Beyond the Interview Guide: Experiences of Practically and Mindfully Implementing Interview Guidelines When Conducting Research With Children and Adolescents With Chronic Conditions and Their Siblings

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Abstract

Children and adolescents who live with chronic conditions are rarely participants in research specifically focused on meeting their needs, nor in intervention planning research. There are, however, special considerations required when conducting research with children and adolescents. This article offers Interview Guidelines designed to ensure children and adolescents’ control of and comfort with interviewing and to maximize the caliber of ethically co-constructed data. We developed, tested, and revised these guidelines with 80 children and adolescents aged 5 to 17 years: 27 with complex Congenital Heart Disease (CCHD) (5–17 years) and 13 with Early Onset Scoliosis (5–12 years) and 28 siblings (7–17 years). The guidelines were further tested with 12 adolescents with Adolescent Idiopathic Scoliosis (10–16 years) and 10 children and adolescents with CCHD (8–12 years). The children and adolescents recounted stories about their everyday life and activities through digitally recorded face-to-face interviews that were transcribed. Detailed field notes were recorded before and after the interview. Our Interview Guidelines address ethics, informed assent and consent, pre-interview planning, establishing trust, and engaging children and adolescents in research. Special attention is given to involving parents in pre-interview planning and disclosing sensitive information post interview. Involving children and adolescents as research participants to gain information from them, not only about them, will assist those in planning appropriate intervention research to meet the needs of children and adolescents living with chronic conditions and their siblings.

Keywords

interviewing children, interviewing adolescents, interviewing siblings, qualitative interviewing, interviewing children and adolescents with chronic conditions, field notes, interview guidelines, congenital heart disease, early onset scoliosis

Introduction

The needs of children and adolescents living with chronic conditions are typically understood from the perspectives of caregivers and health care professionals rather than the children and adolescents themselves (Barnard et al., 2013; Fredriksen et al., 2009; Latal et al., 2009; Lauder et al., 2018; Marino et al., 2016; Vitale et al., 2008). This methodological article presents interview guidelines for conducting research with children and adolescents about living with their condition from their and their siblings’ perspectives. Children and adolescents living with health conditions that are life threatening and/or require invasive treatment have thoughts, feelings and insights that...
they can and want to share with those invested in their well-being (Birks et al., 2007).

Evidence of children’s expertise at relaying meaningful stories about their conditions exists within the cancer literature (Stewart, 2003; Woodgate, 2000; Woodgate et al., 2017) and is emerging in other conditions, including CCHD (Bjorbaekmo & Engelsrud, 2008; Desai et al., 2013). The World Health Organization mandates that children’s voices be heard in areas that directly influence their lives (Lansdown, 2011). Moreover, children and adolescents are competent to tell their stories (Clavering & McLaughlin, 2010; Dockett & Perry, 2007; Teachman & Gibson, 2013). As their perspectives are increasingly elicited (Desai et al., 2013; Levert, et al., 2017) awareness and articulation of both obvious and nuanced elements essential to ethical and co-constructed data generation with children and adolescents creates a “mindfulness” to the practical and ethical issues that may arise (Duncan et al., 2009; Woodgate et al., 2017). Respect both for the children and for their competencies is critical (Woodgate & Edwards, 2010). Establishing trust, having a mindful presence within the research encounter, and constant reflexivity among the researchers is necessary (Carter, 2009; Woodgate & Edwards, 2010). This minimizes potential harm or burden on the child and family and will help ensure that the children’s voices are fairly represented (Woodgate & Edwards, 2010).

As constructivist-oriented clinician scientists, LGR and GRR, rooted the development of these interview guidelines in pragmatism (Ikiugu & Schultz, 2006; Long et al., 2018; Morgan, 2007), with a reflexive intersubjective approach and emphasis on co-constructed realities (Charmaz, 2016). With extensive experience interviewing adults/parents we embarked on research with children, being keenly aware of the vulnerability of children engaged in research (Lane et al., 2019) especially children who had experienced repeated medical trauma from an early age (Nabors et al., 2013). Viewing both parents and children as resilient (Price et al., 2016) while acknowledging need for trauma-informed approach (Kassam-Adams & Butler, 2017) was paramount. Pragmatism fueled our desire to conduct research to solve complex challenges faced by chronically ill vulnerable yet resilient children and their parents (Long et al., 2018). Constructivism enabled us to enact our assumptions rooted in pragmatism, especially related to working with children and with parents as co-constructors. Pragmatism also helped us navigate the ethical landscape of interviewing children for research while acknowledging their vulnerability and resilience (Cascio & Racine, 2018).

Past research tends to focus on use of a single approach to elicit data from children, such as drawing or photography. What was missing in the literature as we embarked on our research were comprehensive and practical guidelines for interviewing children. The objective of this article is to provide integrated practical interview guidelines for research with children and adolescents based on analysis of methodological data from four research studies. We developed, tested, revised and refined a set of interview guidelines within studies conducted between 2013 and 2018. We generated methodological data through detailed field notes to address the research question: What approaches are best for co-constructing data with children with chronic conditions and their typically developing siblings?

**Data Sources and Analysis**

Similar to a format used by Mayaba and Wood (2015), this article is based on the analysis of methodological data from 68 interviews conducted in two studies to test and revise the interview guidelines we developed for these studies. We refined the guidelines based on 22 interviews from two additional studies. We used five sources of methodological data: the interview recordings, transcribed interviews, interviewer’s pre and post field notes, interviewer reflective journals, and team meeting notes. Journaling helped to describe the analytic process that consisted of regular, in-depth conversations among research team members about what was working and what was not working in our interviews, and what needed to change in our interview guidelines.

