A qualitative study of patient and provider perspectives on using web-based pain coping skills training to treat persistent cancer pain

CHRISTINE RINI, Ph.D., 1,2 MAIHAN B. VU, dr.ph., M.ph., 2,3 HANNAH LERNER, B.S., CATHERINE BLOOM, M.ph., JESSICA CARDA-AUTEN, M.ph., WILLIAM A. WOOD, M.D., M.P.H., 2,5 ETHAN M. BASCH, M.D., 2,5 PETER M. VOORHEES, M.D., KATHERINE E. REEDER-HAYES, M.D., M.B.A., 2,5 AND FRANCIS J. KEEFE, Ph.D.

(RECEIVED April 28, 2016; ACCEPTED January 30, 2017)

ABSTRACT

Objective: Persistent pain is common and inadequately treated in cancer patients. Behavioral pain interventions are a recommended part of multimodal pain treatments, but they are underused in clinical care due to barriers such as a lack of the resources needed to deliver them in person and difficulties coordinating their use with clinical care. Pain coping skills training (PCST) is an evidence-based behavioral pain intervention traditionally delivered in person. Delivering this training via the web would increase access to it by addressing barriers that currently limit its use. We conducted a patient pilot study of an 8-week web-based PCST program to determine the acceptability of this approach to patients and the program features needed to meet their needs. Focus groups with healthcare providers identified strategies for coordinating the use of web-based PCST in clinical care.

Method: Participants included 7 adults with bone pain due to multiple myeloma or metastasized breast or prostate cancer and 12 healthcare providers (4 physicians and 8 advanced practice providers) who treat cancer-related bone pain. Patients completed web-based PCST at home and then took part in an in-depth qualitative interview. Providers attended focus groups led by a trained moderator. Qualitative analyses identified themes in the patient and provider data.

Results: Patients reported strongly favorable responses to web-based PCST and described emotional and physical benefits. They offered suggestions for adapting the approach to better fit their needs and to overcome barriers to completion. Focus groups indicated a need to familiarize healthcare providers with PCST and to address concerns about overburdening patients. Providers would recommend the program to patients they felt could benefit. They suggested applying a broad definition of cancer pain and having various types of providers help coordinate program its use with clinical care.

Significance of results: Web-based PCST was acceptable to patients and providers. Our findings suggest that patients could benefit from this approach, especially if patient and provider barriers are addressed.

Address correspondence and reprint requests to: Christine Rini, who is now at the John Theurer Cancer Center, Hackensack University Medical Center, 40 Prospect Avenue, Jurist Research Building, Room 302, Hackensack, New Jersey, 07601. E-mail: christine.rini@hackensackmeridian.org.

¹Department of Health Behavior, Gillings School of Global Public Health, University of North Carolina, Chapel Hill, North Carolina

²Lineberger Comprehensive Cancer Center, University of North Carolina, Chapel Hill, North Carolina

³Center for Health Promotion and Disease Prevention, University of North Carolina, Chapel Hill, North Carolina

⁴Duke Clinical Research Institute, Durham, North Carolina

⁵Department of Medicine, University of North Carolina, Chapel Hill, North Carolina

⁶Levine Cancer Institute, Carolinas HealthCare System, Charlotte, North Carolina

⁷Duke University Medical Center, Durham, North Carolina

KEYWORDS: Cancer pain, Pain coping skills training, eHealth, Cognitive behavioral intervention, Pain management

INTRODUCTION

Pain is one of the most common symptoms experienced by cancer patients (van den Beuken-van Everdingen et al., 2007) and one of the symptoms least likely to be adequately treated (Zhao et al., 2013). Improvements in pain management are needed to help patients manage persistent cancer pain and its impact on their daily activities, relationships, and emotional health (Badr et al., 2010; Gauthier et al., 2014; Laird et al., 2009). One way to improve current approaches is to do a better job of meeting the well-recognized need for multimodal pain management strategies that pair pharmacologic pain treatments with behavioral pain interventions. Guidelines (e.g., Chou et al., 2007; 2009; Raphael et al., 2010; Swarm et al., 2016) recommend behavioral interventions that educate patients about pain and teach them skills for managing it. Pain coping skills training (PCST) achieves these goals using the principles of cognitive behavioral therapy (CBT). Patients learn how cognitive, behavioral, and emotional responses to pain can increase pain severity and impairment (Sharp, 2001), and then learn skills involving relaxation, distraction (e.g., pleasant imagery, pleasant acscheduling), cognitive restructuring address catastrophizing and other maladaptive cognitive patterns), and pacing activities. Randomized controlled trials have shown that PCST and similar interventions can improve pain caused by osteoarthritis (Keefe et al., 1990a; 1990b; 2004), fibromyalgia (Williams et al., 2010), and cancer (Porter et al., 2011) (see also Porter & Keefe, 2011; Tatrow & Montgomery, 2006; Turk et al., 1983; 1998); however, these interventions are underused in clinical care (Gaertner & Schiessl, 2013; Keefe et al., 2005). Expanding patients' access to them is consistent with guidelines for managing cancer pain and would be a step toward meeting national goals to reduce the impact of pain on individual and public health (Goldberg & McGee, 2011; Institute of Medicine, 2011).

There is growing evidence that CBT-based interventions can be efficacious when delivered via the internet, which also addresses barriers limiting patient access to these interventions (Rini et al., 2012). We developed an automated, web-based PCST program for osteoarthritis (OA) joint pain ("PainCOACH") that included eight interactive 35-to 45-minute sessions designed to retain critical therapeutic features of in-person PCST (Rini et al., 2014). Our randomized controlled trial demonstrating the program's feasibility, safety, acceptability, and

potential efficacy (Rini et al., 2015) suggests that web-based PCST could be useful for expanding cancer patients' access to this evidence-based pain therapy. Because cancer patients are likely to have different pain management needs and concerns than people with OA, the present study gathered information necessary for adapting web-based PCST for use by cancer patients with persistent pain and integrating this treatment into clinical care. We conducted in-depth interviews to collect feedback from patients who completed the program and focus groups with healthcare providers (physicians and advanced practice providers) to understand their views of current cancer pain treatments, PCST (including web-based PCST), and ways to support its use in clinical care. Our approach was consistent with frameworks guiding systematic adaptation of evidence-based interventions for use in new target populations (Lee et al., 2008). We began with a strong understanding of the core therapeutic components of web-based PCST (Rini, et al., 2014) and then gathered data from both patients and providers to address the study goal of investigating patients' pain-related needs, patients' and providers' responses to webbased PCST, and their recommendations for adapting it to meet patients' needs. We therefore expected that our findings would be relevant not only to our program but also to the larger goal of expanding patient access to PCST and similar evidence-based behavioral pain interventions with web-based delivery.

