by users and frequency of occurrence.

Theme (n)	Usability Issues (n)			
Data input and collection (15)				
	Unclear how to answer distress scale (7)			
	Unclear how to indicate no to a specific symptom (3)			
	Unclear what to do when no symptoms (2)			
	Unsure if assessment was done and submitted (3)			
Navigation (12)				
	Confusion when needing to vertical scroll (4)			
	Uncertainty on how to start assessment (1)			
	Unclear how to skip sections (3)			
	Unsure how to continue to next part of assessment (2)			

	Accidental navigation to other parts of app (1)	
	Tapping on wrong button to complete surveys (1)	
Instructions (3)		
	In-app instructions not clear (2)	
	Review page unclear (1)	
NCCN (4)		
	Question wording confusing (3)	
	Too many questions (1)	
Color and Interaction (2)		
	Confusion when log button changed colors (1)	
	Hard to take a pic of paper form (1)	

Participant Feedback

Patients had mixed perceptions of the different UIs learnability and usefulness. Positive responses from the participants described the UIs as: easy, simple, intuitive, helpful, and good. Negative responses can be summarized as: difficult, non-intuitive, inconsistent, and not for everyone. Regarding overall willingness to use an app for self-reporting symptoms, (2/30) explicitly said they would want to use a symptom-reporting app more frequently (separate from the SUS item 1 (Multimedia Appendix 1), which states, "I think that I would be willing to use this system frequently"). Participants also expressed that if a doctor told them to use the app, they would. Table 6 presents selected participants' comments after using Assuage.

Desired features and improvements for reporting distress symptoms in a mHealth platform included distress data being sent directly to the doctor, flagging the medical team if a patient reports high distress, prompts following completion of the distress assessment that can direct patients on who to contact depending on symptoms reported, proper feedback letting the patient know that their answers have been recorded, and an option to answer "none" if the patient has no symptoms instead of choosing to skip the question set.

Table 44. Selected participant comments following usability testing. Demographic data of the participants and the UI they used is included.

Sentiment	Comments (Demographics)	UI
Positive	"Someone like me, if they know just a little stuff, then they'd be able	UI 4
	to use it."	
	(Over 50, High school education, Does not use mobile apps)	
Mixed	It was not easy for this participant, but they did not feel it would be	UI 2
	hard for others to learn.	
	(Over 50, High school education, Does not use mobile apps)	
Negative	"Just doesn't pertain to everybody."	UI 2
	(Over 50, High school education, Does not use mobile apps)	
	"Not a lot of people computer savvy."	UI 4
	(Over 50, High school education, Uses mobile apps)	
	"Would be difficult to older people."	UI 2
	(Over 50, Some college, Uses mobile apps)	

Discussion

Principal Findings

This study assessed if state-of-the-art mobile app interface designs from Apple's open-source ResearchKit and CareKit libraries would be usable for cancer patients from rural areas. We leveraged the UI elements from Apple's ResearchKit and CareKit frameworks to implement 4 different UI designs for patients to complete the NCCN distress assessment on the Assuage platform. The UIs varied by how the assessment questions were presented and navigated. This pilot study found that a survey-based app developed with Apple's open-source libraries had a usable interface for cancer patients within our target demographic. Specifically, utilizing these frameworks, we achieved acceptable usability scores among non-traditional users, such as those who were older and did not regularly use mobile apps. The implication is that the frameworks are suitable for carrying out mHealth research with this demographic and can be used as a base for full-stack mHealth apps.

Additionally, we evaluated if co-designing the interfaces was necessary to achieve acceptable usability with cancer patients who were older or from rural areas. The results of this study show that it is possible to achieve good usability without co-design, which can reduce the time and resources spent in the design and development stages of a system or app for conducting mHealth research. Predictably, participants who were older than 50 and did not use mobile devices regularly experienced the most usability issues. The most prominent usability issues were related to data input and navigation, with 15 and 12 occurrences, respectively. The most critical usability issues were participants needing to learn how to answer the distress scale and the UI assuming a participant knows when to scroll vertically. Not only did these two issues have the highest count of participants who experienced them (7/30, 23%) and (4/30, 13%), respectively, but not addressing them can hinder participant completion of the survey, accurate reporting of symptoms and distress, and motivation to use the system.

Finally, we wanted to understand what caused a specific UI to have a higher usability rating than the others as a basis to move forward for future research studies with our target demographic. Our findings show that the majority of participants (20/30, 67%) rated the UIs as having acceptable and above-average usability across the different interfaces, with UI 3 and UI 4 averaging around 10 points higher than UI 1 and UI 2 using the SUS. UI 3 and UI 4 also met the industry threshold for good usability with average SUS scores of at least 80. Despite navigation and input challenges, participants could still complete the in-app survey and expressed the willingness to use an mHealth system for self-reporting symptoms. Unsurprisingly, participants were more concerned about what happened after reporting symptoms, such as whether the doctor would be notified or if the participant would receive feedback on how to continue based on the reported symptoms.