**The Interview Guide**

Questions from the interview guide for our studies elicited the perspectives of children with CCHD or Early Onset Scoliosis (EOS), and their siblings living with their condition (see Supplementary Material). We sensitively elicited accounts of day-to-day life as told by children and adolescents, who had survived surgery for CCHD or were undergoing multiple surgeries for EOS, and siblings from each cohort. Additionally, we generated data about the participant’s lives through use of the Pediatric Activity Card Sort (PACS) (Mandich et al., 2004), which include photographs of children engaged in everyday tasks (not used with siblings). These cards, also available on the interviewer’s iPad, helped to elicit stories about self-care, sports, leisure, play, chores and school.

**Recruitment and Participants**

When children and parents were approached for the study, the children were immediately involved in the invitation to participate. The recruiter made it clear that the study did not involve the clinic, but rather university researchers, and participation was voluntary. An initial recruitment line was that there would be no “pokes” (i.e., needles or procedures) and we would be playing with toys and talking.

In total, we interviewed 80 children and adolescents (2013–2018) of various ages with diverse range of functioning levels, including children with complex CHD who had motor, cognitive or language processing delays (Miatton et al., 2007; Mussatto et al., 2014; Snookes, et al., 2010) in the initial study. Some of the children with EOS also had development delays related to co-morbid syndromes. We initially conducted face-to-face interviews with 68 children: 27 with CCHD aged 5–17 years (13 girls), 13 with EOS, aged 5–12 years (8 girls) and 28 healthy siblings aged 5–17 years (19 girls). Integral to
the development of guidelines was the contextual information about the children. Parents reported that, in addition to CCHD or EOS, five children had cognitive delays, three had developmental delays in one or more areas, one had a hearing loss, one had a cleft palate, one was on a ventilator and had a tracheostomy, and 11 had learning disabilities. These included children with the following syndromes: VACTERL Association, DiGeorge syndrome, and Williams syndrome. Parents identified all siblings as being neurotypical. Parents determined whether their child was able to understand and respond to questions in English and tell stories about their experiences living with their condition including activity restrictions.

Interviews were 45–60 minutes, including time to build rapport and wrap up. We interviewed 44 children in their urban homes, and 15 children in their rural residences. Nine children were interviewed at a university. Eight of these did not live near their pediatric referral centre; seven had EOS and their interview was booked in conjunction with their upcoming surgery.

We further tested the guidelines; LGR and a trainee did face-to-face interviews at home or at the university with 12 children (9 girls; 10–16 years) with Adolescent Idiopathic Scoliosis (AIS) who were typically developing cognitively. In 2018, GRR conducted phone interviews with 10 children (6 girls; 8–13 years) with CCHD who had attended a camp for children with CHD.

Development of Interview Guidelines

There were two stages to developing these comprehensive interview guidelines. First, we developed a list of interview guidelines from evidence-based studies on interviewing children. Second, we tested these guidelines through interviewing children and adolescents with chronic conditions and their siblings, and over five years revised these guidelines based on methodological review. We modified our approach as interviews progressed based on feedback from the participants and parents.

We developed our initial interview guidelines with a focus on employing different ways of engaging children in research based on our literature review and our collective clinical expertise with children in pediatric occupational therapy (LGR) and advanced practice pediatric nursing (KS, SS, LR, GR). Confidentiality and power dynamics (Ericsson & Boyd, 2017; Lane et al., 2019; Teachman & Gibson, 2013) were addressed during the consent process by, for example, assuring children that they could stop the interview at any time and following the child’s lead during the interview. The guidelines were refined following initial pilot testing with three children. As the interviews progressed, the guidelines were modified, further detailing considerations critical in doing research with children and adolescents, especially related to pre-interview planning. Feedback from the participants and parents resulted in further modifications as the interviews progressed. Table 1 represents the final guidelines, which were developed from the literature, and further refined as the interviews progressed.

Ethics

All studies had ethical approval from three university Research Ethics Boards. All interviews were recorded and transcribed verbatim and data were managed using NVivo10 (QSR, 2010). Parents signed consent, children signed assent, and we anonymized all data and assigned pseudonyms to participants. Unless otherwise specified, all quotes are from the post-interview field notes. We use the term children to refer to children and adolescents, unless referring specifically to the adolescents.

The Interview Guidelines

Our interview guidelines provide practical steps for pre-interview planning, the interview, and post-interview documentation (see Table 1).

Determine interview process and approach

Plan for interviewers with relevant pediatric experience

Given the unique challenges of involving children of different ages and ability in research, and the additional vulnerability of interviewing children experiencing chronic conditions, a key strategy was to have experienced pediatric clinicians interview the children and adolescents (Teachman & Gibson, 2013). Experienced clinician interviewers have the expertise to make appropriate decisions in the moment as not all contingencies can be anticipated with children (Woodgate et al., 2017), especially when children have experienced medical trauma and/or have language processing challenges (Kassam-Adams & Butler, 2017; Miatton et al., 2007).

