



Published in final edited form as:

Patient Educ Couns. 2017 May ; 100(5): 818–826. doi:10.1016/j.pec.2016.12.026.

Randomized Trial of a Question Prompt List to Increase Patient Active Participation during Interactions with Black Patients and their Oncologists

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Abstract

Objective—Communication during racially-discordant interactions is often of poor quality and may contribute to racial treatment disparities. We evaluated an intervention designed to increase patient active participation and other communication-related outcomes during interactions between Black patients and non-Black oncologists.

Methods—Participants were 18 non-Black medical oncologists and 114 Black patients at two cancer hospitals in Detroit, Michigan, USA. Before a clinic visit to discuss treatment, patients were randomly assigned to usual care or to one of two question prompt list (QPL) formats: booklet (QPL-Only), or booklet and communication coach (QPL-plus-Coach). Patient-oncologist interactions were video recorded. Patients reported perceptions of the intervention, oncologist communication, role in treatment decisions, and trust in the oncologist. Observers assessed interaction length, patient active participation, and oncologist communication.

Results—The intervention was viewed positively and did not increase interaction length. The QPL-only format increased patient active participation; the QPL-plus-Coach format decreased patient perceptions of oncologist communication. No other significant effects were found.

Conclusion—This QPL booklet is acceptable and increases patient active participation in racially-discordant oncology interactions. Future research should investigate whether adding physician-focused interventions might improve other outcomes.

Practice Implications—This QPL booklet is acceptable and can improve patient active participation in racially-discordant oncology interactions.

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Keywords

patient-physician communication; health disparities; oncology

1. INTRODUCTION

Black-White treatment disparities exist across many cancers[1–6]. Multiple factors contribute to these disparities[7, 8], but one likely contributor is the quality of patient-physician communication during clinical interactions[9–12]. Communication during interactions with Black patients and non-Black physicians is often of poorer quality than during interactions with White patients. For example, patients in racially-discordant interactions tend to ask fewer questions[13] and participate less in decision making[14]; while physicians tend to be less patient-centered[15, 16]; more verbally dominant[16]; more contentious[17]; exhibit fewer positive, rapport building nonverbal communication behaviors[18]; engage in fewer relationship-building attempts[19]; and provide less information[20, 21]. This is extremely important because, due to the very small number of Black oncologists in the United States, most interactions for Black cancer patients are racially-discordant[22].

One well-documented communication-related disparity is the amount of information Black patients and their physicians exchange during clinical interactions. Black patients often ask fewer questions than White patients and are less likely to bring companions who may ask questions on their behalf[13]; and physicians provide less information[19–21, 23]. Also, interactions with Black patients are often shorter[21, 24], possibly indicating less information exchange and lower quality communication and care[24–26]. Thus, interventions are needed to improve information exchange and other aspects of communication during these interactions. One way to do this is by increasing patient active participation. Patient active participation plays an important role in short-, intermediate-, and long-term outcomes[27, 28] due to its association with the amount of information physicians provide[29–31], treatments physicians recommend[11], topics patients and physicians discuss[32], and patient psychosocial and physical health outcomes[33, 34].

We tested the acceptability and effectiveness of an intervention designed to increase patient active participation in racially-discordant clinical interactions. The intervention was a question prompt list (QPL), a list of questions related to a medical condition that patients might want to ask their physician during clinic visits. QPLs are designed as a simple, inexpensive way to help patients gain more information about their diagnosis and treatment and enhance patient-provider communication[35–38]. Although QPLs have been used successfully in several oncology settings[31,39,40], they have not, as far as we know, been evaluated in the context of racially-discordant oncology interactions.

The QPL for this study was developed in collaboration with Black patients and family members, community members, and oncologists[41]. We provided it to patients in one of two formats. In the first (“QPL-Only”), patients received the QPL as a booklet. In the second (“QPL-plus-Coach”), patients received the QPL booklet and the assistance of a communication coach, whose role was to help patients consider which questions they might

ask during the clinical interaction. We tested two QPL formats because of concerns that the booklet alone might have limited benefit for patients with lower levels of education. Additionally, we believed that patients might be more likely to benefit from the QPL if it was presented to them by a coach who was also Black, given research suggesting that Black patients are often less trusting of physicians and medical institutions than White patients[42–45].

This study extends prior research on the acceptability and effectiveness of QPLs in several ways. First, we evaluated acceptability by assessing patient perceptions of both formats of the QPL. Based on prior research and the fact that the QPL was developed collaboratively with stakeholders[41], we expected favorable perceptions. We also assessed acceptability by determining the effect of the intervention on interaction length because significantly increasing interaction length might reduce feasibility in clinical settings. Findings from prior studies evaluating the effect of QPLs on interaction length have been mixed, with most suggesting no significant effects[35, 37, 86]. Thus, we expected neither format to significantly increase interaction length.

Second, we investigated direct effects of the QPL by evaluating whether patients who received it in either format would participate more actively during interactions than patients who did not. We defined active participation to include communication behaviors such as asking questions, making assertions, and stating concerns[46, 47]. Based on prior research[35, 38], we expected patients who received the QPL in either format to participate more actively than patients who did not, and patients who received the QPL-plus-Coach to participate more actively than patients who received the QPL-Only.

