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Development and implementation of an online program to improve how patients communicate emotional concerns to their oncology providers

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Abstract

Purpose—Patients often struggle to express their emotional concerns to their oncology providers, and may therefore experience unmet needs. This paper describes the development and implementation of an online program that teaches patients how to communicate their emotions to their oncology providers.

Methods—The intervention was developed by a multidisciplinary team consisting of palliative care physicians, psychologists, and an intervention software developer, and included input from patients. It incorporated elements of Social Cognitive Theory and validated cognitive behavioral strategies for communication skills training. Strategies to increase intervention adherence were implemented midway through the study.

Results—The intervention consists of four interactive, online modules to teach patients strategies for expressing emotional concerns to their providers and asking for support. In addition to skill-building, the intervention was designed to raise patients' expectations that expressing emotional concerns to providers would be helpful, to enhance their self-efficacy for doing so, and to help them overcome barriers to having these conversations. After implementing strategies to improve adherence, usage rates increased from 47% to 64%.

Conclusions—This intervention addresses an unmet educational need for patients with advanced cancer. Strategies to increase adherence led to improvements in usage rates in this population of older patients. We are currently evaluating the intervention in a randomized clinical trial to determine its efficacy in increasing patient expression of emotional concerns and requests

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Conflict of interest

The authors declare that there is no conflict of interest. In particular, there has not been any personal involvement of any of the authors with the funding agency. The authors have full control of the primary data and they agree to allow the journal to review their data if requested.

for support. If successful, this intervention could serve as a model for future online patient education programs.

Keywords

patient-clinician communication; cancer; emotion; social cognitive theory

Up to 50% of patients living with advanced cancer experience significant levels of psychological distress [1, 2], which is associated with shortened survival [3, 4], decreased quality of life [5, 6], and increased healthcare utilization [3, 4]. Patients want their oncology providers to support them emotionally [7, 8]; however, in many cases, patients' emotional needs are unmet [9, 10]. This may be, in part because patients often do not express their concerns explicitly, instead relying on ambiguous and indirect hints, or "cues", about their underlying emotions which may be difficult for providers to detect [11, 12]

When patients express their needs directly and request emotional support, providers are more likely to recognize their distress and respond empathically. Patients who perceive their provider as being emotionally supportive report lower levels of psychological distress [13]. Independent of the provider's response, cancer patients' expression of emotional concerns is therapeutic [14]. Patients who express their emotions to others tend to report decreased psychological symptoms and cancer-related morbidities [8], while those who hold back from conveying emotions report higher levels of distress [15, 16].

Despite the importance of expressing emotional concerns, many patients find this difficult [17]. In our previous study, we analyzed 398 audio recorded conversations between 51 oncologists and 270 patients with advanced cancer for both direct and indirect expressions of emotion. Patients disclosed emotional concerns in only 37% of these conversations, a relatively infrequent occurrence given the known high prevalence of distress in this population [18, 19].

Several barriers may prevent patients from expressing emotional concerns to their providers. First, patients worry that providers are too busy and may not want to burden them with negative emotions [17]. Second, some patients minimize their negative emotions, attributing them to a normal cancer response [17, 20]. Finally, providers' behaviors may deter patients from communicating their feelings [17, 21] when such expressions are ignored or not met by an empathic response [21, 22]. These and other barriers are unfortunate as patients whose emotional needs are unmet fare worse than others.

Previous interventions focused on patient communication skills training have proven successful in helping patients seek and understand information during clinical encounters. Strategies have included teaching patients to ask questions, providing them with prompt sheets, or providing them with information from their physician visits in either written or audio form [23, 24]. More intensive interventions have added a coaching component [25, 26]. Overall, these approaches enhance patients' abilities to seek information and assume more active roles in their medical care [24]. However, very few interventions have focused on helping patients receive emotional support, and none has targeted patient expression of emotional concerns to their oncology provider [27–29].

In this paper, we describe the development of an online patient education tool entitled “COPE” (Communication in Oncologist-Patient Encounters) which was designed to improve patients’ expression of emotional concerns to their oncology providers. This intervention builds upon our successful computer-based programs targeting oncologist communication [18] and incorporates validated cognitive behavioral strategies for communication skills training [30].

