

The feasibility of using conversational agent technology to improve problem-solving and coping skills of young adults with cancer

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Objective: Young adults with cancer have unique psychosocial needs and often lack the problem-solving and coping skills for effective resolution. We conducted a study to clarify these needs and then developed and tested an educational intervention to coach young adults with cancer in problem-solving and coping skills using a new conversational agent technology that uses a multi-media format to simulate face-to-face encounters.

Methods: We qualitatively assessed online focus groups and chat rooms with 45 young adults with cancer and used the results to develop and test an online 15-minute educational prototype using a new conversational agent technology with 49 young adults (18–35 years of age) with cancer.

Results: Young adults with cancer are most concerned about reproductive issues, emotional issues, communicating with healthcare providers, and the risks and benefits of treatments. The study participants found the I-COPE prototype to be useful, easy to use, and worth recommending to others. They wanted to have more video segments about the experiences of other young adults with cancer; more video segments of actual procedures and treatments; more Internet links to information and resources; and more opportunities to interact with the conversational agent.

Conclusion: New conversational agent technology is useful in coaching problem-solving and coping skills to empower young adults with cancer.

Practice implications: New conversational agent technology is a useful tool in patient education and skill development, particularly among young adults.

Keywords: young adult cancer patients, conversational agent technology, problem-solving, coping, self-efficacy, survivorship

Introduction

A recent article in *US News and World Report* refers to teens and young adults as “cancer’s lost generation”.¹ The incidence of cancer in young adults in North America and Europe has increased by 30% over the last 30 years.² Three times more patients diagnosed during the second 15 years of life than during the first 15 years. In the year 2000, nearly 21,400 persons in the United States from 15–29 years of age were diagnosed with invasive cancer and approximately half of the 15- to 29-year-old patients were 25–29 years of age.³ Furthermore, young people under the age of 40 with a cancer history comprise 7% of the 7.1 million cancer survivors diagnosed with cancer in the last 20 years.⁴ These numbers, however, give no indication of the quality of life expected, enjoyed, or endured by young adult survivors.⁵

The diagnosis of cancer is a traumatic episode in anyone’s life and is a life-changing event for young adults. They may be in college or starting new careers, getting married

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and starting families, and are “just beginning to live”.⁶ Cancer treatments can impact sexual activity, sexuality and self-image, and fertility. Many young adult patients can neither fully comprehend these implications nor know how to acquire expert information. A cancer diagnosis forces individuals to revert to some state of dependence, whether on their parents or on others, and their stress may be more extreme if they have no support system to meet their needs.

In a study of 402 cancer survivors of all ages, Soothill et al reported that items of significant unmet needs cluster around aspects of managing daily life, emotions, and social identity and these unmet needs were more likely to be expressed by younger adult patients.⁷ They also reported a connection between unmet needs and a patient’s ability to talk freely to a caregiver about cancer.

Haase and Phillips⁸ present several research priorities to make the needs of young adult cancer patients more explicit. Our research focused on two of those research priorities in our study: 1) a qualitative pilot study to determine the primary concerns of young adults with cancer and their preferred ways to effectively address these concerns; and 2) using the results of the qualitative study to develop and test an innovative educational intervention for young adults with cancer that would provide them with problem-solving strategies to cope effectively with their primary concerns.

This paper reports on the information gained from the qualitative study and the results of the pilot study to develop and test the intervention.

Methods

The first phase of our study used online focus groups and in-depth telephone interviews with young adult cancer patients and survivors about their primary concerns and preferred ways of addressing those concerns. We identified information needs through three online focus groups with a total of 27 participants, three chat room discussion groups with 18 participants, and eight in-depth follow-up telephone interviews with a sampling from the focus groups and chat rooms. We identified the online resources through recommendations from the American Cancer Society, the Leukemia and Lymphoma Society, and PlanetCancer, a widely used website for young adults with cancer. All the focus groups and chat rooms were existing activities for young adults with cancer. We posted a brief message describing the information we were seeking and invited people to participate. Selection criteria included people between 18 and 35 years of age and diagnosed with cancer within the past 12 months. Participants self-selected from existing online chat rooms and were not

identified by name, but they did reveal gender and length of time from diagnosis.

