Received: 24 June 2016 | Revised: 3 March 2017 | Accepted: 14 April 2017

DOI: 10.1002/pon.4442

WILEY

PAPER

Patient and caregiver perspectives on decision support for symptom and quality of life management during cancer treatment: Implications for eHealth

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Funding information
Patient-Centered Outcomes Research Institute, Grant/Award Number: PI-12-001

Abstract

Objectives: Adequate symptom and quality-of-life (SQL) management is a priority during cancer treatment. eHealth is a timely way to enhance patient-engagement, facilitate communication, and improve health outcomes. The objectives of this study were to describe patient and caregivers' perspectives for providing, processing, and managing SQL data to enhance communication and identify desired components for decision support.

Methods: Data were collected from 64 participants through questionnaires and focus groups. Analysis was conducted using NVivo. Open and axial coding was completed, grouping commonalities and large constructs into nodes to identify and synthesize themes.

Results: Face-to-face meetings with clinicians were the prime time to communicate, and patients strove to understand treatment options and the effect on SQL by bringing caregivers to their visits, taking notes, tracking symptoms, and creating portable health records. Patients/caregivers struggled to self-manage their symptoms and were uncertain when to contact clinicians when experiencing uncontrolled symptoms. Most participants identified eHealth solutions for decision support. However, 38% of participants (n = 24) rarely used computers and identified non-eHealth options for decision support. Core components for both eHealth and non-eHealth systems were access to (1) cancer information, (2) medical records, (3) peer support, and (4) improved support and understanding on when to contact clinicians.

Conclusions: Patients were faced with an overwhelming amount of information and relied on their caregivers to help navigate the complexities of cancer care and self-manage SQL. Health technologies can provide informational support; however, decision support needs to span multiple venues to avoid increasing disparities caused by a digital divide.

KEYWORDS

cancer, decision support, eHealth, oncology, symptoms and quality of life

1 | INTRODUCTION

While most cancer patients report that quality of life is as important as length of life, only a minority report that changes in quality of life during cancer treatment were discussed with their clinicians.[1] The use of decision support (DS) for symptom and quality of life (SQL) management is a timely and innovative way to enhance patient engagement, facilitate communication, and improve outcomes. Decision support assists in shared decision making at the point-of-care and includes tools for information management, focusing attention and/or patient-specific interventions.[2] Patient-reported questionnaires gather information about SQL concerns and have been found to enhance communication and reduce symptom distress.[3-6] However, most settings have not established efficient methods to collect SQL data and integrate DS into the flow of care.[5]

Effective use of health information technology to enhance patient outcomes has been identified as a national priority.[7,8] eHealth is a term that describes the use of health information technology, which includes electronic medical records, electronic collection of patient-reported SQL, DS, and telemedicine, and is the term used in this

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paper.[9,10] As these systems are implemented, it is essential to gather input from patients to ensure that patients' voices are heard and integrated into emerging eHealth technology. Although multiple studies have assessed the usability and/or efficacy of electronic patient-reported outcome systems, none have examined patient and caregiver perspectives regarding their preferences for the type of DS and what components would be desirable.[11,12] Thus, the aims of this study were to (1) describe patient and caregiver perspectives for providing, processing, and managing SQL and (2) explore their perspectives about which components of decision support would be desirable to enhance communication with clinicians about SQL during cancer treatment.

2 | METHODS

A qualitative approach was used to explore patient and caregiver perspectives about what types of DS would enhance communication with clinicians and improve SQL management. Dana-Farber Cancer Institute's institutional review board approved the study (protocol number 12-300).

2.1 | Sample and setting

Participants were recruited from Dana-Farber Cancer Institute and community-based centers (Faulkner, Milford, South Shore Hospital, and Whittier Street Health Center-Boston). Eligible patients were ≥18 years of age, English or Spanish speaking, and were undergoing active cancer treatment or received treatment within the past 6 months. Enrolled patients were invited to identify caregivers (≥18 years old; English or Spanish speaking) to participate in the focus group.

2.2 | Procedures

Nine focus groups (7 in English and 2 in Spanish), with 6 to 12 patient and caregiver participants each, which included both, were audio-recorded. Using a topic guide focused on the patients' experiences to prompt participants to (1) describe communication about SQL at the time of diagnosis, during, and in-between clinic visits, (2) discuss important SQL issues during treatment and how they learned about symptoms, (3) identify ways to gather SQL information and then share this with clinicians, (4) discuss strategies to self-manage SQL, and (5) generate ideas for the types of DS that would enhance communication with their clinicians and improve symptom management.

