

Parent Perceptions of Person-Centered Care: A Randomized Controlled Trial of the Childhood Hearing Loss Question Prompt List for Parents

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Abstract

Objective: When children are identified with hearing loss, parents are often unsure about what they need to know. A Childhood Hearing Loss Question Prompt List for Parents (CHLQPL) was recently developed to help parents and providers address questions. This exploratory study investigated if parents who used the CHLQPL in their audiology appointment perceived their appointment as more person-centered than parents who received treatment as usual. Parent perceptions regarding use of the CHLQPL during the audiology appointment was also sought.

Design: Randomized control trial.

Study sample: Parents of children with permanent hearing loss ($N = 50$).

Results: There were no statistically significant differences found between the intervention and control groups in parent perception of person-centeredness. Parents who used the CHLQPL found it useful and would recommend its use to others.

Conclusions: Further research is needed to explore other factors and benefits of including the CHLQPL in supporting parents of children who are deaf or hard of hearing. Audiologists can incorporate the CHLQPL to facilitate communication on topics of importance to parents and to facilitate parent engagement in a shared process.

Keywords: question prompt list; childhood hearing loss; parent

Acronyms: CHLQPL = Childhood Hearing Loss Question Prompt List for Parents; DHH = deaf or hard of hearing; PCC = person-centered care; QPL = question prompt list

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Pediatric hearing loss is one of the most common congenital conditions with approximately three infants identified with permanent hearing loss per every 1000 births (Centers for Disease Control and Prevention, 2017); however, the diagnosis is often unexpected as more than 90% of parents have typical hearing (Mitchell & Karchmer, 2006). Following hearing loss identification, parents must adjust to this information and navigate the intervention process to learn how to meet their child's needs. In healthcare, Question Prompt Lists (QPL) are often used to help patients consider questions to talk about with their provider and to facilitate their ability to raise issues that are on their mind related to the impact of the condition on their life. Recently, a QPL for permanent childhood hearing loss was developed for parents to support person-centered care (PCC) and focus on parents' immediate questions and concerns during audiology sessions (English et al., 2017).

PCC is applicable broadly in healthcare and reflects an approach that embraces a shared process, in contrast to the medical model of service delivery, and includes understanding and addressing client priorities within each session. PCC encourages patients to be active participants by creating an environment that respects their autonomy and supports a shared process (Grenness et al., 2014). Parents of children who are deaf or hard of hearing (DHH) often experience challenges adjusting to and managing needs related to their child's hearing loss, underscoring the need to address issues of importance to parents. For example, parents have reported wanting more information on a range of topics, including how to meet other parents of children who are deaf or hard of hearing, how to keep hearing aids on their child, how to obtain loaner hearing aids, and how to find financial assistance (Muñoz et al., 2016). As parents adjust to the diagnosis they may

experience a range of emotions including but not limited to grief (Kurtzer-White & Luterman, 2003), increased stress levels (Lederberg, 2002), feeling overwhelmed (Lesperance et al., 2018), and shock (Gilbey, 2010). PCC provides a holistic perspective rather than solely focusing on the health condition (Reynolds, 2009), and values active involvement in the treatment process that respects the family's beliefs (Kiwanuka et al., 2019). Through PCC, audiologists target support specific to each family's needs, based on their values, goals, challenges and barriers; thus, helping parents to more effectively meet the needs of their child.

QPLs have been used to aid communication between the patient, their family, and the health care provider. The Childhood Hearing Loss Question Prompt List (CHLQPL) was created by parents of children who are DHH and audiologists with the goal to promote PCC by having conversations on a broader range of topics of importance to parents (English et al., 2017). The CHLQPL provides a list of questions that families may indicate, thus empowering them to raise issues on their mind for inclusion in discussion during their appointment. Through an iterative process, 32 questions represented in four categories were identified for inclusion in the final version: 1) Our Child's Diagnosis; 2) Family Concerns; 3) Management of Devices; 4) Support Systems. The aim of the current exploratory study was two-fold. First, to explore if parents who used the CHLQPL in their audiology appointment perceived their appointment as more person-centered than parents who received treatment as usual. Second, to obtain feedback from parents on their use of the CHLQPL instrument.

Method

Participants and Procedures

Participants were recruited from two audiology clinics in the western and midwestern United States respectively. Study procedures were reviewed and approved by the corresponding institutional review boards. To be included in the study, parents were proficient in English, had no prior experience using the CHLQPL, and their child had been previously fitted with hearing technology. Parents were presented with a study flyer at the time of their scheduled audiology appointment (e.g., hearing monitoring or hearing device follow-up). Those who were interested signed a consent and were enrolled in the study. A sample size of 50 was determined a priori based on an effect size of $d = 0.3$, power of .85, and an alpha level of .05.