Online interventions have a number of advantages over face-to-face approaches, including accessibility, efficiency, and cost-effectiveness [31], and have proven effective for providing patients with information, support, and skills training [32–34]. Despite their advantages, however, many studies report low rates of participant adherence to recommendations for usage [35, 36]. Treatment adherence is a key determinant of treatment effectiveness [37]; thus, measuring adherence and identifying predictors, obstacles, and solutions for non-adherence is critical to the success of online interventions [38]. In this study, we examined usage of the program and implemented two simple strategies, motivational interviewing (MI) techniques and a raffle, midway through the study to try to improve adherence. We selected these strategies for primarily practical reasons as they are inexpensive and easily incorporated into an ongoing trial; in addition, MI has shown efficacy in increasing adherence to medical and behavior change recommendations. [39]

Method

Participants and Procedures

The present study includes data from the 343 participants enrolled into a randomized clinical trial comparing the COPE intervention to an information-oriented web tool (CHESS; [34, 40, 41]) and an open-use internet-only control group. Participants were recruited from the oncology clinics at Duke Medical Center (n=232) and University of Pittsburgh Medical Center (n=111). This study was approved by the Institutional Review Boards at both institutions, and informed consent was obtained from all participants. Eligibility criteria include (a) English speaking; (b) receiving care for any advanced malignancy; and (c) access to a computer with broadband Internet service and an email account. Exclusion criteria were a documented diagnosis of active psychosis or dementia, and physical impairments that precluded use of a computer. In addition, we chose to focus on the subset of patients who were experiencing emotional difficulty with their cancer as we believed they would be most likely to be in need of and amenable to support in this domain from their provider. Thus, we administered the Impact of Events Scale as a screening instrument and only included patients who had a mean score of 1.375 or higher, or responded 5 (“often”) on at least one item.

Patients were recruited between November, 2010 and April, 2014. We identified potential participants based on medical record review, obtained physician approval, and sent introductory letters to those who were approved. We screened 2,264 patients. 1,315 were ineligible for the study, 581 refused to participate and 368 consented to enroll in the study. We randomized 343 patients of the consented patients.

Participants were 204 women and 139 men. 86% were White, with an average age of 60 (SD=11, range=24–89). After providing informed consent, participants completed baseline measures, which included an audio recording of a visit with their oncology provider. They were randomized to one of four conditions: internet only (n=86), COPE (n=87), CHESS (n=85), or COPE + CHESS (n=85). Participants in all arms were given access to the intervention website. Access and prompts were timed to encourage use of the intervention prior to visits with the participant's oncology provider. After each of two visits, which occurred approximately 57 days (SD=30) and 113 days (SD=49) following randomization, participants completed assessments regarding their satisfaction with the intervention.

Intervention Development

The COPE intervention was developed by a multidisciplinary team composed of palliative care physicians expert in patient-clinician communication interventions (JAT and RMA); a social psychologist knowledgeable in the development of patient-clinician communication behavioral interventions (KIP); a clinical psychologist experienced in the development and delivery of cognitive behavioral communication skills training interventions (LSP); a public health intervention software developer who has created multiple health promotion and patient education interventions (DF); and cancer patients who provided input on intervention prototypes.

The intervention incorporated elements of Social Cognitive Theory (SCT) found to contribute to the efficacy of psychosocial interventions for cancer patients including increasing positive outcome expectations and self-efficacy.[42]

To ensure that the intervention delivered content appropriate to each patient's efficacy expectations, patients were first asked questions assessing their outcome expectations and their self-efficacy, and the program then delivered messages tailored to their ratings. For instance, in the first module, patients indicated the extent to which they expected that talking to their provider will help them feel better. If they checked "not at all" or "very little," the program asked why they felt that way and provided a list of common concerns such as "My doctor doesn't have time to discuss my feelings" and "I feel that I need to stay hopeful and not get negative." Patients checked the relevant concerns and received validating feedback; they were told the program would address these concerns so that they might reconsider the value of discussing their feelings with their provider (see Figure 1). The content of each of the subsequent modules was designed to (a) enhance patients' beliefs that expressing emotional concerns to their provider would be helpful, (b) build their confidence for doing so, and (c) help them work through barriers.