METHODS

Patient Pilot Study

The eligibility criteria for our study included: (1) medically confirmed multiple myeloma or breast or prostate cancer with bone metastases (because pain is common and frequently severe in these patients); (2) moderate to severe bone pain; (3) \geq 21 years of age; (4) English-speaking; and (5) living within two hours of the North Carolina Cancer Hospital (NCCH). Patients were excluded if they planned to undergo short-term pain treatment during the study period (e.g., palliative radiotherapy, surgery), were expected to survive <6 months (according to their physician), were cognitively impaired, or did not have wireless internet access at home.

Potential participants were identified by healthcare providers and then called by staff, who completed a screening interview. Eligible patients were scheduled for an in-person baseline visit. After providing informed consent, they received an iPad to access the program, a program workbook, and a journal to make notes about completed sessions. They were asked to complete one session per week over 8 to 10 weeks. Each session provided interactive

training on a pain coping skill, as summarized in Table 1 and described in detail elsewhere (Rini, et al., 2014; 2015). Session completion was monitored by a staff member, who called participants if more than 10 days elapsed between sessions. After completing the program or ending their participation,

 Table 1. Summary of sessions in web-based pain coping skills training program (PainCOACH)

Session	Pain coping skill	Content	
1	Progressive muscle relaxation	• Introduce concept of pain coping skills and explain how thought feelings, and actions affect pain (therapeutic rationale)	
		 Introduce progressive muscle relaxation 	
		• Exercise: opportunity to practice progressive muscle relaxation	
		• Exercise: help user identify positive aspects of practice experience to reinforce use of skill	
		• Exercise: help user identify and address barriers to use of skill	
		 Set practice goal and reinforce importance of practice 	
2	Mini-practice (brief relaxation)	 Review progressive muscle relaxation and practices completed in prior week 	
		• Introduce "mini-practices"	
		• Exercise: opportunity to do sitting and standing mini-practices	
		• Exercise: help user identify positive aspects of practice experience to reinforce use of skill	
		• Exercise: help user identify and address barriers to use of skill	
		 Set practice goal and reinforce importance of practice 	
3	Activity/rest cycling	Review mini-practice and practices completed in prior week	
		• Introduce activity/rest cycling	
		• Exercise: identify activities user tends to overdo	
		 Vicarious learning: demonstrate how others have changed overdone activities 	
		• Exercise: create personal plan to use skill that fits personal activities and goals	
		• Discuss how other skills help with use of this one	
		 Set practice goals for this skill and review practice goals for other skills 	
4	Pleasant activity scheduling, negative automatic thoughts	• Review activity/rest cycling and practices completed in prior weel	
		Introduce pleasant activity scheduling	
		• Exercise: how to select and add pleasant activities to routine	
		• Exercise: schedule three pleasant activities for week	
		 Vicarious learning: demonstrate how others have overcome barriers to using this skill 	
		 Introduce concept of negative automatic thoughts 	
		• Exercise: how to identify negative automatic thoughts	
		 Set practice goals for this skill and review practice goals for other skills 	

Table 1. Continued

Session	Pain coping skill	Content	
5	Negative automatic thoughts, coping thoughts	Review pleasant activity scheduling and practices completed in previous week	
		 Continue lesson on automatic thoughts, introducing concept of coping thoughts 	
		• Exercise: how to identify negative thoughts and reactions to them	
		• Exercise: how to create coping thoughts to address negative thoughts	
		\bullet Exercise: how to identify and address circumstances barriers to use of skill	
		• Set practice goals for this skill and review practice goals for other skills	
6	Pleasant imagery, other distraction techniques	Review coping thoughts and practices completed in prior week	
		• Introduce pleasant imagery and other distraction techniques	
		Exercise: opportunity to practice pleasant imagery	
		• Exercise: help user identify positive aspects of practice experience to reinforce use of skill	
		\bullet Set practice goals for this skill and review practice goals for other skills	
7	Problem solving	• Review pleasant imagery, distraction, and practices completed in prior week	
		 Introduce concept of problem solving 	
		 Vicarious learning: demonstrate problem solving, illustrated by stories told by other people 	
		• Exercise: select skills for different situations, with personal plan for overcoming barriers	
		• Set practice goals for this skill and review practice goals for other skills	
8	Monitoring for maintenance	Review content of all modules	
		• Exercise: evaluate skill use and helpfulness, including comparison with others' experiences	
		• Exercise: develop plan for maintaining use of skills	
		 Present rationale to motivate continued practice and skill development 	
		• Review practice goals for skills	

participants met with an interviewer in their home or another convenient location for an in-depth, semi-structured, 60- to 90-minute interview that assessed their experiences with pain and, using prompts from their journal, solicited their experiences with using web-based PCST and feedback for improving it. Interview questions were developed to address the study goal by a team of cancer clinicians and behavioral scientists with expertise in pain management and behavioral scientists with

expertise in qualitative research methods. Questions were not changed after the interviews began. Interviews were audiotaped and transcribed. Participants were paid \$200.

Provider Focus Groups

Physicians or advanced practice providers at NCCH were eligible to participate if they spent at least part of their clinical time treating cancer-related

bone pain. They completed a brief screening interview. Eligible providers were scheduled for a focus group meeting for physicians or advanced practice providers, as appropriate. Meetings began with informed consent procedures and a questionnaire gathering demographic and professional/practice data. An experienced moderator used an interview guide to discuss participants' experiences providing care for cancer patients with bone pain and their perception of the meaning of "pain self-management," defined as including "psychosocial resources that teach patients about their pain and methods for managing it," such as patient education and use of pain coping skills. After participants were asked about their history of referring patients for these kinds of services, we described PCST and the web-based PCST program, and participants discussed their views about the program, the reasons why they would or would not recommend it to patients, the best timing for its use, and ways to integrate it into clinical care. As with patient interviews, questions were developed to address the study goal by a multidisciplinary research team. These audiotaped discussions lasted 90 minutes, and participants were paid \$125.

