



HHS Public Access

Author manuscript

J Health Commun. Author manuscript; available in PMC 2015 October 13.

Published in final edited form as:

J Health Commun. 2014 April ; 19(4): 441–459. doi:10.1080/10810730.2013.821557.

Meeting the Information Needs of Lower Income Cancer Survivors: Results of a Randomized Control Trial Evaluating the American Cancer Society’s “I Can Cope”

MICHELLE Y. MARTIN

Department of Medicine, Division of Preventive Medicine, University of Alabama at Birmingham, Birmingham, Alabama, USA

MARY B. EVANS

UAB Center for Study of Community Health, University of Alabama at Birmingham, Birmingham, Alabama, USA

POLLY KRATT

Department of Medicine, Division of Preventive Medicine, University of Alabama at Birmingham, Birmingham, Alabama, USA

LORI A. POLLACK

Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, Atlanta, Georgia, USA

JUDITH LEE SMITH

Division of Cancer Prevention and Control, Centers for Disease Control and Prevention, Atlanta, Georgia, USA

ROBERT OSTER

Department of Medicine, Division of Preventive Medicine, University of Alabama at Birmingham, Birmingham, Alabama, USA

MARK DIGNAN

Department of Internal Medicine–Oncology, University of Kentucky, Lexington, Kentucky, USA

HEATHER PRAYOR-PATTERSON

Department of Psychiatry and Psychology, Cleveland Clinic, Cleveland, Ohio, USA

CHRISTOPHER WATSON

Meharry Medical College, Nashville, Tennessee, USA

PETER HOUSTON

Department of Medicine, Division of Preventive Medicine, University of Alabama at Birmingham, Birmingham, Alabama, USA

SHIQUINA ANDREWS

Department of Medicine, Division of Preventive Medicine, University of Alabama at Birmingham, Birmingham, Alabama, USA

Address correspondence to Michelle Y. Martin, Division of Preventive Medicine, University of Alabama at Birmingham, 1717 11th Avenue South, MT 617, Birmingham, AL 35128, USA. mymartin@uab.edu.

AMANDY LIWO

Department of Medicine, Division of Preventive Medicine, University of Alabama at Birmingham, Birmingham, Alabama, USA

TUNG SUNG TSENG

School of Public Health, Louisiana State University Health Sciences Center, New Orleans, Louisiana, USA

SANDRAL HULLETT

Cooper Green Mercy Hospital, Birmingham, Alabama, USA

JOANN OLIVER

Capstone College of Nursing, University of Alabama, Tuscaloosa, Alabama, USA

MARIA PISU

Department of Medicine, Division of Preventive Medicine, University of Alabama at Birmingham, Birmingham, Alabama, USA

Abstract

The American Cancer Society is a leader in the development of cancer survivorship resources. One resource of the American Cancer Society is the I Can Cope program, an educational program for cancer survivors and their families. Evaluations of this program indicate that cancer patients highly rate its objectives. Yet, there are gaps in the understanding of the full impact of the program on diverse cancer survivors. In this study, the authors used a randomized trial to evaluate the program. Participants included 140 low-income survivors (79% Black; 38% breast cancer) from community hospitals who were randomized to 4 sessions of I Can Cope (learning about cancer; understanding cancer treatments; relieving cancer pain; and keeping well in mind and body) or 4 sessions of a wellness intervention (humor, meditation, relaxation, and music therapy). The authors' primary outcome was "met information needs." After controlling for covariates, their analysis indicated that I Can Cope was no more effective than the wellness intervention in addressing survivor information needs relative to the learning objectives. Participants provided high overall ratings for both interventions. Self-efficacy for obtaining advice about cancer, age, education, and income were associated with information needs. Educational programs tailored to levels of self-efficacy and patient demographics may be needed.

An estimated 12 million Americans are cancer survivors (Centers for Disease Control and Prevention, 2011). To ensure that the needs of this growing population are met, the National Action Plan for Cancer Survivorship: Advancing Public Health Strategies (Lance Armstrong Foundation and Center for Disease Control and Prevention, 2004) includes a comprehensive set of priorities for quality cancer survivorship. One priority is to ensure effective programs and education for cancer survivors.

The provision of information to cancer survivors is central to quality cancer care (Beckjord et al., 2008; van der Molen, 1999). Despite availability of many cancer survivorship educational materials and resources, research about the usefulness of these materials to cancer survivors is limited (Pollack et al., 2005). Few materials and programs developed by cancer organizations to meet survivor information needs have been subject to rigorous evaluation. Furthermore,

gaps in understanding the acceptability and effect of such programs on minority and medically underserved cancer survivors are of particular concern because lower income and/or minority cancer patients are less likely to have their cancer information needs adequately met (McInnes et al., 2008; Mosavel & Sanders, 2011).

We evaluated I Can Cope (ICC), a general education program for cancer survivors and their families developed and offered by the American Cancer Society. The ICC program developed over time since 1979 from the original 16 hour course presented over eight weeks into shorter courses that can be taken as a self-paced online access course or face-to-face=telephone sessions that vary in length according to the facilitators' perception of audience need (American Cancer Society, 2011).

Despite its long history, published evaluations of this program are few (Diekmann, 1988). Moreover, in a national evaluation, only 3% of the ICC participant sample providing an evaluation of the program was African American, and the majority of participants had an income greater than US\$30,000 (Diekmann, 1988; McMillan, Tittle, & Hill, 1993). These findings highlight our limited understanding of the acceptability and efficacy of this program for lower-income minority cancer patients. We conducted a randomized controlled trial, Survivor Education and Evaluation, in partnership with community hospitals to assess the ability of ICC to meet the information needs of lower income primarily minority cancer survivors. Our main hypothesis was that participants in the ICC group would have fewer information needs over time, as measured immediately postintervention and 6 months postintervention, than participants in the comparison group. We also sought to obtain an overall evaluation of the ICC program from study participants.

