

Developing an Educational Intervention to Address Financial Hardship in Cancer Patients

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Abstract

Objective: To develop an educational intervention to empower patients to manage their financial health better.

Participants and Methods: This study was conducted from September 1, 2017, to January 31, 2019. Focus groups were held with social workers, case managers, and patient financial service staff and interviews were conducted with patients and caregivers to inform the content, delivery format, and timing of an intervention for mitigating financial hardship from treatment (phase 1). Based on qualitative data, theories of adult learning, and a review of the literature, we created an educational presentation to be delivered in a classroom setting. Two patient focus groups were then held for feedback on the presentation (phase 2).

Results: In phase 1, both patients and allied health care staff providers believed that an educational intervention about financial aspects of care early during treatment would help them cope and plan better. Participants' suggestions for the intervention's content included billing information, insurance, authorization processes, employment policies related to health care and disability benefits, and alternative financial resources. Based on these suggestions, a preliminary educational presentation was developed with 3 main themes: insurance issues, employment issues, and financial health. Phase 2 focus group participants suggested refinement of the presentation, including targeting specific groups, adding graphics, and more information about resources.

Conclusion: Our study provides the basis for a patient-centered education module for emotional, instrumental, and informational support for financial distress for use in a clinical setting.

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inancial hardship from cancer treatment is a growing challenge for patients, their families, and health care providers. The prevalence of financial hardship ranges from 12% to 80%. Research has identified 3 domains of financial hardship: material hardship from increased out-of-pocket expenses and lower income; psychological distress, often called financial distress; and maladaptive behavioral responses, such as treatment non-adherence due to cost concerns. Psychoeducational interventions provide systematic, structured, and didactic ways to transfer knowledge and provide emotional support or

a problem-solving approach to help patients cope better and improve treatment adherence and efficacy. ¹³ Psychoeducational interventions for financial hardship may include teaching patients how to manage care-related financial issues and/or improve their financial literacy in order to enhance communication about costs of care. A few interventions have been developed, but wide adoption in routine care has yet to be studied. ¹⁴⁻¹⁶ Shankaran et al¹⁶ developed and piloted a financial literacy course and oncology financial navigation program with 2 organizations specializing in financial education. They found challenges in

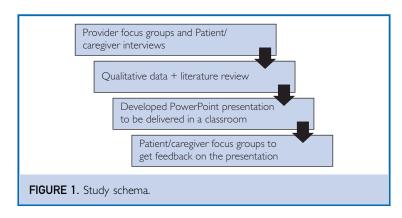
patient participation because of timing in the course of treatment, accessibility of material, and competing burdens, suggesting that interventions will need to attend to patient experiences and context of care to be scalable.

We hypothesized that inclusion of relevant stakeholders such as patients, caregivers, social workers, case managers, and financial counselors in developing and refining an intervention on financial hardship would improve its acceptability, increase its reach, and help integration into routine clinical practice. In this article, we describe the process of developing content and evaluating acceptability of an intervention to decrease financial hardship in patients with cancer and their caregivers. Guiding principles to develop this intervention included the use of adult-centered strategies for engaging the learner based on 7 principles of andragogy, including establishing an effective learning climate, encouraging learners to identify and use resources to achieve their objectives, and having them evaluate their own learning. 17 The goal of this intervention was to provide patients with cancer and their caregivers the knowledge and skills to manage the financial aspects of their care.

PARTICIPANTS AND METHODS

In this study, which was conducted from September 1, 2017, to January 31, 2019, we used a 2-phase approach to develop the intervention and collect feedback regarding the content and feasibility issues (Figure 1). In phase 1, using a qualitative inductive approach, we conducted focus groups (FGs) with nonphysician providers who help patients manage financial problems and telephone interviews with patients and caregivers. Based on findings from these qualitative data, theories of adult learning, and a review of literature, we created a PowerPoint (Microsoft) presentation to be delivered in a 60-minute session in the clinic in a group setting. In phase 2, we shared the presentation with patients and caregivers in 2 FGs to refine the material, its relevance, and usefulness. The study was approved by the Mayo Clinic Institutional Review Board.

