Patient and Provider Use of Electronic Care Plans Generated From Patient-Reported Outcomes

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OBJECTIVES: To determine if patients and providers perceived improved care processes through the delivery of personalized, electronic care plans (CPs) generated from the Carevive Care Planning System™.

SAMPLE & SETTING: 121 women (51 with gynecologic cancer from Billings Clinic and 70 with breast cancer from Moffit Cancer Center) completed electronic patient-reported outcome assessments and were given electronically generated, personalized supportive CPs tailored to individual symptoms and local healthcare resources.

METHODS & VARIABLES: Quantitative instruments evaluated feasibility, usability, acceptability, and satisfaction of the CPs from patient and provider perspectives. Qualitative interviews described patient perceptions of the CPs.

RESULTS: Patients with cancer reported the CPs to be useful. Most perceived that CPs improved team communication, helped find needed resources, and helped manage symptoms. Provider satisfaction was highest with the platform's ability to customize patient recommendations. Interviews indicated that patients with cancer used their CP as a resource, preferred delivery at treatment initiation, and valued information to manage symptoms.

IMPLICATIONS FOR NURSING: Nurses play an integral role in patient education and in discussing individual care. Tailored CPs can be used as a teaching tool that patients with cancer can refer to for self-care.

Symptoms are common across the cancer trajectory, from diagnosis and treatment through to survivorship and/or end of life. Symptom assessment has historically been completed by clinicians whose findings may not coincide with patient reports. Findings from an integrative review of 36 studies on patient-reported outcome (PRO) measures revealed that clinicians tend to underestimate the prevalence, severity, and distress of patients' symptoms (Xiao, Polomano, & Bruner, 2013). Lowest congruence was found in symptoms not easily observed, such as depression and anxiety. Data also suggest that incorporating PRO symptom measurement during treatment can improve patient–provider communication (Berry et al., 2011) and patient outcomes, such as reducing symptom burden (Mooney et al., 2017) and improving quality of life and survival (Basch, Deal, et al., 2017; Denis et al., 2019; Loh et al., 2018). Overall, a need exists for PROs to be incorporated into daily clinical practice using real-time, self-reported descriptions of the patient experience. In turn, clinicians need support to incorporate PROs into patient care. The inclusion of oncology nurses in this workflow appears to be crucial to achievement of outcomes (Mooney et al., 2017).

Implementation of symptom PROs into cancer care remains challenging. A scoping review by Howell et al. (2015) found that PROs were acceptable to patients with cancer, their providers, and nurses, and that PROs enabled earlier detection of symptoms and problems; however, significant implementation barriers were identified, including time constraints, increased visit times, and perceptions that PROs were intrusive and had questionable use. Other barriers included lack of knowledge about how to address information gathered and liability issues for PROs reported between visits (Howell et al., 2015). Mooney et al. (2017) found that assignment of a dedicated oncology nursing resource helped overcome these barriers.

Robust solutions that support electronic self-report of PROs (ePROs) have emerged as a promising solution to overcoming some of these barriers. Novel technologies can capture symptom and distress data, aim to improve efficiency of the office visit, and notify clinicians when symptoms are significant. Although technological and workflow barriers can impede implementation of PROs into practice, linkage to tailored care plans (CPs) is one strategy to enhance their use (Smith et al., 2016). PROs used to design a tailored CP could facilitate communication between the patients and their oncology care teams, including nurses, and foster education and patient engagement. The Carevive Care Planning System™ (CPS) is one such technology platform designed to facilitate efficient collection of ePROs and integrate these, along with other clinical data, into supportive and survivorship CPs that provide clinical decision support to care teams and self-management advice for patients with cancer and their families (Carevive Systems, 2019). The Carevive CPS uses evidence-based and validated patient assessment tools, including the Edmonton Symptom Assessment Scale, the National Comprehensive Cancer Network's (NCCN's) Distress Thermometer, and other symptom and quality-of-life surveys (Chang, Hwang, & Feuerman, 2000; Holland, 2013; Holland et al., 2013), and links these PROs to clinician and patient guidance via published guidelines, including those from the NCCN (2019) and the Putting Evidence Into Practice content from the Oncology Nursing Society (2019). Oncology clinical experts are routinely engaged to develop, validate, and ensure that guidelines are kept current, thereby allowing up-to-date clinician guidance for care that aligns with quality care standards. The current study was constructed as the initial pilot study of the Carevive CPS prior to its use in routine clinical care. Since this study was conducted, use of the Carevive CPS in routine clinical care has grown to 21 academic and community cancer programs in the United States, 10 of which also use or have used the system in research projects, plus an additional 17 cancer programs or practices that have or are currently using this digital platform in research projects only.

