

Original Article

Usability of PCforMe in Patients With Advanced Cancer Referred to Outpatient Palliative Care: Results of a Randomized, Active-Controlled Pilot Trial



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Abstract

Context. Low utilization of palliative care services warrant testing of new solutions to educate and engage patients around the benefits of palliative care.

Objectives. We sought out to develop and test a novel, mobile health solution to prepare patients for an upcoming outpatient palliative care appointment.

Methods. After developing a web-based tool called PCforMe (Palliative Care for Me), we conducted a randomized, active-controlled, trial of PCforMe. The primary outcome was the score on the System Usability Scale (SUS). Secondary outcomes were patient self-efficacy and change in knowledge. We compared PCforMe to three common online resources for patients seeking information about palliative care.

Results. A total of 80 patients were randomized. There were no significant demographic differences. Mean SUS score for PCforMe was 78.2, significantly above the normative average SUS score of 68 (P -value < 0.0001). Mean change in Perceived Efficacy in Patient-Physician Interactions score was -2.2 for PCforMe and -1.7 for control group (P -value = 0.72). Preparedness for an upcoming palliative care visit increased 50% in the intervention group and 13.3% in the control group. Difference in the number of patients with improved knowledge regarding palliative care approached significance (P = 0.06). Lastly, we found that the no-show rate was lower during Q1 2017 (during trial) and Q1 2016 (before trial), at 11.7% and 21%, respectively (P < 0.05). Comparing the full calendar year (CY) 2016 with 2017, we did not find a statistical difference (CY 2016 of 18.8% and 15% in CY 2017; P = 0.22).

Conclusion. PCforMe is a usable mobile health tool to prepare patients for an upcoming palliative care appointment. Further research is needed to test effectiveness. *J Pain Symptom Manage* 2019;58:382–389. © 2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Mobile health, patient engagement, no-show rate, palliative care clinic

Introduction

Oncologists are increasingly referring advanced cancer patients to palliative care specialists.^{1–3} Efforts to connect patients with palliative care specialists

typically take the form of clinical triggers and consultation criteria.^{1,4,5} These efforts focus on referring clinicians and health systems; patients and caregivers are rarely the subject of interventions to promote greater

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use of palliative care. This is particularly an important area of focus as a recent public opinion poll demonstrated that 95% of potential consumers strongly agreed that it is important to educate patients and families about palliative care before a future clinical visit.⁶

Serious illness care is increasingly turning to web-based tools to educate and engage patients. Experiences to date with rigorous, high-impact clinical trials both demonstrate the feasibility and effectiveness of integrating electronic methods into the care of those with significant debility and morbidity. Furthermore, such tools can serve as extensions of specialty palliative care teams while also assisting primary palliative care clinicians in performing advance care planning. Notable examples in the field include the Prepare tool from Sudore et al.^{7–10} and video-based decision aids by ACP decisions and Volandes et al.^{11–13} Additional tools for remote monitoring of patient distress¹⁴ and just-in-time coaching around patient/clinician communication from VitalTalk complement time-intensive, high-touch efforts by clinicians who are in high demand and short supply. Altogether, these efforts demonstrate both the potential of web-based tools in assisting busy clinicians in addressing patient goals while proving that such methods are feasible and superior to usual paper-based and other manual methods.

The impetus for this work began with discovering a high outpatient palliative care clinic no-show rate at our institution. We have previously discussed the need to close an “accessibility/availability gap,”¹⁵ where although services are available, they are not readily accessible by patients. In our case, Duke University has a five-day-per-week outpatient palliative care clinic embedded in the cancer center. Our services were available, but we realized that many patients may harbor hesitations to attend clinic. Realizing that patients cannot achieve the outcomes we desire if our services are not accessed, we developed and tested a novel, multistakeholder-informed, web-based tool, called PCforMe (Palliative Care for Me), to prepare patients for engaging with a palliative care clinician before an already-scheduled outpatient appointment.

Methods

Overall

We conducted a randomized, active-controlled, clinical trial of PCforMe among patients referred to the Duke University Outpatient Palliative Care Clinic. The primary outcome was the score on the System Usability Scale (SUS) after a one-time use of PCforMe before an outpatient palliative care consultative initial visit. Secondary outcomes were patient self-efficacy and change in knowledge. The study was approved

by the Duke University Institutional Review Board (Pro00075906) and funded by the Palliative Care Research Cooperative Group (PCRC) and the Duke Cancer Institute. Some investigators (AHK and JMN) have a financial conflict of interest related to licensing of PCforMe. To mitigate any potential conflicts on statistical analyses and conclusions, all analyses and the writing of the manuscript were overseen and performed by nonconflicted investigators (AVB, FF, GS, and SW), the final manuscript was approved by the PCRC Publications Committee, and all activities were guided by the Duke Office of Research Integrity.