Phase 1: Intervention Development Recruitment and Data Collection for the FGs With Nonphysician Providers. Two provider FGs were conducted in September and



October 2017 at 2 separate sites of an academic cancer center. An FG guide was developed by the study investigators based on clinical experience and relevant literature (Supplemental Table 1, available online at http://www.mcpiqojournal.org). The main aim of the FGs was to understand allied health care staff provider perspectives about how patients can be better prepared for the financial issues they may experience and discuss potential content, timing, and delivery format for a psychoeducational intervention to help address financial hardship.

Email invitations were sent to 32 allied health care staff providers, including all the social workers, case managers, and financial counselors at the 2 sites. Fourteen participated in FGs. All participants gave informed consent and completed a questionnaire about their clinical role, years of experience, age, sex, race, and ethnicity. Each FG lasted 60 minutes, was conducted by a moderator with extensive qualitative research experience, was audiorecorded, and then was transcribed by a transcriptionist with qualitative research experience. Participant names and identifying information were anonymized.

Recruitment and Data Collection for Patient and Caregivers Interviews. We conducted in-depth phone interviews with patients and caregivers to understand perspectives on their cost-related needs. Between September and November 2017, hematology/oncology physicians were provided a brief description of the study and asked to refer patients and caregivers who may be interested in participating. Twenty referred patients/caregivers were

approached by the research coordinator at the time of their visit and asked to participate. Five patients and 5 caregivers (nondyads) who were able to speak and read English agreed and consented to participate. Reasons for declining participation were not collected. Participants were given a \$25 gift card following the interviews for their time and effort. Each interview lasted approximately 30 minutes and was conducted by the same researcher who conducted the FGs.

The interview guide included questions about financial information patients wished they had known earlier in their treatment, comfort and acceptability of sharing financial hardship information with providers, and perceptions on the usefulness, timing, and delivery mode of a proposed educational intervention for financial distress (Supplemental Table 1, available online at http://www.mcpiqojournal.org).

Development of Psychoeducational Intervention. A 39-slide PowerPoint presentation, entitled "Helping You Manage Costs of Cancer Care," was developed based on qualitative data and review of other information sources.

Phase 2: Feedback and Refinement From FGs of Patients and Caregivers

In January 2019, 40 consecutive patients/caregivers coming to an appointment at the cancer center clinic were approached to assess interest in participating in an FG. Twenty-four patients and/or caregivers consented to participate in 2 FGs, and 13 actually participated. Participants were provided a \$20 incentive following participation.

Statistical Analyses

Data collection and analyses were guided by standard qualitative inductive approaches. ¹⁸ In our coding process, the analysis team used a general inductive approach for coding. Some analytic principles of grounded theory methodology, such as open, axial, and selective coding approaches, were used. ¹⁹ We used NVivo software (QSR International) for data management and analysis. As a first step in the coding process, 2 researchers (N.K., A.K.) did the initial open reading of the transcripts to understand the tone and dynamics of the data. In the second step, based on our

initial review of the data and research objectives, we created a few broad categories in the form of a codebook. In the third step, we coded all transcripts using the codebook and reduced the data into relevant and meaningful segments. In the fourth step, we critically examined these segments of data, eliminated redundancy of categories, and analyzed how different categories were related. In the final step, we reorganized these categories in a meaningful way to answer our research objective. The level of agreement between the 2 coders was generally good, and disagreements over assigning and labeling of codes were discussed and resolved in regular team meetings.

RESULTS

Participant Characteristics

For phase 1, two FGs (FG 1, 8 participants; FG 2, 6 participants) included 6 social workers, 2 case managers, 2 specialty pharmacists, and 4 patient financial service representatives. The baseline characteristics of the FG participants and 10 patients and caregivers in phase 1 are summarized in Table 1.

For phase 2, FGs included 8 patients and 5 caregivers. Median age of the 13 participants was 63 years (range, 37-78 years), with 5 (38.5%) males and 11 (84.6%) non-Hispanic whites (Table 1).

Phase I: Intervention Development

Themes From Provider FGs. Nonphysician care professionals provided insights into their understanding of financial hardship, existing counseling practices, and access to information about resources to help patients and families with financial concerns. The 2 following overarching themes emerged from the FG discussions.