Focus groups were held in conference rooms at each clinical recruitment site. Informed consent, demographic information, and use of technology were collected before the focus group. Participants received $50 for their time. Results of analysis were shared with coinvestigators and an expert panel consisting of 7 members, a cancer survivor, caregiver, clinician, administrator, informatics, quality improvement, and health equity specialists. The expert panel members assisted with interpretation of data, discussed implications, and identified future solutions.

2.3 | Data analyses

Transcripts were transcribed, de-identified, and entered into NVivo 9. Data analyses were conducted by 3 research team members (DLB, MN, MEC) who met to organize the data and then conducted inductive content analysis of transcripts. An experienced investigator in qualitative research (DLB) reviewed initial and selected subsequent coding and provided instruction on the method as needed. The group met to develop a codebook and then on a regular basis to review coding, discuss emergent categories, and used group consensus to finalize the categories. Common responses to the topic guide queries were grouped as *manifest content*.[13] Abstracting the content and initial themes resulted in higher order categories.[14] Analytic memos used during the entire analysis served as both an audit trail and a communication tool between coders. A heat map was created to show the parent and child nodes that were coded and created a visual picture of the data to identify patterns and hierarchical relationships (Figure 1). Nodes with a larger number of coding references were displayed as larger rectangles in relation to other nodes and identified prominent themes in the data. The size and color of the rectangles illustrated the nodes that had the greatest number of coding references. In Figure 1, red indicates a larger number of references that were coded as compared with orange, then yellow, and green. In other words, the red-colored themes were the most common themes discussed in the focus groups.

3 | RESULTS

3.1 | Participant demographics

Fifty-six percent (n = 23) of the patients invited caregivers to participate in focus groups. Participant demographics and clinical variables are presented in Table 1. Caregivers tended to be male and less likely to use the Internet for health information as compared with patients. Approximately 58% (n = 37) of participants reported that they accessed the Internet to gather health-related information. Participant characteristics associated with frequency of Internet use are described in Tables 2 and 3. Participants who were older, male, non-White, Hispanic, and had ≤high school education were less likely to use the Internet for health information.

3.2 | Themes

The heat map provided a visualization of the main themes of the data. As Figure 1 illustrates, *education about treatment*, *contacting clinicians*, *self-management*, and *decision support systems* were the most prominent themes—large and red, orange, or yellow rectangles. Other prominent themes included face-to-face meetings with clinicians, getting through it, and side effect appraisal. A summary of the main themes with select quotes is provided below.

3.3 | Face-to-face meetings

Face-to-face meetings with clinicians were considered the prime means for communicating about cancer, its treatment, and SQL. Patients struggled to understand their treatment options and impact on SQL. They used multiple strategies to enhance their understanding: making lists, taking notes, and bringing caregivers to the visits. It was especially helpful if caregivers had health care experience so they could help the patient understand the implications for treatment.

> *"The time when the note taking was important was when the doctors were trying to figure out what to do next. We*

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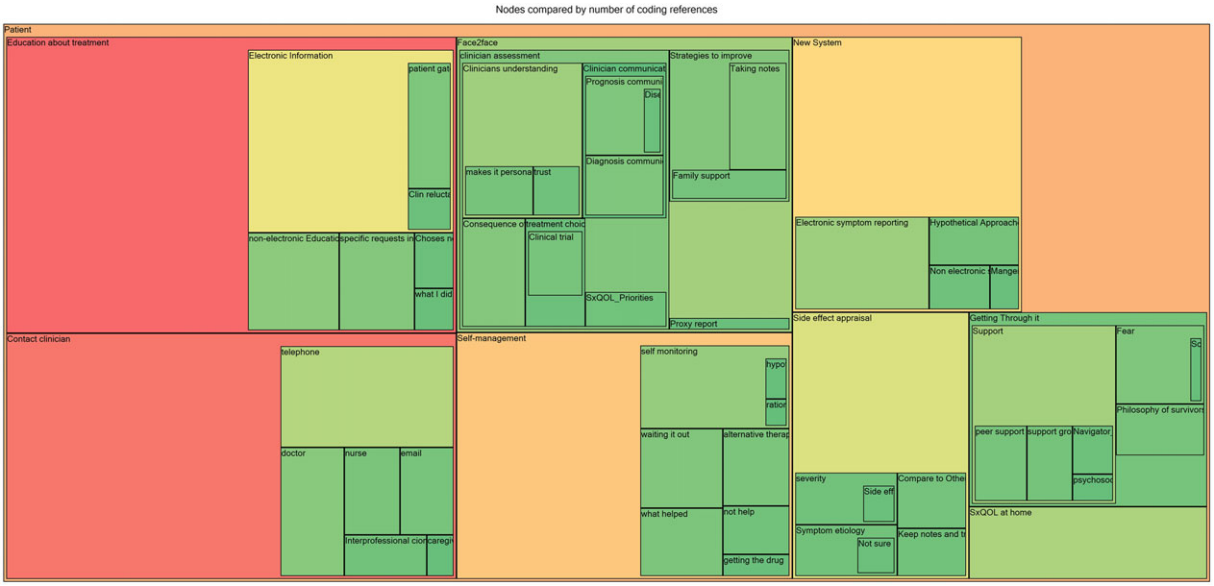

