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Development of a Question Prompt List as a Communication Intervention to Reduce Racial Disparities in Cancer Treatment

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Abstract

Racial disparities have been found in the use of chemotherapy as cancer treatment. These disparities may be, in part, due to well-documented differences in the quality of communication during clinical interactions with oncologists and Black versus White patients. In this study using a Community-Based Participatory Research (CBPR) approach, academic researchers, community members, and oncologists formed a partnership to develop a communication intervention to address racial disparities in cancer care. Partners developed a Question Prompt List (QPL), a simple tool that can be used to improve communication, and thus treatment, during clinical interactions in which oncologists and Black patients discuss chemotherapy. Partners endorsed the use of a QPL, provided specific suggestions for content and format, conducted and analyzed qualitative interviews with Black patients receiving chemotherapy, and approved the final version. The feasibility and effectiveness of the QPL that resulted from this research process are currently under evaluation in a separate study.

Introduction

The purpose of this study was to develop an intervention designed to improve the quality of communication during interactions in which Black patients and their oncologists discuss adjuvant or neo-adjuvant chemotherapy as a treatment for breast, colorectal, or lung cancer. We focused on this type of interaction because racial disparities have been found in the receipt, dosing, regimen, and time to start chemotherapy [1–6]. For example, Griggs and colleagues have found that even after controlling for factors such as stage of cancer, body size, and SES, Black women are more likely to receive reduced initial doses of chemotherapy and/or nonstandard regimens [1, 5]. One factor that clearly contributes to these racial disparities in cancer treatment is differences in the quality of communication during interactions in which treatment is discussed. Studies have shown, for example, that, relative to patient-physician clinical interactions with White patients, interactions with Black patients are shorter; characterized by less positive patient affect, more physician contentiousness, fewer patient questions and less physician information-giving; and followed by less patient trust in physicians and understanding of the diagnosis and treatment after the interaction [7–15]. Clinical communication has been shown to affect patient

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outcomes, including treatment decisions, adherence to treatment recommendations, perceptions of care, and psychosocial and physical health [16–20]. Thus, interventions specifically designed to improve the quality of cancer clinical communication during interactions with Black patients and their oncologists may reduce health disparities in cancer care.

The communication intervention we developed is called a question prompt list (QPL). A QPL is a list of questions related to the physical and psychosocial aspects of illness and treatment that patients may want to ask their physicians during a medical visit. QPLs have been used to encourage patients to participate actively during medical visits (i.e., ask questions and state their concerns) [21–23], based on research showing that physicians are more patient-centered, informative, and supportive when they interact with actively participating patients [11, 24, 25]. In the context of cancer, QPLs have been developed and tested in surgical, medical, radiation, palliative care, and clinical trial settings [26–28]. For example, Clayton and colleagues developed and tested a QPL to improve the active participation of cancer patients and their caregivers at the end of a patient's life. Findings from this randomized controlled trial showed that patients and caregivers who received the QPL asked significantly more questions of their physicians than did those in the control group. Further, seven of the nine QPL topics, including prognosis, were discussed significantly more often in the experimental group than in the control group. These findings suggest that QPLs can be effective in stimulating discussion and improving communication during complex, high-stakes conversations, such as those involving end-of-life cancer care. [29] Other studies using QPLs have been shown to increase the number of patient questions overall, but possibly of greater importance, they have been shown to increase the number of patient questions about topics directly relevant to the context, such as tests, diagnosis, and prognosis [22, 29–31].

Although QPLs have been shown to improve communication in cancer and other medical contexts, most have been developed and tested in majority populations in Europe, Australia, or the US. QPLs may also need to be developed for minority populations because interactions with minorities differ from those with majority populations in some significant ways, as discussed above. Black patients in the U.S. are highly likely to receive cancer care from an oncologist who is not Black, and racially discordant interactions are characterized by poorer quality communication and cancer treatment.[32] Thus, in this study, we developed a QPL to be used in a minority population of cancer patients facing a discussion with their oncologist about chemotherapy treatment. Once developed, this instrument can be tested for the extent to which it improves clinical communication and thus treatment in this population.