Third, we investigated possible additional effects of the QPL beyond patient active participation. Some studies have shown positive effects[35, 37, 38], including patient and observer perceptions of oncologist communication and patient reports of their role in treatment decisions and trust in their oncologist. These studies suggest that if patients participate more actively, oncologists may use more patient-centered communication and, as a result, patient post-interaction perceptions may be more positive. Thus, we expected positive effects on oncologist communication and patient reports of their role in decision making and trust in their oncologist, and that the QPL-plus-Coach format would have more positive effects than the QPL-Only format.

2. METHODS

2.1 Participants and Procedures

The study was conducted in outpatient clinics of two cancer hospitals in Detroit, Michigan, USA, between April 2012 and December 2014. Institutional Review Boards at Wayne State University and both hospitals approved all procedures.

Participants included medical oncologists and their patients. Oncologists were eligible to participate if they treated patients with breast, colon, or lung cancer. Patients were eligible if they (1) self-identified as Black, African American, or Afro-Caribbean; (2) were between the ages of 30 and 85 years of age; (3) had a diagnosis of breast, colon, or lung cancer; (4)

could read and understand English well enough to provide informed consent and complete questionnaires; and (5) had an appointment within two weeks to see a participating oncologist for an initial discussion of medical treatment.

Forty oncologists were eligible; thirty-five (87.5%) agreed. Of these, 18 (51.4%) had patients who participated and were included in the study sample. These 18 oncologists did not differ on any baseline measures (e.g., age, sex, race/ethnicity—See Table 1) from oncologists who agreed to participate but did not have patients included in the sample. Oncologists received a \$50.00 gift card for their participation.

Figure 1 provides a flow diagram of patient enrollment, randomization, and procedures. Research staff were able to contact only 273 (56%) of the 485 eligible patients by U.S. mail and/or telephone. Of the 273 patients invited to participate, 137 (50%) agreed. Fifteen patients were not randomized because they had a diagnosis suggesting they would not discuss medical treatment (e.g., ductal carcinoma in situ, DCIS; n=13) or because the software did not randomize properly (n=2). Eight patients were excluded after randomization because they provided incomplete responses to baseline or outcome measures. Thus, the final sample was 18 oncologists and 114 patients.

2.2 Procedures

Eligible patients were informed of the study via U.S. mail, telephone, or discussion with clinic staff within two weeks prior to a scheduled clinic appointment. Interested patients met with research staff to provide consent and complete baseline measures, using a tablet device with survey software (Qualtrics©). Following completion of baseline measures, the software randomized patients (1:1:1) to either the usual care arm or one of two intervention arms (QPL-Only or QPL-plus-Coach). Patients in the intervention groups received the intervention at this time. Patients received \$60.00 in gift cards for completing the study.

The QPL was a booklet designed to be accessible to patients with low levels of education and health literacy. The booklet included 43 questions related to diagnosis, treatment, chemotherapy, side effects, daily life during treatment, treatment plan and schedule, help with costs, and help with coping.

Research staff participated in a two-day training workshop on providing the study measures and intervention to patient participants. Staff were specifically instructed *not* to provide information about cancer or cancer treatments, or offer general health information, advice, opinions, or their own experiences. Patient baseline interviews were audio recorded and reviewed to assess protocol fidelity. Fidelity assessments showed the research staff strictly adhered to the protocol.

Patients assigned to the usual care arm (Arm 1) did not receive the QPL booklet or any other intervention. Patients assigned to the QPL-Only arm (Arm 2) received the QPL booklet, along with a brief explanation and encouragement to read it, show it to friends and family, and bring it to the visit because “asking questions during medical visits is important.” Patients assigned to the QPL-plus-Coach arm (Arm 3) received the same booklet and explanations/suggestions, but also participated in a discussion with a communication coach.

Coaches were three Black female research staff trained to use a strategy developed by the investigators called “GPS: Generate, Prioritize, Summarize.” Specifically, they read each question aloud (“generate”), and then asked patients whether they wanted to ask the oncologist this question, and why or why not (“prioritize”). Coaches reviewed questions patients indicated wanting to ask (“summarize”), asked if there were other questions they wanted to ask, and offered the opportunity to practice asking the questions.

The clinical interactions occurred within two weeks of the baseline interview and intervention. Interactions were video recorded if logistically possible using unobtrusive, remotely-controlled video cameras[48]. Immediately following the interactions, patients completed questionnaires about their perceptions of oncologist communication. One week later, patients participated in a follow-up telephone interview about their perceptions of the oncologist, the interaction, and the intervention.

