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Question Prompt Lists and Caregiver Question Asking in Pediatric Specialty Appointments: A Randomized Controlled Trial

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Ethics Declaration
The Institutional Review Board at the University of North Carolina, Chapel Hill approved all study procedures. Informed consent was obtained from all participants as required by the IRB.

Conflict of Interest
The authors declare no conflict of interest.

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Abstract

Objective: Question prompt lists (QPLs) have been effective at increasing patient involvement and question asking in medical appointments, which is critical for shared decision making. We investigated whether pre-visit preparation (PVP), including a QPL, would increase question asking among caregivers of pediatric patients with undiagnosed, suspected genetic conditions.

Methods: Caregivers were randomized to receive the PVP before their appointment ($n = 59$) or not (control, $n = 53$). Appointments were audio-recorded. Transcripts were analyzed to determine questions asked.

Results: Caregivers in the PVP group asked more questions ($Mean_{\mathrm{PVP}} = 4.36$, $SD_{\mathrm{PVP}} = 4.66$ vs. $Mean_{\mathrm{control}} = 2.83$, $SD_{\mathrm{control}} = 3.03$, $p = 0.045$), including QPL questions ($Mean_{\mathrm{PVP}} = 1.05$, $SD_{\mathrm{PVP}} = 1.39$ vs. $Mean_{\mathrm{control}} = 0.36$, $SD_{\mathrm{control}} = 0.81$, $p = 0.002$). Caregivers whose child had insurance other than Medicaid in the PVP group asked more total and QPL questions than their counterparts in the control group ($ps = 0.005$ and 0.002); there was no intervention effect among caregivers of children with Medicaid or no insurance (ps = 0.775 and 0.166).

Conclusion: The PVP increased question asking but worked less effectively among traditionally underserved groups. Additional interventions, including provider-focused efforts, may be needed to promote engagement of underserved patients.

Practice Implications: Patient/family-focused interventions may not be beneficial for all populations. Providers should be aware of potential implicit and explicit biases and encourage question asking to promote patient/family engagement.

Keywords

Genetic conditions; Question prompt lists; patient-provider communication; patient engagement; Pediatrics

1. Introduction

Shared decision-making, the predominant model guiding communication between patients and clinicians, promotes bidirectional communication and patients' active engagement [1]. It aims to facilitate patient-centered care by fostering a partnership between patients and clinicians, allowing them to make medical decisions that align with the patient's values, preferences, and goals [2]. These processes are especially important for patients with undiagnosed or suspected genetic conditions because sharing symptom information can help determine appropriate diagnostic testing, including genetic sequencing, and assist with interpreting test findings [3,4]. The quality of communication between providers, patients, and their families is critically important, yet often differs by demographic and social factors. A systematic review of patient and physician communication found that Black patients report worse communication with physicians, share less information with providers, and engage in less shared decision making than white patients [5]. Additionally, patients of lower socioeconomic status (SES) ask fewer questions of providers and are less likely to share information when not prompted compared to patients of higher SES [6–8].

Question Prompt Lists (QPLs) aim to address this imbalance and support patient involvement [9]. This intervention provides patients and families with a list of possible questions to ask physicians in an effort to promote patient and family involvement and communication during medical appointments [10,11]. QPLs have been shown to increase question asking among patients [11–14], including medically underserved patients and patients of color [9, 15–20]. They can be tailored for different clinical encounters and are particularly effective when physicians support their use [12,21]. Therefore, when used by patients and families and supported by physicians, QPLs have the potential to aid communication and information sharing between physicians and patients [10,11].

1.1 Overview of the present study

Our study examines the impact of QPLs on caregiver-physician communication in pediatric specialty appointments through the North Carolina Genomic Evaluation by Next-generation Exome Sequencing (NCGENES) 2 study. NCGENES 2 is a randomized controlled trial that applied a factorial design with two independent randomizations, one to test the benefits of a pre-visit preparation (PVP) intervention that included an educational packet and QPL, and the second to evaluate the utility of diagnostic exome sequencing for pediatric patients with undiagnosed conditions. Here we report on the PVP intervention. The PVP was provided to enrolled parents or guardians (hereafter caregivers or participants) of the pediatric patients. Approximately half the participants were randomized to receive the intervention. Our primary goal was to determine whether the intervention could increase question asking (i.e., total questions and QPL questions asked) in initial pediatric specialty appointments.