Plan to reduce power dynamics

With the history of surgeries for the children in the initial two studies and our acknowledgement of potential influence of medical trauma during interviews, our constructivist approach and pediatric expertise helped us to optimize their comfort and ease to talk with us about what was important to them. We planned for choice and control during the interview to address power dynamics (Teachman & Gibson, 2013). Interviewers followed the participants’ lead and invited them to tell as much or as little about living with their condition as they wanted (Teachman & Gibson, 2013).

Plan to keep the child safe

Although child safety is of paramount importance in conducting children’s interviews (Poku et al., 2019), developing a trusting relationship with vulnerable children in the research relationship is paramount (Boles, 2018). Planning for child comfort and safety included keeping bedroom doors open and using the child’s own toys and props (Gibson et al., 2010). Following the child’s lead (Irwin & Johnson, 2005), and giving the child control over the discussion and direction of the
interview helped to ensure the child’s sense of safety and active participation (Hill, 2006). Many of the following guidelines are geared towards honoring child safety, control and voluntary participation.

**Conduct pre-interview conversation with parent and older children**

**Plan interview logistics and anticipate challenges**

Planning the interview logistics and anticipating potential challenging scenarios ahead of time is important when interviewing young people (Irwin & Johnson, 2005), however it is even more imperative when interviewing children with chronic conditions or disabilities (Boles, 2018; Teachman & Gibson, 2013), other vulnerabilities (Mayaba & Wood, 2015), or pediatric medical trauma (Kassam-Adams & Butler, 2017; Price et al., 2016) to ensure the interviewer knows as much about the child as possible in planning for the interview. We conducted a pre-interview 10–20-minute telephone conversation with the parent, usually the mother, and with the adolescents. Parents provided clues to interacting with their child, insight as to how their child might respond/behave during the interview and worked closely with us to maximize their child’s comfort and therefore the success of the interview.

**Discuss study details**

This was the second opportunity to discuss the purpose of the study, and parents were asked to review the information letter and consent/assent form that was emailed to them after recruitment contact with their child. This was a specific opportunity to emphasize the child’s voluntary participation and address questions from the parent and child/adolescent.

**Confirm child/adolescent’s willingness to participate in research interview**

Our assessment of the child’s willingness to participate in the interview was top priority for the pre-interview conversation with the parent. We emphasized the child’s desire to participate, not the parent’s desire for their child/adolescent to

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### Table 1. Interview Guidelines for Conducting Research with Children.

| Pre-Interview Planning |  |
|------------------------|---|
| 1. Determine interview process and approach | 1.1 Plan for interviewers with relevant pediatric experience |
| 1.2 Plan to reduce power dynamics |
| 1.3 Plan to keep the child safe |
| 2. Conduct pre-interview conversation with parent and older children | 2.1 Plan interview logistics and anticipate challenges |
| 2.2 Discuss study details |
| 2.3 Confirm child/adolescent’s willingness to participate in research interview |
| 2.4 Identify language the child uses for condition |
| 2.5 Ask about child and sibling interests |
| 2.6 Determine best interview location |
| 2.7 Address whether parent to be present |
| 2.8 Teach parent scaffolding |
| 2.9 Discuss potential interview props |
| 3. Complete pre-interview field note | 3.1 Plan interview based on pre-interview field note |
| 3.2 Reflect on unique needs of the child to plan the interview |

| Interview |  |
|-----------|---|
| 4. On location, prepare environment ethically, emotionally, and practically | 4.1 Adhere to ethical principle of child assent |
| 4.2 Discuss voluntary participation and withdrawal |
| 4.3 Discuss roles with child/adolescent |
| 4.4 Establish rapport, integrating pre-interview information |
| 4.5 Adapt to the environment |
| 4.6 Engage the child/adolescent |
| 4.7 Follow the child/adolescent’s lead |
| 5. Mindfully conduct interview | 5.1 Start with close-ended questions; move to open-ended questions |
| 5.2 Reduce power dynamics |
| 5.3 Consider child’s developmental and language needs. |
| 5.4 Attend to non-verbal behaviors |
| 6. Post-interview debrief | 6.1 Debrief with child/adolescent |
| 6.2 Debrief with parent |

| Post-Interview |  |
|----------------|---|
| 7. Complete post-interview field note and reflection. | 7.1 Reflect on interview content and key themes |
| 7.2 Reflect on methodological issues |
participate. As is typical for research ethics, we discussed the balance between the parental consent, child assent and details regarding confidentiality. This was especially important for the parents to hear, as they typically are in much more of a directing situation regarding their child’s clinical care. We confirmed the child’s assent through the parent or with the child/adolescent directly. Parents commented that they were glad to have their child/adolescent talk to someone who had experience with their child/adolescent’s health condition, and in many cases, we obtained a sense of the child’s enthusiasm and anticipation for the upcoming interview.

**Identify language the child uses for condition**

Greig et al. (2013) recommended identifying the terminology the child/adolescent uses regarding their condition to improve communication and to give the child a sense of power and control. Although seemingly a small point, this proved to be one of the most helpful guidelines, providing us with valuable information on how the child’s condition was perceived by both the parent and the child. In one pre-interview conversation, we learned that the parents did not use medical terminology with their child; this enabled us to honor the parents’ philosophy and frame interview questions using child-specific terminology ahead of the time, rather than in the moment during the interviewing, or worse yet to use unfamiliar and potentially scary terminology.