2.3 Measures

Patient and physician characteristics—At baseline, patients completed measures assessing their socio-demographic characteristics and attitudes and beliefs that prior research suggested is associated with patient active participation, clinical communication, and other study outcomes[49]. General trust in physicians was measured using the abbreviated five-item Trust in the Medical Profession Scale[50], which concerns the extent to which patients believe physicians are trustworthy and care about them. A five-point response scale was used (Strongly Disagree to Strongly Agree). The mean item score was 3.51 (SD=.78). Group-based medical suspicion was measured with five items from the six-item suspicion subscale of the Group-Based Medical Mistrust Scale[51], which assesses the extent to which patients believe that members of their racial/ethnic group will be mistreated by the medical community. A five-point response scale was used (Strongly Disagree to Strongly Agree). The mean item score was 1.80 (SD=.77). Past perceived personal discrimination was measured with a seven-item scale[52] in which patients are asked whether they have experienced unfair treatment in various domains. The measure has a yes/no response scale. The total score is the number of “yes” responses. Sixty-eight percent of patients reported some discrimination; among them, the mean score was 2.51 (SD=1.66). Distress was measured with the Distress Thermometer, an 11-point scale (No Distress to Extreme Distress) that assesses current level of psychological distress[53]. The mean score was 4.12 (SD=3.04). Decisional control preferences were measured using a modified version of the Control Preferences Scale[54]. Patients were asked three questions about the extent to which they preferred (a) making decisions on their own; (b) making decisions with physicians; and (c) physicians making decisions on their own. Each question used a six-point response scale (Strongly Disagree to Strongly Agree). The mean item scores were: Own Decision, 3.25 (SD=1.50) Joint Decision, 4.97 (SD=1.34); Physician Only Decision, 3.69 (SD=1.54). Physicians provided socio-demographic and professional information, and also completed the Implicit Association Test (IAT), a widely-used measure of implicit racial bias[55, 56]. The mean IAT score was .26 (SD=.42), which indicates a small to moderate level of implicit racial bias in favor of Whites[57].

Patient Perceptions of the Intervention—Intervention group patients provided perceptions of the intervention during the follow-up telephone interview. They used a three-point response scale (1=Strongly Disagree to 3=Strongly Agree) to answer eight questions about the QPL. Patients in the QPL-plus-Coach arm answered five additional questions about perceptions of the communication coaching.

Interaction Length—One observer viewed the videos and recorded the amount of time patients and physicians were both in the consult room.

Patient Active Participation in Clinical Interactions—Three independent assessments of patient active participation were conducted, all based on video observations. Observers were blind to the hypotheses and study arms. (Table 2 provides descriptive statistics for all outcome measures, including observational and patient self-report).

The first measure of patient active participation was a *global rating of patient active participation*[17]. Three trained observers independently viewed the video recordings and used a five-point scale (1=Strongly Disagree to 5=Strongly Agree) to rate patients on the extent to which they engaged in each of seven behaviors: asking the doctor to explain treatments, procedures and other topics in greater detail; asking the doctor for treatment recommendations; asking the doctor about options for treatment and other topics; letting the doctor know what he/she liked about the treatment options and other topics; telling the doctor his/her preferences; feeling free to express concerns and worries; and expressing opinions. To assess initial inter-rater reliability, three observers rated 15% of the videos (ICC=.89, $p<.01$). Each video was then rated by two observers, but 15% of the remaining videos were rated by three observers to assess continued reliability. Because scores for the individual behaviors were highly correlated (mean $r=.71$, range=.61-.85), ratings of individual behaviors were averaged across the behaviors to form an average *patient active participation* score ($\alpha=.94$).

The second measure of patient active participation was a *frequency count* of three communication behaviors that reflect active participation: asking questions, making assertions, and expressing concerns[17]. Three trained observers watched each video and, using StudioCode software (Studiocode; studiocodegroup.com, Lincoln, NE), marked each time a patient made a verbal statement directed at the oncologist that reflected active participation and also contained only one idea or thought about one topic. Observers then categorized these behaviors as: *questions* (e.g., “Will I need chemotherapy?”); *assertions* (e.g., “I don’t want to wait till after the holidays.”); or *statements of concern* (e.g., “I’m worried about taking time off work.”) To assess initial inter-rater reliability, three observers coded 10% of the videos (ICC=.84 ($p<.01$)). Each video was then coded by one observer, but 15% of the remaining sample was coded by two observers to assess continued reliability. Reliability remained high across the remaining videos (ICC=.64, $p<.01$). The three behavior categories were collapsed to create a *total frequency of active participation statements* score.

The third measure of patient active participation was *oncologist-patient talk time ratio*. Two observers used Studiocode software to record the amount of time each participant spoke

(79.9% observer agreement). The ratio of oncologist talk time to patient talk time was then computed.

Oncologist Communication—Patients and observers both assessed oncologist communication. Patients completed the *perceived patient-centeredness scale*[58] immediately after the interaction. They used a 4-point scale (1=Not at All to 4=Completely) to rate the extent to which they perceived their oncologist had displayed each of 14 behaviors, such as “showed respect” and “was concerned about me as a person.” Scores were averaged across the 14 behaviors ($\alpha=.84$).