Method

Design

We evaluated ICC by comparing the information needs of participants randomized to attend four ICC sessions to the needs of participants randomized to the comparison program, wellness (described in more detail later). Wellness comprised four sessions about stress-reduction. The length, general format, and meeting arrangements for the wellness sessions were the same as for the ICC sessions.

Telephone surveys occurred at baseline, within a month after intervention completion, and again at 6 months postintervention. Participants received a US\$15 incentive per completed survey. University and recruitment hospital institutional review board approvals were obtained.

Intervention Development and Program Implementation

Advisory Board—We established a project advisory board composed of American Cancer Society representatives (including staff responsible for ICC evaluation); hospital-based providers with experience as ICC facilitators; African American cancer patients, family caregivers, and retired health care professionals who worked with patients from our main recruitment site. The board provided guidance on the ICC program implementation, on approaching participants, meeting their needs, and keeping their interest.

Recruitment

Recruitment Sites—The primary study site was the hematology=oncology clinic of a county safety net hospital in urban Alabama. Other area hospitals were prioritized according to the relative percentage of lower income persons served and the percentage of minorities served. A second recruitment site was chosen among those hospitals with the largest low-income minority populations, in particular a radiation oncology clinic with a medical oncology practice.

Recruitment Protocol—Clinic staff introduced recruiters to potentially eligible patients or, when clinic staff was unable to assist, project staff recruiters approached patients in the waiting area. If the patient expressed interest, recruiter and patients went to a private room for additional screening and consent. Cancer patients in active treatment or posttreatment follow-up met study inclusion criteria if they (a) were at least 19 years of age; (b) had received their first cancer diagnosis, (c) were able to speak English, (d) were cognitively able to participate fully in the intervention, (e) had access to a working telephone suitable for a series of 30-min telephone surveys, and (f) were available to attend four weekly afternoon intervention sessions.

Van transportation to and from the sessions was offered if participants desired. Participants who provided their own transportation to any or all of the four intervention sessions were provided a modest reimbursement for driving expenses and provided parking at no cost. Interested and eligible participants provided written consent. A total of 375 patients were screened, of which 175 consented and 140 were randomized. Of the consenting participants, 90% were from our primary recruitment site. A description of our recruitment protocol has been published (Dignan et al., 2011).

Intervention Development

ICC Intervention—The ICC program is a collection of educational modules on coping with cancer that can be delivered individually or combined in a series to meet the needs of participants. In order to maximize ability to attend, given our anticipation that health care challenges might interfere with participation in a longer intervention, we decided to provide four sessions each for the treatment and comparison groups. We tailored the program to offer classes that matched the interests=needs of potential study participants by asking a convenience sample of 25 cancer patients from our primary recruitment site to rank 12 ICC course topics according to their interest. The four topics were chosen based on the highest rankings—learning about cancer; understanding cancer treatments; keeping well in mind and body; and relieving cancer pain (Martin et al., 2011).

For each ICC class, a standardized curriculum guide outlines key aspects of the class and provides a comprehensive framework to help facilitators deliver the program as designed to ensure that course objectives are met. Sections contained in the guide include class purpose and objectives, teaching methods, resources, key presentation points, closing exercise, and handouts. Teaching methods are both didactic and interactive. Speakers for ICC were oncology nurses (registered nurse or nurse practitioner) from the university Health Care System or Comprehensive Cancer Center. Consistent with the ICC model, individuals volunteered their time to present the sessions and were responsible for preparing their PowerPoint presentations

using the American Cancer Society class materials and structuring them to meet the class objectives. All project team members serving as facilitators had successfully completed the American Cancer Society Facilitator Training as required by American Cancer Society in its policy for quality control. Consistent with the American Cancer Society ICC course guides, additional educational materials (e.g., American Cancer Society written materials on treatment options) were also provided to participants in the ICC arm. Each intervention session was approximately one hour, including time for questions from the participants. In each session there were two facilitators, one a speaker and the second a project team member.

Wellness Comparison Intervention—The comparison classes were designed to be “general health and wellness,” with no specific cancer-related content. The investigative team evaluated the literature in cancer coping and discussed potential topics with the advisory board to identify potential wellness topics. The 25 patients who provided rankings for the ICC topics also provided rankings for the eight proposed wellness topics. The four topics with the highest rankings were humor therapy, music therapy, relaxation, and meditation (Martin et al., 2011). Individuals with expertise and/or experience in each of the topics delivered the 1-hour sessions. These sessions were both didactic and experiential (e.g., the benefits of relaxation were discussed and patients had the opportunity to engage in a practice session). For both study arms, each presenter’s class was initially attended by other study investigators to ensure presentations were appropriate in terms of covering content=objectives, literacy level, engagement of participants, and so forth.

Measures

Study data was collected by trained interviewers operating on a computer-assisted telephone information system. Survey interviewers were blind to the participant’s intervention group. Our main outcome, information needs, is described below. In addition, we collected covariates hypothesized or empirically shown to be associated with information seeking (Beckjord et al., 2008; Matsuyama et al., 2011; Mayer et al., 2007). These include self-efficacy, derived from social cognitive theory; informationseeking behavior; and sociodemographic variables.