The purpose of this mixed-methods study was to evaluate feasibility, usability, acceptability, and satisfaction with the Carevive CPS by patients with cancer and providers caring for these individuals.

Methods

A prospective, mixed-methods study was employed to assess study outcomes. This quantitative/qualitative process employed a battery of instruments, followed by a semistructured interview with a subset of patients with cancer to further explore perceptions of feasibility, usability, and acceptability. Provider perceptions of these implementation outcomes were also examined.

Sample and Setting

A convenience sample of women with endometrial, ovarian, or cervical cancer from Billings Clinic in Montana and women with breast cancer from Moffit Cancer Center in Tampa, Florida, participated in the study. Billings Clinic is a community cancer center affiliated with the National Cancer Institute Community Cancer Center Program. Moffit Cancer Center is a large National Cancer Institute–designated academic cancer center. Eligible patients with cancer were aged 18 years or older, had decision-making capacity, spoke and read English, and were able to use a computer. Because the Carevive CPS was designed to support care delivery across the cancer continuum, during active treatment, and during post-treatment survivorship, the authors wished to pilot test its use in these settings. The two pilot sites self-selected the time period of interest for their center. Patients with cancer who agreed to participate were asked to complete at least one assessment using the Carevive CPS platform at point of care. Patients with gynecologic cancer used the Carevive CPS platform on a recurring basis at each office visit during their cancer treatment; those with breast cancer used the platform once following completion of active cancer treatment.

Procedures

Institutional review board approval was obtained prior to initiating study procedures. Patients with cancer were enrolled from March 2014 to July 2015. Research nurses screened the electronic health record daily for eligible patients. Once identified, those individuals were approached during regularly scheduled visits in the outpatient waiting area. Consented patients were provided a secure electronic tablet and asked to complete a 10- to 15-minute ePRO assessment that included cancer history, family history, symptoms, and their top three concerns from the visit. Nurses guided patients through the initial ePRO entry and assisted with technology as needed. The tablet was then taken into the examination room where the provider (i.e., oncologist, oncology nurse practitioner, or physician assistant) reviewed the patient's ePROs and visit concerns, customized the algorithm-generated CP as appropriate (i.e., recommended education, self-management sources,

referrals, appointments to schedule, and/or additional testing), and approved the final CP. Research nurses or nurse navigators often attended visits to help guide the patient's care.

The personalized CP was given to the patient in print or electronic format (USB flash drive), according to the patient's stated preferences, at the end of the ambulatory visit. Clinic or infusion center nurses then followed up with patients in the waiting room, clinic space, or the infusion suite to review the CP and recommended symptom interventions, answer additional questions, and provide additional resources if needed. Follow-up surveys to evaluate feasibility, usability, acceptability, and satisfaction were mailed to participants or gathered during a clinic visit within 12 weeks of platform use. Semistructured telephone interviews were conducted about 12 weeks from study entry to assess the overall experience with use of the Carevive CPS. Selection was purposive, with the goal of interviewing patients from both sites, in different age categories, and of diverse racial and educational background. Providers answered a single usability, acceptability, and satisfaction survey at study completion and participated in a telephone conversation regarding their experience.

Measures

Participant measures: Clinical and demographic data, including diagnosis, stage, level of education, previous computer experience, and attitudes toward computers, were collected from study participants.

Patient satisfaction and acceptability of generated CPs were measured by a single global usefulness item ranging from 1 (not at all useful) to 5 (very useful). Four additional items measured CP acceptability and satisfaction using a five-point Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). Higher scores indicated better acceptability and satisfaction. These questions were taken and minimally adapted from a measure developed to evaluate the Electronic Self-Report Assessment–Cancer (ESRA-C) (Berry et al., 2011). In the current study, the internal consistency reliability of the questionnaire was high, with an alpha coefficient of 0.91 (Berry et al., 2011).