Four trained observers, blind to hypotheses and study arms, independently viewed the videos and used a five-point scale (1=Strongly Disagree to 5=Strongly Agree) to rate oncologists’ *patient-centered communication* using a measure[17] with three 4-item subscales: (1) *informativeness* (e.g., “doctor was very informative about patient’s health”); (2) *supportiveness* (e.g., “doctor made patient feel completely at ease”); and (3) *partnership-building* (e.g., “doctor asked for patient’s thoughts about his/her health”). (See Table 2.) To assess initial inter-rater reliability, four observers rated 15% of the videos (ICC = .57-.74, $p's < .05$). Each video was then rated by two observers, but 15% of the remained sample was rated by four observers to assess continued reliability. Individual item ratings were averaged across all observers, yielding an average rating for each individual item for each interaction. Each subscale’s total score for an interaction was the average of the four average item ratings in that subscale. The total patient-centered communication score was the average of the three subscale averages (informativeness $\alpha=.91$; supportiveness $\alpha=.91$; partnership building $\alpha=.77$; and total scale $\alpha=.88$).

Patient Role in Treatment Decision—Immediately after the interaction, patients answered one question about their perceived role in treatment decisions using a nonlinear five-point scale[54] with three anchors: patient only, shared, and physician only.

Patient Trust in the Oncologist—During the telephone follow-up interview, patients used a five-point rating scale (1=Strongly Agree to 5=Strongly Disagree) to respond to five items about trust in their oncologist ($\alpha=.79$)[50].

2.4 Data Preparation and Analyses

T-tests were used to test differences between study arms on patient perceptions of the intervention. Multi-level regression models, with patients nested within oncologists, were used to test all hypotheses about effects of the intervention on patient active participation, physician communication, and trust. Analyses of data structure from another study[57] using the same dataset disclosed unequal variance among oncologists in the distributions of how physician implicit bias affected some outcome measures. Therefore, for each analysis of an outcome measure, two models were created: one assumed equal variance among oncologists, and the other assumed unequal variance. Fit of the two models was compared using the Akaike’s Information Criterion (AIC)[60], the Bayesian Information Criterion (BIC)[61], and a chi-square increment in model fit test. Unless unequal models provided significantly better fits, equal variance models were used. If either of the two intervention

arms differed significantly from the control arm, the two intervention arms were compared on the outcome of interest. For all outcome measures except *Frequency of Active Participation Statements*, z scores were used in regression models; thus the other regression weights presented in the tables are also estimates of effect size. Because the scale that assessed patients' role in treatment decisions was nonlinear, a chi-square analysis was used to assess the effects of the intervention. Results for all analyses were considered significant at the p .05 level.

G-Power[62] was used to estimate power for the regressions analyses, assuming a small effect size ($f^2=.08$) and 5% Type I error rate. For the analyses of patient post-interaction self-reports ($n=114$), the estimated power was .84; it was between .79 and .80 for the 99 videos. Power was .65 for the X2 analysis.

Prior to conducting the multi-level analyses, binary regression analyses were conducted to identify any baseline measures that should be included as covariates in the models. Specifically, each outcome was regressed onto all patient and oncologist socio-demographic characteristics and the other baseline measures that prior research suggests might covary with study outcomes. Measures that significantly covaried with an outcome were included in the appropriate model.

3. RESULTS

3.1 Sample Characteristics

Characteristics of oncologists and patients are presented in Table 1. There were no significant differences among patients in the three study arms on baseline measures.

3.2 Acceptability of the Intervention

Patient Perceptions (Table 3)—The mean patient response across the eight questions about the QPL booklet was 2.80 ($SD=.23$). T-tests showed no significant differences between the two intervention arms on any of these questions (p 's $>.05$). The mean response across the five questions about coaching was 2.83 ($SD=.29$).

Interaction Length—Oncologist implicit racial bias (measured at baseline) was included as a covariate in this analysis because it negatively covaried with interaction length (i.e., greater bias, shorter interactions), ($p=.01$). There were no significant differences in interaction length between either of the two intervention arms and the usual care arm (Arm 2 vs. Arm 1, $p=.21$); Arm 3 vs. Arm 1, $p=.11$).

3.3 Effects of Intervention on Patient Active Participation (See Table 4)

Global Ratings—In the omnibus comparison of the three arms, the comparison of the QPL-Only arm and the usual care arm approached statistical significance ($p=.06$)--patients in the QPL-Only arm were rated as participating more actively than patients in the usual care arm. There was no significant difference between patients in the QPL-plus-Coach arm and those in the usual care arm.

Frequency of Active Participation Statements—Discrimination (some/none) was entered as a covariate in this analysis because patients reporting some past discrimination made significantly more active participation statements (i.e., asking questions, making assertions, expressing concerns) than patients reporting none ($p=.002$). Patients in the QPL-Only arm made more active participation statements than patients in the usual care arm ($p=.02$; effect size=.55). There was no significant difference between patients in the QPL-plus-Coach arm and those in the usual care arm. Patients in the QPL-Only arm also made more active participation statements than those in the QPL-plus-Coach arm ($p=.02$; effect size=.57).

Oncologist-Patient Talk Time Ratio—Discrimination (some/none) was entered as a covariate in the analyses because it significantly covaried with this outcome; ratios were smaller (i.e., patients talked more relative to their oncologists) for patients reporting some past discrimination ($p=.01$). There were no significant differences in talk time ratios between the intervention arms and the usual care arm.