Our secondary goal was to examine whether the intervention would increase question asking among underrepresented (patients of a race/ethnicity other than non-Hispanic white) or medically underserved (children having Medicaid or no insurance) families; that is, how race/ethnicity and child’s insurance status moderated the effect of the intervention. We hypothesized that caregivers of color or those whose child has either Medicaid or no insurance (MoNI) would ask fewer questions without the intervention and therefore would be more likely to benefit from the PVP. We examined the following potential confounding factors to explore the robustness of effects: number of caregivers at the appointment (e.g., another parent or family member accompanying the participant) [15]; caregivers’ perception of their child’s health (e.g., caregivers may ask more questions when their child is more symptomatic or impaired) [22–24]; group-based medical mistrust (e.g., caregivers who mistrust the healthcare system may ask fewer questions) [9,25]; and caregiver perceived patient-centeredness (e.g., caregivers may ask more questions when their provider uses patient-centered communication) [22,23,26].

2. Methods

2.1 Participants

Participants were recruited from two NCGENES 2 sites: University of North Carolina (UNC) Health in Chapel Hill and Mission Health in Asheville. Eligible participants included one parent or caregiver from a family with a first-time clinic visit to either a pediatric genetics or neurology clinic at these sites. The patient had to be younger than 16 and have an undiagnosed condition with possible genetic cause. Based on demographic data in the electronic medical record, we oversampled patients of color (patients of a race/ethnicity other than non-Hispanic white) and patients medically underserved (children having MoNI). Potential participants were recruited and consented by phone. Randomization for the PVP study arm occurred during this call via computer-generated algorithm within the web-based study tracking system. Random assignments were concealed electronically until the time of disclosure to caregivers. The tracking system limited access to randomization status by study personnel roles and by caregivers' status along the study trajectory. Study clinicians remained blind to the caregivers' PVP intervention status throughout the trial. However, clinicians could become unblinded if the caregiver used the PVP during the clinic visit. UNC's Institutional Review Board approved all study procedures, and informed consent was obtained from all participants. Additional details about the NCGENES 2 clinical trial protocol have been previously published [27].

2.2 Intervention and Control Group

Pre-Visit Preparation.—Prior to their clinic appointment, caregivers randomized to this intervention were mailed the PVP materials—the QPL and educational booklet. These materials were developed by genetics clinicians with our Community Consult Team, a diverse group of advocates for and caregivers of children with special needs [28]. The booklet covered topics such as information about diagnostic testing and the value of asking questions during the visit. The booklet introduced the QPL (Supplemental Figure 1), which included 11 example questions grouped by themes such as: "Questions about your child's condition and the future," "Questions about tests and other evaluations," and "Questions to ask at the end of the visit." Caregivers were instructed to mark questions they were interested in asking, write in their own questions, and hand the QPL to the doctor during the appointment.

Control.—Caregivers assigned to the control group (usual care) completed all study procedures except those associated with the PVP materials.

2.3 Procedures

A research team member met caregiver participants upon arrival at their child's clinic visit. The team member collected a completed intake questionnaire, administered a pre-visit questionnaire on a tablet, and obtained caregivers' consent to audio-record their appointment. The team member did not discuss the PVP materials with caregivers. Immediately after the visit, the team member administered a post-visit questionnaire to caregivers via tablet.

2.4 Audio-Recording Analysis

Appointment audio-recordings were transcribed verbatim for analysis. Research team members developed a codebook based on the topics covered by the QPL, educational booklet, and an initial reading of a subset of transcripts. Included in the codebook was a code to identify when caregivers asked questions during the appointment as well as a code to denote the number of adults accompanying the caregiver and child to the appointment (e.g., other parent, family); these two codes serve as the basis for the analyses presented in this paper.

Eight team members began the coding process in pairs after receiving training from the lead author (MW). Coders were trained to tag any time a question was asked by caregivers during appointments. Coder pairs first coded a transcript independently before comparing coding and resolving discrepancies. Coding of transcripts continued in pairs until consistency in coding was reached, at which point independent coding proceeded. If coders had any issues with whether text should be coded as a question, they brought it to the team for discussion. Random transcripts were checked by senior qualitative analysts (MW and RJC). If changes needed to be made, the transcript was brought to the team for further training. When all transcripts were coded, the two senior analysts met to review all text coded as a caregiver question. During this process, questions that were not related to the care of the patient (e.g., “Where is the bathroom?”) were removed from the dataset. All remaining questions were sorted into the type of question asked (i.e., QPL question or not).

2.5 Measures

Sociodemographic variables.—The intake questionnaire assessed the caregiver and child’s age; the caregivers’ sex, race/ethnicity, education, marital status, employment, and income; and the child’s insurance status. Missing pediatric data were abstracted from medical records, when available.

Clinic site details.—The clinic was genetics or neurology; study site was UNC or Mission.