The System Usability Scale (SUS) assesses usability of a variety of products and services, such as software, mobile devices, and websites. The SUS has been used in multiple studies examining technology in research and medical settings, and found them to be valid and reliable (Cronbach alpha = 0.91) (Ahmed & Ouzzani, 2012, 2013; Bangor, Kortum, & Miller, 2008; Berry et al., 2011; Christoph et al., 2017; Lewis & Sauro, 2009).

The SUS consists of 10 items scored on a five-point Likert-type scale ranging from 1 (strongly agree) to 5 (strongly disagree) (five negative items were reverse scored). Higher scores indicate better usability. A total of 70 or greater is typically considered acceptable for usability (Bangor, Kortum, & Miller, 2009).

Semistructured telephone interviews were conducted with a subset of patients with cancer in the study from each site and examined CPS platform ease of use, recommended modifications, and examined the overall experience and use of the platform and

TABLE 1. Site 1 Patient Characteristics (N = 51)

Characteristic	$\overline{X}$	SD	Range
Age (years)	59.68	10.94	28–81
Time since diagnosis (months)	4.26	5.56	0.5–21.1

Characteristic	n
Self-reported race	
Caucasian/White	47
Missing data	4
Education	
High school or less	8
Some college/associate degree	14
Bachelor's degree	20
Graduate/postgraduate	9
Cancer type[a]	
Gynecologic	49
Ovarian	22
Endometrial	17
Cervical	10
Ovarian cancer stage (N = 22)	
0–II	6
III	12
IV	3
Not yet determined	1
Endometrial cancer stage (N = 17)	
0–II	9
III	3
IV	3
Not yet determined	2
Cervical cancer stage (N = 10)	
0–II	5
III	3
IV	1
Not yet determined	1
[a] Participants could report more than one type of cancer.	

personalized CP. Interviews lasted 10–20 minutes and were recorded, transcribed, and analyzed.

Provider measures: For the purposes of this study, providers were defined as licensed billing providers at the participating institutions, either a physician (medical or gynecologic oncologist) or advanced practice provider (physician assistant or nurse practitioner). These providers completed similar measures as the patients with cancer. Select providers also participated in semistructured interviews.

The SUS used for patients with cancer was also used for providers. Like the patient SUS, higher scores indicate better usability of the software product.

Provider acceptability of and satisfaction with the platform was measured by a 11-item survey scored on a Likert-type scale ranging from 1 (strongly disagree) to 5 (strongly agree). As with the patient survey, the questions were taken and minimally adapted from a measure developed to evaluate the ESRA-C (Berry et

al., 2011). Higher scores indicated better acceptability and satisfaction.

Individual telephone calls were conducted with providers to discuss platform satisfaction, feasibility, and recommendations for improvement. Calls were recorded, and detailed notes from the recordings were reviewed to better understand provider perceptions.

Analyses

Quantitative descriptive analyses were conducted using IBM SPSS Statistics, version 22, to examine dispersion, mean, standard deviation, and central tendency of the measures for patients with cancer and providers. Tests of comparison were used to examine differences between the two study sites. A conventional content-analysis approach was used for qualitative interviews (Elo et al., 2014; Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). Initially, two investigators (J.B. and K.H.) trained in qualitative research methodology reviewed three interviews independently to establish a set of open codes. Then, open codes were reviewed together and grouped into thematic categories, using the constant comparative method to systematically define and refine thematic categories and develop the coding scheme (Hsieh & Shannon, 2005). Disagreements observed in the dually coded transcripts were reviewed and consensus agreement determined. The remaining interview transcripts were divided between the two investigators and coded, applying the developed coding scheme. An audit/decision trail was created containing code development, decisions, and category definitions to maximize consistent application of codes throughout the qualitative analysis (Koch, 2006). Atlas.ti was used to organize and manage coded data.