Eligibility Criteria and Randomization

Patients were eligible to participate in the study if they were adults aged 18 years or older; English-speaking; referred to outpatient palliative care; able to provide written, informed consent; and willing to present up to 60 minutes before the scheduled palliative care appointment to participate in research procedures. For patients who provided consent, we used a 1:1 randomization procedure using a random number generator. Investigators and palliative care clinicians were blinded to the randomization. All participants received a parking and meal voucher valued up to \$25 as compensation.

Intervention

PCforMe is a web-based, mobile health tool that aims to educate and engage patients referred to palliative care to better prepare them for the upcoming appointment. The system does not require a registration process, username, or password to use. It also does not include any patient identifiers. The platform incorporates an adult learning theory^{16,17} approach to education regarding specialty palliative care by presenting short video vignettes on a learning topic, and then asking users to participate in a short activity to apply newly-acquired knowledge to their own situation (Fig. 1). For example, the system displays a four-minute animated video on surrogate decision makers, and then asks users to think and write down who they would prefer to make decisions if they could not.

PCforMe is presented in eight modules. Examples of module topics include the following: difference between palliative care and hospice, symptom assessment and management, discussing hopes and worries, and talking about difficult topics. Each module consists of a short, animated cartoon along with an activity. Activities involve applying knowledge gained from the short videos to a user's own situation or illness. Those answers throughout the use of PCforMe are compiled into a single document that PCforMe generates, called a “Palliative Care Passport.” PCforMe users then present this “Passport” to palliative care clinicians to summarize their concerns,



Fig. 1. Screenshot of PCforMe.

prioritize the topics of the conversation, and serve as a checklist of items to bring to the appointment (e.g., already-completed living will document). Ultimately, the “Passport” serves as a conversation guide between the patient and her specialty palliative care clinician. The overall aim is to better prepare patients to engage with a palliative care clinician.

PCforMe takes under 20 minutes to complete, can be used longitudinally and repeatedly before multiple future palliative care appointments, does not focus on a particular illness or condition, includes content aimed at both patients and informal caregivers, and was designed using language at a seventh grade reading level.

Research personnel presented PCforMe on a preferred device of the patient’s choosing, which could be either tablet computer (e.g., iPad) or laptop computer. Personnel stayed close to answer technical questions related to hardware (but not software) and otherwise did not prompt or assist subjects in their use of PCforMe. Participants were provided up to 30 minutes to access the system.

Active Control

We compared PCforMe with three common online resources for patients seeking information about specialty palliative care. These sites included the Wikipedia page for palliative care (https://en.wikipedia.org/wiki/Palliative_care), and the patient-facing web sites developed by the Center to Advance Palliative

Care (<http://www.getpalliativecare.org>) and the American Academy of Hospice and Palliative Medicine (<http://www.palliativedoctors.org>). Participants were navigated to three open browser windows, each set to one of the web sites. Participants could also opt to use the device web browser to explore other web sites on their own. Participants were provided up to 30 minutes to access the system.

Measured Outcomes

The primary outcome was the score on the SUS measured at the completion of using PCforMe before an initial consultation at outpatient palliative care clinic. The SUS consists of 10 questions with five response options. Each question ranges from strongly agree to strongly disagree. The scale ranges from 0 to 100, with an observed mean of 68 across different software applications reported in the literature. The SUS consists of 10 items, with odd-numbered items worded positively and even-numbered items worded negatively. To use the SUS, present the items to participants as five-point scales numbered from 1 (anchored with “strongly disagree”) to 5 (anchored with “strongly agree”). Thus, SUS scores range from 0 to 100 in 2.5-point increments. The average SUS score is 68.¹⁸

The secondary outcome was change in the Perceived Efficacy in Patient-Physician Interactions (PEPPI) Questionnaire¹⁹ score from preintervention to postintervention. The PEPPI questionnaire measures patient

self-efficacy in interacting with physicians with a score range of 5 to 25. PEPPI serves as a measure of the degree to which systemic changes in healthcare delivery empower or disempower older patients in eliciting needed medical attention to their chief health concerns.²

We also administered the Palliative Care Knowledge Survey at two time points, before the use of interventions in either arm, and right after. The Palliative Care Knowledge Survey is an investigator-developed, five-question multiple choice quiz that asks the patients question about their understanding of principles of specialty palliative care. Answers were scored dichotomously as correct or incorrect. Lastly, participants answered a single-item “Prepared” question (“Are you prepared for the upcoming palliative care visit”) after completing the interventions and right before the outpatient visit. The question includes a five-point Likert scale response option ranging from “strongly disagree” to “strongly agree.”