Other variables.—The *number of caregivers present* at the appointment was obtained from the transcripts (1 = participating caregiver only; 2 = participating caregiver and one additional adult). *Caregiver-reported perception of child’s health* used a 0–100 scale (0 = Worst health you can imagine, 100 = Best health you can imagine) on the pre-visit questionnaire [29]. *Group-based medical mistrust*, a 12-item measure on the intake questionnaire, assessed perceptions of how participants’ ethnic group are treated in a clinical setting [30]. Responses, which ranged from 1 (*Strongly disagree*) to 5 (*Strongly agree*) (reversed scored where appropriate), were summed; higher scores indicated more mistrust (Cronbach’s alpha = 0.92). *Caregiver perceived patient-centeredness* of the clinic visit was assessed on the post-visit questionnaire with an adapted version of the 21-item Patient Perceptions of Patient Centeredness scale [31]. Responses ranged from 1 (*Very strongly disagree*) to 7 (*Very strongly agree*) and were averaged to yield a score. Higher scores indicated stronger perceptions of patient centeredness (Cronbach’s alpha = 0.95).

Primary outcomes.—The number of total questions asked and the number of QPL questions asked, coded as described above.

2.6 Statistical Analysis

The planned enrollment of NCGENES 2 ($n = 800$) was designed for testing potential utility of first-line exome sequencing early in the diagnostic odyssey of pediatric patients and the efficacy of PVP with factorial design with four study arms [27]. The present analyses focus only on the effects of randomization to PVP or control group, which was revealed to study staff and caregivers prior to revealing randomization to exome sequencing. Randomization resulted in enrolling 59 to the PVP study arm and 53 to the control group, audio-recording patients' in-person clinic visits. Enrollment was curtailed when COVID-19 shut down in-person appointments.

Descriptive statistics (e.g., means, standard deviation) were used to report continuous variables. Categorical variables were reported with frequencies and percentages. Bivariate analyses were used to characterize between-group comparison (PVP vs. control) on the primary outcomes (i.e., the total number of questions and number of QPL questions), applying a two-sample t-test when an equal variance was assumed or a Welch-Satterthwaite's test if the equal variance assumption was violated. Levene's test for homogeneity of variance was used to validate the assumption. Using the same approach, we examined the bivariate effects of the proposed moderators (non-Hispanic white vs. participants of color; MoNI vs. insurance other than Medicaid, which included private and military).

A two-sample t-test or Fisher's exact test, when appropriate, was used to compare the difference in sociodemographic and clinical variables—age of caregiver and child at visit, caregiver sex, race/ethnicity, education (Bachelor's degree or greater vs. less education), marital status (married vs. non-married), employment (work for pay, Yes vs. No), annual household income (equal to or over $60K vs. less), child's insurance status, clinic (genetics vs. neurology), and study site (Mission vs. UNC)—between the PVP and control groups to test the success of randomization in distributing these variables across the groups. Variables were controlled in the regression model if they differed across groups at the $p < 0.10$ level. We also sought to examine between-group effects of study arm and the effects of proposed moderators on the primary outcomes after controlling for evidence-based potential confounders. To identify these potential confounders, we examined correlations between the primary outcomes and the number of caregivers present, caregivers' perception of child's health, group-based medical mistrust, and perceived patient-centeredness. Potential confounders were entered into the multivariate regression models as covariates if they were associated with either primary outcome at the $p < 0.10$ level. In addition, race/ethnicity or child's insurance status was entered as a potential confounder if it was not already in the model.

We used four hierarchical linear regression models to test the effect of study arm (PVP vs. control) on the two primary outcomes. Independent variables were entered as follows: the randomly assigned study arm (Step 1); the moderating variable of interest (race/ethnicity or insurance status) (Step 2); the interaction of study arm and the moderating variable (study arm X race/ethnicity or insurance status) (Step 3); and covariates (Step 4). Descriptive statistics and t-tests were used to interpret the moderation effect. The adjusted modification effect was reported as a regression coefficient, concluding statistical significance at the $p <$ 0.05 level based on a Wald-type t-test.

3. Results

3.1 Participant Characteristics

Analysis included 112 participant transcripts and surveys (59 PVP and 53 control; see Supplemental Figure 2). Participants were recruited between August 2018 and March 2020. Table 1 summarizes caregivers' and children's characteristics. Nearly all caregivers were women. About a quarter were caregivers of color. Over half the children had MoNI. Over half the caregivers reported income below $60,000 and had less education than a Bachelor's degree.