FIGURE 1 Nodes compared by number of coding references

> *relied on the notes taken by my daughters. After the appointment we would sit down and say, that was bad news, but my daughters would say, no that wasn't bad news. Listen to what the doctor had said. And I just couldn't absorb all of the stuff that was said."*

> *"My daughter was my interpreter. It's always good to have a second set of ears and even nicer if you have a medical set of ears."*

Patients created portable health records so they could keep track of their medical history. This was particularly important if they received treatment in multiple places.

> *"The oncologist agreed that it was fine to get my chemo here and sent the records. They didn't send all the records. But she had her book. So away they went and copied all the pages of her book."*

Clinicians assessed patient's response to treatment and made adjustments in treatments, as needed during clinic visits. Patients reported that clinicians took symptoms seriously and worked hard to help them tolerate side effects of treatment.

> *"He wanted to know the symptoms that I had from the last treatment. And then the doctor had to focus on those symptoms to know where I was so he could adjust the cocktail of the three different chemos."*

3.4 | Education about cancer treatment symptoms

Patients learned about possible symptoms through both nonelectronic and electronic educational materials. However, receiving written materials with information about when to call was particularly helpful.

> *"They gave us papers of what to look for and one was temperature. I would write down my temperature all the time and when it got up to 102, he said we have to call because it said in the paper that you have to call."*

Some patients, however, wanted more information than clinicians shared and as a result sought out information on the Internet.

> *"My oncologist told me I'm going to tell you this much information until we know the next test but for me that's not good enough. I need to know everything. I think this is how she gets patients to cope and gives out information that she thinks is valid. So I felt like I needed to get it by myself."*

3.5 | Contacting clinicians between visits

Patients expressed uncertainty about when to contact their clinicians, were not clear about the etiology of symptoms, and did not want to bother the clinicians.

> *"You try and rationalize not calling half the time. The other day when I was having pain, I didn't call. There's something about calling the medical establishment you try and avoid sometimes, just whether it isn't important or not interrupting an important person."*

Patients talked about using the telephone versus email communication in-between visits. Overall, patients recounted that it depended on the nature and urgency of the problem.

> *"It depends on the subject matter for example, we had a question about taking something over the counter so I called and the nurse walked us through the pros and cons of doing that and made a suggestion to use half of that and then increase this and so I mean to verbalize that was much more effective than an e-mail."*

3.6 | Self-management at home

Some patients opted to wait until the symptoms passed while others actively participated in self-management.

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TABLE 1 Patient and caregiver demographic, clinical, and computer literacy information (N = 64)