Participants were randomly assigned to either the CHLQPL or No CHLQPL condition. Random assignment was conducted using a random number generator with odd and even numbers representing each condition. Due to a communication error, one group began assignments by alternating participants into each group before using the random number generator, resulting in unequal group sizes. A total of 50 parents were enrolled, 22 were allocated to the intervention group and 28 to the control group (see Table 1 for participant demographic information).

Participants assigned to the CHLQPL condition were given a copy of the CHLQPL (available on the Phonak website) on the day of their appointment to review before seeing their audiologist. Audiologists were instructed to inquire about questions participants had from the CHLQPL and to facilitate discussion about parents' concerns using the CHLQPL as a springboard. Participants assigned to the No CHLQPL condition received treatment as usual. At the end of the appointment, participants completed the study survey. The CHLQPL condition survey contained items to obtain their feedback on use of the CHLQPL.

Measures

Basic Information Form

Demographic information (e.g., age, ethnicity, family income) on the parent and child, along with questions about the child's hearing loss and use of hearing technology was gathered using this measure (18 items). Two additional questions explored the extent parents agreed with statements on a six-point scale (1 = *strongly disagree* to 6 = *strongly agree*): (a) the audiologist wanted to know about my priorities for what I felt was important to talk about today, and (b) I had enough time to talk about my questions/concerns with the audiologist.

Parent Perceptions of Audiology Consultation (PPAC)

This is a post-consultation patient-centeredness questionnaire for doctor visits (Little et al., 2001), and was modified for the study with permission. Wording on the questionnaire was changed (i.e., doctor to audiologist; the problem to child's hearing; symptoms to concerns; illness to hearing difficulty) and section headings were modified (i.e., health to hearing; problem to hearing), so the instrument wording would be relevant for audiology services. The questionnaire assesses five aspects of the patient-centered model: communication and partnership (10 items), personal relationship (3 items), hearing promotion (2 items), positive and clear approach to hearing (3 items), and interest in effect on life (2 items). Items were rated from 1 (*very strongly disagree*) to 7 (*very strongly agree*). This questionnaire has shown convergent validity and its subscales have good to excellent internal reliability (Little et al., 2001). Internal reliability for our sample was excellent (Cronbach's $\alpha = .98$).

Working Alliance Inventory – Short Revised (WAI-SR: Hatcher & Gillaspay, 2006)

The WAI-SR is a 12-item measure of therapeutic alliance (a core aspect of PCC) across three domains: (a) agreement on treatment tasks, (b) agreement on treatment goals, and (c) development of clinician-patient bond. The WAI-SR has demonstrated good to excellent internal reliability, stable factor structure, and convergent validity (Hatcher & Gillaspay, 2006; Munder et al., 2009). Items were rated from 1 to 5 with higher scores indicating stronger working alliance. Internal reliability in our sample was good (Cronbach's $\alpha = .89$). This measure was only administered to a subset of our sample ($n = 18$) due to its later inclusion (see Statistical Analysis section for detail).

Table 1
Child and Family Demographics

Questionnaire Items	QPL (<i>n</i> = 22)		No QPL (<i>n</i> = 28)	
	<i>M</i> (<i>SD</i>)	%(<i>n</i>)	<i>M</i> (<i>SD</i>)	%(<i>n</i>)
Child's current age (in months)	57(28.23)		45(32.07)	
Age hearing loss identified? (in months)	24(30.07)		18(31.47)	
Unilateral hearing loss		17%(4)		21%(6)
Bilateral hearing loss		78%(18)		79%(22)
Parent reported degree of hearing loss				
Mild		17%(4)		32%(9)
Moderate		57%(13)		46%(13)
Severe		9%(2)		11%(3)
Profound		13%(3)		11%(3)
Hearing technology				
Hearing aid		70%(16)		71%(20)
Cochlear implant		22%(5)		14%(4)
Bone anchored hearing aid		4%(1)		18%(5)
FM system (with hearing device)		30%(7)		3%(1)
Other		4%(1)		
Age fit with hearing technology (in months)	31(30.18)		24(31.31)	
Hours of device use*	9(2.80)		9(4.25)	
Additional disabilities				
Yes		39%(9)		39%(11)
No		52%(12)		61%(17)
Child's racial identification				
Asian		4%(1)		
Black		39%(9)		54%(15)
White		44%(10)		39%(11)
Multiracial		4%(1)		7%(2)
Other family members had a hearing loss since childhood		13%(3)		25%(7)
Primary caregiver's racial identification				
Asian				4%(1)
Black		4%(1)		%(2)
White		87%(20)		89%(25)
Primary caregiver's educational level				
Less than 7 th grade				3%(1)
High school graduate				11%(3)
Partial college (at least one year)		4%(1)		7%(2)
College education		35%(8)		43%(12)
Graduate degree		48%(11)		36%(10)
Family annual income				
Less than \$20,000				4%(1)
\$21-40,000		9%(2)		14%(4)
\$41-80,000		26%(6)		21%(6)
More than \$81,000		48%(11)		57%(16)
Prefer not to answer		9%(2)		4%(1)

Note. QPL = Question Prompt List; **n* = 21.