All patient-level outcomes were measured before and after the exposure to PCforMe or active controls. All research procedures including measurements of outcomes were completed before the beginning of the palliative care clinical encounter.

Statistical Analysis

We conducted an intent-to-treat randomized clinical trial, using the progression of outcomes outlined in the Technology Acceptance Model,^{19,20} a common framework in technology testing. Descriptive statistics were calculated to describe the cohort by group (intervention vs. control). Groups were compared using a Wald test for continuous variables and either Fisher exact or chi-squared test, as appropriate.

Our primary hypothesis concerned the usability of PCforMe in the intervention group, and was assessed by using a one-sample t-test, which compared the mean SUS score with the national average of 68. We do not present power calculations because this study is not powered to declare statistical significance as it relates to the following primary outcome: system usability. Usability scores are compared with a historical benchmark for healthcare web sites and the outcome is dichotomous; lower or higher usability than other web sites.

Analyses of secondary outcomes were organized around pre-post comparisons between the two study groups. For PEPPI scores, we created a new variable called score difference based on the difference in pre- and postintervention scores. A two-sample paired t-test was used to compare mean change scores of the two study groups. Knowledge scores were derived similarly, with the groups being compared using a two-sample Wilcoxon test. Finally, to evaluate if PCforMe would significantly improve preparedness, we fit a logistic regression model. The primary outcome was

preparedness postscore (dichotomized). The predictors were preparedness prescore and study group, and our focus was on the impact of study group.

Lastly, we compared no-show rate differences using administrative data to derive quarterly no-show rates, which were then compared using chi-squared tests. The use of PCforMe included a research coordinator phone call to patients before the appointment. As an exploratory aim, we hypothesized that the additional phone contact would decrease the no-show rate.

Results

A total of 670 patients were assessed for eligibility and ultimately 80 patients were randomized from January 15, 2017 to February 1, 2018. Among those 80 patients, 40 were randomly assigned to intervention group and 40 were randomly assigned to the control group (Fig. 2). Eighty percent of our cohort was white, 95% was “Not Hispanic or Latino,” and about half of the patients (54%) were married. Overall, there were no significant differences between race, ethnicity, or marital status across the groups. However, there were significant differences in education levels between groups (P -value = 0.0019), the control group had a lower education level compared with the intervention group (Table 1).

The SUS was completed by 39 patients (98%) in the PCforMe group. This was considered a large sample size for a usability study, as five or more observations are considered adequate for usability evaluations of mobile health technologies.²⁰ The mean SUS score was 78.2 (SD 14.2), which was significantly above the targeted average SUS score of 68 (P -value < 0.0001), indicating that the PCforMe web site had a higher than average usability score compared with other web sites. Based on comparative data, a score of 78.2 puts PCforMe near the 90th percentile for web sites.

The mean change in PEPPI score for the intervention group was -2.2 (SD 4) and -1.7 (SD 3) in the control group, which were not significantly different (P -value = 0.72). The reductions in PEPPI scores over time are interesting to note, but considering scores range from 5 to 25, may not be clinically important. We did not find evidence of the PCforMe web site improving the pre- to post-PEPPI scores compared with control group.

Rates of improvement from pre- to postintervention in the knowledge scores across the two arms varied by questions (Table 2). Notably, for question 4, “What is a common way in palliative care to talk about goals and what matters to you?” (Answer: “Hopes and Worries”), the intervention group had approximately twice the rate of correct answers (42.5% and 22.5%, respectively). Superior performance on this question