We asked three open-ended questions in the focus groups and chat rooms: Since your diagnosis of cancer, what have been your major problems or concerns? How did you resolve those problems or concerns? How easy or difficult was it for you to resolve your problems/concerns? Additional questions were asked to attempt to get more specific detailed information on each question. Eight people self-selected for follow-up in-depth telephone interviews provided contact information. Participants were called and asked to expand on the questions and their earlier responses. The purpose of this phase was to identify major themes and sub-themes that emerged from an analysis of the text from the focus groups, and chat rooms and the telephone interviews provided more detail on the themes.

We used the results of the qualitative phase to develop and test a 15-minute prototype of I-COPE for young adults with cancer, new conversational agent technology in an interactive, multimedia web-based and CD format to “coach” young adults on information-seeking, problem-solving, and coping skills.

Description of the I-COPE program

The I-COPE program uses a framework for approaching problems and challenges that allows for self-improvement based on a model applied and used successfully with caregivers of cancer patients. The problem-solving model, summarized by the acronym COPE (creativity, optimism, planning, and expert information), was designed by D’Zurilla in 1986.⁹ D’Zurilla and Goldfried defined problem solving as a “behavioral process which a) provides a variety of potentially effective response alternatives for dealing with a problematic situation, and b) increases the probability of selecting the most effective response from among those alternatives”.¹⁰ Nezu et al broadened this definition to include both “altering the problematic nature of the situation itself and the persons’ reactions to those situations”.¹¹ This broader definition emphasizes the dual effects of problem solving on the problem itself and on the person coping with the problem; success in solving a problem improves one’s feelings about it, and feelings about the problem (eg, expectations or success) affect the likelihood of success in solving it.¹²

The I-COPE program uses new embodied conversation agent (ECA) technology to provide an online “coach” as a tutor and guide as well as vicarious experiences modeled by other young adult cancer patients who were able to successfully solve problems related to their disease and treatment

and adopt useful coping strategies to model for the study's participants.

ECA technology uses multi-faceted human-like characters that are programmed with personalities and knowledge bases, which allows them to interact with users in a conversational manner (Figure 1).¹³

The idea of the ECA technology is to simulate face-to-face encounters and the virtual experience of cooperating with a human partner rather than just "using a tool", such as reviewing frequently asked questions on a website.¹⁴ The earlier ECA programs were almost totally text-based in their interactions, but our evolution of the technology creates a multimedia environment with audio, video segments, and limited need for text and its distractions from interactions with the agent.

Recruitment and enrollment

The 15-minute prototype demonstration of the I-COPE program was delivered on the web on a secure site with links on several other websites relevant to young adults with cancer such as the Leukemia and Lymphoma Society, Planet Cancer, and the Great Valley Region Chapter of the American Cancer Society. We recruited participants through those organizations and with help from Elliott Benson, a marketing research company. Screening criteria included a diagnosis of cancer and being a young adult between 18 and 35 years of age at time of diagnosis. We collected demographic information, but we did not request any personal identifiers such as name or social security number.

Data collection and analysis

Participants who viewed the I-COPE prototype were asked to complete an evaluation instrument with 25 questions (as illustrated in Table 1). Responses were coded and analyzed using frequency and descriptive statistics.

Results

Qualitative phase

In the preliminary qualitative phase, 45 participants ranged in age from 18–32; 57% were female and 43% were male; and all were within eight months of diagnosis. The following themes emerged in the qualitative phase: 1) sexual and reproductive issues; 2) emotional issues (handling emotional changes, not exhibiting fear); 3) communicating with healthcare providers; and 4) cancer treatment risks and benefits. The categories of information identified as helpful for young adults with cancer included: information and options related to cancer and fertility; cancer and intimate

relationships including issues of sex and sexuality; cancer treatment options with corresponding risks and benefits; and skills/strategies for communicating better with healthcare providers.

I-COPE program

Forty-nine (49) participants were recruited from July through December 2006 to view and evaluate the I-COPE program. Forty participants (81.6%) viewed the program and completed the online survey; three viewed the online program and completed paper surveys; and six viewed the program on CDs and completed the survey online for a total of 49 participants. The majority of participants were male (53%), single (51%), white non-Hispanic (73.5%); a majority (57.1%) had a college degree or attended college for some period (32.7%). The largest group reported a diagnosis of cancer within the past year (57.3%). The most common diagnosis was testis (22.5%) followed by leukemia (16.3%), melanoma (12.3%), and cervical cancer (10.2%).