The non-identified condition: This family does not label the diagnosis—not scoliosis, not condition, nothing negative in any way. I will need to sort out how to frame the questions for this young child. We can refer to surgery. Perhaps just referring to “what is it like for you when you have surgery?” [Pre FN]

In a situation where a detailed pre-interview was not possible, such as when a child was recruited and seen directly from clinic, we still took time to discuss not only the details of the upcoming interview but also the name the child used for the heart condition. This proved invaluable in a brief conversation with a parent of a 7-year-old while walking with the interviewer to the interview room:

We did not have time to do the pre-interview questions but thankfully I asked his mother what he called his heart condition. She said, “he doesn’t really know he has a heart condition.” I clarified that it was okay to talk about his heart.

**Ask about child and sibling interests**

Information obtained about the child and sibling’s interests ahead of time resulted in personalizing the interview. Between the pre-interview and the scheduled interview we, for example, acquired knowledge of “monster high dolls”, constructed coloring pages of one child’s favorite airplane, downloaded photographs of their favorite entertainer to an iPad, or for an older child with an interest in hockey we noted recent hockey scores. These examples indicate the level of preparation required to conduct meaningful interviews, and further the child’s trust in the interviewers.

**Determine best interview location**

Farrell et al. (2016) addressed the importance of conducting research in naturalistic settings; Lane et al. (2019) furthered this argument regarding naturalistic settings and play with children to reduce power dynamics. As is typical in research ethics applications interview location was discussed, but to further ensure choice and control for the child, we asked parents to jointly determine the best interview location with their children either in their home or at the university. We set up a child-centered play environment for interviewing children at the university with toys, a couch and a child-sized table for those requiring this.

**Address whether parent to be present**

We also asked parents to discuss with their child whether they wanted their parent to remain present during the interview. This was particularly important as the children’s needs differed; some welcomed the opportunity to exert their independence and protect their information, while others wanted parents present to provide support as needed or requested.

**Teach parent scaffolding**

*Scaffolding*, a method of providing temporary support for learning that is adapted based on the individual child’s abilities and requirements (Mermelshtine, 2017; van de Pol et al., 2018), was another important strategy that we employed, especially for the younger children and those with developmental disorders. We taught the parents scaffolding in the pre-interview in preparation to help the parent to facilitate the child’s responses but to ensure that they did not answer for the child in the interview (Irwin & Johnson, 2005). Parents used scaffolding by using prompts such as “what about the time when . . . ?” Parent scaffolding was extremely valuable in extending or clarifying the conversation, such as with this 6-year-old:

| Interviewer: | Do you have a best friend at school? |
|--------------|-------------------------------------|
| Jemma:       | No.                                 |
| Mother:      | Who is your best friend? Do you have a best friend—not necessarily at school but out of school? |
| Jemma:       | Oh yes—my friend Jennifer. She was in preschool with me. |

Once we explained scaffolding to parents, they were masterful at keeping the conversation going, as described in these field notes:

Genevieve spoke so softly and in single word answers and short phrases and needed lots of prompting and scaffolding which her mother did beautifully. Dad had said he didn’t know if she would even say anything to me at all.
Kayla often looked to her mom for answers and her mother did a lovely job of scaffolding—sometimes it became a guessing game. Mom would think of a story that Kayla could tell and then she would give her hints for each part of the story.

In a couple of cases where we did not do this teaching, the parent started answering for the child. In some cases, we taught scaffolding on the spot, but in other cases that did not work:

Since there was no opportunity ahead of time to talk about scaffolding, this mother did a lot of talking during the interview. In hindsight, I also see that she was helping him due to his learning problems—good data though in terms of not doing the pre-interview preparation thoroughly.

Discuss potential interview props

Potential interview props were reviewed with parents, as these are helpful to aid memory recall and storytelling (Greig et al., 2013; Linzmayer & Halpenny, 2013; Teachman & Gibson, 2013). One mother set out fancy teacups for the child and sibling to have a tea party with the interviewer. The parent of an extremely shy 12-year-old had toys and sports equipment available. Other props included photo albums of a recent surgery, and photos of the child’s superheroes arriving at the hospital post-surgery. One mother, who could not be present for the interview, had set out a large array of props on a bed in the guest room that the father and child showed the interviewer.

The dad directed me to props near the end of the interview. In the meantime, he had been present throughout the interview helping the child answer questions.

Complete pre-interview field note

Time intensive pre-interview planning included recording a detailed field note about pre-interview conversations and reflecting on the unique needs of the child. Field notes are necessary for recording contextual information (Phillippi & Lauderdale, 2018). In our research they also provided methodological data across studies to strengthen our team’s child interviewing skills, and the ability to individualize the interview for the children.

Plan interview based on pre-interview field note

We documented details about the child based on pre-interview conversations and planned each activity for the interview to optimize the participant’s ability to address our interview questions, while maintaining a welcoming and safe atmosphere.

Reflect on unique needs of the child to plan the interview

As Spriggs and Gillam (2017) emphasized the need to be reflexive before the research interview to protect the interests of the child, this intensive planning helped us to attend specifically to the child’s needs and individual experiences. The relevance of our clinical experience was evident in this field note:

Mother wanted to speak in person about history. I have an idea that there is more to this little girl than her heart condition. Query developmental issues or learning problems. Mother says, “find out what she calls her heart condition”. She has some auditory processing issues, so I need to use single questions and pictures. Give her time to respond. Use the hospital bead bracelet to facilitate her heart story. Take sewing cards, drawing, fidget toys and card sort. [Pre FN]

The Pre FN also alerted the interviewer to sensitive issues.