3.2 Overview of Question Asking Behavior

On average, caregivers asked 3.63 questions ($SD = 4.03$, range 0–21) and 0.72 QPL questions ($SD = 1.20$, range 0–5). In terms of the number of questions asked, the mean for caregivers in the PVP group (M_{PVP}) was greater than the mean for caregivers in the control group (M_{control}) ($M_{\text{PVP}} = 4.36$, $SD_{\text{PVP}} = 4.66$ vs. $M_{\text{control}} = 2.83$, $SD_{\text{control}} = 3.03$, $t_{110} = 2.03$, $p = 0.045$, Cohen's d = 0.39), including QPL questions ($M_{\text{PVP}} = 1.05$, $SD_{\text{PVP}} = 1.39$ vs. $M_{\text{control}} = 0.36$, $SD_{\text{control}} = 0.81$, $t_{94.9} = 3.25$, $p = 0.002$, Cohen's d = 0.61). Non-Hispanic white caregivers tended to ask more questions than participants of color ($M_{\text{non-Hispanic white}} = 4.08$, $SD_{\text{non-Hispanic white}} = 4.38$, vs. $M_{\text{color}} = 2.36$, $SD_{\text{color}} = 2.82$, $t_{105} = 1.93$, $p = 0.056$); this difference reached significance for the QPL questions ($M_{\text{non-Hispanic white}} = 0.87$, $SD_{\text{non-Hispanic white}} = 1.27$, vs. $M_{\text{color}} = 0.32$, SD_{color} 0.86, $t_{105} =2.12$, $p = 0.036$). Caregivers of children with insurance other than Medicaid asked more questions than those of children with MoNI ($M_{\text{non-Medicaid}} = 4.94$, $SD_{\text{non-Medicaid}} = 5.05$, vs. $M_{\text{MoNI}} = 2.69$, $SD_{\text{MoNI}} = 2.78$, $t_{66.1} = 2.76$, $p = 0.007$), including QPL questions ($M_{\text{non-Medicaid}} = 1.04$, $SD_{\text{non-Medicaid}} = 1.35$, vs. $M_{\text{MoNI}} = 0.49$, $SD_{\text{MoNI}} = 1.03$, $t_{110} = 2.44$, $p = 0.016$).

3.3 Evaluation of potential confounders

Analyses revealed differences across study arms ($p < 0.10$) in education (48% with a Bachelor's degree or more in the PVP group vs. 23% in the control, $p = 0.009$) and age of child at visit ($M_{\text{PVP}} = 4.45$, $SD_{\text{PVP}} = 3.80$ vs. $M_{\text{control}} = 5.87$, $SD_{\text{control}} = 4.19$, $t_{110} = -1.89$, $p = 0.062$). (See Supplemental Table 1 for statistics of all comparisons). Correlation analyses of the primary outcomes and these potential confounding variables (Supplemental Table 2; descriptive statistics in Supplemental Table 3) revealed that having additional caregivers at the visit was associated with asking more total questions ($p = 0.001$), but not more QPL questions ($p = 0.259$). Also, a marginally significant correlation suggested a trend towards having a more positive perception of the child's health being associated with asking fewer total questions ($p = 0.060$), but not fewer QPL questions ($p = 0.158$).

3.4 Hypothesis testing

Group Effects on Total Number of Questions Asked with Race/Ethnicity as a Moderator (Table 2).—Step 1 revealed an effect of study arm—participants in the PVP group asked more total questions. Step 2 revealed no main effect of race/ethnicity, although the effect of study arm became marginally significant once race/ethnicity was in the model. Step 3 revealed a marginally significant interaction between study group and race/ethnicity. Non-Hispanic white caregivers in the PVP group asked more questions than their counterparts in the control group ($M_{\mathrm{PVP}} = 4.98$, $SD_{\mathrm{PVP}} = 5.03$ vs. $M_{\mathrm{control}} = 2.82$, $SD_{\mathrm{control}} = 2.92$, $t_{77} = 2.21$, $p = 0.030$); for participants of color, there was no effect of study arm on the total number of questions asked ($M_{\mathrm{PVP}} = 1.82$, $SD_{\mathrm{PVP}} = 1.60$ vs. $M_{\mathrm{control}} = 2.71$, $SD_{\mathrm{control}} = 3.39$, $t_{26} = -0.81$, $p = 0.426$) (Supplemental Figure 3). In Step 4, which controlled for potential confounders, the interaction was not significant; however, more caregivers present was associated with more questions asked and higher education tended to associate with more questions asked.

Group Effects on Number of QPL Questions Asked with Race/Ethnicity as a Moderator (Table 3).—Step 1 revealed an effect of study arm, such that participants in the PVP group asked more QPL questions. Step 2 revealed no main effect of race/ethnicity; the main effect of study arm remained significant with race/ethnicity in the model. Step 3 revealed a marginally significant interaction. Analyses found non-Hispanic white caregivers in the PVP group asked more QPL questions than those in the control group ($M_{\mathrm{PVP}} = 1.26$, $SD_{\mathrm{PVP}} = 1.48$ vs. $M_{\mathrm{control}} = 0.33$, $SD_{\mathrm{control}} = 0.60$, $t_{63.0} = 3.84$, $p < 0.001$). For participants of color, there was no effect of group on the number of QPL questions asked ($M_{\mathrm{PVP}} = 0.36$, $SD_{\mathrm{PVP}} = 0.67$ vs. $M_{\mathrm{control}} = 0.29$, $SD_{\mathrm{control}} = 0.99$, $t_{26} = 0.20$, $p = 0.840$) (Supplemental Figure 4). In Step 4, which controlled for potential confounders, the interaction was not significant; however, being in the PVP group (for non-Hispanic whites) and higher education were associated with more QPL questions asked.