Comparison with Prior Work

Prior work suggests that mHealth systems should be co-designed with target users for optimal outcomes and usability [7,8,40]. Authors in [40] used participatory design to recreate an alternative design to the NCCN assessment. Digital and paper prototypes of the redesigned survey were compared to the original using the SUS, resulting in patients finding the digital prototypes more usable than their paper counterparts. The usability of Assuage's different UIs was comparable to the co-designed prototypes without undergoing the resource-intensive process. Similarly, our usability results were comparable to other mHealth studies using the SUS to assess iterative designs [25,102–104].

While the usability issues encountered by participants could be attributed to digital literacy,

developers can take extra steps to ensure universal design when using development frameworks. Formatting a survey for web and mobile delivery has been evaluated, but has had conflicting results [65-67,69]. For example, usability heuristics say that vertical and horizontal scrolling should be avoided when possible. Apple's Human Interface Guidelines offer suggestions regarding best practices for scroll views, such as scroll indicators, which double as a way to show how much of the screen to progress [97]. Designing using paging instead of scrolling formats surveys in a clean and easy-to-read manner. Minimizing scrolling prevents users from missing questions or important interface elements, such as navigation buttons. Alternatively, studies have also found that scrolling layouts resulted in higher perceived usability and faster survey completion times [65,66]. Our usability results were slightly better with a paging design (UI 2 versus UI 3, with an average usability score of 67.2 (SD 31.2) and 80.0 (14.1), respectively). UI 4 used Apple's CareKit UI (a modular design combined with vertical scrolling) and received good usability scores (80.3 (SD16.1)), contradicting some of the best practices found in the literature. Notably, the modularized surveys display similar to paging designs. In addition, is interesting to note that the two UIs that provided more freedom in navigating the survey were the most highly rated. Reflecting on Nielsen's usability heuristics (Figure 6), the navigation schemes implemented in UI 3 and UI 4 were the only interfaces that satisfied Nielsen's heuristic (#7) flexibility and efficiency of use. Considering the visual similarities between UI 2 and UI 3, we can infer that the flexible navigation, coupled with the grouping of questions on different pages, significantly improved usability scores.

Prior work suggests respondents should be offered a "none" option or similar when presented with a list of other choices [68]. However, the placement of that option influences whether participants choose it. Placing an option, like "none," when other choices do not apply at the top of the page results in more respondents choosing it compared to when placed at the bottom of the survey [67], which can be important to consider for the thoroughness of data. In our case, we did not require participants to input an answer in every section and included a "skip" option at the bottom of the page, separate from the possible symptom choices. Even so, some participants would have preferred an actual answer choice instead of skipping the page, as it made them feel like they were not fully completing the assessment. At times, the "skip" button did not stand out to participants as a tappable button compared to the "next" button, which had a visible background (ex. Figure 5, steps 2-3).

Participants encountered the most problems with the distress scale. The use of rating scales in surveys is fairly common [29,30]; however, for some participants, it was not intuitive to slide or tap to interact with the distress scale. All but one of the participants who experienced this problem (6/7) did not regularly use mobile apps. We attempted to keep the question format as similar to the original NCCN assessment as possible; however, an alternative format to a rating scale could be a number picker or text entry with specific number values. Similar to the symptoms, a list view could also be considered, although potentially less efficient if all numbers do not fit on the device screen. Alternatively, gestural signifiers can be used to demonstrate how to complete tasks. The findings of this usability study support prior research on electronic survey design, particularly with aging users, such as those older than 50, which should be considered when using frameworks that provide predetermined UI features. It should be noted that although important, prior work suggests that question-wording does not affect usability as much as the layout [67].

Regarding the use of dark mode versus light mode in UI designs, studies have investigated how the trend of dark mode, or negative polarity, interfaces impact users [105–108]. A recent study found that light-mode interfaces are more advantageous to young and older users concerning cognitive load [106]. Considering most of our participants were over 50, this could give insight into the drastic difference in usability scores between those who used Assuage in light mode and those in dark mode. Similarly, many cancer patients and survivors experience cognitive effects due to cancer and its

treatment [39]. Therefore, while developers of mHealth systems can implement a dark-mode interface, attention must be given to ensuring the different UI elements do not add unnecessary mental effort for users [107]. However, based on these preliminary results, not implementing dark mode should not have an adverse effect on our demographic of cancer patients who are older than 50 and rural.