Primary Outcomes

Information Needs—Information needs was comprised of 18 questions developed by direct translation from the stated objectives for the four American Cancer Society ICC classes. For example, the question, “What is your level of need for knowing how cancer affects your body?” reflects the learning about cancer objective to describe the body’s anatomy and how it relates to cancer. Participants responded on a 4-point Likert scale ranging from 0 (*no need*) to 3 (*high need*), which was structured so that higher scores indicated a higher level of need. A mean score for each ICC session was calculated: learning about cancer (five questions), understanding cancer treatments (five questions), keeping well in mind and body (five questions) and relieving cancer pain (three questions). An overall mean score provides an index for met information needs across all session topics.

Self-Efficacy—We measured self-efficacy with one item based on a similar item included in the National Cancer Institute Health Information National Trends Survey, a population-based study. Respondents were asked “Overall, how confident are you that you could get advice about

cancer if you needed it?” “Would you say you are completely confident, very confident, somewhat confident, a little confident or not at all confident?” Respondents who reported little confidence or not at all confident ($n = 3$) were recoded and included in the somewhat confidence category.

Information-Seeking Behavior—Information-seeking behavior was assessed with a single item. Respondents were asked, “Have you personally looked for information about cancer from any source other than your doctor, nurse, or other health provider?” Response choices were “yes,” “no,” or “don’t know or not sure.” We recoded “don’t know=not sure” responses as missing.

Sociodemographic and Clinical Variables—Sociodemographic and clinical variables and potential covariates included age, gender, race=ethnicity, education, marital status, income, and employment questions. A history of the participant’s cancer was obtained from patient self-report providing the type of cancer, time since diagnosis, and types of treatment. In addition to the main outcome variables (need information scores), at the end of each session, participants rated the session and provided general comments or suggestions.

Analysis

Using baseline data, we compared randomized participants to those who were enrolled in the study but lost to follow-up before randomization. We also compared participants randomized to ICC to those randomized to the wellness group. For both analyses, comparisons were made on key variables: gender, race=ethnicity, education, self-efficacy, information-seeking behavior, time since diagnosis, income, age, and the five information need scores. Comparisons were performed using the twogroup t test for quantitative variables and the chi-square test (or Fisher’s exact test where needed) for categorical variables. Descriptive statistics were calculated to characterize the sample. In addition, mean need scores for baseline, postintervention, and 6 months postintervention were calculated.

To test the hypothesis that individuals randomized to ICC versus wellness would have lower need scores postintervention, comparisons between the intervention groups across all three time points (baseline, 1 month, and 6 months) were performed using mixed models repeated measures analysis, assuming an unstructured covariance matrix. The Tukey-Kramer multiple comparisons test was used to determine which pairs of means were significantly different when a significant overall group or time effect was found in these models. Outcome variables in this primary analysis included four subscales that corresponded to the four ICC sessions: a “learning about cancer” score, an “understanding cancer treatment” score, a “relieving cancer pain” score, a “keeping well in mind and body” score, and a total needs score that included all four subscales. Covariates included age, time since diagnosis, gender, race=ethnicity, education, income, information-seeking behavior, and self-efficacy. We also include time of assessment (baseline, immediately, and 6 months postintervention) and the interaction between time of assessment and intervention group assignment. In an additional analysis examining the primary outcome, the analysis was repeated with the addition of number of sessions attended (0–4) to control for intervention dose. Statistical tests were two-sided and used a significance level of .05.

The planned study was a two-group randomized design. However, approximately 30% of randomized participants did not attend any intervention sessions. We decided to consider the group of nonattendees as a control group in this study and conducted a three group analysis with ICC, wellness, and the control group as the independent predictors of the need scores. Of note, there was no difference in the rate of nonattendance by intervention group. The same statistical approach used in the primary analysis was used for these subgroup analyses.

An additional subgroup analysis was conducted among ICC participants only. In essence, because it was expected that changes in information needs would align with information content in specific sessions, we conducted an analysis where attendance or nonattendance to specific sessions was the independent variable and the need score from the subscale corresponding to that intervention session was the outcome score. Covariates in this analysis were the same covariates included in the primary analysis. Statistical analyses were performed using SAS 9.2.

Results

The sociodemographic and clinical characteristics of the sample ($N = 140$) are included in Table 1. The majority of participants were female (65.7%), Black (79.3%), and not working (88.6%). The median monthly income was US\$700 with almost 50% of participants with a monthly income of less than US\$700. The majority of patients were breast cancer (38%), hematologic (13.1%) and colorectal (12.4%) cancer survivors. Table 2 shows information need scores at baseline, immediately postintervention, and 6 months postintervention. Across time, need for information decreases across both groups although it appears that the decrease is somewhat larger for the ICC group (Table 2). Across time, decreases in information needs were observed for Understanding cancer treatments, $p = .04$; Keeping well in mind and body, $p = .04$; and Overall needs score, $p = .04$. Significant decreases were not seen for Learning about cancer, $p = .12$ or Relieving cancer pain, $p = .26$.

Our primary hypothesis, that individuals randomized to ICC would have less postintervention information needs was not supported ($p > .10$). Several covariates however, were significant. For all five outcomes (learning about cancer, understanding cancer treatment, keeping well in mind and body; relieving cancer pain, and the overall needs score), there was an inverse relationship between self-efficacy and the information needs scores. Age, education, and income were also significant covariates for selected outcomes (Table 3). Older individuals had greater treatment information needs. Individuals with more education or with more financial resources had lower information needs. When we included the total number of sessions attended as a covariate, the pattern of findings was similar.

The pattern of results was the same when we conducted our subgroup analysis that included the three groups (ICC, wellness, and control). Group was not associated with the study outcomes. As with the previous analyses, several covariates were significant and self-efficacy was significantly associated with all five outcomes (Table 4). Again, self-efficacy was inversely related to information need scores. Adding the number of sessions attended as a covariate in this analysis did not alter the results. No association was found in an additional

analysis that examined attendance to specific ICC sessions and change in the information need score associated with that given session.