Intervention description

The intervention was comprised of four interactive web-based modules. These narrated modules included teaching segments using bullet points, figures and videos, as well as multiple opportunities for patient participation. We used videos to increase patient engagement, and because videos are uniquely able to demonstrate examples of patient-provider interactions and specific communication skills. We tailored the videos to the

patient's gender to enhance patient identification with the actor. Table 1 summarizes the content of the modules and Figures 1–3 display screen shots of the intervention.

In *Module 1*, patients rated their outcome expectations and their self-efficacy and received messages tailored to their ratings. This module also included videos illustrating actor-patients using specific communication skills and clinicians responding empathically to the patients' expressions of emotion. The videos were designed to enhance self-efficacy and positive outcome expectations by having the actor-patient talk directly to the camera about how they were initially reluctant to express their concerns, then model effective communication skills with their provider, see the provider respond empathically, and discuss the perceived benefits of having done so.

Module 2 contained the core of the intervention, a four-step process to help patients effectively express their emotional concerns to their provider illustrated using the acronym "WISH" ("What are you feeling?"; "I'm feeling..."; "Speak in short statements"; "ask for Help"; see Figure 2). This module also addressed common provider behaviors that may inhibit expression of emotional concerns. For example, some providers may focus on medical aspects of concerns and miss the underlying emotion (e.g., patient says, "This pain in my back really concerns me," provider responds "How long have you been having the pain?" rather than "Tell me more about what is making you concerned"). Providers may also provide premature reassurance (e.g., patient says, "I'm nervous about this new treatment," provider responds, "You'll be fine" rather than "Most of my patients are nervous when they start new treatments. I can see why you feel that way"). Providers also may be inclined to try to "fix" the patient's problem rather than empathize and listen (see Figure 3). Video clips were used to review these types of situations along with patient strategies for dealing with these responses.

Module 3 focused on talking with loved ones about emotional concerns. Because patients have many more opportunities to practice the communication skills with their family and friends than with their provider, applying these skills to talking with family and friends may make it easier for patients to share concerns with their providers. It may also lead to enhanced social support [43].

In *Module 4*, patients encountered what may be the most important part of the intervention - tailored feedback on their own audio-recorded clinical encounters which were recorded as part of the baseline assessment. These recordings were coded by investigators to identify times during the visit when the patient expressed negative feelings or asked for help, and loaded onto the password-protected website so that it was available only to that individual patient. In *Module 4*, patients were encouraged to listen to their verbal behaviors in the context of the communication guidelines presented in the intervention, evaluate what they did well, and identify how they might improve their expression of concerns at their next visit. The intervention interface allowed patients to listen to specific segments where they expressed negative emotion or asked for help or listen to the entire visit to provide context to their expressions.

Measures

Usage was measured by the number of times the patient logged on to the study website, the total number of minutes spent on the study website, and the percent of the intervention content that the participant viewed.

Satisfaction ratings—At the post-visit assessments, patients answered three questions about their satisfaction with the COPE website: (a) How would you rate the helpfulness of the COPE website (from 0 “not at all helpful” to 10 “very helpful”); (b) How much do you think viewing the COPE or COPE/CHESS website will change how you talk with your oncologist (from 0 “not at all likely” to 10 “very likely”); and (c) How likely are you to recommend the website to a friend or family member (from 0 “not at all likely” to 10 “very likely”).

Methods to Improve Usage

Two strategies were implemented to increase patient usage of the intervention. First, we taught study staff to use Motivational Interviewing (MI) techniques to help patients vocalize their motivations for viewing the website and to encourage them to set a specific date and time when they would view it. [48] Specifically, to elicit self-motivational statements, staff asked participants why they thought viewing the program might help. Then they asked what day participants planned to view the program. They brought a calendar with them to help participants pick their dates. They asked what might get in the way of viewing on that day and what they might do about that barrier. Finally, after appointments, staff members emailed patients with their chosen dates to remind them to view the program. Second, we implemented a quarterly raffle in which any participant who logged on to the study website became eligible for a \$100 gift card. The MI techniques were implemented 28 months after starting enrollment, after it became apparent that usage was lower than expected. The raffle was started 2 months after that.

Analyses

We conducted descriptive analyses, including percentages, means, standard deviations used to describe login rates and satisfaction ratings. We examined associations between login rates and sociodemographic variables (age, sex, race, education, marital status, income, and financial distress) and the length of the patient’s relationship with their oncologist using bivariable analyses and multivariable logistic regression.