Question prompt lists have generally been developed by academic researchers who collect information about the clinical context and elicit the perspectives of patients and physicians similar to those who may be affected by the research. Given that the QPL for this project was specifically intended for use in a minority population, we opted for a community-based participatory research (CBPR). This approach seemed most appropriate because social and behavioral interventions to address health disparities are ideally developed in collaboration with, rather than based on information obtained from, members of the community who will potentially benefit from them [33]. Community-based participatory research (CBPR) is characterized by an equitable partnership between community members, representatives from community-based organizations, and academic researchers [34]. Partners are involved in every stage of the development of the research, including identification of the research questions, development of interventions and other research materials, and interpretation and dissemination of the findings [35]. Engaging community members in every stage of the research maximizes the potential that the research reflects the needs of a community and

therefore increases participation and enthusiasm for research, and is thus particularly important in addressing health care disparities related to a special population [33].

A particular strength of CPBR approaches to addressing health care disparities, at least potentially, is their ability to combine scientific rigor with community wisdom. One of the greatest challenges of this approach is to achieve the best possible balance between the academic and community perspectives, roles, and responsibilities. These perspectives and roles are often in competition, as members of the academic community turn to theory and scientific literature to identify and address problems, while community members are more likely to turn to their experience [36]. Despite these challenges, a growing number of organizations are committed to using CBPR principles to create academic-community partnerships to address health disparities [37]. Outcomes, including research quality, community capacity, and health status, are more likely to be improved when community members are involved in the full spectrum of action, from the definition of the problem to the intervention to the evaluation.[37] In the current study, academic researchers, medical oncologists, community members, and representatives of community organizations worked together, despite their different perspectives, to develop a QPL as an intervention to reduce racial/ethnic disparities in cancer care by improving communication during interactions in which Black patients and their oncologists discuss chemotherapy as cancer treatment.

In this article, we describe the development of the QPL in two parts. First, we describe the CBPR process through which the QPL was developed. Second, we describe a qualitative research project conducted as part of the QPL development.

Method

Setting

The research is part of a National Cancer Institute-funded Community Network Program Center known as Southeast Michigan Partners Against Cancer (SEMPAC). The overall goal of SEMPAC is to reduce cancer health disparities among older African-Americans with cancer in Southeast Michigan through research, outreach, and training. SEMPAC represents a partnership between the two of the major hospitals that provide cancer care in Detroit and Southeast Michigan. The research was conducted at these two hospitals and was approved by the Institutional Review Boards of Wayne State University, Karmanos Cancer Institute, and Henry Ford Hospital.

Overview

There were two distinct phases to the development of the QPL, with extensive partner involvement in each phase. In the first phase, partners met to discuss the research question (i.e., whether and how a communication intervention may reduce racial disparities in cancer care), the research process (i.e., development of the communication intervention), and to develop an initial draft of the QPL. In the second phase, partners conducted a qualitative research project to gain the perspectives of Black patients who were currently undergoing or had recently completed chemotherapy for breast, colorectal, or lung cancers at one of the participating hospitals.

Partners were academic researchers, including psychologists and communication scientists with expertise in health behavior, and members of two distinct groups who may be affected by or benefit from the research. The first of these groups was called a community

Research Advisory Committee (RAC), comprised of six individuals who were residents of the surrounding community (i.e, Southeast Michigan) and/or representatives of community health organizations. Among these individuals, five were Black, five were women, three

were cancer survivors who had received treatment at one of the two participating hospitals, and five had collaborated on SEMPAC projects in the past. The second group was comprised of seven practicing medical oncologists who regularly see patients at one of the two participating hospitals and who have collaborated with SEMPAC in the past.

Phase I (Initial Development of the QPL)—Partners met in small groups to discuss the research questions and procedures. There was general agreement on the nature of the problem and the potential of a Question Prompt List to improve communication, and thus reduce racial disparities, in this setting. Next, the researchers assembled potential content and formats for the QPL by searching the Internet and websites of professional organizations such as the American Cancer Society and the National Cancer Institute. Partners discussed potential QPL content and format in small groups and individual meetings between January and September 2011. Partner comments and suggestions were captured in field notes to be used to inform the initial draft of the QPL. (A summary of these meetings follows.) Finally, partners discussed plans for Phase 2, in which researchers would conduct interviews with Black chemotherapy patients to elicit their experiences and perspectives on asking questions and gathering information from oncologists during clinical interactions in which chemotherapy was discussed.

During meetings to discuss QPL content and format, RAC members proposed specific language for the instructions; questions that may facilitate patient comprehension and appropriate language; font size; and design for patients who may have difficulty reading due to low literacy levels, vision problems, or physical limitations related to the cancer or treatments. They also suggested ways to enhance the usability of the QPL such as paper size and quality, order of questions and sections, white space for notes, and graphics. Regarding question content, RAC members expressed reluctance to remove any questions from the initial pool of questions and suggested adding many specific questions. For example, RAC members suggested adding questions about side effects that may be of particular importance to Black (and other) patients, such as changes to skin, hair, and nails. They also suggested questions about dietary changes or supplements they perceived as frequently used in this population that may prevent or manage side effects or interfere with chemotherapy.