Group Effects on Total Number of Questions Asked with Child's Insurance Status as a Moderator (Table 4).—Here, Step 1 was the same as in Table 2. Step 2 showed a main effect of child's insurance status and that the effect of study arm remained significant even after controlling for child's insurance status. Step 3 revealed a significant interaction. Among caregivers of children with insurance other than Medicaid, those in the PVP group asked more questions than those in the control group ($M_{\mathrm{PVP}} = 6.92$, $SD_{\mathrm{PVP}} = 5.86$ vs. $M_{\mathrm{control}} = 2.87$, $SD_{\mathrm{control}} = 2.93$, $t_{34.1} = 3.01$, $p = 0.005$). For caregivers of children with MoNI, there was no effect of study arm on the number of questions asked ($M_{\mathrm{PVP}} = 2.60$, $SD_{\mathrm{PVP}} = 2.45$ vs. $M_{\mathrm{control}} = 2.80$, $SD_{\mathrm{control}} = 3.16$, $t_{63} = -0.29$, $p = 0.775$) (Supplemental Figure 5). In Step 4, which controlled for other covariates, the interaction remained significant. In addition, more caregivers present was associated with more questions asked.

Group Effects on Number of QPL Questions Asked with Child's Insurance Status as a Moderator (Table 5).—Step 1 was the same as that in Table 3. Step 2 revealed a main effect of child's insurance status, and the effect of study arm remained significant after controlling for child's insurance status. Step 3 revealed a marginally significant interaction between study arm and child's insurance status, such that among caregivers of children with insurance other than Medicaid, those in the PVP group asked more QPL questions than in the control ($M_{\text{PVP}} = 1.63$, $SD_{\text{PVP}} = 1.50$ vs. $M_{\text{control}} = 0.43$, SD_{control} 0.84, $t_{36.6} = 3.37$, $p = 0.002$). For caregivers of children with MoNI, there was no effect of study arm on the number of QPL questions asked ($M_{\text{PVP}} = 0.66$, $SD_{\text{PVP}} = 1.19$ vs. $M_{\text{control}} = 0.30$, $SD_{\text{control}} = 0.79$, $t_{63} = 1.40$, $p = 0.166$) (Supplemental Figure 6). In Step 4, which controlled for other covariates, the interaction became significant and higher education was associated with more QPL questions asked.

4. Discussion and Conclusion

4.1 Discussion

We examined the effects of a PVP intervention that combined a QPL and educational booklet, hypothesizing that it would increase question asking among caregivers attending a pediatric specialty appointment for their child's undiagnosed health condition. Like prior research, question asking (including asking questions from the QPL itself) was conceptualized as an indicator of caregivers' engagement in shared decision making [11]. Compared to the control group, caregivers who received the PVP intervention asked more questions, including more QPL questions, indicating our intervention had the intended effect. However, this effect became more nuanced when considering differences by race/ethnicity and insurance status.

When developing our intervention, we wanted to increase question asking among caregivers from underrepresented (defined as patients of a race/ethnicity other than non-Hispanic white) and medically underserved (defined as children having MoNI) populations, who in prior studies have been shown to ask fewer questions, on average [9,15–20]. We found that caregivers of children with MoNI asked fewer questions than those of children covered by insurance other than Medicaid. Additionally, a marginally significant association suggested that caregivers of color may ask fewer questions than non-Hispanic white caregivers. However, the PVP intervention had different effects across groups. Caregivers of children with insurance other than Medicaid asked more questions if they received the PVP compared to their counterparts in the control group. However, in caregivers of children with MoNI, question asking was not statistically different among those who received the PVP versus those who did not. A similar pattern was found for caregivers of color and non-Hispanic white caregivers. Analyses suggest that receiving the PVP increased question asking in non-Hispanic white caregivers but not in caregivers of color. Thus, the positive effects of the PVP were mostly observed in the traditionally served populations.

After controlling for potential confounders in the model, the moderating effect of caregiver race/ethnicity became non-significant for predicting total and QPL questions asked. Having more education (in the model to predict the number of QPL questions), and more caregivers present (in the model to predict total number of questions), were associated with asking more questions, suggesting that the effect of race/ethnicity on intervention efficacy could be partially explained by differences in education and number of caregivers present. These findings should be interpreted in light of the systemic factors contributing to differences in educational attainment in people of color compared to non-Hispanic whites [32,33].