The procedures for interviews and focus groups were approved by the University of North Carolina at Chapel Hill (UNC) Institutional Review Board. Interviews, focus groups, and analyses were completed by experts in these methods (including M.B.V. and J.C.A.), who are members of the Communication for Health Applications and Interventions (CHAI) Core at the UNC Lineberger Comprehensive Cancer Center.

Analytic Approach

Transcriptions were independently coded by M.B.V. and J.C.A. using a directed content analysis approach (Hsieh & Shannon, 2005) and ATLAS.ti7 software (Scientific Software Development GmbH, Berlin, Germany). Interview questions guided initial codebook development. Codes were interactively revised during analysis to capture all the relevant information provided by participants. Combining deductive and inductive coding allowed for both emergent and anticipated themes. The coders compared results and reconciled discrepancies to reach consensus. Interrater reliability before reconciliation was excellent (Fleiss' $\kappa = 0.89$).

RESULTS

Some 11 patients were approached for the pilot study, 4 of whom declined due to being in another study (n = 1), lack of interest (n = 2), or medical problems

(n=1). Table 2 shows the descriptive statistics for the 7 enrolled patients. All men and women in the study were non-Hispanic white, and most were married and well-educated.

A total of 12 providers enrolled in focus groups (one group of four oncologists and two groups of advanced practice providers, including four nurse navigators, two nurse practitioners, one physician assistant, and one pharmacist). Eight of the providers (67%) were women. Their mean age was 47 years (SD=12.45), and they had been in professional practice for 15 years on average (SD=14.00). They spent an average of 22 hours a week treating cancer pain (SD=15.44).

The findings from our analyses are described below and summarized in Table 3.

Patient Pilot Study

Pain in Everyday Life

Patients discussed how pain kept them from engaging in work and daily chores and how it limited their ability to enjoy social and leisure activities. Limitations appeared to be more emotionally difficult than pain itself. "Nonstop pain" was a significant challenge. Many patients' pain had been affecting them for years. Most had no formal training in pain coping skills, although a few described trying nonpharmacologic pain management strategies such as walking, relaxation, or heat and ice.

Experiences with Web-Based PCST

Patients described web-based PCST as "helpful" and "useful." They felt that it would benefit most people if they "stuck with it" and would recommend it to others. They liked being able to use the program from the comfort of their own home: "Of course, it's awfully good to have the tools at home to use when you can find the time. So, it had that advantage." The fact that it presented an alternative to "pills" was mentioned, as was the fact that the skills could be used away from home, when taking pain medications was not always possible (e.g., because none were on hand)

Pain, other symptoms, disease-related events, and life events sometimes interfered with a patient's ability to complete a session. One described a time when his "numbers shot up out of control" and he had to focus on his "number one fight"—his cancer. Although unable to complete sessions every week, he managed to continue the program, which he found helpful. Cognitive and memory problems led several patients to have difficulty remembering things they learned in the program. As one patient explained,

Table 2. Demographic characteristics of enrolled cancer patients $(N = 7)^a$

	n (%)	$M\left(SD\right)$	Observed range
Sex			
Male	3 (42.9%)		
Female	4 (57.1%)		
Age		63 (5.28)	56 - 70
Race/ethnicity			
Non-Hispanic white	7 (100%)		
Marital Status			
Married	5 (71.4%)		
Never married/divorced	2~(28.6%)		
Educational attainment			
High school or less	2(29%)		
4-year college degree	3~(43%)		
Graduate or professional degree	1 (14%)		
Missing	1 (14%)		
Income (median)		\$45,000-59,999	<\$14,999-<12.000
Work status			
Retired	3(43%)		
Unemployed	2(29%)		
On temporary leave	1 (14%)		
Missing	1 (14%)		
Cancer Type			
Multiple Myeloma	2(29%)		
Breast	4 (57%)		
Prostate	1 (14%)		

^a Participants include one woman who was enrolled and completed a single session in the web-based pain coping skills training program but who ended her participation due to technical problems and did not complete a final interview due to scheduling problems. We report her behavior as an enrolled participant, but she did not contribute to the qualitative data.

With me having chemo brain, sometimes I would have to go back and try to remember what I was supposed to do because I would forget it the next day ... It wasn't something wrong with the program. It's just the way my brain was working.

All patients required at least one reminder call from study staff when 10 days elapsed since their previous session. Two patients ended their participation after completing one session, one because of personal problems and the other because of difficulties accessing a wireless internet connection. The latter participant did not complete a follow-up interview and thus provided no feedback on the program.

Conversely, a few patients worked through sessions faster than the suggested rate because they were eager for information and tools for addressing their pain. As one patient explained, "like I did number four today. Well, if I can't sleep at night, I'll get up and do number five. That's why I finished it up in a couple of weeks ahead of time." Some said it was easy to stay motivated through the sessions, in part because each session taught a different skill. Noticing reduced pain and improved ability to engage in valued activities also made patients want to continue. One participant described his motivation thus:

The fact that some of them really were useful to me right away, that I could use right away, suggested to me that [...] if the next section's anything like the last, it'll be useful to me, and why shouldn't I go ahead and go forward?

Other people supported patients' use of the program in various ways. Several patients described family members helping with computer use and technical difficulties. Others had spouses with pain and shared information from the program with them. One patient who completed sessions during chemotherapy infusions said his nurses supported his use of the program, as did his family. Patients who told their healthcare providers about the program found them to be interested and encouraging.

Patients generally liked the program's features, including having a virtual coach lead them through the program. As one participant said, "The lady with the brown hair, she gave the presentation. It was really, really good. She had that really soft voice for you to relax and do what she says." The program illustrated skill use by portraying the experiences of a diverse group of individuals (Rini, et al., 2014) as they applied the skills. Several patients mentioned that these examples helped them discover meaningful ways to apply their skills.