Oncologists suggested content that is routinely discussed during patient visits in which chemotherapy is initially discussed and thus should be considered as relevant to the QPL. Suggested content included: diagnosis and disease process; goals of prior and additional treatments (before or after surgery); specific treatment recommendations (including plans, risks, side effects, costs, expected benefits, roadmaps, and long-term goals); implications of not pursuing additional treatment; clinical trial availability; prognosis and risk of relapse; differences between physician roles (e.g., medical oncologist v. surgeon); factors that may affect or change treatment; and genetic implications for family members

Although oncologists endorsed the idea of using a QPL to encourage patients to ask questions, they also expressed some concerns. First, some oncologists felt that a QPL may increase visit time and provide little benefit, given their belief that oncologists routinely cover important topics thoroughly and clearly. To address this concern, some oncologists suggested limiting the number of questions on the QPL and explicitly instructing patients to select and ask only the questions that specifically concerned them rather than asking all the questions on the QPL. A second concern expressed by some oncologists was that some questions could be troublesome or difficult to answer, but that patients would be particularly likely to ask them if they were on the QPL. Questions that were mentioned as potentially troublesome were related to whether the oncologist would make the same treatment recommendation to his or her own family member, the costs of treatment, alternative

treatments or treatments patients found on the Internet, sexuality during and after treatment, and explanations for not having discovered the cancer earlier.

Finally, researchers developed a QPL draft that was acceptable to partners using the following procedures. Questions were included in the draft if all partners had endorsed them, such as questions about rationale for treatment and logistics related to receiving treatment. Questions were eliminated if more than one partner strongly objected to their inclusion, such as those described above as troublesome. Included questions were grouped into sections and redundancies eliminated. This draft was used in the second phase of the research, a qualitative research project to further inform the development of the QPL.

Phase 2 (Qualitative Research Project)—In this phase, a qualitative research project was conducted following standard qualitative procedures for conducting and analyzing semi-structured interviews. The purpose of the interviews was to elicit the perspectives of Black patients in this context and to gain their feedback on the current draft of the QPL. The researchers, RAC members, and some of the oncologists developed the interview guide and research procedures (described below). The researchers conducted and analyzed the interviews; the RAC and some of the oncologists were regularly informed of emerging themes and participated in revisions to the QPL based on these themes.

Recruitment and Interview Procedures for the Qualitative Research Project

Research participants were Black patients who had recently completed or nearly completed chemotherapy. They participated in interviews during which they were asked to discuss their experiences and perspectives about asking questions and seeking information from oncologists during clinical interactions. Patients were referred by clinic staff at one of the two participating hospitals if they met the following criteria: self-identification as Black or African-American, currently receiving or recently completed chemotherapy for one of the three cancers of interest at one of the participating hospitals, and over the age of 40. Researchers contacted interested patients by telephone or in the clinic, explained the study to them, and scheduled a meeting at the clinic in which they received an IRB-approved information sheet and participated in one one-hour interview. No personal identifying information was collected. Patients were invited to bring a friend or family member if they were so inclined. Researchers planned an initial goal of 15 patient interviews, after which they would evaluate whether data saturation had been reached (i.e., no new themes or concepts were evident) [38]. Three of the researchers conducted the semi-structured interviews. The interview guide included three open-ended questions and an opportunity for feedback on the initial draft of the QPL. Patients were asked to discuss: (1) questions they remembered asking their medical oncologist during their first visit to discuss chemotherapy; (2) additional questions they thought they should have asked, now that they had more experience with chemotherapy; and (3) questions other patients should consider asking their medical oncologist during these visits. Interviews with patients were audio recorded and professionally transcribed verbatim for later analysis.