After viewing the program prototype, respondents were asked to rank the top five concerns/problems that they would like to see addressed in a full operational version of the I-COPE program. Respondents could rank each listed topic from 1–5, with 1 being a major concern and add an unlisted topic. The top ranked concerns can be grouped into four categories: 1) reproduction including reproductive issues, sexual functioning and body image; 2) emotions including emotional issues, stress and anxiety; 3) communication, eg, communicating with doctors and nurses; and 4) treatment, eg, risks/benefits of treatment. Table 2 lists all concerns/problems with their rankings.

When asked "What is your preference for receiving information about your cancer experience?" participants reported preferring to receive information from an interactive, multimedia delivery system (77.7%) over print media (6.1%) and even face-to-face encounters (4.1%).

In response to the question, "If you were designing the I-COPE program what would you change or add", the majority of participants would add more "experiences by other cancer patients my age" (87.8%), including more video segments of actual procedures such as receiving chemotherapy or radiation (75.5%); provide "more" Internet links to information and resources such as the Cancer Information Services and the National Cancer Institute (51%); and use the I-COPE coach "more" (47%). The web (77.5%) was the preferred means of receiving the program over DVDs (18.3%), podcasts (2%), or hand-held devices such as cell phones (2%).

Table 1 I-COPE program evaluation instrument**Demographic questions (#1–7)**

1. Age
2. Sex
3. Marital status
4. Race/ethnicity
5. Education
6. Timing of diagnosis
7. Type of cancer

Response scale: 1 (strongly agree), 2 (agree), 3 (disagree), 4 (strongly disagree)

8. Overall, this demonstration was useful to help me see how the I-COPE program would work.
9. I would be interested in seeing the full I-COPE program when it is completed.
10. The concept of having a coach (James or Jessie) available on demand to answer my questions and provide information is helpful.
11. If the full I-COPE program was available to me now, I would use it.
12. If the full I-COPE program was available now, I would recommend it to other cancer patients my age.
13. Overall, the I-COPE program would be easy to use.
14. I have experienced situations where the I-COPE program would have been helpful to me.
15. I think the I-COPE program is a good idea.
16. I think a program like I-COPE is needed by cancer patients my age.

Please rank your preferences on the following: 1 (first choice), 2 (second choice), etc.

17. Please rank your preferences for how I-COPE should be available: Web, DVD, Hand-Held Device (cell phone, Blackberry, etc), podcast
18. What is your preference for receiving information about your cancer experience? Print, Audio, Video, Combination (multi-media), One to-One (face-to-face), Groups, Not sure.
19. If you were designing the I-COPE program what would you change or add? (Scale using More, Less, About the Same, Eliminate).
 - a. Use of the coach (James or Jessie).
 - b. Sharing of experiences by other cancer patients my age.
 - c. Video of actual procedures such as receiving chemotherapy or radiation.
 - d. Links to information and resources such as Cancer Information Services and the National Cancer Institute.
20. The purpose of I-COPE is to help you acquire good problem-solving skills. Please rank your top five concerns/problems that you would like to see addressed in the full I-COPE program (from 1, highest concern through 5, lowest concern).
 - a. Reproductive issues
 - b. Body image
 - c. Sexual functioning
 - d. Communicating with family and friends
 - e. Communicating with doctors and nurses
 - f. Financial issues
 - g. Work-related issues
 - h. Transportation issues
 - i. Asking others for help
 - j. Making my own decisions
 - k. Risks and benefits of treatments
 - l. Treatment options and how to choose best treatment
 - m. Emotional issues
 - n. Stress, anxiety
 - o. Other _____

For the following, select excellent, good, fair or poor:

21. Ease in downloading the media player.
22. Ease in navigating the I-COPE demo.
23. Quality of the video in the I-COPE demo.
24. Quality of the ECA coach (James) in the I-COPE demo.
25. Overall technical quality of the I-COPE demo.

In response to questions about usefulness, ease of use, and whether they would recommend the program, the majority of participants thought the I-COPE program was helpful, easy to use, and a good idea. They believe that a program such as I-COPE is needed by cancer patients their age and they would use it, recommend it to other patients their age, and had

experienced situations previously in which I-COPE would have been useful to them. Table 3 illustrates the rankings.