3.4 Effects of Intervention on Additional Outcomes

Patient Perceptions of Oncologists' Patient-Centeredness (Table 4)—Oncologist implicit racial bias was entered as a covariate in this analysis because it negatively covaried with patient ratings of oncologist patient-centeredness; higher levels of implicit racial bias were associated with lower patient ratings of patient-centeredness ($p=.01$). Patients in QPL-plus-Coach arm rated their oncologists as significantly *less* patient-centered than patients in the usual care arm ($p=.02$). There was a nonsignificant trend in the same direction in the comparison between patients in the QPL-Only arm and in the usual care arm ($p=.08$).

Observers' Perceptions of Oncologist Patient-Centered Communication (Table 4)—The three subscales were combined into a total score. There were no differences between the two intervention arms and the usual care arm on any of the subscales or the overall score on this scale.

Patient Role in Treatment Decisions—A chi-square analysis of differences in patient perceptions of their role in treatment decisions across the three study arms was nonsignificant, $\chi^2(8)=5.80$, $p=.67$.

Patient Trust in Oncologist (Table 4)—General trust in physicians was entered as a covariate in this analysis because it positively covaried with trust in the oncologist ($p=.001$). There were no significant differences between the two intervention arms and the usual care arm.

4. DISCUSSION AND CONCLUSION

4.1 Discussion

This study examined two presentation formats of a QPL intervention designed to increase patient active participation during interactions with Black patients and their oncologists. Patients perceived both the QPL-Only and the QPL-plus-Coach formats very positively. This

finding was anticipated, given favorable perceptions of similar interventions in other settings[35, 37, 38], and the fact that we developed this QPL in collaboration with stakeholders[41]. Despite concerns that the QPL might lengthen interactions, making it less feasible in clinical settings, this did not occur. These findings suggest the intervention is acceptable for use in routine clinical practice in the context of racially-discordant oncology interactions.

Findings were mixed, however, regarding the effectiveness of the intervention. Most (but not all) prior studies of similar interventions have found increases in patient active participation[35, 37, 38]; this study, too, found this effect in the QPL-Only format. However, counter to our expectations, patients in the QPL-plus-Coach arm showed no increase in active participation relative to the usual care group, and they participated significantly *less* actively than patients in the QPL-Only arm. This finding is consistent with findings from a prior study that conducted a similar QPL and coaching intervention[63]. However, patients in our study had relatively low levels of education, and thus we anticipated that coaching would be especially beneficial. These findings suggest that coaching provided to complement a QPL booklet, which can be resource intensive, may not increase active participation. As suggested in a prior study examining patients' endorsements of interventions to support them in communicating with health care providers, patients may prefer to work through QPLs on their own or with their families, rather than with a coach[64].

One possible reason for our mixed findings is that the QPL broadly addressed medical treatment for cancer, and might not have been specific enough to address the informational needs of many patients in the study. QPLs focused more precisely on a specific topic, such as on a particular treatment, or on aspects of treatment such as palliative care, genetic tests, or clinical trials, may be more beneficial. Alternatively, encouraging patients to tailor questions to their specific needs using electronic, tailored QPL formats may increase benefit.

This study also examined a QPL's effects beyond active participation. We expected patient active participation to positively influence oncologist communication and related outcomes, such as patient trust, but no such benefits were found in either QPL format. In fact, the QPL-plus-Coach arm did not affect patient active participation, but did, unexpectedly, lower patient perceptions of oncologist patient-centeredness. A possible explanation for this finding is that the coaching, conducted by trained research assistants who were also Black, may have raised patients' expectations about what information they might gain from their oncologist during the interaction. However, these higher expectations may have led to more negative perceptions if oncologists did not or could not adequately address these needs.

If it is true that this patient-focused intervention increases patients' informational needs and expectations related to patient-oncologist interactions, then the intervention places a burden on oncologists to meet these needs. In this study, oncologists were informed that some patients would be given a QPL, but were not specifically asked to endorse it or encourage its use in any way, nor were they specifically trained to elicit patients' questions or to engage in patient-centered communication. Prior research suggests that a QPL *combined* with physician endorsement of active patient participation is more effective in increasing

participation than either the QPL or physician endorsement alone[32, 65]. Similarly, communication skills training can improve the quality of oncologists' patient-centered communication, and especially oncologists' ability to elicit and address patients' questions and concerns[66]. Thus, future research should explore whether an intervention focusing on both patients and oncologists is more effective than a patient-focused intervention QPL.

4.2 Limitations

This study was conducted in the context of racially-discordant interactions with an underserved patient population in an urban setting, and findings may not generalize to interactions with other racial/ethnic groups or in other locations. Also, many eligible patients could not be reached, and among those who were contacted, only half agreed to participate. Thus, the possibility of a selection bias exists; however, an analysis of zip codes of participants and nonparticipants suggested they came from areas with similar socio-demographic characteristics. Further, it is unclear how a selection bias would explain findings showing the QPL-Only format was more effective than the QPL-plus-Coach format.

4.3 Conclusion

Findings suggest that a QPL, especially in the form of a booklet, is an acceptable and effective intervention to improve patient active participation in racially-discordant interactions. However, future research is needed to find ways to increase the potential for these types of communication interventions to improve additional outcomes, such as oncologist communication and patient trust.