Patient pilot study

Theme 1: pain in everyday life

- Pain limited patients' role, social, and family functioning an important cause of distress
- Constant nature of pain a significant challenge
- Many patients had tried nonpharmacologic pain management strategies of various types but did not have prior training in cognitive behavioral pain coping skills

Theme 2: experiences with web-based pain coping skills training (PCST)

- · Web-based PCST experienced as helpful
- Positive views of program's approach, language, and features
- Skills an alternative to pain medications in some circumstances and may have helped some patients reduce use of pain medications
- Ability to complete the program at home was useful
- Symptoms and life events interfered with completing sessions and practicing skills; solutions included mobile applications (e.g., to facilitate practice, overcome memory problems)
- Some patients worked through sessions faster than suggested due to eagerness for information in upcoming sessions
- · Family and healthcare providers supported program use
- Eight-session program generally acceptable
- Suggested changes: adding examples with younger patients, making recommendations and examples specific to cancer, and using mobile applications to support program activities

- "I just enjoy nothing." (patient 1)
- "You can't do anything anymore. You just— You can't sit for a long time. You've got to get up, and move, and move your neck, and your back, and you can't walk for a long time. It just takes everything out of you. You just get depressed." (patient 2)
- "Is my life going to be curtailed to where I can ... get up and dress myself and do my own personal hygiene, but that's about it?" (patient 3)
- "I feel very socially kind of isolated because I can't drive a lot
 of times. If I take like an extra [pain pill] for my
 breakthrough pain, then I can't drive so that's— not being
 able to go places, not being able to drive is a very big
 problem." (patient 6)
- "The fact that some of [the sessions] were really useful to me right away, that I could use [them] right away, suggested to me that... if the next session is anything like the last, it'll be useful to me." (patient 3)
- "There's been a number of times where the pain has come up while I'm away from the house, away from my pill bottle. I didn't remember to take a spare pill with me and I never knew what to do ... Well now, I've got tools to use." (patient 3)
- Regarding program content, "Some of it may not apply to me, but all of [the sessions] were interesting." (patient 4)
- "I can see [the skills] being helpful not just for pain, but number one for procedures. We go through a lot of procedures ... Using some of these techniques to relax or visualize to get through those procedures ... is really helpful, and it's also helpful psychologically." (patient 5)
- Regarding support for using the program from family and nurses: "Everybody said, 'that's good—you should be doing this." (patient 4)
- "Everybody looks at their phone all the time. This could actually go on a phone and if, yes, every day for 5 minutes or 10 minutes or 15 minutes I'll do this, and then I'll make you practice." (patient 5)

Theme 3: changes resulting from use of web-based PCST

- All patients had positive outcomes, including reduced pain and feeling better equipped to manage pain
- Each skill noted to be especially useful by one or more patients
- Skills used to manage pain and distress during medical procedures
- Improved ability to enjoy social and family activities
- Family members noticed positive changes

- "The pain itself didn't seem like it was excruciating, hurting that bad as it was when I first started [the program]." (patient 1)
- "From the titles of the ... last two sessions, it didn't look to me like they were ready to teach me new skills. So, for some reason, I gave it less value in my mind ... However, once I took the time to go through them, I think they were great." (patient 3)
- "I could find myself in the middle of, for instance, a visit with
 my oncologist or somebody and say, 'Just give me a second,'
 and then I could use some of the [skills]. I was able to relax
 enough so that my pain was in fact diminished enough so
 that I could continue a little bit better with my visit."
 (patient 6)
- Describing a procedure involving a needle stick: "At one point [the provider] actually hit a nerve, and I jumped, but I was able to take a deep breath and go back to being relaxed after that and not sit there the whole time afraid she's going to do it again. And even if she does, it's just not as bad." (patient 5)
- "[My family] saw me helping myself rather than them trying to figure out how to help me ... When I told them I was going through this program, they said, 'that's amazing because we see a change." (patient 4)
- Regarding using cognitive restructuring to recognize and reduce self-imposed social isolation due to pain: "I just figured that they didn't want me around because I didn't want to be around. So it made a big improvement that I just accepted and they were willing to do anything for me to make me more comfortable. I didn't have to sit in the other room ... So that was a big eye-opening thing." (patient 1)

Patient 1: 64-year-old woman with breast cancer. Patient 2: 70-year-old man with prostate cancer. Patient 3: man of unreported age with multiple myeloma. Patient 4: 61-year-old man with multiple myeloma. Patient 5: 58-year-old woman with breast cancer. Patient 6: 56-year-old woman with breast cancer.

Healthcare provider focus group

Theme 1: describing "pain selfmanagement"

- Initial responses focused on helping patients have greater role in managing pain medications, but aware of need to manage psychosocial problems
- Few had ever referred patients to behavioral/psychosocial services or recommended specific techniques
- Low awareness of specific interventions or their availability a barrier to referring patients for them
- Favorable attitudes toward self-management, and support for patients taking more ownership of their care, although it was perceived to be complicated

Theme 2: acceptability of webbased PCST

- Providers need evidence for program's efficacy
- Viewed as low risk
- Suggest evaluating program as a quality or cost-saving measure, using it as an example of how costs could be cut to get attention of institution's "top level"

Theme 3: selecting patients for the program

- Focusing program on one type of cancer pain (e.g., bone pain) considered unnecessary; suggested broadening inclusion criteria to reach more patients, including those with difficulty distinguishing source of/reason for their pain
- Providers would refer patients they felt would benefit most from web-based PCST, considering many factors
- Concern about overburdening patients by asking them to do too much
- Concern that some patients may not have access to a computer or the internet

Theme 4: supporting webbased PCST

- Providers would have difficulty finding time and remembering to tell patients about the program, putting it at risk for becoming just another program that may or may not make it to the awareness of providers
- One solution: have as many healthcare staff as possible become aware of it
- Another solution: identify providers with more opportunity and time to discuss it with patients (e.g., pharmacists, regular clinic nurses, navigators)