Patient Demographic and Clinical Characteristics

A total of 121 women were enrolled in the study. Participants were primarily White (86%), had a mean age of 56.3 years, and had at least a college education (52%). Billings Clinic (site 1) enrolled 51 participants with gynecologic cancer, and Moffit Cancer Center (site 2) enrolled 70 participants with breast cancer. A subset of 17 participants with cancer, purposefully selected from both sites to ensure heterogeneity by age, race, type of cancer, and time since diagnosis, were interviewed. No significant differences existed between sites in self-reported race, ethnicity, or education. Site 1 patients were younger (p < 0.01) and qualitative interview participants were older (p = 0.03) than the combined sample. Patients from site 1 reported significantly shorter time since diagnosis

TABLE 2. Site 2 Patient Characteristics (N = 70)			
Characteristic	**X̄**	**SD**	**Range**
Age (years)	54.37	10.79	30–75
Time since diagnosis (months)	21	25	0–123
Characteristic			**n**
Self-reported race			
Caucasian/White			53
African American/Black			7
White/Hispanic			4
American Indian			1
Black/Hispanic			1
Hispanic/Latino			1
Asian			3
Self-reported ethnicity			
Hispanic/Latino			6
Education			
High school or less			14
Some college/associate degree			23
Bachelor's degree			23
Graduate/postgraduate			9
Missing data			1
Cancer type			
Breast cancer			70
Cancer stage			
0–II			52
III			14
Not yet determined			4

(p < 0.001); qualitative interview participants did not differ from the overall sample. A description of site 1 and 2 participants, as well as qualitative interview participants, can be found in Tables 1–3.

Patient Satisfaction and Acceptability

Ninety-four of 121 individuals provided responses at 12 weeks regarding CP satisfaction and acceptability (78% response rate). Reasons for not responding included disease progression, not feeling well enough to complete surveys, loss to follow-up for many rural patients, and death. Patients reported high levels of overall usefulness; 83% (n = 78) reported the CP as somewhat to very useful. Regarding satisfaction and acceptability of the generated CP, patients with cancer agreed or strongly agreed that it improved team communication (59%; n = 55), helped manage cancer and find needed resources (70%; n = 66), and helped to manage cancer-related symptoms (67%, n = 63). In addition, 68% (n = 64) recommended that other patients with cancer receive similar CPs (see Table 4).

Patient system usability scale: Patients with cancer reported high scores of system usability; 79% (n = 74) agreed or strongly agreed that the Carevive CPS platform was easy to use and 71% (n = 67) reported confidence using the system. Seventy-seven percent (n = 72) disagreed or strongly disagreed that the Carevive CPS was unnecessarily complex, that they would need assistance to use the system, found the system cumbersome or awkward, or needed to learn a lot of things before they could use the system (see Table 5).

Qualitative themes: Participants responded positively about the Carevive CPS, noting the ease of entering ePRO data, its ability to list top visit concerns at the point of care, and to structure the CP provided within the visit.

> In prior visits, before the care plan, you get in and, even if you have a list of things that you want to discuss, it's so easy to jump off track and never go back. The care plan . . . gave you a format, and we went through it and were able to cover everything. . . . Even my follow-up visit was much more thorough because of the care plan.

Three major themes related to impact of the CPS emerged: (a) the CP as a resource, (b) usefulness regarding symptom management, and (c) ability to share information with others.

Care plan as a resource: Sixteen participants described using the CP-generated reading materials

and recommended websites as a resource. Relatedly, respondents reported liking that they could refer to the CP for a refresher.

Usefulness regarding symptom management: Eleven patients with cancer described the symptom management information as useful, recalling some aspect of symptoms being addressed within the CP. Among participants noting symptoms as a top visit concern, sentiments were shared that the CP was "very useful for giving [you] suggestions of ways to

TABLE 3. Qualitative Interview Patient Characteristics (N = 17)

Characteristic	X̄	SD	Range
Age (years)	61.94	8.92	38–72
Time since diagnosis (months)	24.9	17.1	4–56
Characteristic			**n**
Self-reported race			
Caucasian/White			14
African American/Black			1
Asian			1
White/Hispanic			1
Self-reported ethnicity			
Hispanic/Latino			1
Education			
High school or less			2
Some college/associate degree			4
Bachelor's degree			9
Graduate/postgraduate			2
Cancer type[a]			
Breast			14
Gynecologic			3
Cervical			2
Ovarian			1
Breast cancer stage (N = 14)			
0–II			9
III			4
Missing data			1
Ovarian cancer stage (N = 1)			
0–II			1
Cervical cancer stage (N = 2)			
0–II			1
Not yet determined			1

[a] Participants could report more than one type of cancer.
Note. Patients who completed qualitative interviews are a subset of the overall study population.

help some of your symptoms" and "offered opportunities, like if you were needing to be with someone if you were feeling depressed or discouraged."