4.4 Practice Implications

This QPL and similar interventions may be critically important in a population of Black patients, who bear the disproportionate burden of cancer disparities and often experience poor quality communication during interactions with non-Black oncologists. Findings show that the QPL intervention is acceptable to Black patients with cancer, and, in the form of a booklet, is effective in increasing their active participation in racially-discordant interactions. However, increasing patient active participation may only be effective in improving outcomes to the extent that physicians respond by providing requested information in the context of high-quality, patient-centered communication.

Acknowledgments

Funding: This research was supported in part by grants from the National Cancer Institutes/National Institutes of Health (1U54CA153606-01 and P30CA022453).

We gratefully acknowledge collaboration with members of the Southeast Michigan Partners Against Cancer (SEMPAC) Community Research Advisory Committee.

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Highlights

- A Question Prompt List (QPL) to increase patient active participation in racially-discordant oncology interactions was tested.
- The QPL was viewed positively by patients and did not affect interaction time.
- The QPL booklet increased active participation but had no effect on other outcomes.
- The QPL-plus-coach did not affect active participation, and decreased patient perceptions of oncologist communication.
- QPLs can increase patient active participation in racially-discordant oncology interactions.

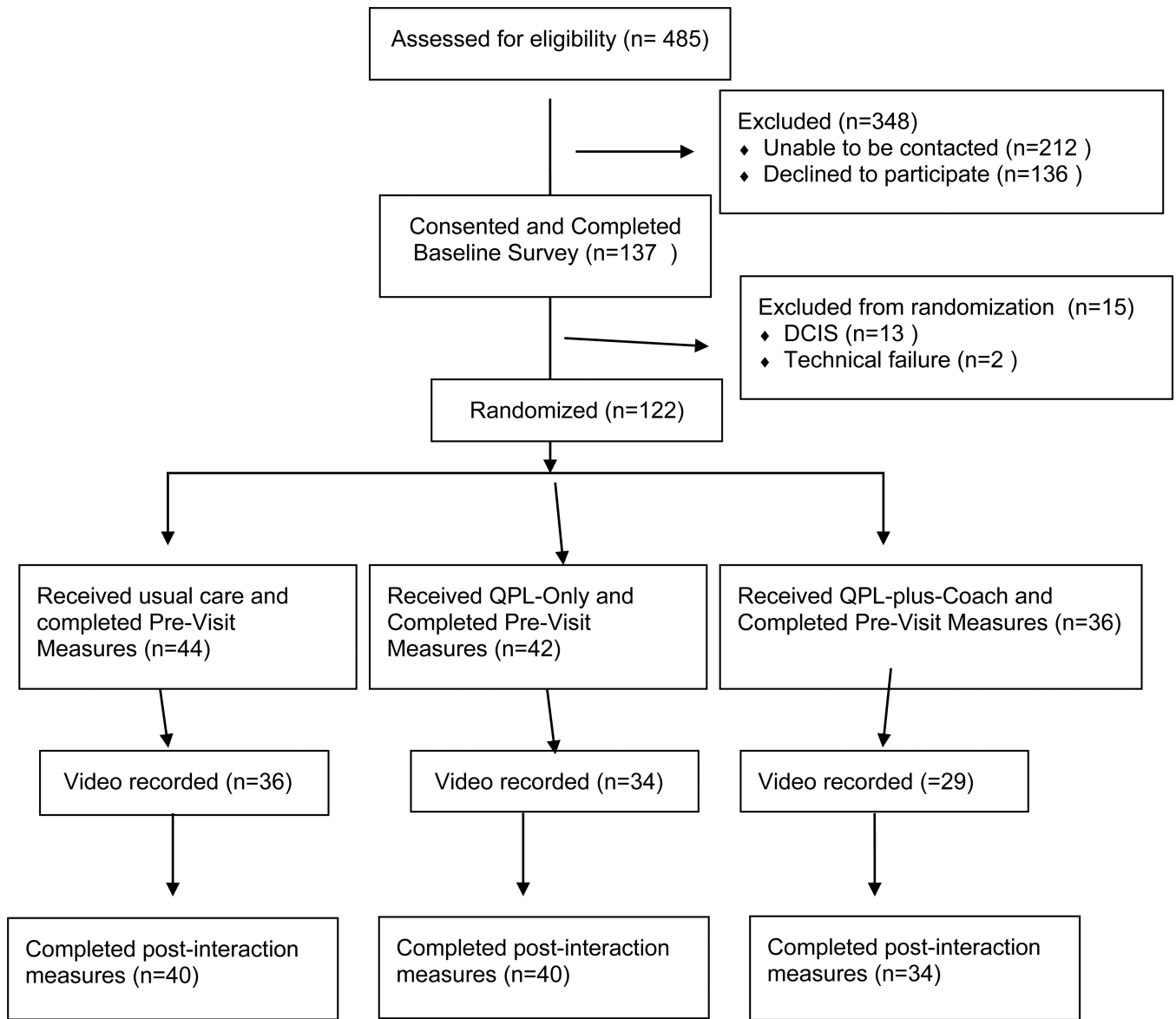


Figure 1.
Flow Diagram of Patient Enrollment, Randomization, and Procedures

Table 1

Socio-Demographic Characteristics of Participants

| Patients (n=114) | Usual Care (n=40) | QPL Only (n=40) | QPL+Coach (n=34) | Total (N=114) |
|---------------------------|---------------------|-------------------|--------------------|--------------------|
| Age | M=57.35 (SD=11.07) | M=60.82 (SD=9.32) | M=58.44 (SD=10.56) | M=58.89 (SD=10.35) |
| Sex | | | | |
| Female | 36 (90%) | 37 (92.5%) | 31 (91.2%) | 104 (91.2%) |
| Male | 3 (7.5%) | 3 (7.5%) | 3 (8.8%) | 9 (7.9%) |
| Education | | | | |
| < High School | 11 (27.5%) | 6 (15.0%) | 9 (26.5%) | 26 (22.8%) |
| Graduated High School | 3 (7.5%) | 6 (15.0%) | 5 (14.7%) | 14 (12.3%) |
| Some College | 14 (35.0%) | 15 (37.5%) | 9 (26.5%) | 38 (33.3%) |
| Graduated College | 9 (22.5%) | 7 (17.5%) | 5 (14.7%) | 21 (18.4%) |
| Post-graduate degree | 3 (7.5%) | 6 (15.0%) | 6 (17.6%) | 15 (13.2%) |
| Annual Household Income | | | | |
| 0 – \$19,999 | 18 (45.0%) | 14 (35.0%) | 14 (41.2%) | 46 (40.4%) |
| \$20,000 – \$39,999 | 12 (30.0%) | 13 (32.5%) | 7 (20.6%) | 32 (28.1%) |
| \$40,000 – \$59,999 | 3 (7.5%) | 4 (10.0%) | 3 (8.8%) | 10 (8.8%) |