Data Analysis Procedures for the Qualitative Research Project

Analysis of the interviews was ongoing during data collection and interviews were conducted until data saturation was reached. Patient interviews were transcribed and imported into NVIVO 9 software for thematic analysis. Researchers who had conducted the interviews used an iterative process to identify key themes emerging from the interviews. This process involved independently reading the transcripts to identify initial themes, discussing and refining the themes and creating operational definitions of the themes, returning to the transcripts for line-by-line coding of themes, and discussing final coding

decisions [39, 40]. As mentioned above, members of the RAC and oncologists were regularly informed of themes as they emerged and participated in revisions to the QPL.[41]

Results of the Qualitative Research Project

Nineteen patients were interviewed. Patients in seven of these interviews brought at least one companion; companions (n=9) included a spouse, adult child, sibling, parent, or cousin. Patients had: breast cancer (n=11), colon or rectal cancer (n=5), or lung cancer (n=3). All patients were Black; 15 (79%) were female. Patients were not asked to provide any other demographic or medical information that might identify them because the research question and qualitative design did not require this information. Of the nineteen patients, 6 were currently undergoing chemotherapy and 12 had completed chemotherapy within the past three months prior to participating in the study. The remaining patient was referred to the study by clinic staff and agreed to participate, but revealed during the interview that he had chosen not to receive the recommended chemotherapy. His interview was included in the study because he provided his perspective on the interaction in which chemotherapy was discussed.

Two key themes emerged from the analysis: *topics* patients felt were relevant and should be asked in this context and *barriers* to asking these questions. These themes are described briefly below; patient quotations to illustrate the themes are provided in Tables 1 and 2. Patient feedback on the QPL in general is also briefly described below.

Topics (Table 1)—The first key theme that emerged from the analysis of the interviews was topics patients remembered asking their oncologist about during this clinic visit, topics they wished they had asked about, and/or topics they suggested future patients ask about. The topics were: (1) description of the diagnosis and stage, including genetic and other potential causes; (2) recommended treatment, including names of medications, how they work, how they would be delivered, and alternatives; (3) potential side effects, including managing them, preventing them, and effects on lifestyle in the short and long term; (4) goal of treatment and prognosis; (5) support services, such as financial advice, yoga/massage, or assistance with coping; and (6) treatment schedule.

Barriers to asking questions (Table 2)—The second key theme that emerged from the analysis of the interviews was barriers to asking questions in this setting. These included: 1) feeling overwhelmed by the circumstances and the setting; 2) trusting that the medical team would provide all needed information, either verbally or through written materials; 3) preferring to avoid knowing some information; 4) feeling that some information was irrelevant; 5) feeling they already had information based on their personal or professional experience or from the Internet; 6) not knowing what questions to ask; and 7) feeling intimidated by the medical team.

General impressions of the QPL—Finally, some patients provided their general impressions of the QPL draft during the interviews. Overwhelmingly, patients endorsed the QPL as a communication tool. For example, a patient commented: “I had a million thoughts. At different times I had the opposite thought of what I was thinking. This [QPL] kind of puts me in focus, takes all the fragments and puts it together, centers it in.” Another said, “I don’t care how much you’ve done made up your mind on what you’re going to ask. If you don’t write down the list the day or so before, every time you think of something, by the time you get to the doctor you done forgot it.” Another said, “If I had had this material to read over at home, then I could have asked more questions because I would have been more aware and maybe I wouldn’t have been in denial so much.” One patient, however, did not feel the QPL would be useful for the following reason: “I’m with asking questions, but some stuff is just,

you gotta go through it, you know what I mean? You can say, 'well how am I gonna feel,' but you will know when you go through, and you kind of got to handle it day-to-day is how I look at it."

Results

A final version of the QPL resulted from Phases 1 and 2 and was acceptable to all partners. (See Table 3 for the complete final version.). The final QPL included 43 questions in seven general sections and additional space for questions and notes. Final sections and the wording of section titles, discussed with all partners, were: 1) Where do I stand with my cancer?; 2) What treatment is right for me? 3) What is chemotherapy?, 4) How will I feel during treatment?, 5) What about my daily life during treatment?, 6) What is my treatment plan and schedule?, and 7) Where can I get help with costs and coping?.

Discussion

As far as we are aware, this is the first study to use a community-based participatory research (CBPR) approach to develop a QPL to improve clinical communication, and thus care, in a minority population of patients who bear the disproportionate burden of cancer health disparities. QPLs have been developed to improve clinical communication and patient outcomes in several medical settings [22, 31]. In general, QPLs are developed by academic researchers based on information gained from physicians and/or patients who may benefit from the research using formative research, such as focus groups. In this study, academic researchers formed a partnership with representatives from two distinct groups that may benefit from the research: residents of the surrounding community (i.e., Southeast Michigan) and medical oncologists from the two hospitals that provide the greatest amount of cancer care in this community. Additionally, as part of the research process, partners conducted qualitative interviews to gain the perspective of patients who may ultimately benefit from this research.