Limitations and Future Work

A sample size of thirty (30) is typically considered small; however, previous research on system usability studies implies that small sample sizes, ~5, can capture most usability issues [85,86]. This study was also interrupted due to a spike in COVID-19 cases, which resulted in the hospital halting all non-essential and non-medical activities, limiting our sample size. We attempted to use additional techniques during usability testing, such as a think-aloud approach; however, as patient participants were being seen between appointments, brain fog from chemo treatments resulted in frustration from participants with this approach. Excluding cognitive impairment due to cancer-related treatments, the normal aging process can also cause a decline in cognitive function for older people in similar studies. Likewise, with respect to participant time, the study survey was kept as short as possible. This further supported our choice to use the SUS versus a more in-depth questionnaire, such as the Mobile Application Rating Scale (MARS) [109], the Health Information Technology Usability Evaluation Scale (Health-ITUE) [110], or the mHealth App Usability Questionnaire (MAUQ) [111]. Finally, we invited healthcare professionals to assess Assuage; however, only 1 responded, and we did not include their SUS score in this paper.

Despite limitations, we identified areas of improvement for the interface design of surveys in mobile apps. We also determined which UIs in Assuage would be suitable for future deployment studies with our target demographic of cancer patients who are rural, older than 50, and may not regularly use mobile apps. Not all participants owned mobile devices, posing a potential wide-scale implementation problem. While reports show smartphone use to be consistently rising among members of the rural United States, this may not be consistent across all rural areas. Conversely, participants without mobile devices usually had other family members with mobile devices and smartphones. Most participants expressed a willingness to use an application to monitor their symptoms. However, deploying the app among rural patients in the Southeastern and Appalachian regions is necessary to determine if apps are a viable solution for this demographic. In the future, we plan to conduct follow-up studies to assess adherence and reasons for engagement with Assuage to report distress symptoms of patients over time.

Conclusions

Digital implementations of validated paper-based surveys can have unexpected outcomes on the usability of the survey and an application. If a digital survey has low usability, patients could be deterred from entering information, or data could be unreliable, limiting the tool's effectiveness. This could also affect research findings from this method or how the clinic responds. The findings show that 67% (20/30) cancer patients who participated in this pilot usability study rated the different interfaces of Assuage as above average with the SUS (68) [115]. This suggests that Apple's health and research frameworks provide usable UIs with minimal alterations to the default interface for users older than 50 and with limited digital literacy. The usability issues observed align with common usability problems for designing surveys. ResearchKit and CareKit can be used to reliably design a mobile app for collecting survey-based data. However, heuristics for both usability and electronic survey design should be considered when deciding how to best segment and navigate

surveys and how to present important interface elements.

The main difference between the UIs was how users could navigate between the different survey sections. The interfaces that satisfied Nielsen's heuristic, (#7) flexibility and efficiency of use, allowed users to freely jump between survey sections non-sequentially and achieved the highest usability scores. Therefore, it can be inferred that flexible question navigation is a feature that should not be overlooked when digitizing surveys. Other ways to increase the usability of interface designs for self-reporting outcomes by patients who do not frequently use mobile apps include gestural signifiers, visual cues when scrolling is available, such as scroll indicators, minimizing scrolling per page, and dedicated answer choice when none apply.

Findings from this paper do not aim to undermine the importance or benefits of co-design or participatory design for underserved and understudied populations but to demonstrate the possibility for successful digital implementations when resources cannot be heavily allocated to the design process. Although the UIs in the Assuage app had overall good usability, if resources and time permit, involving end-users in the design process can improve the overall usability of the final product, increasing the chance for sustained use. However, for survey-based mHealth iOS apps, ResearchKit and CareKit are legitimate options for developers and researchers seeking open-source libraries with suitable interface designs to use with similar populations to this study. Participatory design is still suggested to understand key features to support users unfamiliar with smart devices and touch interfaces when assistance is not readily available. A follow-up longitudinal study deploying Assuage with end users is currently underway.

Conflicts of Interest

The Assuage research platform was developed in the Network Reconnaissance Lab which is led by Dr. Corey Baker, an author of this paper.