Sessions were favorably received as reflected both by the quantitative assessment as well as the narrative responses provided by participants (Table 5). Participants in the ICC arms enjoyed the sessions, the information learned, and the opportunity to hear from others. Some also thought the sessions would be beneficial early during treatment or soon after diagnosis. Participants also enjoyed the sessions of the wellness arm and felt they helped them release stress and temporarily forget their problems.

Discussion

Our study is the first to evaluate the American Cancer Society's ICC program among low-income, primarily minority cancer survivors. Consistent with ICC as offered in community settings, community experts delivered the ICC sessions. The hypothesis that ICC would result in less information needs as it related to cancer when compared to the wellness condition was not supported. However, participant ratings of both the ICC and wellness sessions obtained immediately after the sessions suggested that the intervention was meaningful for participants and of value.

Independent of the intervention, information needs decreased over time for most of our information need outcomes. These findings suggest that information needs may be met to some degree without formal intervention as patients navigate the cancer journey. While the decrease in information needs may be encouraging, it should be noted that need scores at 6 months indicated that not all their information needs were met. Thus, cancer patients continue to seek information after the time of their initial diagnosis and completion of treatment. This finding is consistent with the work by Heese and colleagues that demonstrated that information-seeking behavior among cancer survivors does not decrease over time (Hesse, Arora, Burke Beckjord, & Finney Rutten, 2008).

It is important to note that pain management was one area where we did not observe a decrease in information needs. This is in line with the continued difficulty of pain control in individuals with a history of cancer, especially minority populations. For example, a recent study found that compared to whites, Black patients with cancer had more pain interference and disability and Black race predicted pain severity (Green, Hart-Johnson, & Loeffler, 2011). Efficacious interventions to provide cancer survivors with the needed information to minimize or eliminate cancer-related pain are needed, and especially for minority, medically underserved populations.

We found that the cancer patient's confidence that they could obtain advice about cancer was consistently associated with lower information needs. This finding is important from both a theoretical and practical perspective. In theory, self-efficacy is a central construct of several health behavior theories (e.g., social cognitive theory and the health belief model). In our study, it is possible that those with more confidence in obtaining advice about cancer also tended to ask more questions of their physician and thus had lower information needs. We did not assess question-asking behavior; future studies would have to test this hypothesis. Interestingly, it is not the case that those with higher self-efficacy were simply looking for more information

beyond their doctor, nurse, or healthcare provider: when we controlled for information-seeking behavior, self-efficacy continued to have a significant relation with met informational needs. On a practical level, given the apparent role of confidence, researchers might use qualitative methods to better understand the sources of self-efficacy in this context and population and its relationship to meeting their informational needs. Information learned from this in-depth exploration can then inform interventions that aim to increase information-seeking confidence in cancer survivors.

Our finding that older cancer patients had more information needs related to treatment was also of great interest. In part, this finding might be explained by previous work that suggested that younger cancer survivors (<60 years at diagnosis) sought more cancer information from all sources when compared to older cancer survivors (Bennett, Cameron, Whitehead, & Porter, 2009). The greater need for treatment related information may reflect older individuals not seeking treatment-related information on their own. Alternatively, the fact that the age effect was specific to treatment is intriguing: studies suggest that older cancer patients are less likely to receive recommended treatment (Pisu et al., 2010). One hypothesis perhaps is that in addition to being under treated, older cancer patients may be provided less information by their physician as it relates to cancer treatment compared to younger cancer patients. Future research should seek to better understand the treatment-related information needs of older cancer patients.

A limitation of the study is that nearly one third of participants did not attend both the ICC and wellness sessions. Although this percentage of nonattendance may be considered high, reports from our advisory group suggest it is not uncommon for ICC sessions delivered in community settings. The low attendance rate may also be a reflection of our population. In an evaluation of ICC, those with less education were more likely to not complete the ICC program (Diekmann, 1988). In follow-up qualitative interviews with individuals who did not attend any sessions, we learned that reasons for nonattendance included illness burden (cancer or other), treatment side effects, or caregiving responsibilities. Notably there were some non-attendees that we could not engage even in the qualitative study, suggesting that there may be a subset of individuals who choose to, or are unable to, participate in some programs. Alternatively, these patients may be individuals who prefer to not seek information. For example, Miller suggests that under threatening conditions some individuals engage in monitoring (i.e., attending to information) while others engage in blunting (i.e., avoiding information; Miller, 1995). A recent study highlighted the heterogeneity of information-seeking among cancer patients (Protiere, Moumjid, Bouhnik, Le Corroller Soriano, & Moatti, 2012). It may be erroneous to assume that everyone desires cancer information (Leydon et al., 2000) and even the best educational programs may not be able to engage these patients.

A second limitation may be our measure for information needs. Because the content of our outcome measure had to match the content included in the sessions, an appropriate assessment tool did not exist in the literature. Thus, we created one for the specific purposes of the project. Furthermore, the wording of the questions may have been somewhat difficult (e.g., rating one's level of need for information). Nonetheless, the fact that our measure was significantly correlated with education, income, and self-efficacy in the expected direction inspires some confidence in our assessment tool.