Ability to share information with others: The ability to share information with others was also commonly noted (n = 15) to be a positive attribute of the CP. One patient reported that the CP was useful during a visit to her primary care physician when the issue of elevated cholesterol was raised.

> I went to my regular physician and she said, "Your cholesterol level is high. If you don't get it down, I'm going to have to put you on medication," and I said, "Well, [anastrozole] can cause your cholesterol to go up."

The patient went on to describe that her physician was not aware of that side effect.

All interviewed patients commented at least once about using the CPS technology. Although most found the platform easy to use, some indicated a learning curve. Slightly fewer found it helpful to have assistance to use the CPS, and even fewer noted the preference to receive hard copies of the individualized CP. In terms of learning curve, one patient stated the following:

> You know, at first, I really had some problems. . . . You have to keep it super, super simple because . . . most of the people who are in that oncology department are going to be older people, and a lot of them are not real familiar with computers

and the technology. . . . I was pleased from the first time that I went on and tried to work my way through it to the next time, it just seemed like it was much easier, so I was pleased with that. After about the second or third time, it just seemed like I went right through it very quickly.

Of note, six patients with breast cancer mentioned timing of use of the CPS, specifically mentioning that, although the CP was useful, it could have been more useful if provided earlier in treatment. One participant stated the following:

> They didn't start having me fill out the questionnaire on the computer until I was, I think, almost done with my chemo, like maybe into my fourth chemo out of six, so many of the things that they suggested I had already kind of figured out, but for someone starting out new, they would have been very helpful.

Negative comments about the CPS were infrequent. Some patients with cancer made suggestions on how they felt the system could be augmented or improved, such as the addition of a text box to trigger a reminder to discuss specific questions with the healthcare provider, a check box for the patient to indicate no major changes, and a text box to ask about changes since the last visit. Only one patient noted visual issues with the technology, and, similarly, only one noted that use of the CPS was particularly time consuming.

TABLE 4. Patient Satisfaction and Acceptability Survey: Post-Test (N = 94)								
Question[a]	**1**	**2**	**3**	**4**	**5**	**NA**	**$\overline{X}$**	**M**
How useful overall are the care plans you are given at your visit(s)?	1	10	16	28	34	5	3.94	4
Statement[b]	**1**	**2**	**3**	**4**	**5**	**NA**	**$\overline{X}$**	**M**
My care plans improve my communication with my cancer care team.	2	8	22	26	29	7	3.82	4
My care plans help me to manage my cancer care and find the resources I need.	1	7	13	32	34	7	4.04	4
The information I was given in my care plans was just what I needed to manage my cancer-related symptoms.	–	9	16	32	31	6	3.97	4
I would recommend that other patients with cancer receive similar care plans.	1	3	20	18	46	6	4.19	5
[a] Rated on a scale from 1 (not at all useful) to 5 (very useful) [b] Rated on a scale from 1 (strongly disagree) to 5 (strongly agree) M—median; NA—not available or no answer								

Provider Results

Three gynecologic oncologists and physician assistants (site 1) and four medical oncologists (site 2) participated in the qualitative and quantitative evaluations for this study. In terms of workflow, oncologists and advanced practice providers assisted with enrolling patients into the study in collaboration with research coordinators or nurses, discussed CPs with patients during office visits, and provided customized CPs to patients at the end of the visit. At site 1, the research nurses then reviewed the CPs with the patient; at site 2, it was the providers who performed this function, but research coordinators often provided reinforcement. Research coordinators or nurses were not surveyed or interviewed for this study.

Provider satisfaction and acceptability: Most providers (n = 5) were overall very satisfied or satisfied with the Carevive CPS. Six providers perceived the CPs to be highly customized to the patient, clinically useful, easy to understand, able to assist with evidence-based symptom approaches, and helped them address patient concerns and distress. Table 6 includes a summary of provider responses.

Provider system usability scale: Usability was rated high regarding ease of use and confidence in using the system. All providers (n = 7) agreed or strongly agreed they would like to use the system frequently.

Telephone interviews: Five providers participated in telephone interviews that lasted an average of 11 to 25 minutes. Provider comments confirmed survey results. One breast oncologist said, "The care plans help to focus my visits—this was especially helpful one day when I was running two and a half hours behind." One gynecologic oncologist stated, "The system is fantastic. It is what you and I would want if we had cancer." Finally, a cancer center director and oncologist felt that the system "helps identify problems and issues patients don't otherwise tell me."