- "The main thing that I would do is to give them the liberty to adjust their dose—so I would say, 'Well, you can take one or two, five or ten milligrams."
- Regarding a definition of pain self-management: "Providing a patient with a range of options and then kind of having them [choose among them] based on their pain score or how they're feeling and other factors."
- Patient education defined as training "to properly administer the right medication at the right dose at the right interval so that they're getting enough pain relief while still mitigating toxicities—as many as they can anyway."
- "Put the benefit of this intervention on the top of whatever resource you're going to show the physicians or the patients—'this reduces pain by 50% and consider it for your patients"—because if I see that I would be willing to offer it and it's a very low-risk intervention."
- "When I heard 'bone pain,' it threw me off because I don't think in those terms. I kind of think [of] 'pain or no pain."
- Regarding patients' difficulty distinguishing cancer-related pain from non-cancer-related pain: "[It is] less threatening to think that pain is due to a slipped disc or something" than believing the "cancer is progressing."
- "Maybe I underestimate their skill or their capacity, but they're not feeling well, and so I think we can't expect them to do too much for the most part ... I think sometimes asking them to do too much self-management is probably not going to be as successful as we might think. I may be wrong."
- "The issue you have [with supporting web-based PCST] is not that any of us are going to be resistant, but that we'll never be aware of it and we'll never remember it."
- "[Pharmacists] can spend an extra 45 minutes going through the list of seven options that they have, which I can't do, or I'm here until 2:00 a.m."

Table 3. Continued

Theme 5: enhancing patient engagement

• Web-based PCST a way to let patients be more actively involved in managing their care

game ... really make [them] the center [of] their own care.

opportunity to] take the lead and have some skin in the

Regarding web-based PCST: "[It gives patients an

- Pain one of many challenges, so program should also address distress and help set realistic expectations about pain reduction
 - Introduce to patients before they are acutely affected by severe pain or pair with certain pain-related events (e.g. surgery, painful therapies)

No patients thought that the 35- to 45-minute sessions were too long, and most viewed the 8-week course of the program favorably. One suggested reducing it to six sessions and another skipped the last session. The explanation for this pattern appeared not to be that the program was too long. Rather, the program's descriptions of the last sessions made them appear as if they were not teaching skills, leading these patients to perceive them as less useful. One patient stated, "From the titles of the last three, last two sessions, it didn't look to me like they were ready to teach me new skills. So, for some reason, I gave it less value in my mind." This finding highlighted patients' emphasis on gaining skills and not just information.

Patients suggested making photos and examples more relevant to cancer patients (e.g., depicting younger people and emphasizing types of pain and situations experienced by cancer patients). Other suggestions included adding support for practices, incorporating reminders and features to increase motivation, and using mobile technologies to increase access and convenience (e.g., allowing completion of sessions on a smartphone or developing applications to identify challenging situations and provide suggestions for managing them). One patient suggested adding discussion of using skills during painful medical procedures. Similarly, several suggested expanding the program to help patients cope with anxiety about cancer and medical procedures.

Changes Resulting from Using Web-Based PCST

All patients described experiencing benefits from using the program. Each skill was mentioned by one or more patients as being particularly helpful. They noted that they felt better equipped to manage pain. Some described specific instances when the skills helped, such as during a stressful medical visit or painful medical procedure. Many mentioned reduced pain—for example: "It didn't completely go away but brought it down to a level where I can tolerate it. It's just like concentrating on something else." One patient said that, aside from medication, the pain coping skills were the only things that had helped her manage her pain. Another patient added,

I feel like now I've got a host of tools besides the bottle of pills to deal with the pain because there's been a number of times where the pain has come up while I'm away from the house, away from my pill bottle, I didn't remember to take a spare pill with me, and I never knew what to do. I'm stuck. I'm going to have to suffer through with this before I can get back home to get to my pill bottle. Well now, I've got tools to use.

One patient who said her pain medications kept her from driving said that using the skills "enabled me to be able to get out and see my friends." Another explained how she continued to benefit from the program: "And, of course, I know it's hurting, but it's not hurting as bad as it was if I had not done these relaxations that I did earlier this morning."

Another change involved improved social and family interactions. One patient explained how his family saw him helping himself and noticed a change (e.g., his wife noticed him "not [being] a wallflower"). He had gotten into the habit of staying in a separate room at family gatherings because he did not feel well. Cognitive restructuring helped him see his situation in a new light and change it:

I just figured that they didn't want me around because I didn't want to be around. So it made a big improvement that I just accepted, and they were willing to do anything for me to make me more comfortable. I didn't have to sit in the other room. I could join in all the reindeer games, you know?

Healthcare Provider Focus Groups

Describing "Pain Self-Management"

When providers described their views of the term "pain self-management," their descriptions focused on pain medication (e.g., patients' use of or concerns about medication use), rarely mentioning behavioral strategies. Giving patients control (e.g., over adjusting pain medication doses or choosing among medical pain management options) was a common theme. Patient education was generally agreed to be important for self-management, although this discussion tended to focus on managing medications and their side effects.

Providers realized they were generally unaware of specific behavioral interventions. Few had referred patients to these kinds of services or recommended use of specific techniques. Yet, providers discussed the idea favorably and supported patients taking more ownership of their care:

This is something that could potentially give back a significant chunk of that control if patients feel like they're actively involved in some of the decision-making process especially ... if they can do it at home when they're not in clinic, ...

although they felt that "it's so incredibly complicated."

Acceptability of Web-Based PCST

We described web-based PCST and answered questions about it before asking providers whether they

thought it would be an acceptable option for their patients. Providers strongly agreed they would need evidence for the program's efficacy:

You need to show, you know, probably a little summary about some of your data and show that it actually has benefit, because if I don't believe that it's going to work for my patient, I don't care what you say, I'm not going to recommend it.

Selecting Patients for the Program

Providers said they would refer patients for webbased PCST by weighing various factors to determine which pain management options would be best for the patient (e.g., age, ability to tolerate treatments, cognitive functioning, costs of treatments/financial burden, side effects, other medications available or being used, pain tolerance and severity).

Providers expressed concern and confusion regarding our focus on cancer-related bone pain, generally agreeing that pain is a problem regardless of cancer type, duration of disease, or treatment. They suggested broadening the inclusion criteria to reach more patients—for instance, "To say only bone pain might limit the availability to reach people who could also benefit." They discussed how patients are often unable to distinguish between different sources of pain and may think that their pain is not cancer-related even when it is.