Causes and Awareness of Financial Hardship and Resources for Help. Providers discussed the challenge of managing escalating costs of care with mounting demands on patients to share costs. Treatment-related expenses not covered by insurance, prescription copayments, and nonmedical aspects of care were important sources of financial hardship. One FG 1 participant noted, "Yesterday I collected \$145,000 from a patient for a

TABLE 1. Baseline Characteristics for Providers and Patients/Caregivers in Study Phases 1 and 2		
Variable	Value ^a	
Phase I		
Allied health care staff providers		
(n=14)		
Role		
Patient financial service	4 (28.6)	
representative		
Case manager	2 (14.3)	
Social worker	6 (42.9)	
Pharmacist	2 (14.3)	
Type of patients seen		
Outpatient	7 (50.0)	
Inpatient	4 (28.6)	
Both	3 (21.4)	
Diagnosis of patients seen		
Hematologic malignancies/	3 (21.4)	
hematopoietic cell		
transplantation	4 (20 ()	
Solid tumor	4 (28.6)	
All	7 (50.0)	
Duration in current role (y)	1 (7.1)	
<	1 (7.1)	
1-5	10 (71.4)	
>5	3 (21.4)	
Race/ethnicity	10 (71 4)	
Non-Hispanic white	10 (71.4)	
Hispanic white	2 (14.3)	
African American	2 (14.3)	
Patients/caregivers for interviews (n=10)		
Median age, y (range)	56 (28-74)	
Male	4 (40.0)	
Ethnicity	. (13.0)	
Non-Hispanic white	7 (70.0)	
Hispanic white	3 (30.0)	
Diagnosis	3 (30.0)	
Hematologic malignancies/	7 (70.0)	
hematopoietic cell	, (, 0.0)	
transplantation		
Solid tumor	3 (30.0)	
Time since diagnosis (y), median (range)	2 (1-8)	
Monthly household income ^b		
\$1000-\$2999	l (II.I)	
\$3000-\$4999	5 (55.6)	
\$5000-\$6999	l (II.I)	
≥\$7000	2 (22.2)	
Continued or	n next column	

Variable	Value ^a
Phase I, continued	
Educational level ^b	
Bachelor or higher	5 (55.6)
Less than bachelor	4 (44.4)
Current employment status ^b	
Working full- or part-time	5 (55.6)
Unemployed	0 (0)
Retired/student/homemaker	3 (33.3)
On disability	1 (11.1)
Marital status ^b	
Married	6 (66.7)
Not married/widowed	3 (33.3)
Caregiver (n=5) relationship	
Spouse	4 (80.0)
Parent	I (20.0)
Phase 2	
Patients/caregivers for focus	
groups (n=I3)	
Median age, y (range)	63 (37-78)
Male	5 (38.5)
Ethnicity	
Non-Hispanic white	11 (84.6)
Hispanic white	2 (15.4)
Diagnosis	
Hematologic malignancies/ hematopoietic cell transplantation	7 (53.8)
Solid tumor	6 (46.2)
Time since diagnosis (y), median (range)	1.6 (0.3-8)
^a Data are presented as No. (percentage) of pa indicated otherwise. Percentages may not to of rounding. ^b Missing for one caregiver.	

treatment because the insurance doesn't wanna pay for it because it's off label."

Providers commented on the complexity of insurance coverage and the challenge to patients and families to navigate through the rules, exceptions, and requirements. They remarked that most patients lacked knowledge about their insurance plan and were unaware and unprepared for the costs associated with treatment. Plans to address treatment costs are usually made after a patient receives the bill, which can increase the worry. One FG 2

participant noted, "Um, they're kind of that "deer in the headlights" worried about just their day-to-day things and how to navigate the whole process." An FG 1 participant remarked, "I think a lot of times patients tell me, 'I had no idea.' So then you're kinda doing damage control it feels like, like patching it up, um, rather than being proactive and that is emotionally distressing to every patient."

Barriers for Delivering Financial Services in the Clinic. Participants discussed existing programs such as preauthorization and charity care through benefactor or donor funding that financial services have to assist with costs. However, they noted suboptimal staffing for delivering services and identifying resources and competing demands for their time for things other than education on the topic as barriers in delivering these services. An FG 1 participant stated, "I have over 30 providers. I do pre-cert [precertification]. I have zero time to do education about benefits."

Themes From Patient and Caregiver Interviews. Interviews with patients and caregivers provided insights into their understanding of the contributions to financial hardship, the consequences of financial hardship, and their understanding of insurance coverage. The following 2 themes emerged from the discussions.