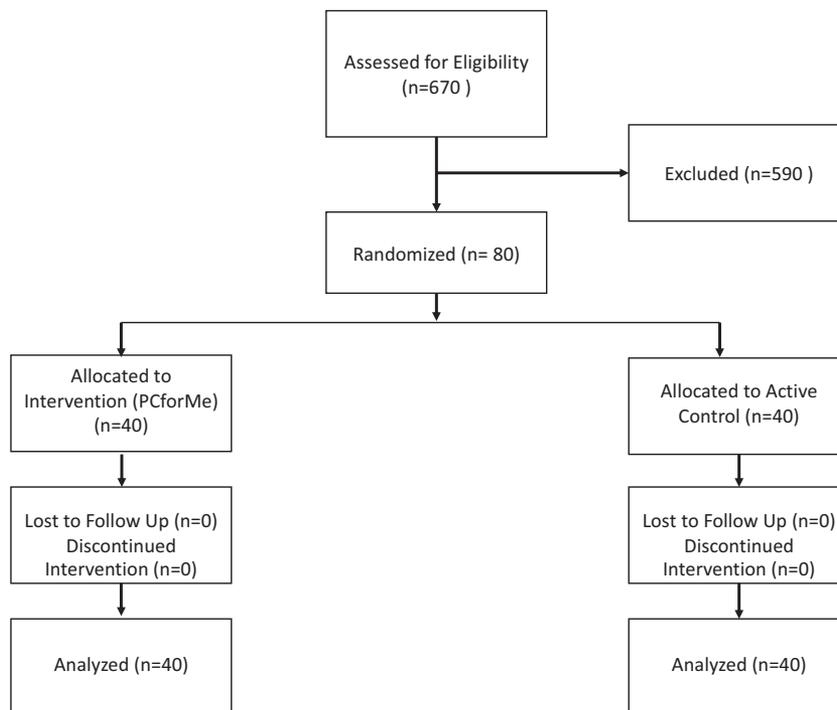


Fig. 2. Consort diagram of participants in PCforMe trial.

was expected, as PCforMe, but not the active controls, introduces users to the “hopes and worries” framework for discussing values and preferences.²¹ This was the focus of question 4. A total of 28 patients in the intervention group and 23 patients in the control group had an

improved score after the intervention. The difference in the number of patients with improved knowledge scores was not statistically significant ($P = 0.06$).

The intervention group had lower rates of preparedness before the intervention compared with the control

Table 1
Demographics of Trial Participants

Demographic Characteristics	Control (N = 40)	Intervention (N = 40)	Total (N = 80)	P-value
Race				0.5595
American Indian or Alaska Native	0 (0.0%)	1 (2.5%)	1 (1.3%)	
Asian	0 (0.0%)	1 (2.5%)	1 (1.3%)	
Black or African American	7 (17.5%)	7 (17.5%)	14 (17.5%)	
White	33 (82.5%)	31 (77.5%)	64 (80.0%)	
Gender				0.8217
Male	17 (42.5%)	18 (45.0%)	35 (43.8%)	
Female	23 (57.5%)	22 (55.0%)	45 (56.3%)	
Ethnicity				0.1318
Hispanic or Latino	0 (0.0%)	3 (7.5%)	3 (3.8%)	
Not Hispanic or Latino	39 (97.5%)	37 (92.5%)	76 (95.0%)	
Unknown	1 (2.5%)	0 (0.0%)	1 (1.3%)	
Marital status				0.8505
Married	21 (52.5%)	22 (55.0%)	43 (53.8%)	
Living with a partner in a marriage-like relationship	3 (7.5%)	2 (5.0%)	5 (6.3%)	
Widowed	5 (12.5%)	3 (7.5%)	8 (10.0%)	
Divorced	7 (17.5%)	8 (20.0%)	15 (18.8%)	
Separated	3 (7.5%)	2 (5.0%)	5 (6.3%)	
Never married	1 (2.5%)	3 (7.5%)	4 (5.0%)	
Highest level of education				0.0019
Some high school or less	0 (0.0%)	5 (12.5%)	5 (6.3%)	
High School/GED	17 (42.5%)	4 (10.0%)	21 (26.3%)	
Associates Degree or Some College	6 (15.0%)	13 (32.5%)	19 (23.8%)	
Bachelor's Degree	10 (25.0%)	7 (17.5%)	17 (21.3%)	
Master's Degree or other Advanced Degree	7 (17.5%)	11 (27.5%)	18 (22.5%)	

GED = General Education Development.

Table 2
Correct Responses to Five-Item Palliative Care Knowledge Survey

Questions	Intervention Pre (N%)	Control Pre (N%)	Intervention Post (N%)	Control Post (N%)
Question 1: Palliative care is for what type of patient?	22 (55.0%)	17 (42.5%)	31 (77.5%)	28 (70.0%)
Question 2: Code status or resuscitation status is?	21 (52.5%)	21 (52.5%)	29 (72.5%)	24 (60.0%)
Question 3: What statement is true regarding palliative care compared with hospice?	22 (55.0%)	20 (50.0%)	38 (95.0%)	32 (80.0%)
Question 4: What is a common way in palliative care to talk about your goals and what matters to you?	17 (42.5%)	9 (22.5%)	34 (85.0%)	16 (40.0%)
Question 5: What is the best way to describe palliative care?	25 (62.5%)	23 (57.5%)	38 (95.0%)	36 (90.0%)

group (55.0% and 72.5%, respectively). The rates of preparedness postintervention were the same for both groups (82.5% and 82.5%, respectively). The rates of preparedness increased 50% in the intervention group and only 13.3% in the control group. When examining preintervention scores in both arms, we found that those with prior preparedness were 6.2 (1.7, 22.2; $P < 0.01$) times more likely to report feeling prepared compared with unprepared encounters.