Our study also has several strengths. First, we evaluated a national cancer program among low-income, primarily African American cancer survivors. Traditionally, ICC attendees do not reflect this demographic, and our engagement of this population is of great significance. In addition, previous evaluations of ICC were primarily internal to the organization (e.g., ICC facilitators provided feedback about the program). The evaluations that were completed by attendees were more limited in scope and a published evaluation included responses from only a small number of racial=ethnic minorities (Diekmann, 1988). Our study may become even more relevant with recent shifts in the United States that include a decline in median household income and an increase in the poverty rate. (DeNavas-Walt, Proctor, & Smith, 2011) Second, we delivered ICC sessions that resonated with the population. The narrative comments from study participants and their rating of the sessions suggested that the intervention was meaningful to participants. In fact, participants expressed an interest for a longer intervention. We believe having cancer survivors from the county hospital choose the topics of most interest for both intervention arms was thus an important formative step (Martin et al., 2011). In addition, it highlighted the potential need for such programs in county hospitals. Third, we facilitated participation by providing transportation and off-setting in part the costs incurred by transportation for those who provided their transportation to the study. This was an important barrier to overcome. Approximately 50% of study participants used our transportation service. A fourth strength of our study was its design. This is the first evaluation of ICC using a randomized controlled design and including a 6-month follow-up. A fifth strength of our study is that we were able to engage African American cancer patients in an intervention in which they were willing and in fact did discuss their own personal experiences with cancer openly in a group setting. This support was important given the lack of support that is often reported by African American cancer survivors (Hamilton, Moore, Powe, Agarwal, & Martin, 2010; Mosavel & Sanders, 2011). Our study also provides important information for effect size. In planning the study, there was no information upon which to estimate effect. In a post hoc power analysis, in light of the changes in information needs observed postintervention, investigators would need over 400 cancer survivors to find a significant difference between groups. As this sample size may be difficult to attain with fluctuating patient flow at a single county hospital, researchers should consider multi-site studies that engage several public hospitals. An important and final strength of our study was our ability to design and deliver a comparison intervention that was well-received by study participants. The quantitative ratings and the narrative responses speak to the importance of addressing the multidimensional aspect of cancer including the usefulness of teaching techniques that can help with stress management and coping. Moreover, the positive assessment of our comparison intervention highlights the potential of less traditional approaches to interventions for cancer survivors. In our study, the comparison condition was novel both in content (e.g., humor and music were stand alone sessions) and in approach (we partnered with community organizations and a county hospital, and their staff served as the interventionists). Building on the assets and skill set already in place in the community to collectively offer a program for cancer survivors is important for leveraging resources and producing interventions that may be sustainable beyond initial grant funding. Future research should continue to explore how interventions such as our wellness intervention, further impacts patient-centered outcomes over the course of coping with cancer.

In this study, we found that although many had been coping with cancer for some time, cancer survivors presented with a moderate level of information needs at baseline. The consistent finding that those with less education and income had greater information needs suggests that our educational interventions should continue to prioritize cancer survivors drawn from this population. Our findings also suggest that delivering quality cancer care involves ensuring that cancer survivors have the skills and confidence needed to obtain desired information. Because information needs vary greatly across patients and the need for information is dynamic, the approach used in this study may better meet the needs of cancer survivors compared to programs delivered with a standard, predetermined educational content that cannot be tailored to individual patient needs, and/or may not be delivered at a time when cancer survivors have need for or the capacity to process the information (e.g., during times of distress, during active treatment). There are many opportunities to further understand how best to support cancer patients and their information needs. Other types of benefits from the group environment and the structure of ICC have not been rigorously measured (e.g., question-and-answer sessions with an expert and information sharing with others in the group). From the comments provided to us from participants and our own observations during intervention delivery, these appeared to be components that were important to patients. We challenge future researchers to consider varied ways to deliver information to survivors. Typically, research interventions evaluate one delivery method (e.g., group sessions, Internet, print). While these studies have advantages, a one-size-fits-all approach with regard to delivery method may not be ideal. Future studies should explore individual patient preferences with regard to how they would like to receive the information and, potentially, evaluate whether the preferred educational approach provides advantages and improves outcomes to a greater degree than delivery channels not tailored to patient preferences. Similarly, the preferred delivery channel may also depend on the type of information that is being imparted. For example, learning about cancer treatment may be a topic best served by an in-person conversation while other cancer related topics, could be easily and effectively delivered through print interventions.

In conclusion, minority low income cancer survivors appreciated the ICC sessions offered in one arm of the trial. While their information needs did not change compared to participants in the control group, the ICC program is important in this population, and represents an important tool among those available to improve the survivorship experience of this population. Several lessons learned from our trial can be applied to improve the program and assure its maximum benefits for disadvantaged cancer survivors. Despite the complexity of tailoring the information to the patient at the appropriate time and the difficult task of delivery, information is necessary for the survivor to manage physical aspects of the disease, participate in medical decisions to be made, and cope with the mental and emotional toll of the disease and uncertainty of outcomes (Beckjord et al., 2008; Sheehan, Sherman, Lam, & Boyages, 2007). For lower income and minority survivors who continue to have worse cancer outcomes than the higher income majority population (Adler & Rehkopf, 2008; Institute of Medicine, 1999; Kagawa-Singer, Dadia, Yu, & Surbone, 2010), the need for information remains critically important.