	Patient (N = 41)		Caregiver (N = 23)	
	N	%	N	%
Age				
<50	11	26.8	8	34.8
≥51	30	73.2	15	65.2
Median (range)	60	(28-80)	60	(26-83)
Gender				
Male	12	29.3	13	56.5
Female	29	70.7	10	43.5
Ethnicity				
Hispanic/Latino	8	19.5	7	30.4
Non-Hispanic/non-Latino	19	46.3	13	56.5
Did not report	14	34.1	3	13.0
Race				
White/Caucasian	28	68.3	13	56.5
Black/African American	5	12.2	3	13.0
Other	1	2.4	3	13.0
Did not report	7	17.1	4	17.4
Education				
High school or less	13	31.7	8	34.8
Some College and above	28	68.3	15	65.2
Median time since diagnosis at time of consent (range)	1 y	(4 mo-13 y)		N/A
Stage of disease at time of consent[a]				
I	11	31		N/A
II	3	9		
III	4	11		
IV	17	49		
Income				
$49,999 or less	20	48.8	10	43.5
$50,000 or more	19	46.3	12	52.2
Did not report	2	4.9	1	4.3
Type of cancer				
Breast	14	34.1		N/A
Gastrointestinal	4	9.8		
Genitourinary	11	26.8		
Gynecologic	2	4.9		
Hematologic	2	4.9		
Head and neck	2	4.9		
Thoracic	6	14.6		
Used internet to obtain health information				
Never, rarely	11	26.8	13	56.5
Sometimes, often, and very often	29	70.7	8	34.8
Missing	1	2.4	2	8.7

[a]N = 35.

"You're waiting with all these symptoms and you have this tendency to blame everything on chemo or cancer. So now you're sitting here, oh God, I've got a pain here. Is it or isn't it related to what I'm going through? And that's very difficult to figure out. Should I just let it go and see what happens? You wait and see if it goes away or you have a doctor's appointment before it goes away."

Sometimes, it took a while to recognize the symptoms were associated with their treatments so patients delayed calling the clinicians.

"I was stuck on the toilet for a week with post-chemo constipation, which I had been warned about. So I kept having this little fantasy of, this will pass. It took several days to realize that this is what the nurses were trying to

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TABLE 2 Patient characteristics associated with Internet use to obtain health information

	Study Patient Participants n = 41 Internet Usage to Obtain Health Information						
	Never, Rarely		Sometimes, Often, and Very Often		Missing		Total
	N	%	N	%	N	%	N
Age							
<50	1	9.1	10	90.9	0	0.0	11
≥51	10	33.3	19	63.3	1	3.3	30
Gender							
Male	1	8.3	11	91.7	0	0.0	12
Female	10	34.5	18	62.1	1	3.4	29
Ethnicity							
Hispanic/Latino	3	37.5	5	62.5	0	0.0	8
Non-Hispanic/non-Latino	3	15.8	16	84.2	0	0.0	19
Did not report	5	35.7	8	57.1	1	7.1	14
Race							
White/Caucasian	7	25.0	21	75.0	0	0.0	28
Other	2	33.3	3	50.0	1	16.7	6
Did not report	2	28.6	5	71.4	0	0.0	7
Education							
High school or less	6	46.2	7	53.8	0	0.0	13
Some College and above	5	17.9	22	78.6	1	3.6	28

explain to me and- this was not going to resolve. So when I finally realized that, it was, OK, you must call."

Patients who engaged in self-management described strategies to get through their treatments and facilitate communication with their clinicians, for example, self-monitoring through tracking symptoms. The benefits identified with self-monitoring were that patients recognized patterns associated with the symptoms and could anticipate how they would feel after the treatments.

"Every day I would chart my symptoms. I found it interesting for my own benefit that when I started the next one to see, okay on the third day I get these pains here. So I call it the pattern."

Patients experienced difficulty coordinating care across settings; as a result, some reported wanting to discontinue their treatment.

"I was so sick. I was throwing up. I had pain in my stomach, I was crying. I called up the doctor and he ordered some nausea medicine. And the drug store said they get the fax. So by the time they got the fax, they said, oh, we're closed now. So it was all that day and the next day and when I came in here the following time- I said no more. I'd rather have the quality of life than the quantity."

3.7 | Side effect appraisal

Some patients felt fortunate that they did not experience as many side effects as others. In other cases, patients had a difficult time anticipating the severity of symptoms and did not think that they would need medications and wanted until they could no longer bear the severity of symptoms contact the clinicians.

"I'm the kind of person that doesn't do well on medication. Like getting on chemo, which in itself was a challenge for me, but then to take these piles of pills every morning, was so hard. I'm like I don't need this—I'm feeling good. And an hour later I felt horrible and couldn't keep down the medication. So for me it was when I felt like — I can't handle any more that I would finally call."

3.8 | Getting through it

Patients described receiving the diagnosis of cancer and how difficult it was to process the information and understand the treatment and potential side effects. Patients relied on support from others, especially caregivers, to get through this experience.