Abbreviations

mHealth: mobile health

NCCN: National Comprehensive Cancer Network

SUS: System Usability Scale

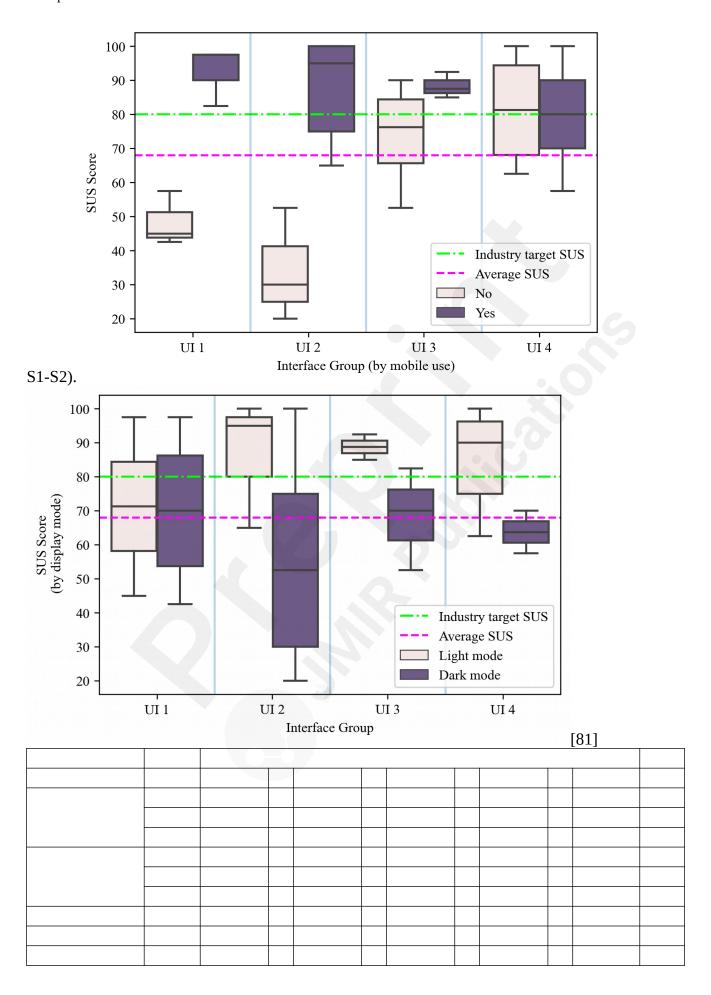
UI: user interface

Multimedia Appendix 1

System Usability Scale

Multimedia Appendix 2

Additional tables and figures related to interface design (Table S1) and results (Table S2-S3, Figure



5		

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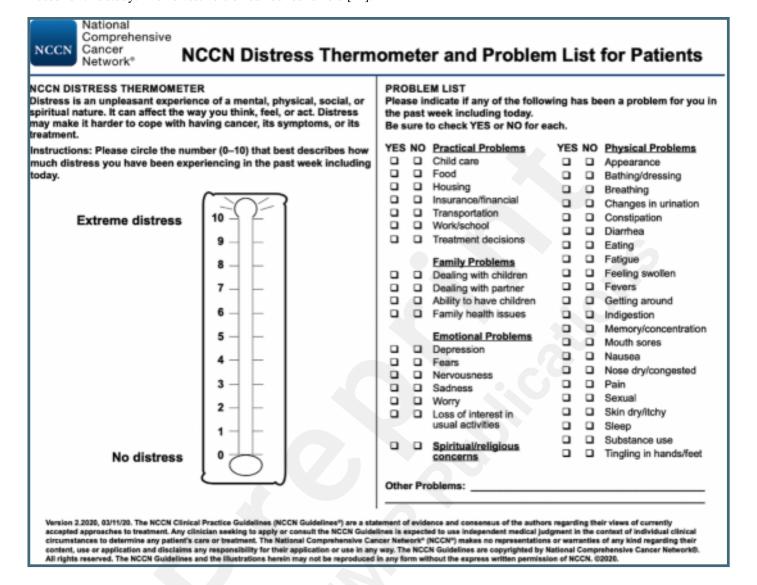
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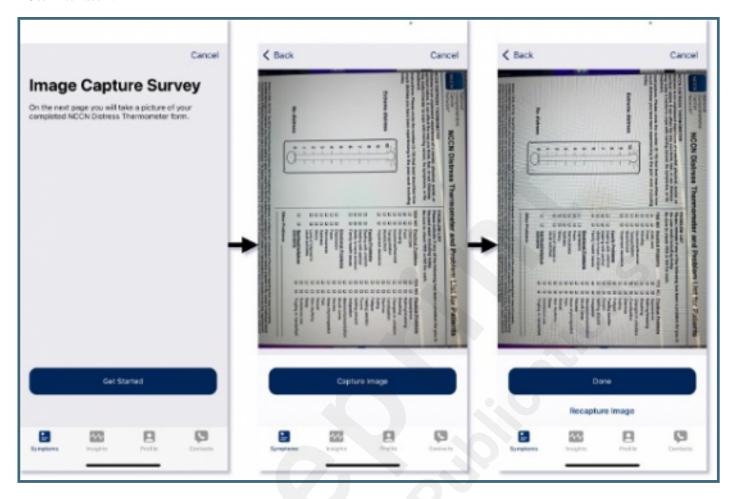
Supplementary Files