In this study, partners had worked together in the past on research and community outreach and thus had an established relationship. These types of academic-community relationships often take years to develop, so it was a distinct advantage that trust and respect existed prior to the start of the research.[36] Possibly because of the established relationship, we were able to identify and overcome conflicts between partners representing these communities, such as concerns about the length of the QPL. However, we also found complementary perspectives; for example, community members provided information about content and formats that had the potential to be especially valuable to Black patients in this setting, while oncologists were able to provide information on the medical content that may be important for patients to elicit during these high-stakes interactions.

In qualitative interviews, chemotherapy patients generally endorsed the use of a QPL as a communication tool, provided topics they thought to be relevant in this context, and also provided insights into barriers to asking questions in this setting. Patients indicated that this type of communication tool may have "organized and prompted their thinking." Thus, although this tool has not yet been tested for feasibility or effectiveness, findings from this study suggest that the CBPR process was effective in building a communication tool that will be feasible and acceptable to stakeholders in this clinical setting.

Question prompt lists have been shown to increase the number of questions patients ask during clinical interactions but have only infrequently been tested in a clinical setting for feasibility and effectiveness, especially on longer-term outcomes [21, 31]. Our partnership is currently testing the QPL using a randomized controlled trial design to determine the extent

to which it improves communication and, as a result, treatment outcomes for Black patients seeking cancer care in this setting. This type of research not only has the potential to be acceptable to community members, but also may reduce racial health disparities by improving the quality of care for black cancer patients and their families.

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References

1. Griggs JJ, Sorbero ME, Stark AT, Heininger SE, Dick AW. Racial disparity in the dose and dose intensity of breast cancer adjuvant chemotherapy. *Breast Cancer Research and Treatment*. 2003; 81(1):21–31. [PubMed: 14531494]
2. Shavers VL, Brown ML. Racial and ethnic disparities in the receipt of cancer treatment. *Journal of the National Cancer Institute*. 2002; 94(5):334–357. [PubMed: 11880473]
3. Morris AM, Billingsley KG, Hayanga AJ, Matthews B, Baldwin LM, Birkmeyer JD. Residual treatment disparities after oncology referral for rectal cancer. *Journal of the National Cancer Institute*. 2008; 100(10):738–744. [PubMed: 18477800]
4. Berger M, Lund MJ, Brawley OW. Racial disparities in lung cancer. *Curr Probl Cancer*. 2007; 31(3):202–210. [PubMed: 17543948]
5. Griggs JJ, Culakova E, Sorbero ME, Poniewierski MS, Wolff DA, Crawford J, Dale DC, Lyman GH. Social and racial differences in selection of breast cancer adjuvant chemotherapy regimens. *J Clinical Oncol*. 2007; 25(18):2522–2527. [PubMed: 17577029]
6. Lin CC, Virgo KS. Association between the availability of medical oncologists and initiation of chemotherapy for patients with Stage III colon cancer. *Journal of Oncology Practice*. 2012:1–7. [PubMed: 22548002]
7. Jean-Pierre P, Fiscella K, Griggs J, Joseph JV, Morrow G, Carroll J, Hendren S, et al. Race/ethnicity-based concerns over understanding cancer diagnosis and treatment plan. *Journal of the National Medical Association*. 2010; 102(3):184–189. [PubMed: 20355347]
8. Eggy S, Harper FW, Penner LA, Gleason MJ, Foster T, Albrecht TL. Variation in question asking during cancer clinical interactions: A potential source of disparities in access to information. *Patient Educ Couns*. 2011; 82(1):63–68. [PubMed: 20430566]
9. Cooper LA, Roter DL, Johnson RL, Ford DE, Steinwachs DM, Powe NR. Patient-centered communication, ratings of care, and concordance of patient and physician race. *Ann Intern Med*. 2003; 139(11):907–915. [PubMed: 14644893]
10. Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient-physician communication during medical visits. *American journal of public health*. 2004; 94(12):2084–2090. [PubMed: 15569958]
11. Gordon HS, Street RL Jr, Sharf BF, Soucek J. Racial differences in doctors' information-giving and patients' participation. *Cancer*. 2006; 107(6):1313–1320. [PubMed: 16909424]
12. Siminoff LA, Graham GC, Gordon NH. Cancer communication patterns and the influence of patient characteristics: disparities in information-giving and affective behaviors. *Patient Educ Couns*. 2006; 62(3):355–360. [PubMed: 16860520]
13. Song, L.; Hamilton, JB.; Moore, AD. Health psychology: official journal of the Division of Health Psychology. American Psychological Association; 2011. Patient-healthcare provider communication: Perspectives of African American cancer patients.
14. Eggy, S.; Barton, E.; Winckles, A.; Penner, LA.; Albrecht, TL. Disparity of words: racial disparities in offers of clinical trials. under review