Discussion

This study confirms other research reported in the sparse literature on the psychosocial experiences and concerns of

Table 2 Concerns/problems to be addressed in full I-COPE program n = 35

Concern/problem	Percent ranking it top concern
Reproductive issues	24.4%
Emotional issues	22.4%
Communicating with doctors and nurses	16.3%
Risks and benefits of treatments	12.2%
Stress, anxiety	6.1%
Sexual functioning	4.0%
Body image	4.0%
Making my own decisions	4.0%
Financial issues	2.0%
Transportation issues	2.0%
Communicating with family and friends	2.0%
Work-related issues	0.0%
Asking others for help	0.0%
Treatment options/how to choose best	0.0%
Other	0.0%

young adults with cancer.¹⁵ While adjusting to treatments and side effects, they must cope with emotional distress, self-esteem issues, and uncertainty about the future, including questions about fertility and reproduction. Treatment recommendations and services for adolescent and young adult cancer patients can vary widely depending on whether the therapeutic setting is pediatric oncology or adult oncology and whether appropriate psychosocial support is available. It seems especially important for young adults to share experiences and coping skills with peers when they are undergoing cancer therapy, yet most hospitals and clinics do not have specific support groups or activities for young adults, leaving them emotionally isolated.

Utilizing good problem-solving and coping skills for active self-management results in higher adherence to treatment regimens and is associated with improved outcomes even when the treatments themselves are ultimately found to be ineffective. Young adults with cancer may not have developed good problem-solving and coping skills. The process

of defining a personal health-related goal, developing a self-care regimen to make an incremental step toward the goal, and adhering to and revising the regimen as needed over time appears as important as the specifics of the goal and regimen.^{16,17} Jerant et al argue that developing programs to promote active self-management and determining the mechanisms by which they influence outcomes should become a high priority in the overall care of patients.¹⁶ One specific mediator of self-management programs is self-efficacy.

Perceived self-efficacy is defined as a person's belief about his/her capabilities to produce designated levels of performance that exercise influence over events that affect their lives.¹⁸ For example, a belief that "I can ask my doctor questions" assumes an ability to formulate a question and ask it with the expectation that the doctor will provide an answer. Bandura defines self-efficacy beliefs as determinants for how people feel, think, motivate themselves, and behave. Thus, people with high confidence in their capabilities approach difficult tasks as challenges to be mastered rather than as threats to be avoided. People's beliefs about their efficacy can be developed by four main sources of influence: *mastery experiences*, *vicarious experiences*, *social persuasion*, and *reducing stress reactions*. The I-COPE program offers mastery and vicarious experiences through video segments of other young adults effectively solving problems and learning new coping skills. The ECA coach can provide inspiration and motivation, answer questions, and "tutor" users in skill development. Higher levels of self-efficacy are associated with more optimal self-care behaviors,^{19,20} and interventions, such as the I-COPE program can strengthen patient self-efficacy and result in positive changes in health behaviors²¹ and health outcomes.^{22,23}

Technology offers a new way to reach adolescents and young adults where they are and when they need information, support, or help. It may be obvious to note that younger adults are more likely than older adults to use new technologies.²⁴

Table 3 Experience with the I-COPE program, n = 35

Experience with the I-COPE program	Mean	Standard deviation
Overall, this demonstration was useful to help me see how the I-COPE program would work.	3.83	0.39
I would be interested in seeing the full I-COPE program when it is completed.	3.84	0.43
The concept of having a coach (James or Jessie) available on demand to answer my questions and provide information is helpful.	3.77	0.47
If the full I-COPE program was available to me now, I would use it.	3.69	0.51
If the full I-COPE program was available now, I would recommend it to other cancer patients my age.	3.91	0.27
Overall, the I-COPE program would be easy to use.	3.86	0.41
I have experienced situations where the I-COPE program would have been helpful to me.	3.80	0.41
I think the I-COPE program is a good idea.	3.96	0.20
I think a program like I-COPE is needed by cancer patients my age.	3.90	0.31



Figure 1 James, the ECA coach.

Indeed, adolescents and young adults are typically the early adopters of new technologies. The Internet, in particular, provides innovative opportunities for involving young adults, including hard-to-reach populations (ie, young adults in rural settings) and those indifferent to traditional health education approaches. In fact, those traditional sources of health information are no longer satisfying their needs, and they are instead increasingly using the Internet for health-related information.^{25,26} In addition, young adults increasingly use online technologies to form and maintain interpersonal relationships (eg, friends, family, romantic partners).²⁷

There are an increasing number of web-based programs that provide information and resources for adolescents and young adults with diabetes; offer support for smoking cessation; and provide disease-specific information. Additionally, there are numerous health-related blogs aimed at adolescents and young adults. This relational dimension of new technologies, as it correlates with seeking health-related information, merits further study. Examining how young adults interact with new technologies, and how they use these technologies to gather information and achieve their objectives, continues to be a research priority.^{28,29}