Discussion

This study found high levels of feasibility, usability, and acceptability of and satisfaction with the Carevive CPS to collect ePROs and generate a tailored CP. Patients with cancer and providers reported the CPs to be very useful and that the CPs improved clinical encounters and patient–provider communication. Patients were highly satisfied with the CP in finding needed resources and in helping to manage symptoms. These results are similar to a study of 44 patients with gynecologic cancer who completed PROs during outpatient visits via paper or electronically (Webster et al., 2018). Use of PROs was found to be feasible, with high satisfaction by patients with cancer and providers. Patients perceived improved clinical care

TABLE 5. System Usability Scale: Post-Test (N = 94)								
Statement	1	2	3	4	5	NA	$\bar{X}$	M
I think that I would like to use the Carevive CPS frequently.	3	4	36	32	16	3	3.59	4
I found the Carevive CPS unnecessarily complex.[a]	45	27	13	6	1	2	1.82	2
I thought the Carevive CPS was easy to use.	2	2	13	32	42	3	4.21	4
I think I would need assistance to be able to use the Carevive CPS.[a]	52	15	11	8	6	2	1.92	1
I found the various parts of the Carevive CPS worked well together.	3	3	28	26	29	5	3.84	4
I thought there was too much inconsistency in the Carevive CPS.[a]	40	29	15	5	–	5	1.83	2
I would imagine that most people would learn to use the Carevive CPS very quickly.	2	5	21	28	34	4	3.97	4
I found the Carevive CPS very cumbersome/awkward to use.[a]	49	18	19	3	2	3	1.8	1
I felt very confident using the Carevive CPS.	4	2	17	27	40	4	4.08	4
I needed to learn a lot of things before I could get going with the Carevive CPS.[a]	48	17	22	2	2	3	1.82	1

[a] Reverse-scored item
CPS—care-planning system; M—median; NA—not available or no answer
Note. Responses were rated on a scale from 1 (strongly disagree) to 5 (strongly agree).

TABLE 6. Provider Satisfaction and Usability Data: Post-Test (N = 7)

Question	Dissatisfied/ Very Dissatisfied	Neutral	Very Satisfied/ Satisfied	NA	$\bar{X}$	M
How satisfied are you overall with the CPS?	–	1	5	1	4.33	4.5

Question	Not at All Customized	Neutral	Highly Customized	NA	$\bar{X}$	M
How customized to the individual patient did you find the care plans generated by the CPS?	–	–	6	1	4.67	5

Question	Not Very Useful/ Not at All Useful	Neutral	Very Useful/ Useful	NA	$\bar{X}$	M
How useful was the information provided in the clinical considerations section of the care plans?	–	–	6	1	4.5	4.5

Question	Difficult to Understand	Neutral	Easy to Understand	NA	$\bar{X}$	M
Do you find the information provided in the CPS easy to understand?	–	–	6	1	4.5	4.5

Question	Not Very Appropriate/Not at All Appropriate	Neutral	Very Appropriate/ Appropriate	NA	$\bar{X}$	M
How appropriate are the patient-facing recommendations and tasks in the care plans?	–	1	5	1	4.33	4.5

Statement	Disagree/ Strongly Disagree	Neutral	Strongly Agree/Agree	NA	$\bar{X}$	M
The CPS improved patient–clinician encounters and communication.	–	2	5	–	4	4
The CPS helped me to identify and assess my patients' symptoms and concerns.	–	1	5	1	4.33	4.5
The CPS helped me to apply evidence-based practices for symptom management and supportive care.	–	–	6	1	4.5	4.5
I would recommend the CPS as a clinical decision support system for symptom management and supportive care.	–	1	5	1	4.33	4.5
The CPS helps me to address patients' concerns and distress.	–	–	6	1	4.67	5
The CPS saves me time.	2	1	3	1	3.17	3.5
I would recommend that other providers use the CPS.	–	1	5	1	4.17	4
I think that I would like to use the Carevive CPS frequently.[a]	–	2	5	–	4	4
I found the Carevive CPS unnecessarily complex.[a,b]	5	2	–	–	1.86	2
I thought the Carevive CPS was easy to use.[a]	–	2	5	–	4.29	5
I think I would need assistance to be able to use the Carevive CPS.[a,b]	4	3	–	–	2.29	2
I found the various parts of the Carevive CPS worked well together.[a]	–	1	6	–	4.14	4