Figures

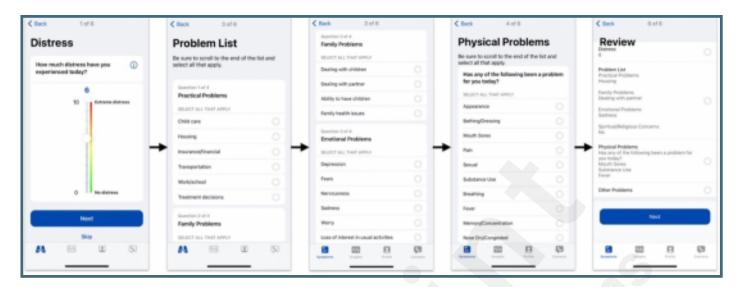
National Comprehensive Cancer Network's Distress Thermometer and Problem List. The version shown here was the version used for this study. The newest version can be found here [41].



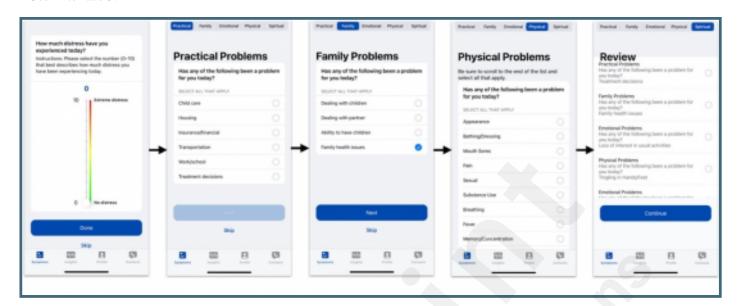
User interface 1.



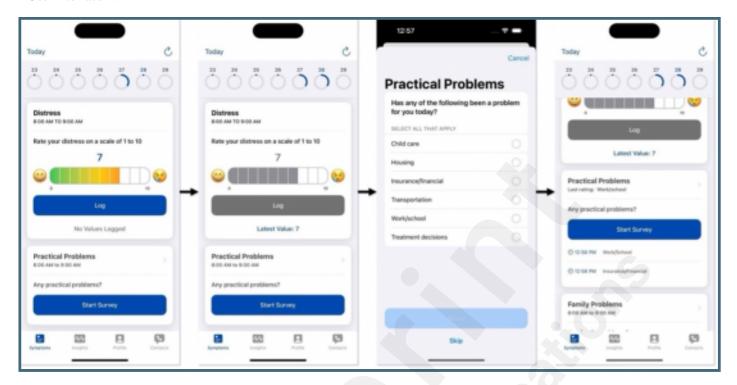
User interface 2.



User interface 3.



User interface 4.



Nielsen's 10 usability heuristics and the different heuristics covered in Assuage's 4 UIs.

Nielsen's Usability Heuristics for UI Design	ш	<u>UL2</u>	шэ	1114
1. Visibility of system status		1. Visibility of system status	1. Visibility of system status	1. Visibility of system status
2. Match between system and real world	2. Match between system and real world	2. Match between system and real world	Match between system and real world	2. Match between system and real world
3. User control and freedom	3. User control and freedom	3. User control and freedom	3. User control and freedom	3. User control and freedom
4. Consistency and standards	4. Consistency and standards	4. Consistency and standards	4. Consistency and standards	4. Consistency and standards
5. Error prevention	5. Error prevention	5. Error prevention	5. Error prevention	
6. Recognition rather than recall		6. Recognition rather than recall	6. Recognition rather than recall	6. Recognition rather than recall
7. Flexibility and efficiency of use			7. Flexibility and efficiency of use	7. Flexibility and efficiency of use
8. Aesthetic and minimalist design	8. Aesthetic and minimalist design	8. Aesthetic and minimalist design	8. Aesthetic and minimalist design	8. Aesthetic and minimalist design
9. Recognize, diagnose, and recover from errors				
10. Help and documentation	10. Help and documentation	10. Help and documentation	10. Help and documentation	10. Help and documentation
= Custom added feature				

Multimedia Appendixes

The System Usability Scale (SUS).

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Additional tables and figures related to interface design (Table S1) and results (Table S2-S3, Figure S1-S2).

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CONSORT (or other) checklists

CONSORT checklist pdf.

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