15. Gordon HS, Street RL Jr, Sharf BF, Kelly PA, Soucek J. Racial differences in trust and lung cancer patients' perceptions of physician communication. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*. 2006; 24(6):904–909. [PubMed: 16484700]
16. Epstein, RM., Jr; Street, RL. NIH Publication No 07–6225. Bethesda, MD: National Cancer Institute; 2007. Patient-centered communication in cancer care: Promoting healing and reducing suffering.
17. Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, Jordan J. The impact of patient-centered care on outcomes. *J Fam Pract*. 2000; 49(9):796–804. [PubMed: 11032203]
18. Albrecht TL, Eggy SS, Gleason ME, Harper FW, Foster TS, Peterson AM, Orom H, Penner LA, Ruckdeschel JC. Influence of clinical communication on patients' decision making on participation in clinical trials. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*. 2008; 26(16):2666–2673. [PubMed: 18509178]
19. Kaplan SH, Greenfield S, Ware JE Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Medical care*. 1989; 27(3 Suppl):S110–127. [PubMed: 2646486]
20. Beach MC, Keruly J, Moore RD. Is the quality of the patient-provider relationship associated with better adherence and health outcomes for patients with HIV? *Journal of General Internal Medicine*. 2006; 21(6):661–665. [PubMed: 16808754]
21. Dimoska A, Butow PN, Lynch J, Hovey E, Agar M, Beale P, Tattersall MH. Implementing patient question-prompt lists into routine cancer care. *Patient Education and Counseling*. 2012; 86(2): 252–258. [PubMed: 21741195]
22. Dimoska A, Tattersall MH, Butow PN, Shepherd H, Kinnersley P. Can a “prompt list” empower cancer patients to ask relevant questions? *Cancer*. 2008; 113(2):225–237. [PubMed: 18484592]
23. Brown RF, Butow PN, Dunn SM, Tattersall MH. Promoting patient participation and shortening cancer consultations: A randomised trial. *Br J Cancer*. 2001; 85(9):1273–1279. [PubMed: 11720460]
24. Cegala DJ, Street RL Jr, Clinch CR. The impact of patient participation on physicians' information provision during a primary care medical interview. *Health Commun*. 2007; 21(2):177–185. [PubMed: 17523863]
25. Cegala DJ, Chisolm DJ, Nwomeh BC. Further examination of the impact of patient participation on physicians' communication style. *Patient Education and Counseling*. 2012
26. Langbecker D, Janda M, Yates P. Development and piloting of a brain tumour-specific question prompt list. *European journal of cancer care*. 2012; 21(4):517–526. [PubMed: 22309311]
27. Brown RF, Bylund CL, Li Y, Edgeron S, Butow P. Testing the utility of a cancer clinical trial specific Question Prompt List (QPL-CT) during oncology consultations. *Patient Education and Counseling*. 2012
28. Clayton J, Butow P, Tattersall M, Chye R, Noel M, Davis JM, Glare P. Asking questions can help: development and preliminary evaluation of a question prompt list for palliative care patients. *Br J Cancer*. 2003; 89(11):2069–2077. [PubMed: 14647140]
29. Clayton JM, Butow PN, Tattersall MH, Devine RJ, Simpson JM, Aggarwal G, Clark KJ, et al. Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*. 2007; 25(6):715–723. [PubMed: 17308275]
30. Butow P, Devine R, Boyer M, Pendlebury S, Jackson M, Tattersall MH. Cancer consultation preparation package: changing patients but not physicians is not enough. *Journal of clinical oncology: official journal of the American Society of Clinical Oncology*. 2004; 22(21):4401–4409. [PubMed: 15514382]
31. Henselmans I, de Haes HC, Smets EM. Enhancing patient participation in oncology consultations: a best evidence synthesis of patient-targeted interventions. *Psycho-oncology*. 2012
32. Penner LA, Eggy S, Griggs JJ, Orom H, Underwood W, Albrecht TL. Life-Threatening Disparities: The Treatment of Black and White Cancer Patients. *J Soc Issues*. 2012; 68:328–257.
33. De las Nueces D, Hacker K, DiGirolamo A, Hicks LS. A systematic review of community-based participatory research to enhance clinical trials in racial and ethnic minority groups. *Health services research*. 2012; 47(3 Pt 2):1363–1386. [PubMed: 22353031]