Note: Child is sensitive about her bowel issues, but her Mom said ok to ask her about it—may come up in the card sort with toileting.

On location, prepare environment ethically, emotionally, and practically

Once in the home or university setting, the researcher prepared the interview location as quickly and efficiently as possible, mindful that the family was sacrificing their time for this research encounter. In preparing to be able to construct meaning from the children’s stories, we knew it would be necessary to attend to the relationship and be fully prepared to listen actively to the children (Lane et al., 2019).

Adhere to ethical principle of child assent

The consent/assent process for young people involves more than their signature on an assent form (Ericsson & Boyd, 2017). Creating an atmosphere of trust and respect for the child and respecting the child’s competencies are paramount (Woodgate & Edwards, 2010). The key ethical guiding principles are that the child has a right to choose, beneficence (non-maleficence) and justice (Mishna et al., 2004; Woodgate & Edwards, 2010). While all parents discussed the purpose of the interview ahead of time with their child, most did not discuss assent with their child, so we reviewed the interview purpose and assent process at the beginning of every child/adolescent interview. This was our third opportunity to ensure that the child wanted to be part of the study, what that involved, and ascertain whether the child was being “talked into” the study by the parent.

The importance of talking to the child directly about their choices was played out in one interview where the mother had wanted her child to participate. This is what happened when they got into the interview room with this 10-year-old:

I explained the information letter to him and told him about the tape recorder and turned it on. He immediately turned it off. I explained that I talk to kids who have scoliosis and was not part of the hospital or the clinic. I said nobody would get upset if he did not want to talk with me or answer my questions. He could just say
“No.” He said he did not want to answer questions. I asked him who he thought was in charge of this interview. He sighed and said—“You.” I said, “No it is you.” His face lit up. I said, “So you don’t want to answer questions?” He said “No” and circled No on the assent form. Although his mother was disappointed, the interview ended before it began. I gave him the gift card.

Respect for the child’s confidentiality as well as the circumstances for disclosure of information were discussed with parent and child at the beginning of the interview, and again with the child as required, as the conversation progressed (Dockett & Perry, 2007). The interviewers informed the children and adolescents that what they said was confidential except if they told us that anyone was hurting them in any way, we would have to tell their parents. This became another critical point with the children, many of whom we found had been bullied.

**Discuss voluntary participation and withdrawal**

The children were assured that they were free to participate or not (Mishna et al., 2004). The words “we will not be unhappy if you do not want to participate” from Ondrusek et al. (1998) were particularly helpful. Giving the words to the child on how they could say they wanted to withdraw from study participation at any time was essential (Hill, 2006; Mishna et al., 2004). They could say “I changed my mind” or “I want to stop now” (Ondrusek et al., 1998). If they wanted to stop for a while, they could ask for a break, and they did.

**Discuss roles with child/adolescent**

At the beginning of each interview, the researcher made sure that the child/adolescent understood the role they would play and what they could expect during the interview (Docherty & Sandelowski, 1999) and about how long it would take (Hill, 2006). The interviewers invited the participants to talk about what it was like to have their condition and about everyday life and activities they enjoyed, while accessing toys and props to help them tell their stories and keep them engaged (Irwin & Johnson, 2005). Siblings were asked what it was like to have a sibling with the condition.

**Establish rapport, integrating pre-interview information**

Given the pre-interview planning, we were able to personalize the questions using the child’s terminology, which helped with rapport building. The 5 and 6-year-olds often had a pet name such as “half a heart” or “robot back”.

This 6-year-old devised this way to explain his condition: “He tells people that he ‘broke his back’.”—then his mom told him that he could tell me the real thing because I knew about it. He then talked about his scoliosis related to the rods.

By age 8–10 years (developmentally) most children knew that they had a “heart problem” or “scoliosis”; however, some children as old as 15, did not know the exact name of their heart condition.

Understanding the child’s interests and needs allowed us to gain the child’s trust. Adequate pre-interview preparation not only facilitated trust, but it also averted this potentially difficult situation:

Mother, talking to researcher ahead of time: So, we find when she’s getting stressed or upset about procedures, she talks a lot about [relatives’] deaths. I’m not sure why. So, when she’s getting nervous, usually before a surgery, she asks questions, like, is she going to die? That’s the only thing, if she starts to talk about these people, then she definitely needs a break because that’s how she shows us she’s getting stressed.

In the interview this occurred:

**Interviewer:** And do you like to go for a walk?

**Fawn:** Yes, I do.

**Interviewer:** Where do you go for a walk to?

**Fawn:** Well, I go with my mom. And my Grandma’s aunty, her sister died. She got sick and—yeah.

**Researcher notes:** This was the signal that I had to change the task so we did not finish the cards as it was too stressful for her. I immediately got a toy.

**Adapt to the environment**

Giving the child the opportunity to determine the interview location was intended to afford them a sense of safety and control. Our field notes commonly included statements that “being in their home worked well as child and sibling appeared comfortable.” We interviewed the children in various home locations; in the living room, dining room or family room; two locations in a large back yard that were set up by the child and sibling, and even a tree fort where the interviewer and sibling sat on child-sized chairs. If a child and sibling were being seen at the same time by two interviewers, two different rooms or locations were pre-arranged.