More research is needed on how systemic factors, cultural differences, and power dynamics impact question asking by caregivers of color to develop beneficial interventions. Additional research is also needed to evaluate why caregivers of children with MoNI who received the intervention did not ask more questions than their counterparts in the control group. Potential confounders did not provide evidence to help explain this finding—the interactions between insurance status and intervention group were not diminished when covariates were added to the models for total questions asked or for QPL questions.

Qualitative research may elucidate why our PVP intervention did not affect question asking in caregivers of color and those with children with MoNI. Race/ethnicity and insurance status represent various socioeconomic, social, cultural, and other factors that may have associations with question asking and, more broadly, interactions with healthcare providers [34,35]. We believe it may be worthwhile to investigate whether elements of socioeconomic deprivation may be playing a role. For instance, since having low income is a requirement for qualifying for Medicaid, caregivers of children with MoNI may have more daily stressors and less time to review the PVP materials, so shorter intervention materials may be more effective for these participants. In fact, other studies reveal that providing patients with just 3 “generic” questions helps patients get information in medical appointments and leaves them with similar perceptions of their level of involvement in appointments compared to those who received QPLs [36,37]. Although our PVP materials were measured for easy readability, the 11 QPL questions, in addition to the booklet, may have been too burdensome, resulting in lower efficacy in this population. Moreover, previous research revealing the effectiveness of QPLs has occurred in oncology settings among patients with diagnoses [10,11,21,38–40]. In these settings, QPLs can focus on specific questions, like prognosis or recommended treatments, increasing their effectiveness [9,11,41]. Given our setting—initial appointments for potentially genetic conditions—our QPL questions had to be relevant to genetic conditions and testing, but broad enough to cover diverse symptoms and conditions. It may have been too broad to help people who are already less likely to ask questions in medical appointments [6–8].

4.2 Limitations

Our study’s sample size was smaller than intended because COVID-19 curtailed in-person appointments during the study. Nevertheless, our findings could inform a trial with a larger sample, ideally using mixed methods to understand participants’ perspectives on PVP materials and any effect on question asking. A qualitative component and additional quantitative measures (e.g., of relevant beliefs that may affect question asking) may address a second limitation: race/ethnicity and child’s insurance status are broad categories that obscure effects of a variety of potentially important factors affecting question asking. However, this study’s strengths include a diverse sample, rigorous assessment of question asking using audio-recorded clinical encounters, and ability to control for a number of potential confounds to help inform the design of additional studies. These strengths are important to help understand and address disparities in health care and provide guidance for future in-depth investigations of factors that impact engagement and effective methods for addressing this important issue.

4.3 Conclusion

Shared decision making may improve patient outcomes by, in part, enhancing communication between patients, family members, and providers. Addressing disparities in communication in health care settings is critical. Our PVP intervention worked less effectively among underserved groups, indicating that to attain equitable benefits across populations, a variety of interventions are needed as opposed to a single, one-size-fits-all approach. These findings underscore the need for additional, in-depth research on interventions to improve communication between providers and caregivers and ensure that research benefits are widely accessible to diverse populations.

4.4 Practice Implications

Given unequal power dynamics between patients and clinicians, simply providing patients and caregivers tools to support question asking may not be sufficient to increase engagement. Instead, efforts to encourage *providers* to support question asking may be more effective in promoting engagement of underserved and underrepresented patients [9,12,21]. Physicians should be trained on implicit and explicit biases that may impact their interactions with various patient populations. Prior studies demonstrate that patients with Medicaid or no insurance report worse clinical experiences, unfair treatment, and providers not listening to or answering their questions, which they attribute to their insurance status [42–44]. In addition, physicians may perceive patients of low SES, which is linked to insurance status, as less intelligent and responsible, give them less information, and listen to them less carefully than other patients [6,8]. Thus, improving information sharing and shared decision making in patient-provider interactions likely requires changes by patients and providers.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data Availability Statement

Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

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Highlights:

- A question prompt list increased question asking among pediatric patient caregivers
- But the question prompt list worked less effectively among underserved groups
- Additional interventions are needed to ensure research benefits diverse populations
- Improving engagement of underserved patients also requires changes by providers

Table 1.