There was some concern about asking patients to do more than they were already doing. Furthermore, some providers were concerned that a subgroup of patients may lack a computer or internet access, or that some would not know how to use a tablet computer or get to the website.

Supporting Web-Based PCST in the Clinic

Providers said they would have difficulty finding time and remembering to tell patients about webbased PCST. Yet, they were aware that treatments recommended by providers may be perceived as having more value and suggested having as many healthcare staff as possible discuss the program with patients. They also suggested identifying providers with both opportunity and time to engage with patients. They described pharmacists as being a good contact point because of their focus on pain management and their early and extensive access to patients. Clinic nurses were described as spending significant time reviewing pain medicines with patients and being a very motivated and well-trained, yet underutilized, resource. They felt that nurse navigators could be involved in supporting use of webbased PCST, but it would take time. Some providers said that navigators would give the program traction, although it would be important to address their organizational structure, work responsibilities, and time commitments.

Enhancing Patient Engagement

Providers saw web-based PCST as an opportunity to let patients be more actively engaged in managing their pain to give them a sense of control. Because pain is just one of the challenges that patients face, providers felt that the program should also address such issues as intrusive thoughts, distress, and spiritual health to help patients feel that they were seen as whole people and that their providers were helping them get back to the life they wanted.

Providers suggested introducing the program before patients become acutely affected by severe pain, when "they can't even hear you" and "just want to quit hurting." Determining the best time to introduce the program would be complicated by patients' diversity, yet providers felt the likelihood of success would be highest if it were offered when patients were "stable-ish" and willing and able to hear about it or, given the incremental nature of pain onset, "in the middle of the trajectory." They suggested pairing web-based PCST with pain-related events (e.g., before surgery or therapy). They also explained that it would be important to help patients understand that web-based PCST was a part of their care but not the only thing providers would do for them.

DISCUSSION

We gathered feedback about web-based pain coping skills training from seven patients with cancer-related bone pain who had been given access to the training at home, and from healthcare providers who treat them. Our findings suggest strong promise for using a web-based approach in helping patients to manage pain in their daily lives. Patients described profound emotional and physical benefits and offered feedback to make the approach better fit their needs—a critical objective necessary for maximizing adoption and adherence. Providers were supportive of web-based PCST; however, their feedback indicated a need for evidence and education familiarizing them with PCST and addressing their concerns about overburdening patients. Overall, our findings provide valuable guidance for using the technology to increase cancer patients' access to empirically supported behavioral pain interventions with a scalable and cost-effective approach.

It is important that the acceptability of web-based PCST was good among both patients and providers. As expected, adaptations will be needed to improve the extent to which web-based PCST addresses this

population's needs. Although 71% of patients completed all sessions (versus 91% in our trial for older adults with OA pain) (Rini, et al., 2015), all required phone calls to encourage completion. Physical and psychosocial challenges were barriers to initiating and completing the program. Encouragement and help from family were often useful and motivating. Consistent with research showing the benefits of training caregivers to support patients' use of PCST (e.g., Hendrix et al., 2016; Valeberg et al., 2013), adding a formal role for family members could enhance adherence to web-based PCST.

Enhancing provider support for program completion is also important, according to behavior change theory (Green & Kreuter, 1992; Rosenstock, 1966) and empirical evidence (Puts et al., 2015) indicating that patients are more likely to use treatments recommended by their healthcare providers. To gain their support, it will be important to increase their awareness of PCST and address concerns about asking too much of patients. Strategies for having providers support use of web-based PCST must also be sensitive to their limited time availability. Providers suggested having pharmacists or nurses support program use. We note that these findings should be viewed as preliminary because of our small sample size, recruitment at a single site, and lack of data on patient satisfaction and pain characteristics and treatments. The extent to which the foregoing findings generalize to patient populations with varied cancers in different treatment settings requires further investigation.

Our findings also revealed that adaptations will need to address memory problems that hinder completing program sessions, remembering to practice skills, and remembering how to use skills. Cognitive impairment affects many adult cancer patients (Janelsins et al., 2014; Wefel et al., 2015). Web-based PCST is well-positioned to address this barrier: it allows at-will review of information and automated and tailored reminders. Functions could also be added to use mobile technologies to recognize challenging situations and to deliver information at key times.

Both patients and providers suggested adding sessions to help patients manage pain-related distress and enhance their use of pain medications. This feedback is consistent with patients' concerns about pain medications (Closs et al., 2009; Simone et al., 2008; 2012; Valeberg et al., 2015) and evidence that reducing distress helps reduce pain (Wang et al., 2012). Additionally, providers suggested that programs such as web-based PCST should focus broadly on insufficiently controlled pain rather than a particular source of cancer pain (e.g., bone pain). Fortunately, distinguishing between cancer and non-cancer pain

is not necessary for treating pain (Turk, 2002), and PCST is applicable to various persistent pain conditions.

Several study limitations should be considered in light of possible effects on generalizability. First, the study was conducted at a single institution with a small sample that was non-Hispanic white and mostly well-educated. In a more diverse sample, socioeconomic or ethnic/racial differences could be seen with respect to access to, ability to use, or responses to web-based PCST. Notably, our trial of web-based PCST for OA pain (Rini, et al., 2015) included ethnic/racial minorities and people with low levels of education and little computer experience. Our findings showed that they were interested in and able to use the program, which was specifically designed to be usable by a broad audience. Moreover, evidence shows a narrowing of racial gaps in internet access and usage, particularly for mobile devices (Smith, 2014). Also, cancer patients, who may have limited ability or willingness to attend in-person training, could be especially receptive to the convenience of web-based PCST. These and related factors may minimize socioeconomic and racial/ethnic differences in responses to the program. A critical next step will be to evaluate web-based PCST in a more diverse sample, exploring group differences. Second, patients who complete automated web-based PCST may be more highly motivated than patients who complete in-person PCST, because they must complete the program independently, without therapist contact. This concern may be offset to some extent by recognizing substantial barriers to attending inperson PCST (e.g., the need to travel). Also, extending access to PCST can be achieved with a web-based approach even if some patients lack interest in or would be relatively unlikely to benefit from this approach. Third, future research should assess the features of patients' pain (e.g., its severity and sites) in order to evaluate whether the nature of their pain influences their ability to benefit from web-based PCST.