Causes of Financial Hardship. Patients discussed factors that contribute to financial hardship, including direct treatment costs and indirect costs, such as transportation, food, and housing. Interviewee 3 stated, "It's the cost of your fuel driving over there. It's the cost of wear and tear on your vehicles. It's the cost of having to buy food out all the time."

Participants shared that the navigation of insurance and employment issues, the impact of high premiums and deductibles, and job loss were main sources of distress. Interviewee 4 remarked, "I've gone and looked online for insurance, health insurance and it's so complicated. There's so many different options and I don't know which one to get...how much we have to pay out of pocket." Interviewee 5 asked, "What am I going to do about insurance when my insurance runs out? I gotta go

on COBRA [the Consolidated Omnibus Budget Reconciliation Act] and what if they don't carry—what if this center is not in their network?"

Impact of Financial Hardship. Participants reflected on how the costs of care impact their emotional and physical health as well as their family's financial well-being. Interestingly, perceived stigma of admitting financial difficulty or fear of being "profiled," distracting providers by bringing up financial concerns and perceived consequences of admitting hardship (eg, fear of treatment being withheld, receiving inferior treatment) as have been described elsewhere, 20,21 were not reported by our study participants. Participants did, however, discuss the ever-present concern about finances, the anxiety it causes, and the tradeoffs they need to manage their finances. Interviewee 8: "Everything that is in your mind is how am I going to pay for this. How am I going to pay my-my house payment? How am I going to put food on the table? How am I going to pay my car payment?" Interviewee 1: "Money is always on my mind. I'm always thinking about what else, what do I need to pay next and then sometimes I have to prioritize what I can pay cause I have limited money that is available to me."

Participants also shared thoughts about the financially devastating consequences related to their care and the longer-term consequences on their families' financial and emotional well-being. Interviewee 5: "Is bankruptcy the easiest way to go? Probably." Interviewee 6: "The cancer diagnosis put a big stop in my ability to generate financial support. As a result of that, it creates a stream of stressful situations....when you're head of household; it has to do with other people being impacted by your inability. And so as much as you don't want to be stressed, you can't help but experience some of it."

Provider and Patient Perspectives About Educational Intervention. Table 2 summarizes the themes from FGs and interviews to inform an educational intervention for financial hardship. Participants expressed concerns about the usefulness of a single, uniform, generic intervention because of the heterogeneity of sociodemographic characteristics,

Variable	Patients	Caregivers	Providers
The content of educational intervention	"I think a main point in the presentation has to be what's the best type of insurance you should be going forwould have been good to be more prepared is to know it was if I knew how like insurance in general worked." (Interviewee I) "I think that people need to have good quality information that they can then digest and see how it applies to their situation." (Interviewee 6)	can we get financial help? That's a big subject. I	me 'I had no idea.' So we also do see as we just mentioned here, the overhead cost, the out of the box things. I mean I
The mode of the intervention	"I don't like group therapy. I would rather sit there one-on-one and talk to my therapist instead of be in a room with a bunch of people." (Interviewee 5) "I always preferred a one-on-one consultation personallyeven like a PowerPoint or like a video would be fine." (Interviewee 1)	"Some type of presentation or even a seminar or something would really be helpful. Not only for myself but a lot of people that are in this same predicament that I am." (Interviewee 4)	"Well, and a lot of our patients are auditory. Well, I'm an auditory learner so I have to, like, hear what someone is telling me so that's where that faceto-face comes in." (Focus Group 2 participant) "I think to start something like an education class. We're big on classes in the Cancer Center as I find that patients have a big desire to learn." (Focus Group I participant)
Who should implement the intervention	"I guess in my ideal world I would just be able to have those financial conversations with the oncologist." (Interviewee 2) "A social worker and a financial planner would be an excellent combination that I would look at in addressing this." (Interviewee 6)	"Probably the financial people." (Interviewee 7)	"Our financial counselorsthey meet with the patients, explain the benefits, and explain what is going to happen. They explain what is going to be covered, what is not covered, and what their out-of-pocket is." (Focus Group participant)
The timing of the intervention	"All the education you can give somebody up front is going to be extremely helpful." (Interviewee 8)	"In the beginning, because it's already stressful when you find out. It's very stressful but if you're there in the beginning, then you have a little more awareness because if I was the instructor it was, like, I know what you're going through and this is—I know it's stressful. Here's a door that can open for you to help you get through this." (Interviewee 3)	

financial reserves, and coping styles of patients but also described the need for good-quality information at the outset to help manage financial aspects of care. Both patients and providers expressed a need for a financial checklist and a list of resources. They also agreed that a presentation in a classroom was a good delivery mode.