Descriptive Statistics of Demographics and Clinical Variables

	All	PVP (*n* = 59)	Control (*n* = 53)
		M **(*SD*, Range) or Frequency (Percentage[*])**	
Demographics			
Age of caregiver at visit	36.1 (7.7, 20.4–63.1)	36.4 (7.4, 20.4–53)	35.8 (8.2, 22.8–63.1)
Sex			
Female	108 (96%)	58 (98%)	50 (94%)
Male	4 (4%)	1 (2%)	3 (6%)
Race/ethnicity			
White, non-Hispanic	79 (74%)	46 (81%)	33 (66%)
African American/Black, non-Hispanic	12 (11%)	7 (12%)	5 (10%)
Hispanic/Latino(a) Only	6 (6%)	2 (4%)	4 (8%)
Asian	3 (3%)	1 (2%)	2 (4%)
American Indian, Native American, or Alaska Native	4 (4%)	0 (0%)	4 (8%)
Other	3 (3%)	1 (2%)	2 (4%)
Child’s insurance status			
No insurance	3 (3%)	2 (3%)	1 (2%)
Has insurance			
Private	39 (35%)	20 (34%)	19 (36%)
Medicaid	58 (52%)	29 (49%)	29 (55%)
Military	8 (7%)	4 (7%)	4 (8%)
Private and Medicaid[†]	3 (3%)	3 (5%)	0 (0%)
Military and Medicaid[†]	1 (1%)	1 (2%)	0 (0%)
Education			
High school or less	30 (29%)	14 (25%)	16 (33%)
Some post-high school training	36 (35%)	15 (27%)	21 (44%)
Bachelor’s degree	24 (23%)	16 (29%)	8 (17%)
Master’s degree or above	14 (13%)	11 (20%)	3 (6%)
Marital status			
Married	66 (65%)	34 (62%)	32 (68%)
Living with partner	7 (7%)	5 (9%)	2 (4%)
Divorced	5 (5%)	3 (5%)	2 (4%)
Separated	3 (3%)	2 (4%)	1 (2%)
Widowed	1 (1%)	1 (2%)	0 (0%)
Single, never married	20 (20%)	10 (18%)	10 (21%)
Work for pay			
Yes	63 (61%)	33 (59%)	30 (63%)
No	41 (39%)	23 (41%)	18 (38%)
Income			
\$5,000 – \$24,999	33 (33%)	17 (30%)	16 (36%)

	All	**PVP (*n* = 59)**	**Control (*n* = 53)**
		***M* (*SD*, Range) or Frequency (Percentage[*])**	
$25,000 – $59,999	26 (26%)	14 (25%)	12 (27%)
$60,000 – $119,999	24 (24%)	13 (23%)	11 (24%)
$120,000 or more	18 (18%)	12 (21%)	6 (13%)
Age of child at visit	5.12 (4.04, 0.4–16.0)	4.4 (3.8, 0.4–15.0)	5.9 (4.2, 0.4–16.0)
Clinical Factors			
Clinic			
Genetics	100 (89%)	52 (88%)	48 (91%)
Neurology	12 (11%)	7 (12%)	5 (9%)
Study site			
Mission	34 (30%)	18 (31%)	16 (30%)
UNC	78 (70%)	41 (69%)	37 (70%)

[*] Percentages were calculated after excluding missing data.

[+] Counted as Medicaid in analyses

Table 2.

Summary of Multiple Regression Analyses Predicting Total Number of Questions Asked (Race/Ethnicity as the Moderator

Outcome	**Total Number of Questions Asked**							
	Unadjusted Model		**Adjusted Model** [a]		**Moderation Model**		**Adjusted Model** [b]	
	B (se)	***P***	***B (se)***	***P***	***B (se)***	***P***	***B (se)***	***P***
Step 1								
Pre-visit preparation (ref: Control)	1.526 (0.752)	0.045	1.374 (0.786)	0.084	2.160 (0.904)	0.019	1.138 (0.956)	0.237
Step 2								
Participant of color (ref: non-Hispanic white)			−1.459 (0.893)	0.105	−0.112 (1.184)	0.925	−0.263 (1.179)	0.824
Step 3								
Pre-visit preparation X Participant of color					−3.048 (1.781)	0.090	−1.607 (1.775)	0.368
Step 4								
Medicaid and no insurance (ref: Insurance other than Medicaid)							−1.204 (0.922)	0.195
Bachelor’s degree or greater education (ref: less education)							1.688 (0.939)	0.076
Age of child at visit							−0.019 (0.100)	0.851
Number of caregivers present							2.374 (0.773)	0.003
Perception of child’s health							−0.026 (0.022)	0.242

[a] Model included race/ethnicity as the moderating variable of interest.

[b] Model controlled child’s insurance status, caregiver educational attainment because educational attainment was higher in the PVP study arm compared to the Control study arm ($p = 0.009$), age of child at visit because it was lower in the PVP study arm compared to the Control study arm ($p = 0.062$), and the number of caregivers present and perception of child’s health because they were significantly correlated with the total number of questions asked ($p = 0.001$ and 0.060, respectively).

Table 3.