Taken together, our findings support continued development of web-based PCST for cancer patients, especially in light of the Institute of Medicine's call for programs that enable patients' pain self-management and address current barriers to adequate pain care (Institute of Medicine, 2011). Compared to resource-intensive in-person behavioral interventions, web-based interventions may be an effective way to integrate currently underused behavioral pain interventions into clinical practice. Our findings provide initial feasibility data and feedback supporting this possibility. The next steps will include applying our findings by adapting the program using a standard iterative approach that gathers additional feedback

from a larger and more diverse group of patients, and then evaluating the adapted program's efficacy. We will also evaluate whether web-based PCST is acceptable, feasible, and effective across patient subgroups.

DISCLOSURES

The authors hereby declare that they have no conflicts of interest to disclose.

ACKNOWLEDGMENTS

We would like to thank Jermaine Pinckney for his technical and IT assistance during the PainCOACH pilot study, Randall Teal for his assistance with planning and executing the research, and Carey K. Anders, Betsy Blanton, Ellen M.I. Cohen, Frances Collichio, E. Claire Dees, Julie Benbow, Amy L. Garrett, Diane M. Joyal, Anna Kate Owens, Jennie Petruney, and Elizabeth Tita for their advice on the project and assistance with recruitment. This work was funded by a grant from the University of North Carolina Lineberger Comprehensive Cancer Center (PI: C.R.). Work reported in this paper was conducted by CHAI (Communication for Health Applications and Interventions) Core, which is supported in part by a grant from the National Institutes of Health (DK056350) to the University of North Carolina Nutrition Obesity Research Center and from the National Cancer Institute (P30-CA16086) to the UNC Lineberger Comprehensive Cancer Center.

REFERENCES

- Badr, H., Laurenceau, J. P., Schart, L., et al. (2010). The daily impact of pain from metastatic breast cancer on spousal relationships: A dyadic electronic diary study. *Pain*, 151(3), 644–654. Epub ahead of print Sep 15.
- Chou, R., Qaseem, A., Snow, V., et al. (2007). Diagnosis and treatment of low back pain: A joint clinical practice guideline from the American College of Physicians and the American Pain Society. *Annals of Internal Medicine*, 147(7), 478–491. Available from http://www.danmurphydc.com/wordpress/wp-content/uploads/archive/2008/Article 33-08.chou.pdf.
- Chou, R., Fanciullo, G.J., Fine, P.G., et al. (2009). Clinical guidelines for the use of chronic opioid therapy in chronic noncancer pain. *The Journal of Pain*, 10(2), 113–130. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4043401/.
- Closs, S.J., Chatwin, J. & Bennett, M.I. (2009). Cancer pain management at home (II): Does age influence attitudes towards pain and analgesia? *Supportive Care in Cancer*, 17(7), 781–786. Epub ahead of print Dec 6, 2008.
- Gaertner, J. & Schiessl, C. (2013). Cancer pain management: What's new? Current Pain and Headache Reports, 17(4), 328.
- Gauthier, L.R., Young, A., Dworkin, R.H., et al. (2014). Validation of the short-form McGill Pain Questionnaire—2 in younger and older people with cancer pain. *The Journal of Pain*, 15(7), 756—770. Epub ahead of print Apr 26.

- Goldberg, D.S. & McGee, S.J. (2011). Pain as a global public health priority. *BMC Public Health*, 11, 770. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3201926/pdf/1471-2458-11-770.pdf.
- Green, L.W. & Kreuter, M.W. (1992). Health Promotion Planning: An Educational and Environmental Approach, 2nd ed. Mountain View, CA: Mayfield Publishing.
- Hendrix, C.C., Bailey, D.E., Jr., Steinhauser, K.E., et al. (2016). Effects of enhanced caregiver training program on cancer caregiver's self-efficacy, preparedness, and psychological well-being. Supportive Care in Cancer, 24(1), 327–336. Epub ahead of print Jun 12, 2015. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4670577/pdf/nihms699683.pdf.
- Hsieh, H.F. & Shannon, S.E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277–1288. Available from http://journals.sagepub.com/doi/pdf/10.1177/1049732305276687.
- Institute of Medicine (2011). Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research. Washington, DC: National Academies Press.
- Janelsins, M.C., Kesler, S.R., Ahles, T.A., et al. (2014). Prevalence, mechanisms, and management of cancerrelated cognitive impairment. *International Review of Psychiatry*, 26(1), 102–113. Available from https:// www.ncbi.nlm.nih.gov/pmc/articles/PMC4084673/pdf/ nihms-568444.pdf.
- Keefe, F.J., Caldwell, D.S., Williams, D.A., et al. (1990a). Pain coping skills training in the management of osteoarthritic knee pain: A comparative study. *Behavior Therapy*, 21(1), 49–62.
- Keefe, F.J., Caldwell, D.S., Williams, D.A., et al. (1990b). Pain coping skills training in the management of osteoarthritic knee pain–II: Follow-up results. *Behavior Therapy*, 21(4), 435–447.
- Keefe, F.J., Blumenthal, J., Baucom, D., et al. (2004). Effects of spouse-assisted coping skills training and exercise training in patients with osteoarthritic knee pain: A randomized controlled study. *Pain*, 110(3), 539–549.
- Keefe, F.J., Abernethy, A.P. & Campbell, L.C. (2005). Psychological approaches to understanding and treating disease-related pain. Annual Review of Psychology, 56, 601–630.
- Laird, B.J.A., Boyd, A.C., Colvin, L.A., et al. (2009). Are cancer pain and depression interdependent? A systematic review. *Psycho-Oncology*, 18(5), 459–464.
- Lee, S.J., Altschul, I. & Mowbray, C.T. (2008). Using planned adaptation to implement evidence-based programs with new populations. *American Journal of Community Psychology*, 41(3–4), 290–303. Available from https://deepblue.lib.umich.edu/bitstream/handle/2027.42/106177/2008-Lee-Altschul-Mowbray-AJCP.pdf? sequence=1.
- Porter, L.S. & Keefe, F.J. (2011). Psychosocial issues in cancer pain. *Current Pain and Headache Reports*, 15(4), 263–270.
- Porter, L.S., Keefe, F.J., Garst, J., et al. (2011). Caregiver-assisted coping skills training for lung cancer: Results of a randomized clinical trial. *Journal of Pain and Symptom Management*, 41(1), 1–13. Epub ahead of print Sep 15, 2010. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3010525/pdf/nihms-235259.pdf.
- Puts, M.T., Tapscott, B., Fitch, M., et al. (2015). A systematic review of factors influencing older adults' decision to accept or decline cancer treatment. Cancer Treatment Re-