Providing the I-COPE program on the web was the first choice of respondents in this pilot study. A recent study by the Kaiser Family Foundation found that 90% of teens and young adults have gone online and 49% of them go online once a day or more; 68% of young people use the Internet to search for healthcare information; and a significant proportion of them are acting on what they find.³⁰ The survey also found, surprisingly, that 75% of young adults have searched for health information, which is about the same percentage as those who have played games online (72%), downloaded music (72%), chatted (67%), and shopped (50%). This survey

suggests that young adults are inclined to use the Internet for health information.

In terms of the four categories of most concern to young adults with cancer, they are clearly concerned about reproduction and issues related to sexual intimacy and body image. The qualitative phase found reproductive issues to be among the top concerns ranked by respondents. While there is well-documented research on the effects of cancer and its treatment on reproduction and fertility, Schover et al suggest that infertility comes as a surprise and that many young adult cancer survivors do not recall being warned at the time of their treatment about the risk of being infertile.³¹ They note that only about 10% of oncologists reported that they had discussed sperm-banking as a matter of course with all male patients at risk of infertility.³² Other researchers have identified salient themes for young adults, which include fertility, reproductive problems, desire for children in the future, sperm banking, concerns about genetic risks, pregnancy complications, and attitudes about having children after cancer. While some young adult survivors profess to know nothing about their risk for infertility, others have knowledge that influences their beliefs about having children and the options available to them.^{33,34}

Participants also ranked communicating with doctors and nurses and the risks and benefits of treatment as important concerns and these are frequently linked to reproductive issues. Increased understanding of a disease could improve self-efficacy and influence overall outcomes. Patients are required to interact frequently with health providers and allied health professionals and are expected to possess a basic understanding of treatment regimens and options. They should actively participate in healthcare decisions and must cope with the everyday psychosocial stressors associated with the disease and side effects of treatments.³⁵ It is also important that patients fully understand the potential risks associated with treatment options. Those patients who are not able to fulfill these tasks successfully are at greater risk for anxiety and depression.³⁶

The limitations of our research include the small sample size and the constraints of a short 15-minute prototype of the educational intervention. Due to limited funding, we were not able to include the highest quality video and audio segments. We could only develop one ECA coach, a male, and we were limited in the amount of programming of verbal and nonverbal information we could include. The prototype was offered in a linear fashion in order to test the various segments, while a full version of the program will allow for greater choice and control over what segments are accessed and used.

The next version of the I-COPE program will examine the effectiveness of the program over standard procedures in providing information and support in a randomized study and will track the time that users spend in the I-COPE program, how they navigate through the program, how many times they return, and what links they use. Information will be gathered about medical visits during the time they are enrolled in the program and whether they report any changes in the quality of those visits. This future research will help to determine if the I-COPE program may be a cost-effective way to deliver “on demand” information and support to cancer patients and survivors.

Future studies need to further address how social and spatial presence occurs through ECA technology and whether it immerses the user resulting in a richer learning experience. This study indicates users respond differently to the ECA coach and the video segments and we need to better understand the exact nature of the relationship between users and ECAs. Some researchers have hypothesized that social science theories may be applied to the virtual domain of the ECA, but few studies exist to support this position. Future research also should examine the applications of this technology in addressing cultural issues including the use of multiple languages.

Conclusion

Our research supports previous research on the special needs of young adults with cancer and provides information to further the development and testing of ECA technology in patient education and support.

Clinical implications

ECA technology has a range of possibilities in health care, but seems particularly appropriate for situations requiring time and repetition, such as promoting appropriate eating habits, encouraging active lifestyles, skill training in problem-solving and coping (as in our current study), symptom management, and ongoing support.

Recent trends in health care impose time and resource constraints on health care providers, making it difficult for them to spend as much time as needed to do effective counseling for health-related behavior change (eg, smoking cessation, nutrition, exercise).³⁷ The use of interactive health communication technologies, such as ECAs, in providing behavioral counseling in health care settings and elsewhere offer an efficient and effective alternative.

In addition, ECA coaches, developed in any race/ethnicity and programmed to speak any language, make this

technology potentially useful in delivering information and education to multiple populations. Providing information in a more visual and aural medium potentially also addresses the issue of literacy.

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