Summary of Multiple Regression Analyses Predicting Number of QPL Questions Asked (Race/Ethnicity as the Moderator)

Outcome	**Number of QPL Questions Asked**							
	Unadjusted Model		**Adjusted Model** [a]		**Moderation Model**		**Adjusted Model** [b]	
	B (se)	***P***	***B (se)***	***P***	***B (se)***	***P***	***B (se)***	***P***
Step 1								
Pre-visit preparation (ref: Control)	0.692 (0.219)	0.002	0.706 (0.223)	0.002	0.928 (0.257)	< 0.001	0.718 (0.282)	0.013
Step 2								
Participant of color (ref: non-Hispanic white)			−0.418 (0.253)	0.102	−0.039 (0.336)	0.907	−0.039 (0.348)	0.911
Step 3								
Pre-visit preparation X Participant of color					−0.858 (0.505)	0.092	−0.594 (0.524)	0.260
Step 4								
Medicaid and no insurance (ref: Insurance other than Medicaid)							−0.097 (0.272)	0.721
Bachelor’s degree or greater education (ref: less education)							0.623 (0.277)	0.027
Age of child at visit							0.006 (0.030)	0.849
Number of caregivers present							0.138 (0.228)	0.546
Perception of child’s health							−0.006 (0.007)	0.357

[a] Model included race/ethnicity as the moderating variable of interest.

[b] Model controlled child’s insurance status, caregiver educational attainment because educational attainment was higher in the PVP study arm compared to the Control study arm ($p = 0.009$), age of child at visit because it was lower in the PVP study arm compared to the Control study arm ($p = 0.062$), and the number of caregivers present and perception of child’s health because they were significantly correlated with the total number of questions asked ($p = 0.001$ and 0.060, respectively).

Table 4.

Summary of Multiple Regression Analyses Predicting Total Number of Questions Asked (Child's Insurance Status as the Moderator)

Outcome	**Total Number of Questions Asked**							
	Unadjusted Model		**Adjusted Model** [a]		**Moderation Model**		**Adjusted Model** [b]	
	B (se)	***P***	***B (se)***	***P***	***B (se)***	***P***	***B (se)***	***P***
Step 1								
Pre-visit preparation (ref: Control)	1.526 (0.752)	0.045	1.588 (0.724)	0.030	4.047 (1.077)	< 0.001	3.369 (1.211)	0.007
Step 2								
Medicaid and no insurance (ref: Insurance other than Medicaid)			−2.288 (0.733)	0.002	−0.070 (1.023)	0.946	0.925 (1.136)	0.418
Step 3								
Pre-visit preparation X Medicaid and no insurance					−4.247 (1.416)	0.003	−4.302 (1.474)	0.004
Step 4								
Participant of color (ref: non-Hispanic white)							−1.018 (0.845)	0.231
Bachelor's degree or greater education (ref: less education)							1.334 (0.912)	0.147
Age of child at visit							−0.030 (0.095)	0.751
Number of caregivers present							2.074 (0.750)	0.007
Perception of child's health							−0.031 (0.021)	0.142

[a] Model included child's insurance status as the moderating variable of interest.

[b] Model controlled caregiver race/ethnicity, caregiver educational attainment because educational attainment was higher in the PVP study arm compared to the Control study arm ($p = 0.009$), age of child at visit because it was lower in the PVP study arm compared to the Control study arm ($p = 0.062$), and the number of caregivers present and perception of child's health because they were significantly correlated with the total number of questions asked ($p = 0.001$ and 0.060, respectively).

Table 5.

Summary of Multiple Regression Analyses Predicting Number of QPL Questions Asked (Child’s Insurance Status as the Moderator)

Outcome	**Number of QPL Questions Asked**							
	Unadjusted Model		**Adjusted Model** [a]		**Moderation Model**		**Adjusted Model** [b]	
	B (se)	***p***	***B (se)***	***P***	***B (se)***	***P***	***B (se)***	***P***
Step 1								
Pre-visit preparation (ref: Control)	0.692 (0.219)	0.002	0.708 (0.213)	0.001	1.190 (0.324)	< 0.001	1.172 (0.365)	0.002
Step 2								
Medicaid and no insurance (ref: Insurance other than Medicaid)			−0.570 (0.216)	0.009	−0.135 (0.308)	0.663	0.399 (0.342)	0.247
Step 3								
Pre-visit preparation X Medicaid and no insurance					−0.833 (0.426)	0.053	−0.990 (0.444)	0.028
Step 4								
Participant of color (ref: non-Hispanic white)							−0.312 (0.255)	0.224
Bachelor’s degree or greater education (ref: less education)							0.548 (0.275)	0.049
Age of child at visit							0.002 (0.029)	0.959
Number of caregivers present							0.072 (0.226)	0.750
Perception of child’s health							−0.008 (0.006)	0.218

[a] Model included child’s insurance status as the moderating variable of interest.

[b] Model controlled caregiver race/ethnicity, caregiver educational attainment because educational attainment was higher in the PVP study arm compared to the Control study arm ($p = 0.009$), age of child at visit because it was lower in the PVP study arm compared to the Control study arm ($p = 0.062$), and the number of caregivers present and perception of child’s health because they were significantly correlated with the total number of questions asked ($p = 0.001$ and 0.060, respectively