- views, 41(2), 197–215. Available from http://www.sciencedirect.com/science/article/pii/S0305737214002151.
- Raphael, J., Ahmedzai, S., Hester, J., et al. (2010). Cancer pain, part 1: Pathophysiology; oncological, pharmacological, and psychological treatments: A perspective from the British Pain Society endorsed by the UK Association of Palliative Medicine and the Royal College of General Practitioners. *Pain Medicine*, 11(1), 742–764. Available from https://academic.oup.com/painmedicine/article-lookup/doi/10.1111/j.1526-4637.2010.00840.x/.
- Rini, C., Williams, D.A., Broderick, J.E., et al. (2012). Meeting them where they are: Using the internet to deliver behavioral medicine interventions for pain. Translational Behavioral Medicine, 2(1), 82–92. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3423892/pdf/13142_2011_Article_107.pdf.
- Rini, C., Porter, L.S., Somers, T.J., et al. (2014). Retaining critical therapeutic elements of behavioral interventions translated for delivery via the internet: Recommendations and an example using pain coping skills training. *Journal of Medical Internet Research*, 16(12), e245. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4285744/.
- Rini, C., Porter, L.S., Somers, T.J., et al. (2015). Automated internet-based pain coping skills training to manage osteoarthritis pain: A randomized controlled trial. *Pain*, 156(5), 837–848. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4402249/pdf/nihms-660865.pdf.
- Rosenstock, I.M. (1966). Why people use health services. The Milbank Memorial Fund Quarterly, 44(Suppl. 3), 94–127. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2690262/.
- Sharp, T.J. (2001). Chronic pain: A reformulation of the cognitive-behavioural model. *Behaviour Research and Therapy*, 39(7), 787–800.
- Simone., C.B. 2nd, Vapiwala, N., Hampshire, M.K., et al. (2008). Internet-based survey evaluating use of pain medications and attitudes of radiation oncology patients toward pain intervention. *International Journal of Radiation Oncology, Biology, Physics*, 72(1), 127–133. Epub ahead of print Jun 9.
- Simone., C.B. 2nd, Vapiwala, N., Hampshire, M.K., et al. (2012). Cancer patient attitudes toward analgesic usage and pain intervention. *The Clinical Journal of Pain*, 28(2), 157–162. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3522466/.
- Smith, A. (2014). African Americans and Technology Use: A Demographic Portrait. Washington, DC: Pew Research Center. Available from http://www.pewinternet.org/2014/01/06/african-americans-and-technology-use/.
- Swarm, R.A., Anghelescu, D.L., Benedetti, C., et al. (2016). NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)—Adult Cancer Pain, Version 2.2016. Washington, DC: National Comprehensive Cancer Network. Available from http://williams.medicine.wisc.edu/pain.pdf.
- Tatrow, K. & Montgomery, G.H. (2006). Cognitive behavioral therapy techniques for distress and pain in breast cancer patients: A meta-analysis. *Journal of Behavioral Medicine*, 29(1), 17–27. Available from https://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0023351/.
- Turk, D.C. (2002). Remember the distinction between malignant and benign pain? Well, forget it. *The Clinical Journal of Pain*, 18(2), 75–76.
- Turk, D.C., Meichenbaum, D. & Genest, M. (1983). Pain and Behavioral Medicine: A Cognitive-Behavioral Perspective. New York: Guilford Press.

- Turk, D.C., Sist, T.C., Okifuji, A., et al. (1998). Adaptation to metastatic cancer pain, regional/local cancer pain and non-cancer pain: Role of psychological and behavioral factors. *Pain*, 74(2–3), 247–256.
- Valeberg, B.T., Kolstad, E., Småstuen, M.C., et al. (2013). The PRO-SELF pain control program improves family caregivers' knowledge of cancer pain management. *Cancer Nursing*, 36(6), 429-435.
- Valeberg, B.T., Miaskowski, C., Paul, S.M., et al. (2015). Comparison of oncology patients' and their family caregivers' attitudes and concerns toward pain and pain management. *Cancer Nursing*, 39(4), 328-334.
- van den Beuken-van Everdingen, M.H., de Rijke, J.M., Kessels, A.G., et al. (2007). Prevalence of pain in patients with cancer: A systematic review of the past 40 years. *Annals of Oncology*, 18(9), 1437–1449. Epub ahead of print Mar 12. Available from https://academic.oup.com/annonc/article-lookup/doi/10.1093/annonc/mdm056.
- Wang, H.L., Kroenke, K., Wu, J., et al. (2012). Predictors of cancer-related pain improvement over time. *Psychosomatic Medicine*, 74(6), 642–647. Epub ahead of print

- Jun 28. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3392436/.
- Wefel, J.S., Kesler, S.R., Noll, K.R., et al. (2015). Clinical characteristics, pathophysiology, and management of noncentral nervous system cancer-related cognitive impairment in adults. CA: A Cancer Journal for Clinicians, 65(2), 123–138. Epub ahead of print Dec 5, 2014. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4355212/.
- Williams, D.A., Kuper, D., Segar, M., et al. (2010). Internetenhanced management of fibromyalgia: A randomized controlled trial. *Pain*, 151(3), 694–702. Epub ahead of print Sep 19. Available from https://www.ncbi.nlm. nih.gov/pmc/articles/PMC2972378/.
- Zhao, F., Chang, V.T., Cleeland, C., et al. (2013). Determinants of pain severity changes in ambulatory patients with cancer: An analysis from Eastern Cooperative Oncology Group Trial E2Z02. *Journal of Clinical Oncology*, 32(4), 312–319. Epub ahead of print Dec 23. Available from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3897256/.