| \$60,000 – \$79,999 | 3 (7.5%) | 3 (7.5%) | 4 (11.7%) | 10 (8.8%) |
| >\$80,000 | 2 (5.0%) | 4 (10.0%) | 3 (8.8%) | 9 (7.9%) |
| Primary Tumor Site | | | | |
| Breast | 32 (80.0%) | 34 (85.0%) | 28 (82.4%) | 94 (82.4%) |
| Colorectal | 3 (7.5%) | 3 (7.5%) | 2 (5.9%) | 8 (7.0%) |
| Lung | 5 (12.5%) | 3 (7.5%) | 4 (11.8%) | 12 (10.5%) |
| Oncologists (n=18) | Across Arms | | | |
| Age | M=46.76 (SD= 10.60) | | | |
| Male | 10 (56%) | | | |
| Race/Ethnicity | | | | |
| Caucasian or White | 10 (56%) | | | |
| Asian or Pacific Islander | 4 (22%) | | | |
| Arab-American/Mideastern | 4 (22%) | | | |
| Position | | | | |
| Attending | 15 (83.3%) | | | |
| Fellow | 3 (16.7%) | | | |

Table 2

Descriptive Statistics for Outcome Measures (Observational and Patient Self-Report)

| | Usual Care | QPL Only | QPL+Coach | Total |
|--|-------------------|-----------------|------------------|---------------|
| | M (SD) | M (SD) | M (SD) | M (SD) |
| <i>Observational Measures (n=99)</i> | | | | |
| <i>Patient Active Participation: Global Rating</i> | 3.30 (.88) | 3.64 (.66) | 3.43 (.77) | 3.45 (.78) |
| Patient asked for greater detail | 3.56 (1.08) | 3.84 (.79) | 3.74 (.96) | 3.71 (.95) |
| Patient asked for treatment recommendation | 2.60 (.92) | 2.87 (.86) | 2.80 (.96) | 2.75 (.91) |
| Patient asked questions | 3.28 (1.15) | 3.84 (.98) | 3.70 (1.05) | 3.59 (1.08) |
| Patient offered opinion of treatment | 3.06 (1.07) | 3.40 (.84) | 3.22 (.81) | 3.23 (.93) |
| Patient stated preference | 3.25 (1.02) | 3.59 (.84) | 3.13 (.78) | 3.33 (.91) |
| Patient expressed concerns | 3.77 (.76) | 4.11 (.62) | 3.93 (.81) | 3.94 (.74) |
| Patient expressed opinions | 3.54 (.90) | 3.83 (.71) | 3.53 (.79) | 3.64 (.81) |
| <i>Patient Active Participation: (Frequency Count)</i> | 14.42 (12.33) | 20.71 (15.11) | 13.83 (10.57) | 16.40 (13.15) |
| Patient information seeking | 11.19 (10.52) | 14.82 (12.63) | 10.90 (9.21) | 12.35 (10.98) |
| Patient assertions | 2.83 (3.34) | 5.09 (4.26) | 2.31 (2.24) | 3.45 (3.60) |
| Patient expressed concern | .39 (.73) | .79 (1.10) | .62 (1.15) | .60 (1.00) |
| <i>Oncologist-Patient Talk Time Ratio</i> | 4.17 (3.47) | 3.27 (1.99) | 3.97 (2.12) | 3.81 (2.67) |
| <i>Oncologist Patient-Centered Communication (Observed)</i> | 3.50 (.60) | 3.62 (.49) | 3.64 (.42) | 3.58 (.51) |
| Informativeness | 3.76 (.68) | 3.97 (.55) | 4.01 (.53) | 3.90 (.60) |
| Supportiveness | 3.50 (.72) | 3.53 (.59) | 3.67 (.46) | 3.56 (.61) |
| Partnership building | 3.23 (.54) | 3.35 (.56) | 3.25 (.42) | 3.28 (.51) |
| <i>Patient Self-Report Measures</i> | | | | |
| <i>Oncologist Patient Centeredness (n=107)</i> | 3.65 (.38) | 3.65 (.40) | 3.63 (.31) | 3.64 (.36) |
| <i>Patient Role in Treatment Decision (n=85)</i> | 3.07 (1.07) | 3.13 (1.25) | 2.92 (1.09) | 3.05 (1.13) |
| <i>Patient Trust in Oncologist (n=97)</i> | 4.08 (.54) | 4.16 (.63) | 4.3 (.67) | 4.20 (.61) |