Because the child and parent determined the interview location, the interviewers found that they were not in a position to engineer the environment as much as to adapt to it. One interview noted “It was a bit squishy in the corner that we were in but it worked to be on the floor with Ella. I found the room a bit dark and longed to open the curtains but restrained myself from taking over the environment.” Adapting involved sitting on the floor or following the child around with the recorder so they could show their toys. We were generally able to be flexible, but it was not without its mishaps; “There was no table. I was juggling things on my lap on the oversized furniture. At one point the cards fell on the floor and that was the end of that.”

We also relinquished power over the digital recorder. As many young people are highly skilled with a variety of communication technologies (Hastings et al., 2009), we explained the basic function of the digital recorder and gave them control...
over when the recorder was on or off. However, even with the best intended plans, in an interview with a fast-fingered 5-year-old.

I’m not sure what we actually got on tape. I had two tape recorders and he was quick to grab them and push buttons. I reset both part way through. I tried to keep one for me to handle and one for him but he got mine a couple of times.

**Engage the child/adolescent**

We endeavored to create an atmosphere of trust and respect for the child, and to respect the child’s competencies (Woodgate & Edwards, 2010). Overall, given how much we learned about the child ahead of time, we did not have difficulty engaging with the children. Most children were as interested in talking to us as the parents were in having them participate.

She said she was excited about her interview and having a chance to talk about her heart. Even though she was talking about personal experiences, she said that it wasn’t hard to discuss this.

Our detailed pre-interview field notes assisted us in preparing to engage the child, such as in this field note:

Establish rapport. This 9-year-old can be known to be shy and shut down. Have her tell stories her own way. She likes to scribble and then “read” the story to others. She also uses stickers to tell stories. Use props to tell stories. She likes cars, crafts, her playhouse. Try using the card sort. She likes running, playing, jumping, swimming. See if the card sort identifies those. Grandma will attend and I have discussed scaffolding.

**Follow the child/adolescent’s lead**

When conducting the interview, we recognized that the child’s story-telling path might wander and not include a sequence of beginning, middle and end (Irwin & Johnson, 2005). While we were willing for the child to go off-topic, we were also mindful that tangents might tire the child and limit how many interview questions we could ask (Docherty & Sandelowski, 1999). We therefore followed the child’s lead, which worked well.

She was relaxed touring around the room, choosing her next activity. The fidgets, sewing cards and stickers all worked well at her having something to do while she was talking.

Based on the pre-interview, we took props and activities to assist the child in describing their experiences, to create a safe atmosphere and to help retain the child’s attention (Linzmayer & Halpenny, 2013). For props we chose real life items (Docherty & Sandelowski, 1999), the child’s own toys or memory prompts, puppets, picture cards, books, photographs, toys or the iPad to facilitate storytelling (Gibson, et al., 2010), as needed based on the child’s development, attention span, and the pre-interview information. Drawing, coloring and the card sort activity (PACS) were also available.

We anticipated that picture drawing would need to be used judiciously; while drawing pictures has been shown to help facilitate children telling their stories (Literat, 2013), we did not use it as our only strategy as we were concerned about children with CCHD who are verbal and social but who tend to have motor difficulties (Alton et al., 2010). Further, drawing is not helpful in some cases, and can even be stressful (Irwin & Johnson, 2005).

He was reluctant to use the marker at all. He held it awkwardly with a fisted grasp to make a mark for consent. After that he did not want to use the marker and had me do the coloring of the airplanes I had copied for him.

Drawing was used successfully by at least seven children, mostly the young ones who liked to chatter while drawing.

The PACS card sort (Mandich et al., 2004) not only assisted us in answering the research questions about the child’s everyday life but also for some was an excellent vehicle for starting the interviews and engaging the children. Many experienced the PACS card sort as a game. The PACS was one of our most helpful strategies as it gave the children a focus for conversation. It worked well for all ages, and was a great activity to start the interview, or break up the interview by doing several cards at a time.

I showed her the toys. She chose PACS, which I was happy about as I thought it might be a nice ice-breaker and it was. She really got into it. I read the cards and she placed into piles of Yes, No and Want to. She even went back and changed some cards, so was really thinking about it. I used the cards for entry into some conversations. She was emphatic in most of her Nos and some of her Want-tos. So I probed, “Why don’t you climb a tree?” “I might die.”

We also had several options as to us holding the cards, the child doing the task independently, or using the cards to facilitate talking while they played with toys.

The PACS worked well with him. I handled the cards because his hands were busy with the building toy. He offered comments in addition to his Yes and No.

We also obtained insight into the child’s learning abilities through how they used the PACS. For one child the PACS did not facilitate conversation, due to her language processing difficulties.

I was not able to complete the PACS, as this type of questioning and quick change of topic and quick reply was much too difficult for her.

We also used toys and puppets to facilitate storytelling (Gibson et al., 2010). Gender-neutral puppets were used, but were
definitely not for everyone, as some of the younger children were scared of them. For one 7-year-old sibling, they became a window into the relationship between her and her sibling.

I felt that the puppet time was when I got some insight as I played the child and she was the sibling, and we acted out some scenarios. One time when I [child] said I was feeling low, she [sibling] brought her puppet in to be with her sister and just laid her puppet down beside her. She knows everything about her sister—her favorite color, food, what she likes about the hospital. For her, the puppets were definitely a way of getting her to show things about her relationship with her sister that she did not say in words. I also thought that it was her most relaxed time in the interview. She laughed and enjoyed the play.