For the content of a potential intervention, participants requested information on billing, insurance terminology, preauthorization processes, employment policies, and availability of alternative financial resources, especially with inadequate coverage. Both providers and patients felt that providing up-front information about financial issues early in treatment would help patients and caregivers cope and plan better for costs during the care continuum. Providers articulated that such guidance on costs needed to be repeated and to be customized to each patient. Some patients and caregivers felt that sharing about financial implications of cancer treatment should be no different from discussions about treating medical complications (eg, improving nutrition) and that it should be done as soon as they were settled into their treatment routine. Although patients and caregivers wanted their treating physician to be aware of the cost aspect of their treatment, there were conflicting views about whether the physician should present financial information because of their lack of expertise in this area.

Development of the Educational Intervention. We integrated our qualitative findings with recommendations from financial assistance resources/guides from the American Cancer Society, American Society of Clinical Oncology, and National Comprehensive Cancer Network to develop the educational intervention. The PowerPoint presentation began with an introduction, "Financial Toxicity of Cancer Treatment," followed by information divided into 3 sections: insurance issues, employment issues, and financial health. The section on insurance issues included health insurance terminology and tips for making the best of health insurance, including how to handle denied claims and organizational tips. Employment issues comprised information about COBRA, FMLA (Family and Medical Leave Act) tips, and Social Security/disability benefits. A section on financial health included the kind of costs that patients will encounter, advice for financial planning, and options for financial assistance. The presentation encouraged participants to ask for help early and not to change/delay treatment because of cost burden without discussing it with their health care team. A checklist to help deal with financial matters was provided at the end of the presentation (Figure 2).

Phase 2: Feedback on the Educational Intervention From Patient FGs

Participants in the phase 2 FGs reviewed the format, style, and content of the presentation. The groups agreed on the need for an intervention but felt that the intervention needed to be shortened, simplified, and tailored to specific groups of patients in order to have optimal impact. An FG 1 participant stated, "I think it's an excellent idea, but if you segment it, and you try different ways to do that—the new patient idea vs an experienced patient...you could look at who's working, who's retired, who's unemployed, and those mixes might give you an idea."

In addition to suggestions on content reorganization, participants wanted to make the intervention more personalized, stylized, interactive, and possibly animated. One FG 2 participant remarked,

I'm kind of a picture person, and so I was sitting here thinking about information mapping from my old jobs, and you put the person here in the middle....Below that is your support team. So you have your family members, you have your health care support people, your team, all of that stuff on the bottom, and you begin to relate this information about those information paths that you need so that this person in the middle begins to understand that they have to deal with this first, then this, then this, and they set the stage.

Patients had different reactions to the tips on how to organize finances and bills. Some suggested that keeping organized records and tracking bills was related to personality and that the information provided would not be beneficial to those for whom this is not a strength. One FG 2 participant noted,

With the financial organization part, I kind of turned off because it's easy to say, 'Make sure that you get it all organized and everything'...but it's impossible for some people, and I'm one of those people. So I just don't—I just pay what I get in. The first year or so, I kept a loose-leaf book, and I kept everything, and I tried to match every payment to everything, and it just got crazy, and it—you really need help to do that.

Another stated, "All those things about keeping track of things, some people are cut out for that, and some people aren't. I was what I call a—a bean counter, a financial manager...for 36 years. I love to keep track of all that stuff, and I can."

Participants had conflicting ideas on the optimal timing. Similar to the views of initial interviewees, most FG participants suggested that after treatment has started and patients have settled into a routine, "You're emotionally charged at the time and it's, like, I don't care about the financial part. I have insurance. I don't care. And then after I settle down, then maybe a couple weeks later, that's when I would like to hear about this stuff" (FG 2 participant).

When asked about who should deliver the presentation, most participants felt that physicians should recommend the intervention but a social worker and staff from patient account services should deliver the information in a sensitive manner. An FG 1 participant remarked, "You want somebody who's warm and caring, and so I don't really care if they're—where they're from as long as—as they're really sensitive to—to the fact that you're on the verge of tears all the time."