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TABLE 6. Provider Satisfaction and Usability Data: Post-Test (N = 7) (Continued)

Statement	Disagree/ Strongly Disagree	Neutral	Strongly Agree/Agree	NA	$\overline{X}$	M
I thought there was too much inconsistency in the Carevive CPS.[a,b]	5	1	1	–	2.14	2
I would imagine that most people would learn to use the Carevive CPS very quickly.[a]	1	–	5	1	4	4.5
I found the Carevive CPS very cumbersome/awkward to use.[a,b]	2	1	4	–	2.43	2
I felt very confident using the Carevive CPS.[a]	1	2	4	–	3.71	4
I needed to learn a lot of things before I could get going with the Carevive CPS.[a,b]	2	–	5	–	2.43	2

[a] From the System Usability Scale
[b] Reverse-scored item
CPS—care-planning system; M—median; NA—not available or no answer

and important symptoms were readily addressed. In a prior study, patients with cancer tended to prefer ePROs over paper (Girgis et al., 2017).

A unique finding of the current study is that half of the providers (n = 3) reported that the platform saved them time, perhaps the most valuable commodity during a patient encounter. This contrasts with other literature that reports time as a major barrier for implementing PROs (Howell et al., 2015) but is consistent with another study of ePRO monitoring and management in 724 individuals with metastatic solid tumors, wherein the volume of nursing calls did not increase in the ePRO-based proactive symptom monitoring (intervention) arm versus the standard care (control) arm (Basch et al., 2016). It is likely that, once clinical workflow using ePROs was established, clinicians found that the platform facilitated focused patient visits. Patients with cancer in the current study selected and/or wrote their top three visit concerns, and this may have aided in time savings by focusing the visit on what mattered most to the patient, consistent with qualitative findings.

Implementation barriers did not organically emerge from qualitative interviews as a significant problem in this study. This is consistent with a study by Basch, Pugh, et al. (2017), who found that minimal effort was required by staff to incorporate ePROs into the clinical setting. However, this contrasts with the findings of Mooney, Beck, Friedman, Farzanfar, and Wong (2014), wherein adoption and use was low when the authors sought to implement ePROs into existing nursing and clinical workflow without additional staff support. In the current study and in Basch, Pugh, et al.'s (2017) study, research assistants and/or research nurses were engaged to educate patients with cancer about the technology, to ensure results were delivered to clinicians, and to review CPs with participants. Training, workflow integration, and assisting patients and providers to engage with the technology are all essential components when implementing ePROs into practice (Pereira et al., 2014; Santana et al., 2015). More research is needed to better understand what implementation strategies are most supportive in various settings.

The customized CP generated for each patient was a novel part of the intervention within this study, and qualitative findings suggest that this contributed to the high degree of patient satisfaction. Individual patient ePRO responses algorithmically generated supportive care recommendations using rules logic, and these recommendations were acted on by providers and nurses during the visit and subsequent clinic or infusion time. This aided in real-time communication about symptoms and a tailored approach to symptom relief. Treatment planning has been found in other studies to improve patient–provider communication (Berry et al., 2011; Blinder et al., 2013; Partridge et al., 2013). The qualitative findings of this study reveal additional information about the use of CPs that has not previously been mentioned in the literature. Patients with cancer found the CPs to be a practical resource, useful in managing symptoms, and a template to discuss their cancer and management plan with others, including family, friends,

and other providers. Two previous studies reported that patients with cancer used ePROs to prioritize their symptom needs, but CPs were not a part of those studies (Kotronoulas, Connaghan, et al., 2017; Kotronoulas, Papadopoulou, MacNicol, Simpson, & Maguire, 2017).

It is important to note that this study would not have been possible without the support of nurses. Research nurses screened patients for eligibility, facilitated entry of the ePROs, answered questions related to the technology, and then escorted patients to their individual visit. If available, they attended the patient–provider visit. Following the visit, the nurse reviewed the CP, discussed referrals and recommendations, scheduled appointments as needed, and answered any questions. Nurses were able to decrease disruption in the workflow, which is commonly reported by clinics trying to implement ePROs into practice. Translation of these findings into practice without the research staff is an important next step to facilitate broad dissemination.