Results

48% of all participants in the study did not log on to the website; 52% logged on between one and 30 times (see Table 2). There was one significant association between logins and sociodemographic variables: In both bivariable and multivariable analyses, financial distress was associated with logins. Specifically, patients who reported financial distress (e.g., not having enough money for essentials) were less likely to log onto the website (OR=1.84; 95% CI 1.08, 3.15).

For participants assigned to an arm that included the COPE intervention (COPE alone or COPE + CHESS) and logged onto the COPE intervention website at least once (n=92), we collected information regarding the portion of the COPE intervention completed. Fourteen participants (15%) completed less than 25% of the intervention; eight (9%) completed 25–49%; eight (9%) completed 50–74%; eight (9%) completed 75–95%; and 54 (59%) completed 96–100% of the intervention. The average time spent on the intervention website was 44.3 minutes (SD=52.5; median = 29.4). Amongst participants who completed the entire intervention, the average time spent was 65.4 minutes (SD=60.0, median=54.8, range=7.1–397.5).

Next, we explored the effect of implementing the MI and raffle strategies on logons. 251 patients (73%) entered the study prior to implementing either strategy. Overall, logon rates rose from 47% to 64% after implementing both strategies. Table 3 displays the percentage of participants who logged onto the study website at least once depending on when they entered the study: prior to implementing the MI or raffle strategies, after the MI strategies were implemented but before the raffle was started, or after both the MI and raffle were implemented. The MI strategies led to increases in logon rates for participants in the CHESS, COPE, and CHESS+COPE arms. Logon rates dropped somewhat in the CHESS and COPE arms after starting the raffle, but remained higher than baseline rates. For participants in the COPE and the Internet Only arms, logon rates improved following implementation of the raffle.

Finally, we examined satisfaction ratings with the COPE website collected during the post-visit interview. Mean ratings on the 0–10 scale were 7.0 (SD=2.5) for helpfulness, 5.6 (SD=3.4) for changing how they talked to their oncologist, and 7.2 (SD=2.7) for recommending it to a friend or family member. Two-thirds or more of the participants gave highly favorable ratings (7 or higher) on the items asking whether they found the website helpful (66%) and would recommend it to a friend or family member (64%); 48% said it was very likely to change the way they talked to their oncologist.

Discussion

This article provides a description of the development process and content of a novel online intervention that combines educational material and communication skills training with the goal of facilitating patient expression of emotional concerns to their oncology providers. While prior studies have found that patient communication skills training can help patients seek and understand medical information during clinical encounters, none of these interventions included training in skills to help patients express emotional concerns to their provider [27–29]. We designed the COPE intervention to optimize behavioral change by incorporating elements of Social Cognitive Theory and well-validated cognitive behavioral communication skills training. The COPE intervention is also unique in providing patients with audio recordings of their own conversations with their providers as a learning tool.

One factor that is critically important in determining the efficacy of the intervention is whether patients login to the program and use it as intended. A recent review found that adherence, as measured by logins and module completion, was related to the effectiveness of

e-therapy interventions for both physical and psychological health [44]. In this study, we found that midway through the study, slightly less than half of the participants had logged onto the study website. This rate is consistent with other studies testing internet-based interventions [35], however certainly lower than desired. We therefore implemented two strategies to increase adherence, Motivational Interviewing techniques and a quarterly raffle. Following implementation of these strategies, log on rates improved from 47% to 64%. While these findings are preliminary, they suggest that both strategies may be helpful in improving the likelihood that patients will log on to an online intervention. Given the short time between the implementation of the two strategies, it is not possible to determine which was more effective. However, both strategies are easy to implement, require very little staff time, and could be readily incorporated into study protocols to enhance patient adherence to online interventions.

Among those participants who were assigned to receive the COPE intervention and logged onto the intervention website at least once, 76% completed half or more of the intervention and 59% completed the entire intervention. This suggests that once patients viewed the program they were likely to continue. On average, it took patients about one hour to complete the intervention, which is consistent with our expectations in designing the program. Overall, satisfaction ratings were high. However, while most patients indicated that they found the program helpful and they would be likely to recommend it to a friend or family member, they were less likely to say they thought it would change the way they talked with their oncology provider. This may be indicative of the difficulty of addressing challenges that older cancer patients may face to patient-provider communication such as memory impairment, language difficulties, and intergenerational and cultural barriers [45] as well as differential attitudes about their willingness to express their emotional concerns. Future analyses will examine associations between participants' response to this item, as well as their login and completion rates, with study outcomes. We hypothesize that patients assigned to one of the arms including the COPE intervention (COPE alone or COPE + CHESS) will demonstrate increases in the number of their emotional expressions to their provider compared to patients in the CHESS or internet-only conditions, and that these effects will be stronger for patients who view all or most of the intervention.