DISCUSSION

Our study provides insight into better understanding the financial hardship from cancer treatment that can impact psychosocial outcomes and create uncertainty during recovery. 11,22-26 Although most challenges arise from high direct and indirect costs, the process of navigating and dealing with insurance and billing issues is also a source of distress for some patients.

Our results indicate that having a discussion about care costs in a more structured

Checklist

- Know insurance terminology
- Know your benefits
- Avoid letting insurance lapse
- Stay organized with paperwork
- Be aware of appeals process
- Don't ignore bills
- Ask for information for resources
- Be aware of your employer policies and disability benefits
- Notify early if you plan to use COBRA
- Talk to your HR representative
- Track your overall spending
- Consider hiring a financial planner
- Know members of your health care team who will help with these matters
- Discuss financial concerns with your health care team

FIGURE 2. Checklist at the end of the presentation. COBRA = Consolidated Omnibus Budget Reconciliation Act; HR = human resources.

fashion or having better educational tools to understand costs of care may help lower distress associated with cost burden, similar to what other investigators have reported, ^{27,28} although the scope suggested by our data is much wider than just out-of-pocket costs. Our findings validated the rationale for iteratively developing an intervention to reduce financial hardship. The process included understanding informational, instrumental, and emotional needs of stakeholders and their views on content, preferred mode, and barriers to implementation and then using these data and evidence from the literature to inform the development of a PowerPoint presentation endorsed fully by patients and providers. Feedback from the targeted audience is being used to refine the presentation and make it more interactive and animated and to break it into independent segments for easier delivery. A next step in this line of inquiry is to test the efficacy of the intervention on reducing financial hardship.

A financial literacy course to help provide basic information about employment, disability, insurance, and existing assistance resources to empower the patients has been reported to be feasible in a study of patients with breast and colon cancer. ¹⁴ When combined with a financial navigation program by external nonprofit financial advocacy organizations, the course led to modest improvement in anxiety about costs. ¹⁶ Because the development of our intervention is grounded

in the actual experiences of its stakeholders, it may better mitigate the impact of financial hardship on patients and families. Our study is unique in that we gathered perspectives of social workers, case managers, and patient financial representatives, those often responsible for explaining or counseling patients about finances and who are well aware of the financial difficulties endured by patients. Having buy-in from the institutional personnel who help address this problem is crucial to the success of such an intervention.²⁹

Our study does have a few limitations. The participants came from the same health care system, impacting the generalizability of our findings. However, this impact may be minimal because the topics covered by our intervention are well-known financial stressors, and use of adult-centered strategies for engaging the learner to develop this presentation would make it more generalizable. In phase 2, 24 participants agreed to take part in the study, but only 13 actually participated. We recruited a large sample, knowing that during cancer treatment, patients who consent at one time are often not able to fully participate when the group finally convenes. In qualitative research, sampling is intended to cast a wide net to capture diversity in experiences, not to reflect the population of cancer patients, and the participants in phase 2 shared a wide swath of perspectives in refining the intervention. Most participants were non-Hispanic whites, which constrained our ability to capture the perspective of racial/ethnic minorities who are often more vulnerable to adverse financial consequences and, therefore, would have even a higher degree of benefit from such an intervention. Additionally, we do not have any data about the effectiveness of the intervention and how it would compare to currently available strategies. However, we plan to assess and report the impact of the refined intervention on different domains of financial burden in near future. Finally, the convenience sampling for both patients and providers may have resulted in selection of a specific subset from both groups and, hence, may not capture the extent of diversity of perceptions.

CONCLUSION

Notwithstanding the limitations, our study captures multistakeholder perspectives regarding

development of patient education materials based on key themes from the qualitative work with methodological and data triangulation. We hope that once refined further, our intervention can be used in routine clinical practice to provide the knowledge and skills to patients and caregivers to ensure that medical treatment does not come at the cost of catastrophic financial outcomes. Future research should compare interventions for their effectiveness in producing higher patient satisfaction, lower financial distress, and increased treatment adherence within the constraints of available resources for implementation for patients with cancer from diverse races/ethnicities.

SUPPLEMENTAL ONLINE MATERIAL

Supplemental material can be found online at http://www.mcpiqojournal.org. Supplemental material attached to journal articles has not been edited, and the authors take responsibility for the accuracy of all data.

Abbreviations and Acronyms: FG = focus group

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