"I was comfortable knowing that I had a family member with me that could hear for me instead of me having to worry, I don't know what to go and say. I forget. It took half the load off just knowing that someone was there."

In addition, many patients described how their philosophy of life helped them cope with living with cancer.

"You know I've got this philosophy. When He says it's my turn, okay, it's my turn and until then, go do what I have to do—Enjoy life."

3.9 | New systems for decision support

Two main themes were identified related to DS: eHealth and non-eHealth systems. Patients discussed creating a DS system that would

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TABLE 3 Caregiver characteristics associated with Internet use to obtain health information

	Study Caregiver Participants n = 23 Internet Usage to Obtain Health Information						
	Never, Rarely		Sometimes, Often, and Very Often		Missing		Total
	N	%	N	%	N	%	N
Age							
<50	3	37.5	4	50.0	1	12.5	8
≥51	10	66.7	4	26.7	1	6.7	15
Gender							
Male	5	38.5	6	46.2	2	15.4	13
Female	8	80.0	2	20.0	0	0.0	10
Ethnicity							
Hispanic/Latino	5	71.4	2	28.6	0	0.0	7
Non-Hispanic/non-Latino	6	46.2	5	38.5	2	15.4	13
Did not report	2	0.0	1	33.3	0	0.0	3
Race							
White/Caucasian	5	38.5	6	46.2	2	15.4	13
Other	5	83.3	1	16.7	0	0.0	6
Did not report	3	0.0	1	25.0	0	0.0	4
Education							
High school or less	8	100.0	0	0.0	0	0.0	8
Some College and above	5	33.3	8	53.3	2	13.3	15

meet their needs, especially those that were not computer literate. It is important to recognize that a significant proportion (38%, n = 24/64) of participants reported that they rarely accessed the Internet for health information.

> *"I am completely computer illiterate. I own a cell phone, but it doesn't do anything. It's not a smart one. I have to say for those of us who are dinosaurs I'm doing just fine with phone calls and snail mails."*

3.10 | eHealth-based systems

Patients and caregivers described components of an eHealth system that might facilitate communication with their clinicians and meet their needs: (1) the ability to track symptoms over time, (2) access to Web-based information, including visual information, (3) DS that provides prompts for when to contact the clinicians to report their symptoms (ie, when pain severity reaches a "5" on a 0-10 scale) and/or an alerting system for clinicians, (4) peer support, and (5) access to medical records.

3.11 | Non eHealth-based systems

Patients and caregivers described components of a non-eHealth system that would facilitate communication with their clinicians and meet their needs: (1) having a centralized place to access print information, (2) a telephone hotline or centralized place to have their questions answered so that they could minimize bothering clinicians for questions and know when it is appropriate to contact clinicians, (3) access to written or tape-recorded notes from medical visits, and (4) peer support.

4 | DISCUSSION

Patients and caregivers identified key issues during treatment for cancer. One key issue was the lack of understanding regarding medical terms and treatment options that were presented during discussion with clinicians. Patients described using multiple strategies, which included bringing family members with them and taking notes in an attempt to understand the information that was being presented during visits. In addition, patients often created portable medical records to carry with them across treatment settings.

This finding underscores the potential usefulness of patient access to electronic medical records through Web-based, personal health record (PHR) portals. Personal health record usage has been explored in primary care and was associated with improved communication with clinicians and improvement in medication adherence.[15-17] Cahill and colleagues[18] examined the use of PHR and the relationship among PHR usage, symptom severity, uncertainty, and mood in 186 patients with brain tumors. The investigators found that at least 60% of patients accessed PHR at least once (range, 0-126). Patients undergoing treatment were more active users, and access was associated with lower disease-related uncertainty and symptom severity.

As access to medical records increases, it will be important to reform the content and format of notes if the notes are to become an efficient communication tool between clinicians and patients.[19] Content that is more easily understood by patients provides an opportunity for patients to review the treatment options and recommendations discussed during the visit and get a better understanding of their plan for care to enhance shared decision making and self-management of symptoms that are expected to occur with the treatment.