In summary, the COPE intervention addresses an important unmet educational need for patients with advanced cancer. While initial adherence was unsatisfactory, strategies to increase adherence led to improvements in log on rates. If the intervention proves successful in increasing patients' expression of emotional concerns and decreasing their psychological distress, it could serve as a model for future web-based patient education programs.

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Figure 1.

Figure 2.

Figure 3.

Table 1

Intervention content

Module	Topics	Goals	Activities and behavioral techniques employed
1. Introduction	<ul style="list-style-type: none"> Cancer and emotion The Benefit of Talking to Your Doctor Your Doctor Cares An Example 	<ul style="list-style-type: none"> Normalize the experience of emotional concerns for cancer patients Present a rationale for expressing emotional concerns to the oncology provider 	<ul style="list-style-type: none"> Video clips of patients expressing common emotions associated with cancer (e.g., fear, uncertainty, relief) Assessment of outcome expectancies and self-efficacy Education regarding providers' interest in their patients' emotional concerns, and why this may not always be apparent Video clip of patient (a) describing desire to express emotional concerns to provider but hesitancy to do so; (b) expressing the concerns to the provider; and (c) describing perceived benefits of having done so
2. How to talk to your doctor	<ul style="list-style-type: none"> WISH method (What are you feeling, I'm feeling, Speak in short statements, Ask for Help) When You Don't Get the Response You want 	<ul style="list-style-type: none"> Teach patients strategies for expressing emotional concerns to the provider Teach patients strategies for dealing with common provider behaviors that may inhibit expression of emotions 	<ul style="list-style-type: none"> Presents a four step method for expressing emotional concerns (WISH) Common provider behaviors that can inhibit expression of emotional concerns are described, along with strategies for dealing with them
3. Talking with family and friends	<ul style="list-style-type: none"> Issues to Discuss Obstacles to Talking An Example 	<ul style="list-style-type: none"> Present a rationale for talking with loved ones about emotional concerns Present suggestions for effectively discussing emotional concerns with loved ones 	<ul style="list-style-type: none"> Patients identify concerns they would like to discuss with a loved one Assessment of barriers to talking with loved ones Video clip of patient and spouse discussing the patient's concern (fear of the future). The video illustrates common partner inhibitory behaviors such as reassurance and patient strategies to express concerns despite these behaviors. Following their discussion, both the patient and partner describe the perceived benefits of having the open discussion about the patient's concerns.
4. In Your Own Words	<ul style="list-style-type: none"> Your Visits Your Examples 	<ul style="list-style-type: none"> Give patients the opportunity to learn the communication skills by reviewing an audio recording of a recent visit they had with their provider 	<ul style="list-style-type: none"> Patients are encouraged to review the audio recording of their last visit with their provider to identify what they did well in terms of expressing emotional concerns and what they could do differently next time. If there were times in their visit where the patient expressed feelings or asked for help, those

Module	Topics	Goals	Activities and behavioral techniques employed
			specific segments of the visit can be reviewed separately.

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Table 2

Number of logins by treatment condition.

	Internet Only N=86	CHESS N=85	COPE N=87	COPE+CHESS N=85
# of Logins				
0	46	43	41	35
1	19	20	21	27
2	8	11	9	6
3 or more	13	11	16	17

Percent of participants logging onto the study website at least once before and after implementing MI and raffle

Table 3

	Internet Only		CHES		COPE		COPE+CHES	
	Total N	N (%) who logged in	Total N	N (%) who logged in	Total N	N (%) who logged in	Total N	N (%) who logged in
Before MI or raffle	63	27 (43)	63	30 (48)	63	29 (46)	62	33 (53)
After MI	7	3 (43)	4	3 (75)	8	5 (62)	6	6 (100)
After raffle	16	10 (63)	18	9 (50)	16	12 (75)	17	11 (65)