CHLQPL Use

The CHLQPL is a new measure and parent perceptions on use of the instrument has value and can inform audiologists considering incorporating the instrument in their practice. Participants in the CHLQPL condition were asked an additional 6 questions to obtain information on their perceptions, and they were asked to estimate duration spent discussing the CHLQPL in session. Five items measured use of the CHLQPL with item scores ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Higher scores reflect more positive perceptions. For one item parents were asked to circle all that applied regarding use of the CHLQPL, with the stem "Using the QPL..." (i.e., was a comfortable experience; helped my discussion with the audiologist; seemed unnecessary; caused some anxiety for me; supported my understanding of my child's hearing loss).

Statistical Analysis

The IBM Statistical Package SPSS v25 was used for data analyses (IBM SPSS, Statistics for Macintosh, Version 25.0). Descriptives (e.g., means, standard deviations) were calculated for demographic variables and QPL feedback. Between-group comparisons (*t*-tests) were used to determine difference in outcomes of interest: PPAC and WAI-SR.

Preliminary *t*-test analyses ($n = 29$) revealed no differences between conditions on the PPAC ($M_{\text{QPL}} = 117.1$, $M_{\text{No QPL}} = 126.8$, $p = .309$). Because we wanted to examine if the PPAC lacked sensitivity to detect differences in our construct of interest, patient centeredness, or if the CHLQPL simply did not enhance patient centeredness, we later added the WAI-SR to the study.

Results

Parents reported information about their child's condition (see Table 1). There were differences in the demographic make-up between the groups. The children in the QPL group were older compared to the no QPL group ($d = .4$), and they received hearing technology later ($d = .23$). Over one-third of the children had additional disabilities (vision [QPL 26%; no QPL 7%]; intellectual [QPL 9%; no QPL 14%]; autism [QPL 4%; no QPL 4%]; syndromic [QPL 13%; no QPL 7%]; emotional/mental [QPL 9%; no QPL 0%]; physical [QPL 13%; no QPL 14%]; and other [QPL 13%; no QPL 14%]). Some families reported a history of childhood hearing loss (sibling [QPL 9%; no QPL 9%]; parent [QPL 4%; no QPL 4%]; and other [QPL 9%; no QPL 9%]).

All parents were asked the extent they agreed with two statements on a six-point scale (1 = *strongly disagree* to 6 = *strongly agree*): (a) the audiologist wanted to know about my priorities for what I felt was important to talk about today, and (b) I had enough time to talk about my questions/concerns with the audiologist. The majority strongly agreed with both statements (a: [QPL 78%; no QPL 82%]; b: [QPL 86%; no QPL 89%]). One person strongly disagreed in the no QPL group that the audiologist wanted to know about their priorities.

Parent Perception Measures

Parents completed two questionnaires regarding their perception of working with the audiologist, the PPAC and the WAI-SR (see Table 2). An independent samples *t*-test was conducted to compare the QPL and no QPL conditions. There was no statistically significant difference between parent perceptions on the PPAC (total scale scores) in the QPL group compared to the no QPL group ($M_{\text{QPL}} = 124.09$, $SD = 26.55$; $M_{\text{No QPL}} = 124.07$, $SD = 11.97$); $t(49) = -.891$, $p = .101$. Parent responses on the WAI-SR (total scale scores) also revealed no statistically significant differences ($M_{\text{QPL}} = 628.8$, $SD = 472.1$; $M_{\text{No QPL}} = 695.5$, $SD = 449.1$); $t(49) = -.515$, $p = .322$. Results from the WAI-SR and the PPAC suggest that the parents who used the CHLQPL did not perceive their audiology session as more person-centered when compared to parents who did not use the CHLQPL.

Two additional questions were asked to evaluate parent perceptions of the interaction with their audiologists. First, parents were asked if the audiologist wanted to know about their priorities for the appointment. Second, parents were asked if they had enough time to talk about their questions or concerns with the audiologist. Results indicate that the majority of parents in both groups reported the audiologist was interested in their priorities (QPL 100%, $n = 23$; no QPL 96%, $n = 27$) and that they had enough time to address their concerns (QPL 96%, $n = 22$; no QPL 100%, $n = 28$).