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One issue that created uncertainty for patients and their caregivers was how to self-manage symptoms at home and when to call clinicians. The experience of uncertainty in the context of cancer is common, and information support is an essential strategy to help mitigate this uncertainty.[20] Patients with cancer often undergo complex treatments. Responsibility for monitoring side effects has shifted to patients and their caregivers, who are often unprepared to self-manage at home.[21] In our study, patients often waited until their symptoms were so severe that some patients considered stopping treatment in part because they were not entirely sure when to call their clinicians. The symptoms identified by patients as problematic included pain and gastrointestinal problems (ie, nausea/vomiting), which are among the most common symptoms and are associated with urgent care visits.[22] This finding suggests that providing information to patients and caregivers about self-management strategies and when to call clinicians may be beneficial. Similar to our findings, Lubberding and colleagues[23] also found that cancer survivors reported being ill-prepared to manage symptoms during the posttreatment period and that receipt of personalized advice and tailored supportive care were identified as desirable interventions. Two recent studies evaluated the efficacy of using proactive automated telephone-based monitoring of symptoms to improve symptom management at home during cancer treatment and were found to improve uncontrolled symptoms.[24,25]

This is the first study to our knowledge that explored patient perspectives about which components of DS would be desirable for enhancing communication with clinicians. Previous studies have focused on examining the usability or efficacy of eHealth systems.[26,27] In our study, patients and caregivers identified components for DS through the use of eHealth and non-eHealth systems. Many eHealth features identified are available, such as the ability to track symptoms, access disease-specific information and alert clinicians about symptom severity, and have demonstrated efficacy for increasing communication and decreasing symptom distress.[3,4,28] However, additional features, such as peer support, access to medical records, and DS to prompt contacting clinicians about uncontrolled symptoms, were identified as desired features. Kuijpers and colleagues[29] conducted focus groups to identify desirable features of a patient portal system among cancer survivors and found that access to information, including cancer survivorship plans, and their medical records were the most desired features. Our findings may differ since Kuijpers and colleagues[29] provided predetermined mock-ups of portal features, and patients were up to 5 years posttreatment, whereas in our study, patients with recent treatment experience described which components would be most helpful. Advances in health information technology and increased use of patient portals make it possible to integrate patient preferences for DS.[30] As these systems are further refined, it will be essential to include patients, caregivers, and clinicians in the development—codesigning interventions where with end-user involvement is more likely to change attitudes and behaviors.[31,32]

Non-eHealth systems were also identified as desirable by patients who were not computer literate, underscoring that information and DS needs to be made available across various platforms to avoid increasing health disparities among vulnerable groups of patients. Participant use of the Internet to access health information in our study (57.8%, n = 37) was similar to rates found by Chou and colleagues (51.2%, n = 1379).[33] Moreover, Chou and colleagues[33] identified that cancer survivors accessed the Internet at lower rates as compared to the general population and those who were younger age, non-Hispanic White ethnicity/race, lived in a city, had higher levels of education, and better self-rated health were more likely to access the Internet.

Taken together, the main themes identified in this study were that patients struggle to understand their cancer treatments, how to self-manage symptoms at home, and when to contact their clinicians regarding symptom severity. Interventions that provide informational support are critical, especially related to self-management of common symptoms and when to contact their clinicians about uncontrolled symptoms. Moreover, decision support must span multiple venues, including non-eHealth. Given the national push to move toward eHealth technologies, exacerbation of disparities among older, less educated, and poor patients has the potential to be an unintended consequence.

4.1 | Limitations

A limitation of this study was that data were collected within one health system. To offset this limitation, we collected data across affiliated centers, including a comprehensive cancer center, community-based center, and a federally qualified health center. The sample consisted of adults with cancer who received treatment in an outpatient setting, as well as their caregivers; findings cannot be generalized beyond this setting.

5 | CONCLUSION

Patients are faced with an overwhelming amount of information that is hard to digest during the context of a clinic visit and rely on caregivers' presence to help them understand the information. Patients and caregivers need to self-manage their symptoms at home and are often uncertain about when to call their clinicians regarding uncontrolled symptoms. As a result, patients waited until they could no longer bear the severity of their symptoms, and some may even decide to forego treatment. Decision support is an important component of care that has not yet been integrated into routine care. Future refinement of DS programs based on the preferences of patients that include eHealth and non-eHealth options are an important avenue for future research.

CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

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How to cite this article: Cooley ME, Nayak MM, Abrahm JL, et al. Patient and caregiver perspectives on decision support for symptom and quality of life management during cancer treatment: Implications for eHealth. *Psycho-Oncology*. 2017;26:1105-1112. https://doi.org/10.1002/pon.4442

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