Limitations

Although these findings shed light on the implementation of ePROs and customizable CPs, limitations should be noted. First, the sample size was small. Although the study was conducted in two diverse settings, the sample was limited in terms of sociodemographic diversity, and additional work is needed to determine generalizability to other populations and settings. Missing data were another limitation. Follow-up measures were mailed to patients with cancer or presented to patients during a routine visit, but response rate was 77%. In some cases, death and patients not feeling well from treatment or progressive disease resulted in lack of response; however, in some cases, lack of response was unknown. Some patients were from rural areas, and they did not return to the clinic or complete 12-week measures. It is possible that individuals who perceived less value from the CPs were the nonrespondents.

Implications for Research

This study highlights important avenues for future research. First, uncertainty exists regarding the timing of CP distribution. Patients with cancer in this study received CPs at the beginning of treatment (gynecologic) or after completion of active treatment (breast). For patients with cancer enrolled near the completion or after active treatment, the CP information and symptom management resources were either redundant or less salient. Patients with cancer may be overwhelmed

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KNOWLEDGE TRANSLATION

- Customizable supportive care plans (CPs) generated through electronic patient-reported outcome assessments provide a novel, patient-centered tool for patients with cancer to refer to for recommendations to manage symptoms.
- Oncology clinics can feasibly integrate supportive CPs into practice, resulting in improved patient and oncology care team satisfaction.
- Supportive CPs have potential to improve clinic efficiency, improve pain and symptom outcomes, and decrease healthcare use.

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at diagnosis and treatment initiation; therefore, it appears that the CP may be more helpful if delivered early in the cancer trajectory, but whether that is at diagnosis, at the first treatment visit, or following the first visit is uncertain. One possible approach would be to have the onset of symptoms prompt distribution of the first CP. Future investigations could provide opportunities to explore patient reporting beyond PROs to include goals, values, preferences, and shared decision making. Incorporating patient preferences into care aligns with the foundations of evidence-based practice (Sackett, Strauss, Richardson, Rosenberg, & Hayes, 2000). Finally, examining the influence of PROs and CPs on patient outcomes is essential. Although some outcomes have been found, such as improved symptom control (Mooney et al., 2017), communication (Berry et al., 2011; Blinder et al., 2013; Partridge et al., 2013), and survival (Basch, Deal, et al., 2017; Denis et al., 2019), additional studies are needed to confirm these results and to examine other outcomes, such as healthcare costs and use.

Implications for Nursing

Individualized patient CPs have been a part of nursing care for decades. Historically, CPs have been used by nurses to provide comprehensive care using the nursing process. The novel approach employed in this study (i.e., providing patients with CPs to optimize self-care at home) could be one foundational approaching to ensuring the delivery of patient-focused care in today's healthcare environment. Using ePROs to electronically generate customizable CPs is feasible, provides high satisfaction for patients with cancer and providers, and may even improve efficiency in ambulatory oncology settings.

Nurses should keep in mind, however, the importance of the delivery of these CPs. Although plans are generated during the office visit and discussed with

the provider, patients with cancer are often overwhelmed by the complexity involved in self-care. It is important for nurses to follow up with patients at the time of and following CP delivery to reinforce teaching and answer outstanding questions. In the current study, such follow-up education and reinforcement often occurred in the infusion center during cancer treatment or following the office visit with the nurse. When patients fully understands their individualized plan of care, significant potential exists for improvement in pain and symptom management and quality of life, earlier detection of complications, and a decrease in emergent visits and healthcare use. Ongoing ePRO monitoring following initial care plan delivery, with iterative generation of self-management plans, is another promising strategy that is currently being investigated at centers using the Carevive CPS.

Conclusion

ePROs were used in this novel technology platform to develop individualized supportive CPs for patients with gynecologic or breast cancer. Implementing these CPs in cancer clinics was feasible, and patients and providers reported high satisfaction. These plans can be used as a teaching guide for nurses and as a reference guide for patients to refer to for self-care interventions, with potential to better manage symptoms and identify potential complications early. The potential for this approach to improve patient outcomes is great, and implementation and clinical outcomes of innovative approaches combining ongoing ePRO monitoring and management with the ongoing provision of CPs should be rigorously studied if the potential of such proactive symptom care interventions are to be realized.

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