Table 3

Perceptions of Intervention (1=Strongly Disagree to 3=Strongly Agree)

| | QPL-Only (n=40) M (SD) | QPL-Plus-Coach (n=34) M (SD) |
|---|---------------------------------------|---|
| The booklet was helpful. | 2.90 (.31) | 2.87 (.35) |
| The booklet made it easier for me to ask questions when I met with the doctor. | 2.77 (.43) | 2.67 (.61) |
| Some questions in the booklet were useful to me when I met with the doctor. | 2.80 (.41) | 2.77 (.43) |
| The booklet helped me to put some of my questions or concerns into words. | 2.73 (.52) | 2.70 (.60) |
| The booklet will be useful to me in the future. | 2.93 (.25) | 2.83 (.38) |
| The booklet contained too many questions for me. ¹ | 1.17 (.46) | 1.27 (.64) |
| The questions were easy to understand. | 2.73 (.45) | 2.77 (.43) |
| Some questions made me uncomfortable. ¹ | 1.10 (.31) | 1.07 (.25) |
| Discussing the questions with the coach helped me during my visit. | NA | 2.72 (.53) |
| I would recommend that other patients discuss questions like these before they see their doctor. | NA | 2.97 (.19) |
| Discussing the questions with the coach helped me to put some of my questions or concerns into words. | NA | 2.83 (.47) |
| Discussing the questions with the coach helped me to understand the questions and how to use them. | NA | 2.79 (.56) |
| Discussing the questions with the coach made me uncomfortable. ¹ | NA | 1.0 (0.00) |

¹Items reversed scored prior to analysis

Table 4

| Effects of the Intervention on Patient Active Participation | | | |
|--|---------------|----------|---------------|
| | B (SE) | p | 95% CI |
| <i>Active Participation: Global Ratings</i> | | | |
| Arm 2 vs. Arm 1 | .45 (.24) | .06 | -.02, .92 |
| Arm 3 vs. Arm 1 | .18 (.25) | .47 | -.31, .67 |
| <i>Active Participation: Frequency Count</i> | | | |
| Arm 2 vs. Arm 1 | 6.95 (2.93) | .02 | 1.11, 12.79 |
| Arm 3 vs. Arm 1 | -.55 (3.06) | .86 | -6.65, 5.54 |
| Arm 2 vs. Arm 3 | 7.61 (3.19) | .02 | -14.0, -1.19 |
| Past Discrimination (None vs. Some) | 8.27 (2.64) | .002 | 3.02, 13.53 |
| <i>Oncologist-Patient Talk Time Ratio</i> | | | |
| Arm 2 vs. Arm 1 | -.08 (.05) | .11 | -.19, .02 |
| Arm 3 vs. Arm 1 | -.04 (.05) | .45 | -.15, .07 |
| Past Discrimination (Some vs. None) | -.12 (.05) | .01 | -.22, .03 |

| Effects of the Intervention on Additional Outcomes | | | |
|--|---------------|----------|---------------|
| | B (SE) | p | 95% CI |
| <i>Patient Perceptions of Oncologist Patient Centeredness</i> | | | |
| Arm 2 vs. Arm 1 | -.17 (.10) | .08 | -.36, .02 |
| Arm 3 vs. Arm 1 | -.27 (.12) | .02 | -.50, .03 |
| Implicit Physician Bias | -.25 (.08) | .01 | -.42, -.07 |
| <i>Observer Perceptions of Oncologist Patient Centeredness</i> | | | |
| Arm 2 vs. Arm 1 | .19 (.23) | .40 | -.26, .56 |
| Arm 3 vs. Arm 1 | .25 (.22) | .25 | -.18, .69 |
| <i>Patient Trust in Oncologist</i> | | | |
| Arm 2 vs. Arm 1 | .07 (.23) | .76 | -.40, .54 |
| Arm 3 vs. Arm 1 | .36 (.24) | .13 | -.11, .84 |
| General Trust in Physicians | .47(.13) | .001 | .21, .73 |