Acknowledgments

This research was supported by Cooperative Agreement U48=DP000567-1 from the Centers for Disease Control and Prevention and the American Cancer Society awarded to Michelle Y. Martin. The findings and conclusions in this

report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

References

- Adler NE, Rehkopf DH. U.S. disparities in health: Descriptions, causes, and mechanisms. *Annual Review of Public Health*. 2008; 29:235–252. doi:10.1146=annurev.publhealth.29.020907.090852.
- American Cancer Society. 2011. Retrieved from <http://www.cancer.org>
- Beckjord EB, Arora NK, McLaughlin W, Oakley-Girvan I, Hamilton AS, Hesse BW. Health-related information needs in a large and diverse sample of adult cancer survivors: Implications for cancer care. *Journal of Cancer Survivorship*. 2008; 2:179–189. doi:10.1007=s11764-008-0055-0. [PubMed: 18792791]
- Bennett JA, Cameron LD, Whitehead LC, Porter D. Differences between older and younger cancer survivors in seeking cancer information and using complementary=alternative medicine. *Journal of General Internal Medicine*. 2009; 24:1089–1094. doi:10.1007=s11606-009-0979-8. [PubMed: 19685099]
- Centers for Disease Control and Prevention. Cancer survivors—United States, 2007. *MMWR*. 2011; 60:269–272. [PubMed: 21389929]
- DeNavas-Walt C, Proctor BD, Smith JC. Income, poverty, and health insurance coverage in the United States: 2010. 2011 Retrieved from <http://www.census.gov/prod/2011pubs/p60-239.pdf>.
- Diekmann JM. An evaluation of selected “I Can Cope” programs by registered participants. *Cancer Nursing*. 1988; 11:274–282. [PubMed: 3233577]
- Dignan M, Evans M, Kratt P, Pollack LA, Pisu M, Smith JL, Martin MY. Recruitment of low income, predominantly minority cancer survivors to a randomized trial of the “I Can Cope” cancer education program. *Journal of Health Care for the Poor and Underserved*. 2011; 22:912–924. [PubMed: 21841287]
- Green CR, Hart-Johnson T, Loeffler DR. Cancer-related chronic pain: Examining quality of life in diverse cancer survivors. *Cancer*. 2011; 117:1994–2003. doi: 10.1002=cnr.25761. [PubMed: 21509777]
- Hamilton JB, Moore CE, Powe BD, Agarwal M, Martin P. Perceptions of support among older African American cancer survivors. *Oncology Nursing Forum*. 2010; 37:484–493. doi:42H7715264735727 [pii] 10.1188=10.ONF.484-493. [PubMed: 20591808]
- Hesse BW, Arora NK, Burke Beckjord E, Finney Rutten LJ. Information support for cancer survivors. *Cancer*. 2008; 112(11 Suppl):2529–2540. doi:10.1002=cnr.23445. [PubMed: 18428201]
- Institute of Medicine. *The unequal burden of cancer*. National Academy Press; Washington, DC: 1999.
- Kagawa-Singer M, Dadia AV, Yu MC, Surbone A. Cancer, culture, and health disparities: Time to chart a new course? *CA: A Cancer Journal for Clinicians*. 2010; 60:12–39. doi:60=1=12 [pii]10.3322=caac.20051. [PubMed: 20097836]
- Lance Armstrong Foundation and Center for Disease Control and Prevention. *A national action plan for cancer survivorship: Advancing public health strategies*. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; Atlanta, GA: 2004.
- Leydon GM, Boulton M, Moynihan C, Jones A, Mossman J, Boudioni M, McPherson K. Cancer patients’ information needs and information-seeking behaviour: In-depth interview study. *BMJ*. 2000; 320:909–913. [PubMed: 10742000]
- Martin M, Pollack L, Evans M, Lee-Smith J, Kratt P, Proyor-Patterson C, Pisu M. Tailoring cancer education and support programs for low income, primarily African American cancer survivors. *Oncology Nursing Forum*. 2011; 38:E55–E59. [PubMed: 21186152]
- Matsuyama RK, Wilson-Genderson M, Kuhn L, Moghanaki D, Vachhani H, Paasche-Orlow M. Education level, not health literacy, associated with information needs for patients with cancer. *Patient Education and Counseling*. 2011; 85:e229–236. doi:S0738-3991(11)00188-1 [pii] 10.1016=j.pec.2011.03.022. [PubMed: 21543182]
- Mayer DK, Terrin NC, Kreps GL, Menon U, McCance K, Parsons SK, Mooney KH. Cancer survivors information-seeking behaviors: A comparison of survivors who do and do not seek information about cancer. *Patient Education and Counseling*. 2007; 65:342–350. doi:S0738-3991(06)00295-3 [pii] 10.1016=j.pec.2006.08.015. [PubMed: 17029864]

- McInnes D, Cleary P, Stein K, Ding L, Mehta C, Ayanian J. Perceptions of cancer-related information among cancer survivors: A report from the American Cancer Society's studies of cancer survivors. *Cancer*. 2008; 113:1471–1479. [PubMed: 18666212]
- McMillan SC, Tittle MB, Hill D. A systematic evaluation of the “I Can Cope” program using a national sample. *Oncology Nursing Forum*. 1993; 20:455–461. [PubMed: 8497415]
- Miller SM. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. *Cancer*. 1995; 76:167–177. [PubMed: 8625088]
- Mosavel M, Sanders K. Needs of low-income African American cancer survivors: Multifaceted and practical. *Journal of Cancer Education*. 2011; 26:717–723. doi: 10.1007/s13187-011-0253-8. [PubMed: 21706193]
- Pisu M, Richardson LC, Kim YI, Krontiras H, Martin MY, Salas M, Pollack LA. Less-than-standard treatment in rectal cancer patients: Which patients are at risk? *Journal of the National Medical Association*. 2010; 102:190–198. [PubMed: 20355348]
- Pollack LA, Greer GE, Rowland JH, Miller A, Doneski D, Coughlin SS, Ulman D. Cancer survivorship: A new challenge in comprehensive cancer control. *Cancer Causes Control*. 2005; 16(1 Suppl):51–59. [PubMed: 16208574]
- Protiere C, Moumjid N, Bouhnik AD, Le Corroller Soriano AG, Moatti JP. Heterogeneity of cancer patient information-seeking behaviors. *Medical Decision Making*. 2012; 32:362–375. doi: 10.1177/0272989X11415114. [PubMed: 21865607]
- Sheehan J, Sherman KA, Lam T, Boyages J. Association of information satisfaction, psychological distress and monitoring coping style with post-decision regret following breast reconstruction. *Psycho-oncology*. 2007; 16:342–351. doi:10.1002=pon.1067. [PubMed: 16874745]
- van der Molen B. Relating information needs to the cancer experience: 1. Information as a key coping strategy. *European Journal of Cancer Care*. 1999; 8:238–244. [PubMed: 10889622]