34. Israel BA, Krieger J, Vlahov D, Ciske S, Foley M, Fortin P, Guzman JR, et al. Challenges and facilitating factors in sustaining community-based participatory research partnerships: lessons learned from the Detroit, New York City and Seattle Urban Research Centers. *Journal of urban health: bulletin of the New York Academy of Medicine*. 2006; 83(6):1022–1040. [PubMed: 17139552]
35. Israel, BA.; Eng, E.; Schulz, AJ.; Parker, EA. Introduction to methods in community-based participatory research for health. In: Israel, BA.; Eng, E.; Schultz, AJ.; Parker, EA., editors. *Methods in Community-Based Participatory Research for Health*. San Francisco: Jossey-Bass; 2005. p. 3-26.
36. Gehlert S, Coleman R. Using community-based participatory research to ameliorate cancer disparities. *Health & social work*. 2010; 35(4):302–309. [PubMed: 21171537]
37. Meade CD, Menard JM, Luque JS, Martinez-Tyson D, Gwede CK. Creating community-academic partnerships for cancer disparities research and health promotion. *Health promotion practice*. 2011; 12(3):456–462. [PubMed: 19822724]
38. Francis JJ, Johnston M, Robertson C, Glidewell L, Entwistle V, Eccles MP, Grimshaw JM. What is an adequate sample size? Operationalising data saturation for theory-based interview studies. *Psychology & health*. 2010; 25(10):1229–1245. [PubMed: 20204937]
39. Corbin, J.; Strauss, A. *Basics of qualitative research: techniques and procedures for developing grounded theory*. London: Sage Publications Ltd; 2008. 3rd Aufl
40. Charmaz, Kathy. *Constructing grounded theory*. London; Thousand Oaks, Calif: Sage Publications; 2006.
41. Ryan, GW.; Bernard, HR. Data management and analysis methods. In: Denzin, NK.; Lincoln, YS., editors. *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage; 2000. p. 769-802.

Table 1

Topics and patient quotations

Topic	Quote
1: Diagnosis/Stage	<ul style="list-style-type: none"> • “I asked him because I didn’t know what type of cancer I had because the fact is, I found it myself.” • “I asked was the mammograms the possible cause of the cancer or does it increase the size of the tumor”
2: Treatment	<ul style="list-style-type: none"> • “[She asked] why she couldn’t get radiation instead of chemotherapy.” • “I don’t think I had a clear understanding of what chemo is, I know it attacks the healthy cells as well as the bad cells, and I just don’t think I understood exactly what it does to the body.” • “[I asked] about why the treatment was so aggressive, I guess I was reading everything on the Internet.”
3: Side effects	<ul style="list-style-type: none"> • “I just wanted to know how quick I would lose my hair because I had, like, Oprah hair, real thick.” • “I was concerned about what my energy level would be and they don’t tell you. You could read the side effects, but they don’t tell you exactly how bad this is gonna be.” • “I wish I would have asked about steroids, but I didn’t know anything about that. I’m new to the game, I wasn’t aware. • “Long term, what’s going to go on if I survive five years from now, are there any effects of this?”
4: Goal of Treatment & Prognosis	<ul style="list-style-type: none"> • “I did ask her what the point of chemotherapy was since they—we had the lumpectomy so it was all removed.” • “I wanted to know was this gonna be a cure; I guess it’s maybe a dumb question. I wanted to know was this a 50–50 chance or a 90% chance that this treatment was going to knock out all the cancerous lymph nodes that they found, that’s what I wanted to know. But I didn’t ask that because I was afraid to ask that.” • “I did ask what would happen if I decide not to take the treatments.”
5: Support Services	<ul style="list-style-type: none"> • “[People should as] if there are any programs that the hospital has that could help with bills and stuff because they do, they got a bunch....”
6: Treatment schedule	<ul style="list-style-type: none"> • “[I should have asked] about scheduling because when you’re new to the process, there are apparently things that happen that...longstanding people know and the newcomers don’t know, like the flow of your appointment day.” • “Ask your doctor all the information that you think you’ll need to know, where would you go to take the treatments, how big of a dose, how long of a dose, I was here for like two hours.” • “I did ask her can I take breaks for holidays or vacations because I was going to see my daughter when I was taking chemotherapy, but I had to wait until I finished, so I did.”