CHLQPL Use

Parents assigned to the QPL condition completed the CHLQPL use questionnaire. Parents estimated the amount of time the audiologist spent talking with them about their questions on the CHLQPL. Thirty-five percent ($n = 8$) estimated more than 10 minutes, 26% ($n = 6$) 6–10 minutes, 35% ($n = 8$) less than 5 minutes, and 4% ($n = 1$) reported that questions on the CHLQPL were not discussed. Parents also rated their agreement (*strongly disagree* to *strongly agree*) on five questions regarding use of the CHLQPL. The majority of parents indicated they thought the CHLQPL was easy to understand (100%; $n = 23$), helpful (91%; $n = 21$), relevant (95%; $n = 22$), they would use it again (78%; $n = 18$), and would recommend its use to other families (96%; $n = 22$). Parents selected all that apply for "Using the QPL..." (i.e., was a comfortable experience [83%]; helped my discussion with the audiologist [72%]; seemed unnecessary [70%]; caused some anxiety for me [0%]; supported my understanding of my child's hearing loss [52%]).

Discussion

The purpose of this exploratory study was to investigate if use of the CHLQPL in audiology appointments increased parent perception of person-centeredness compared to treatment as usual, and the secondary purpose was to obtain parent perceptions on use of the CHLQPL. The findings revealed no statistically significant differences in parent perception of patient-centeredness between those who used the CHLQPL in their session and those who did not.

Table 2
Person-centered Measures

Questionnaire and items	QPL M(SD)	No QPL M(SD)	t (DF)	p
Parent Perceptions of the Audiology Consultation (PPAC)	<i>n</i> = 23	<i>n</i> = 28	-0.891(49)	.101
Was interested in my worries about my child's hearing	6.48(1.34)	6.75(0.44)		
Was interested when I talked about my concerns**	6.43(1.34)	6.81(0.39)		
Was interested in what I wanted to know	6.48(1.34)	6.86(0.36)		
I felt encouraged to ask questions	6.43(1.34)	6.82(0.39)		
Was careful to explain information so I could understand	6.43(1.34)	6.86(0.36)		
Was sympathetic	6.35(1.34)	6.57(0.79)		
Interested in my thoughts about challenges experienced	6.35(1.34)	6.54(0.69)		
Discussed and agreed together what the problem was	6.30(1.36)	6.61(0.63)		
Was interested in what I wanted done	6.30(1.36)	6.57(0.69)		
Discussed and agreed on a plan for addressing challenges	6.17(1.47)	6.54(0.79)		
Knows me and understands me well	6.04(1.46)	5.93(1.25)		
Understands my emotional needs	6.00(1.48)	6.04(1.17)		
I'm confident the audiologist knows me and my history	6.00(1.45)	6.43(0.88)		
Discussed lowering risk of hearing difficulty for my child	5.96(1.61)	6.07(1.05)		
Discussed preventing future hearing difficulty for my child	5.83(1.61)	6.11(1.07)		
Explained clearly how my child is hearing*	6.09(1.48)	6.50(0.92)		
Was definite about intervention steps	6.22(1.45)	6.29(1.05)		
Was positive about how to monitor my child's hearing**	6.35(1.43)	6.37(0.97)		
Interested in effect of child's hearing loss on family life	6.04(1.49)	6.39(0.96)		
Was interested in the effect of my child's hearing loss on everyday activities	6.09(1.51)	6.50(0.75)		
Working Alliance Inventory-Short Revised (WAI-SR)	<i>n</i> = 9	<i>n</i> = 9	-0.512(49)	.322
After sessions I am clearer as to how I might be able to change.	4.56(0.53)	4.11(1.69)		
Today's session gives me new ways of looking at my problem.	4.11(0.60)	3.89(1.83)		
I believe ___ likes me.	4.78(0.44)	4.78(0.44)		
___ and I collaborate on setting goals for my sessions.	4.67(0.50)	4.78(0.67)		
___ and I respect each other.	4.78(0.44)	4.78(0.67)		
___ and I are working towards mutually agreed upon goals.	4.78(0.44)	4.78(0.67)		
I feel that _____ appreciates me. ***	4.63(0.52)	4.44(1.13)		
___ and I agree on what is important for me to work on.***	4.88(0.34)	4.89(0.33)		
___ cares about me even when I do things that he/she does not approve of. ***	4.63(0.52)	4.56(0.73)		
I feel that the things I do in sessions will help me to accomplish the changes that I want. ***	4.75(0.46)	4.56(0.88)		
___ and I have established a good understanding of the kind of changes that would be good for me. ***	4.75(0.46)	4.22(1.72)		
I believe the way we are working with my problem is correct.***	4.88(0.35)	4.89(0.33)		

Note. QPL = Question Prompt List; **n* = 22 for item; ***n* = 27 for item; ****n* = 8. For the PPAC, a higher score is consistent with greater perceived person-centered care. For the WAI-SR, a higher score is indicative of a stronger working alliance. Item ratings for the PPAC are on a 1 to 7 scale and items on the WAI-SR are on a 1 to 5 scale.