Table 1

Sociodemographic and clinical characteristics of study sample (N=140)

Characteristic	<i>n</i>	%
Gender		
Female	92	65.7
Race=ethnicity		
Black	111	79.3
Marital status		
Not married or partnered	104	74.3
Education		
Less than high school	33	23.6
High school or GED	50	35.7
Some college or vocational	36	25.7
College graduate, professional or graduate school	21	15.0
Employment		
Employed	16	11.4
Retired or unemployed	62	44.3
On disability	62	44.3
Type of cancer (N=137)		
Breast	52	38.0
Colon=colorectal	17	12.4
Hematologic (blood)	18	13.1
Lung	10	7.3
Head and neck	13	9.5
Other	30	21.9
Income (n=109)		
<\$700	54	49.5
\$700	55	50.5
Type of treatment		
Surgery (n=139)	88	63.3
Chemotherapy	105	75.0
Radiation therapy	57	40.7
Hormone therapy (n=55) ^d	17	30.9
In treatment at baseline		
Total in treatment at baseline (n=85) ^b	78	91.8
Chemotherapy (n=104) ^c	59	56.7
Radiation therapy (n=57) ^d	15	26.3
Hormone therapy (n=55) ^e	13	23.6
	<i>M</i>	<i>SD</i>
Age (years)	53.0	10.5
Time since diagnosis (years)	2.1	3.1

^a Hormone therapy applies only to patients who were diagnosed with breast cancer or prostate cancer.

^b Total in treatment at baseline indicates patients who received at least one of the following treatments: chemotherapy, radiation therapy, or hormone therapy.

^c Chemotherapy applies only to those who responded that they had received chemotherapy for their cancer.

^d Radiation therapy applies only to those who responded that they had received radiation treatments for their cancer.

^e Hormone therapy applies only to those who had been prescribed a hormone treatment.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Table 2
Participant mean information needs at baseline, postintervention, and 6-month postintervention

	Overall sample						I Can Cope						Wellness intervention					
	Baseline (n=140)		Postintervention (n=126)		6-month postintervention (n=94)		Baseline (n=73)		Postintervention (n=66)		6-month postintervention (n=52)		Baseline (n=67)		Postintervention (n=60)		6-month postintervention (n=42)	
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
Learning about cancer	2.22	0.84	2.10	0.92	2.01	1.03	2.17	0.82	2.13	0.91	1.86	1.05	2.26	0.86	2.06	0.93	2.20	0.98
Understanding cancer treatments	2.38	0.81	2.23	0.94	2.12	1.05	2.41	0.79	2.20	1.00	1.99	1.09	2.35	0.83	2.27	0.88	2.29	0.97
Keeping well in mind and body	2.57	0.69	2.43	0.81	2.33	0.90	2.59	0.71	2.41	0.81	2.22	0.95	2.55	0.68	2.45	0.82	2.48	0.82
Relieving cancer pain	2.25	0.93	2.18	1.03	2.10	1.11	2.32	0.90	2.19	1.02	1.96	1.15	2.18	0.97	2.17	1.05	2.27	1.03
Total needs	2.37	0.73	2.24	0.84	2.15	0.93	2.38	0.71	2.24	0.86	2.01	0.96	2.37	0.76	2.25	0.83	2.31	0.87

Note. Scale scores ranged from 0 (no need for information) to 3 (high informational needs).

Table 3
Analysis of participant information needs at baseline, postintervention, and 6-month postintervention

Outcome	Covariates										
	Group	Time ^a	Group × Time	Age	Time since diagnosis	Gender	Race	Education	Income	Information-seeking ^b	Self-efficacy
Learning about cancer	.70	.05	.40	.42	.99	.60	.37	.03	.20	.27	<.01
Learning about cancer treatments	.82	.04	.81	.03	.85	.35	.40	.05	.03	.27	<.01
Keeping well in mind and body	.68	.07	.46	.19	.85	.31	.07	.07	.02	.33	.02
Relieving cancer pain	.74	.15	.26	.10	.95	.14	.12	.04	.01	.08	.03
Overall needs score	.74	.04	.46	.14	.83	.35	.22	.02	.03	.26	<.01

Note. Values in bold represent significant covariates. Data represent *p* values.

^aTime of assessment (baseline, postintervention, 6-month postintervention).

^bInformation-seeking behavior (i.e., looking for information about cancer from sources other than doctor, nurse, or other health provider).

Table 4
Analysis of participant information needs at baseline, postintervention, and 6-month postintervention

Outcome	Covariates								Self-efficacy		
	Group	Time ^a	Group × Time	Age	Time since diagnosis	Gender	Race	Education		Income	Information-seeking ^b
Learning about cancer	.49	.10	.62	.52	.92	.66	.34	.04	.23	.17	<.01
Learning about cancer treatments	.49	.05	.91	.05	.90	.39	.33	.07	.03	.15	<.01
Keeping well in mind and body	.29	.06	.75	.25	.90	.39	.05	.09	.02	.15	.02
Managing pain	.57	.17	.88	.14	.99	.16	.10	.05	.02	.04	.04
Overall needs score	.42	.06	.81	.20	.90	.40	.19	.03	.04	.13	<.01

Note. Values in bold represent significant covariates. Data represent *p* values.