Table 2

Potential Barriers to Question Asking

Barrier	Quote
1. Feeling overwhelmed	<ul style="list-style-type: none"> • “I just felt numb, my mind was just gone, I just didn’t ask the questions I should have, but afterwards...you keep thinking of things you should have said.” • “If you never had cancer, you know, you just be kind of lost.”
2. Trusting the medical team	<ul style="list-style-type: none"> • “I’m not educated in that, so I wouldn’t ask about that.” • “I figured they had more to say than me. Back in the day when I was on my job, if somebody came to my job, I’m the one with the information.” • “I didn’t have to ask many questions because here they are very, very thorough.”
3. Avoiding information	<ul style="list-style-type: none"> • “I was downplaying it. I didn’t want to get all worked up about it.” • “That is gonna cause worry, and that worry, then, can affect not only your treatment but it can affect your health in general.” • “One question I don’t want to know is how long do I have. I don’t want to know. I think if a person wants to know, they should ask. I don’t think the doctor should tell them.”
4. Feeling some information is irrelevant	<ul style="list-style-type: none"> • “I didn’t ask about how chemo would affect other conditions because I don’t have any other conditions.” • “I didn’t ask about transportation because my husband drives me.”
5. Feeling they already knew enough	<ul style="list-style-type: none"> • “I didn’t ask about how to prevent side effects because there is no way to prevent them.” • “My mom had gone through it, two of my aunts have gone through it.”
6. Not knowing what questions to ask	<ul style="list-style-type: none"> • “I didn’t think about getting chemo at another site. I didn’t know I had a choice.” • “I guess at that time I didn’t think of it.”
7. Feeling Intimidated by the medical team	<ul style="list-style-type: none"> • “I guess maybe it was a dumb question.” • I had a lot of questions, but I just, when you’re sitting there talking, it’s almost intimidated...I think sometimes you feel like, who am I to question the doctor? He knows what’s best.”

Table 3

Final QPL Questions

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- 1 Where do I stand with my cancer now?
 - a. What is my diagnosis and stage?
 - b. Has my cancer spread anywhere?
 - c. Is it possible to cure my cancer?
 - d. Is it possible that my siblings or children will also get this cancer?
 - 2 What treatment is right for me?
 - a. Why do I need more treatment now if I had (or will have) surgery?
 - b. What might happen if I decide not to have more treatment?
 - c. How will this treatment affect other problems (i.e. diabetes or high blood pressure)?
 - d. Are there are guidelines for treating this kind of cancer?
 - e. Are there any other options for people with the kind of cancer I have?
 - f. Are there any clinical trials? Alternative treatments?
 - g. Do you have any other patients on this treatment? How are they doing?
 - h. Can I stop treatment if I want to?
 - i. Do I need to decide right away, or can I wait until after (holiday or vacation)?
 - j. Where can I find more information about this treatment?
 - k. Should I get a second opinion or ask my family doctor?
 - 3 What is chemotherapy?
 - a. How is it different from radiation or hormonal treatment?
 - b. How will you decide what kind of chemotherapy to give me, or how much?
 - c. How will I receive it? What is a port, and will I need one?
 - d. Is the chemotherapy I will get the same as other people with my condition?
 - 4 How will I feel during treatment?
 - a. Will I have side effects (such as hair loss, skin and hair changes, weight gain or loss, changes in my sex life or fertility)?
 - b. Will the side effects get better or worse during treatment?
 - c. Will I have the side effects for the rest of my life?
 - d. What can I do to take care of myself or prevent side effects?
 - e. What foods should I try to eat or avoid?
 - f. Who can I call if I have questions or problems anytime, day or night?
 - 5 What about my daily life during treatment?
 - a. What can I do and not do during treatment (such as work, take care of my family, drive, eat and drink, exercise)?
 - b. How much help will I need at home?
 - c. Can I take my other medications (such as prescriptions for diabetes or aspirin for the pain)?
 - d. Can I take vitamins or other supplements (such as soy or St. John's Wort)?
 - 6 What is my treatment plan and schedule?
 - a. When will my treatment start?
 - b. How much time will my treatment take? (For example, how often will I come?)
 - c. How long will I be here each time?
 - d. For how many months or weeks will I have treatment?
 - e. Will I have to stay overnight?
 - f. Can I take breaks for holidays or vacations?