Lastly, we compared initial consultation no-show rates to the outpatient palliative care clinic during the course of the study versus four-quarters during the calendar year (CY) prior. We found that the no-show rate was lower during Quarter 1 of 2017 (during trial) and Quarter 1 of 2016 (before trial), at 11.7% and 21%, respectively ($P < 0.05$). Comparing the full CY 2016 with 2017, we did not find a statistical difference (CY 2016 of 18.8% and 15% in CY 2017; $P = 0.22$).

Discussion

PCforMe demonstrated high usability, with a score of 78.2 (SD 14.2), putting it near the 90th percentile for healthcare web sites. We found no difference in patient visit self-efficacy, or sense of preparedness between the intervention and control groups, with a trend toward increased change in knowledge. Even among a population who felt at baseline less prepared than controls, PCforMe was able to achieve equal preparedness sentiment after its use. Furthermore, in an isolated calendar quarter, a significant reduction in the no-show rate was observed because of the effect of research personnel calling patients before a scheduled palliative care appointment; this effect was not consistent throughout the study.

As palliative care moves further upstream in care, more solutions will be needed to familiarize patients with the services and benefits of palliative care. A common marketing and sales adage is: "Describe benefits, not features," indicating that the critical need to share with customers the tangible assistance palliative care provides in improving or preserving quality of life. As the adage states, this goes beyond describing the features, such as components of the team (e.g.,

"interdisciplinary"), the timing ("at any time") or the locations services are offered (e.g., "hospital or clinic"). A quick online search will reflect this point, as many web sites and online pamphlets go into great detail defining and describing services, yet are often short on personalized benefits to patients. Palliative care does not lack proven benefits resulting from its services, but improvements can be made in describing these benefits to patients. PCforMe and other tools like it represent a wave of new efforts to demystify and clarify the intent and benefits of palliative care. The goal is for patients to invite palliative care into their usual care, not convince them of its value as a means to persuade them of its inclusion.

Looking toward future studies, we aim to continue testing of PCforMe along the Technology Acceptance Model framework. Subsequent studies will be adequately powered to detect the downstream outcomes related to technology use, including change in knowledge, perceptions, self-efficacy, and behavior change. Furthermore, we aim to test the ultimate outcomes of importance in increasing quality of serious illness care, such as improvements in patient-level outcomes (e.g., symptom control) and clinic-level participation rates (e.g., reduced no-show rates to clinic). Improving such outcomes will require providing patients with access to PCforMe more upstream to the time in the waiting room of an impending palliative care appointment, such as when a palliative care referral is made. This gap in time between access to PCforMe and the actual appointment will allow us to test the effect of the application on no-show rates and patient engagement.

There are important limitations to this trial to highlight. First, our primary aim was usability and not efficacy. Subsequent studies are planned to understand the effect of PCforMe on patient and clinic-level outcomes. Second, we enrolled only patients already referred to outpatient specialty palliative care clinic. We did not test patients with a serious illness who are receiving disease-directed care only, as means to capture patients naïve to a referral. Third, demonstrating differences in no-show rates between control and intervention arms

is difficult when both arms involve research coordinators calling patients to introduce the study in the context of an upcoming palliative care appointment. Future studies that deliver PCforMe in ways that do not remind patients of an upcoming appointment will be needed to assess no show rates as a primary outcome. Fourth, despite randomization our groups were imbalanced in terms of education level and underrepresented by racial and ethnic minorities. Further trials with larger sample sizes and stratified sampling techniques are planned to address this. Lastly, we only included patients who could arrive to palliative care appointments 60 minutes early to participate in research procedures. This led to a selection bias of patients who likely had greater transportation and scheduling freedom.

Conclusions

Our pilot trial demonstrates high usability of PCforMe alongside feasibility of our study design. Such feasibility supports our goal to conduct a larger, multisite study to rigorously examine efficacy. Furthermore, implementation and dissemination studies will be required to better understand how this electronic tool can seamlessly fit into the workflow of busy palliative care practices, where communicating with patients before a palliative care appointment (e.g., provide patients access to PCforMe) may not be commonplace.

Disclosures and Acknowledgments

PCforMe is owned by Duke University, and is licensed for use by Prepped Health LLC, which is owned by two authors (AHK and JMN). Dr. Samsa, Dr. Bennett, Mr. Wolf, and Mr. Friedman do not have any relevant disclosures. All analyses were completed by authors without any relationship to Prepped Health.

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