The toys and puppets were mostly used by the children under age ten and “toys that did not require concentration were the best for eliciting conversation.” The older children liked having a fidget toy, but most just wanted to get right down to the interview. “He [10-year-old] was prepared to talk and declined playing with the toys but did take advantage of the fidget toys.” The presence of the toys also helped the siblings want to engage. “I asked why he was interested in showing things about me and he said that his sister said it was a lot of fun as you got to play with toys.”

While we had these toys and props available, many interviews developed their own flow and evolved as a conversation. “This interview seemed to unfold on its own. I did have interview guide in front of me but found myself using it as a source of ideas rather than a question by question guide.” And in another,

This interview was interesting from the perspective of its evolution. It was a child-led interview and we had the structured PACS and questions when we needed a new topic but otherwise she ran with it. I think she felt comfortable. She certainly opened up about many things.

With others, we did not need to do much to facilitate the conversation.

Kayla seemed comfortable with the interview process. She plunked herself on the floor. She was very quick to show me her scars. When I asked her questions, she always wanted to show me something or pretend something in her answer. That fascinated me. It prolonged the interview and I could tell that I was getting a bit interview-weary when we were putting the names of the dogs on her family drawing.

We also integrated iPad technology with our facilitative techniques. One child enjoyed using the PACS card sort that we had put on the iPad, as the appeal for her in doing the interview was that we would have an iPad. In another interview, the iPad was used to play a video of the child’s favorite singer, which he then imitated, with a play guitar and all. We were privileged to have the children dance, sing, and share their lives with us.

Mindfully conduct interview

Start with close-ended questions; move to open-ended questions

To set the child at ease and build rapport, we were mindful to start with concrete, close-ended questions and then move to abstract, open-ended questions (Irwin & Johnson, 2005). The emphasis early in the interview, was to ask them about their everyday and favorite activities, before asking about their medical condition. As we moved to abstract, open ended questions, we started by using the third person to ask them what a child with a heart condition or scoliosis would do. This was the least effective questioning strategy. Children less than seven years did not understand the question, and older children often looked puzzled and either did not answer or said they did not know what other kids would do but would tell us what they did.

When I asked her to tell a story about a child with scoliosis, she often did not want to. Following her lead worked well as she then had permission to talk only about what she wanted to. She responded a bit better to me asking more indirectly about her scoliosis experiences—tell me a story about you on holidays.

Reduce power dynamics

The interviewers were constantly mindful of the power dynamics in a child-adult/stranger interview. At the outset and when needed during the interview, the interviewer assured the child that there was no right or wrong answer, as children often assume there is a correct answer (Clarke et al., 2005). To assist with this the interviewer refrained from evaluative comments and/or controlling and thereby connotative of a teacher/child relationship such as asking them to stop squirming (Clavering & McLaughlin, 2010). An 8-year-old “seemed to feel at ease when she was the one to tell the puppet to focus and sit still, as I, as the interviewer was tempted at times to say that to her!” We had children who exercised their rights when they did not want to talk about their condition. This mostly happened with the 5 and 6-year-olds.

Consider child’s developmental and language needs

By using experienced pediatric clinician-researchers as interviewers, we were confident that we could adapt to the individual developmental and language needs of the child, some of whom had learning problems and various delays (Hill et al., 1996), and/or pediatric medical trauma (Price et al., 2016). We ensured an appropriate pace and allowed for sufficient breaks in the conversation as needed by each child. Although the use of open-ended questions is the technique best suited to inviting participants to guide the research conversation, we considered the linguistic abilities of the child. Starting with close-ended questions and then following with open-ended questions helped the children relax and “engage in the interview process” (Irwin & Johnson, 2005, p. 825). We adapted to the child’s need to
attend and process the information. In another case “the mother had discussed with me the child’s language processing problems, so I gave her lots of time to answer.”

He was focused on his project but was responsive to questions and sometimes would keep working on what he was doing and sometimes stop what he was doing to think about his answer.

We were also able to adapt to participant’s speech (articulation) difficulties. The mother of a child with a cleft palate repeated the child’s responses verbatim, and for a child with a paralyzed vocal cord the interviewer repeated the child’s responses to verify the information.

**Attend to non-verbal behaviors**

Having face-to-face interviews allowed us access to non-verbal behaviors of the children/adolescents and this helped be attuned to their needs and reactions.

She was relaxed and liked to talk. She conveyed her interests or difficulties through her tone of voice and facial expressions; for example, for simple card sort questions her voice tone response indicated that the question was ridiculous to her.

However, the non-verbal cues also gave us further insights:

The 15-year-old’s non-verbal behavior was so notable. The mother and son sat beside each other and often the son rested his hand on his mom’s leg or tipped his head sideways onto her shoulder in reassuring, comforting or loving gestures. They have an obvious bond. He was not too “cool” to show this affection in front of a stranger.

One child turned off the recorder twice; another turned it off 11 times.

He was hyper-vigilant in noticing every movement of mine especially if it involved the tape recorder. He needed to test whether I meant what I said about him having control. What is happening with him in terms of trust of adults?

We were also alert to the children’s non-verbal behaviors such as looking away, becoming silent, and abruptly changing the subject as cues to stop pursuing an area or seek further permission to continue (Clarke et al., 2005). We reminded the children about these concepts if needed throughout the interview. For example, a 5-year-old said they did not want to answer a question, not only did the interviewer say that it was ok, she repeated this information throughout the interview when needed.