^aTime of assessment (baseline, postintervention, 6-month postintervention).

^bInformation-seeking behavior (i.e., looking for information about cancer from sources other than doctor, nurse, or other health provider).

Table 5

Evaluation of I Can Cope and wellness sessions

Session	Session rating ^a	Worth their time ^b	Useful ^c	Taught something did not know ^d	Selected narrative comments ^e
<i>ICC sessions</i>					
Learning about cancer	3.7	9.1	9.2	9.2	<ul style="list-style-type: none"> Gives me a lot of positive and good feelings about me having cancer.
Understanding cancer treatments					<ul style="list-style-type: none"> It was very good information they gave me that can benefit me in the future.
Speaker 1	3.6	8.8	9.1	8.8	<ul style="list-style-type: none"> It helped me to learn more about my tumor.
Speaker 2	3.8	9.7	9.4	9.1	<ul style="list-style-type: none"> I am glad that I came in, I learned a good bit.
Relieving cancer pain	3.8	9.6	9.6	9.1	<ul style="list-style-type: none"> Overcome to continue living.
Keeping well in mind and body					<ul style="list-style-type: none"> Topic was presented and represented excellently.
Speaker 1	3.8	9.6	9.5	9.1	<ul style="list-style-type: none"> Make longer.
Speaker 2	3.8	9.6	9.6	9.1	<ul style="list-style-type: none"> I think this session was wonderful and very informational.
<i>Wellness sessions</i>					
Humor therapy	3.6	9.1	9.5	NA	<ul style="list-style-type: none"> I enjoyed the session, looking forward to the next.
Meditation	3.7	9.5	9.4	NA	<ul style="list-style-type: none"> It would help so much if the patient had access to this help as soon as they are give the news.
Relaxation	3.9	9.7	9.8	NA	<ul style="list-style-type: none"> Talk about things I don't already know or let participants share their stories. I learn from other people's experience.
Music therapy	4.0	9.7	9.7	NA	<ul style="list-style-type: none"> This would really be a good session for people just learning they have cancer. Very good session. The program was excellent. I was surprised to hear the antidepressants can be used for pain. Great lesson and I enjoyed the speaker. Thoroughly learned something enjoyable. It was great, very helpful. I enjoyed this session very much. I wish I could come during my treatment. A good positive lesson. Best speaker in series/received information I can use. It was excellent motivation to strive to improve. It helps me to understand the other kinds of cancer and how I may be able to help others. I wish these classes were given before my treatment started. Please try to do this for others. A real fun class.

Session	Session rating ^a	Worth their time ^b	Useful ^c	Taught something did not know ^d	Selected narrative comments ^e
					<ul style="list-style-type: none"> • I really enjoyed this and looking forward being at the next one. • Humor has taken my mind off my cancer treatments. I was feeling depressed and now I feel better. Thank you for this session. • This session was excellent. • First time in my life I'm at a loss for comments. Enjoyed the jokes. Next session start with explanation for group; then explain the important role of humor in coping with life. • We need more humor in each session. • Very informative; Thank you. • I enjoyed the class today on meditation. It really helped me to relax. Now my thoughts are much clearer than before. I don't just focus on cancer but getting free from cancer. • Things were brought up that I use to do and didn't anymore and I was made to remember. • I think today's session will benefit multiple aspects of my life. • The demos were helpful. A few more exercises would be great. • I really needed the calming music, it was great. The deep breathing helps a lot. • I am glad that I am a part of this session, because my mind was filled with appointments, things going on in my life that I need to break free from stress. Thank you! • The session informed me that I can still exercise and gain strength to my spine and body which is cancer diseased. • This information and some of the techniques are some I have been using and didn't know what I was doing (smile). Thank you very much. • I know stretching and relaxation is good for me. Thank you for helping me. • A great session, I felt relaxed at the end of the session. • Best session yet, should come first in order; has several techniques that I may be able to use. • This session was very much needed. I felt relaxed and had energy when I left today. • I need more suggestions that can help me about and how it can be useful about cancer. • This was the best of all. I'm going to miss the meetings. I have learned a lot and it was very inspiring to me. God Bless!

Session	Session rating ^a	Worth their time ^b	Useful ^c	Taught something did not know ^d	Selected narrative comments ^e
					<ul style="list-style-type: none"> • I enjoyed just being here and the speaker was very good. It is a blessing to have this program. • I truly enjoyed this class. You should have it more often. • More people should get involved because the sessions relieved a lot of stress. • I don't even sing in the shower but this was fun. It is very good to talk with people who have or had the same problems. • This was a great session. The sun is bright and problems don't seem so hard. The music was great. • I enjoyed the music and games. Thank you. • I really enjoyed the session today. It was very uplifting.

^a“Today’s session was...” reported on a 4-point scale ranging from 4 (*excellent*) to 1 (*poor*).

^b“The session was worth my time,” reported on a 10-point scale ranging from 1 (*disagree*) to 10 (*agree*).

^c“This session presented information or techniques that can be useful to me as a cancer survivor,” reported on a 10-point scale ranging from 1 (*disagree*) to 10 (*agree*).

^d“The session taught me something I did not know” reported on a 10-point scale ranging from 1 (*disagree*) to 10 (*agree*). This was asked of the ICC participants only.

^eResponses were transcribed verbatim here.