When interpreting the results, it is important to consider study limitations, including the participant population, the background of the audiologists, and the settings. The sample size was small, was not reflective of the population that makes up the United States (United States Census Bureau, 2018), and parents were recruited at the time of regularly scheduled hearing device monitoring appointments, not based on how recently their child received hearing devices. Furthermore, parents reviewed the questions at the time of their appointment, which may not have provided adequate time for parents to consider their questions. Additionally, the audiologists were experienced in pediatrics and they had established relationships with the participants. The influence of these factors on the results are not known; however, given this composition it is likely parents were more willing to ask their questions, regardless of group assignment. In addition, the study was completed at two settings, a University clinic and a Medical Clinic. The CHLQPL may enhance PCC in other environments and circumstances.

Including the CHLQPL may enhance PCC for audiologists less experienced or confident in working with the pediatric population, as it is a tool audiologists can easily incorporate into their practice to facilitate addressing questions of importance to parents. Furthermore, the CHLQPL can help parents consider questions they may not have thought to ask, prompting a more comprehensive discussion with their audiologist. The parents who used the CHLQPL indicated they would recommend its use to other parents.

A foundational aspect of PCC is understanding and addressing issues of importance through a shared process. This has been found in other areas of healthcare. In a study with cancer patients, 90% found the QPL helpful or useful in aiding communication (Clayton et al., 2007). In a review evaluating various QPLs, findings were mixed related to effectiveness to facilitate communication and encourage patient participation (Dimoska et al., 2008). For example, in the Clayton et al. (2007) study, 85% of respondents indicated the QPL encouraged them to ask more questions and 95% reported they felt the QPL made it easier to ask the physician questions, while in a larger study only 33% felt the QPL helped them ask more questions (Glynne-Jones et al., 2006). Sansoni and colleagues (2015) reviewed the use of QPLs in various health care settings and emphasized that although QPLs can aid communication, they do not replace effective communication or repair poor communication between the provider and patient.

Research in other areas of healthcare has found a range of benefits to using a QPL. For example, a study evaluating the use of a QPL for cardiac patients found that the QPL had a significant impact on patient anxiety. Researchers reported that the reduction in anxiety was likely due to better preparation for the appointment (Martinali et al., 2001). Other benefits of QPL use have included increases in the number of questions patients ask (Kinnersley et al., 2011), increase in patient knowledge

(van der Meulen et al., 2008), and a significant increase in the amount of information provided to patients and their families (Brown et al., 2001; Little et al., 2001). Parents of children with attention-deficit/hyperactivity disorder reported use of a QPL helped them ask more questions, that it was helpful for use during the initial visit, and that it would continue to be useful at future follow-up appointments (Ahmed et al., 2017). Furthermore, the pediatricians in the study reported that parents were more likely to initiate discussion of difficult topics with the assistance of the QPL.

Research Implications

Further research is needed with the CHLQPL to better understand potential benefits for parents of children who are deaf or hard of hearing and to improve audiologists' understanding of when and how to use the CHLQPL in practice. For example, it would be beneficial to explore use of the CHLQPL in various clinical settings, with audiologists less familiar with the pediatric population, during transitions (e.g., transition out of early intervention), with parents of recently identified children or who are new to the practice, use with parents over time, and use by other professionals working with the family (e.g., early interventionists). Additionally, studies exploring providers' perceptions regarding addressing the broader range of topics included in the CHLQPL and how to navigate the discussion when they may feel less confident with certain topics would be useful. Comparing the total number of questions asked and the types of questions asked when the CHLQPL is used compared to when it is not used may offer additional insights.

Conclusion

The findings of this exploratory study revealed that there was not a statistically significant difference in parent perception of person-centeredness when parents used the Childhood Hearing Loss Question Prompt List (CHLQPL) compared to appointments when the CHLQPL was not used. Further research is needed to explore other factors and benefits of including the CHLQPL in supporting parents of children who are deaf or hard of hearing.

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