**Post-interview debrief**

Early in the process, we realized that it would be helpful to debrief both with the child and parents after the interview. As another example of the extensive ethical process, we were required by the ethics board to provide an amendment including a script for the debrief. This gave us the opportunity to ensure that the child was okay after the interview and get process suggestions from both parties.

**Debrief with child/adolescent**

The interviewer informed the child/adolescent that they could get help to talk about things after the interview if needed. No one asked for this. “I asked her if she was ok and needed anyone to help her as she was relaying some difficult information.” In situations where it was clear that the child/adolescent could benefit from help we discussed with the child whether we could discuss the issue with their parent (Mishna et al., 2004). Both before and during the interview we were clear about things that would be disclosed to their parents (Mishna et al., 2004). The child was informed that in cases of abuse (being hurt) or neglect we would report their stories.

I asked her if she had talked to her parents about the bullying she disclosed to me—she explained why she had not talked to her mom about it and I took this into consideration during the debriefing.

If the interviewer felt the child wanted to tell their parent something that had been discussed, we asked the child if they wanted help in talking to the parents. In the case of the child who did not know about his heart condition:

He said he is not allowed to play hockey because his Mom says he has a heart condition, but he does not know what that means and why he can’t play. I asked him if he wanted us to tell his mother that he wanted to know more about his heart, and he gave a strong “Yes!” We talked with his mother together after the interview.

**Debrief with parent**

The guidelines included a debriefing recorded phone call with the parent within a few days of the research conversation; in fact, we ended up debriefing with most parents after the interview. At that time, the parent was told about any issues regarding abuse or neglect divulged by the child. If the child had divulged that there was possible abuse or neglect by the parent, the appropriate reporting mechanisms were to be followed immediately after the interview. (This was not required). An ethics amendment included our intent to record these conversations, but this type of conversation was not needed in any of our studies. While we did not disclose content of the interview, we did discuss some situations of bullying that the child had relayed.

I made a point after both interviews to take the father aside and talk to him about the bullying. He was not aware of some of it and seemed glad to get the heads up.

The parent was also asked for their feedback on the interview, if they thought the child enjoyed the research encounter, any methodological recommendations, and if any follow-up was
needed. Names of clinicians for follow-up counseling were made available.

**Complete post-field note and reflection**

The post-interview field notes not only provided important reflections on interview content and key themes in the co-constructed data but also addressed the process of co-construction that served as important methodological data that was brought to the research team for discussion and possible implementation for subsequent interviews.

As this is now my fourth interview I am left with some questions for the team. I am not sure what it is that constitutes good data. What are we actually trying to get? We are getting data about the kinds and range of activities the children are engaged in.

The reflections also helped researchers refine their interviews.

The interview was all about play. As I listened to the interview reading it for the transcriptionist, I immediately noticed that I had a “play voice” and then a “research question voice” when I tried to get her to talk about being at the hospital and later being at home.

Reflections also prepared the researchers to hone their interview skills.

When she said that she worried about something happening to her sister that she might need more surgery I probed a bit. But I wished that I would have then asked—and what would that be like for you? For [child]? For others in family?

This was a difficult interview to get the child to talk but I think it is temperament related for this child and not necessarily a result of good or bad methods. I did get her to smile a couple of times.

These post interview reflections contributed to initial data analysis, researcher reflexivity, and improving the interview guide as well as the individual interviewers’ approaches.

**Conclusions**

Our methodological reflections have yielded practical guidelines for research interviews with children/adolescents; they are however not a formula for success. Foundational to generating high quality interview data in an ethically sound manner is sustaining mindful presence (Woodgate et al., 2017). Sustaining a mindful presence for us meant being in the moment with the children, managing the unexpected, actively listening, attending to verbal and non-verbal cues, and attending to nuance. Knowing when to probe and not to probe too much, and when to give more of ourselves demanded a high level of flexibility and reflexivity. In fact, Boles (2018) suggests that “there is no cookie cutter approach to working with children in research” (p. 74), and flexibility is key. Our in-the-moment creativity and ingenuity was called upon to impart developmentally appropriate, and often playful negotiation with our young participants. We endeavored to negotiate data generation methods that were of interest without “becoming a gimmick” (Dockett & Perry, 2007, p. 50). Our intentional efforts to personalize our interview approaches to set children/adolescents at ease and our nuanced probing set our participants up to provide meaningful information about their lives while respecting them as gatekeepers of their stories and data (Dockett & Perry, 2007). Poor interviewing can do harm and/or yield shallow data (Olson, 2011). Our concerted efforts and persistent reflections contributed to ethically conducted interviews that yielded rich data.

Although the children/adolescents were forefront to this research, the involvement of parents was critical to our ability to contextualize and personalize each interview. This was especially important for our single-interview studies. Pre-interview parent input and their scaffolding during the interview was essential as many of the participants had cognitive disabilities. Teachman and Gibson (2013) applied “collaboration with parents, a toolkit of customizable interview techniques, and strategies to consider the power differential” (p. 264) in their research with children/youth with disabilities. Interview customization, a dynamic interview process, and viewing the toolkit as an adjunct to highly skilled clinician researchers/interviewers (Teachman & Gibson, 2013) are highly congruent with the interview guidelines we propose.

A crucial next step in methodologic development is to involve children/adolescents in the design of studies (Kellett, 2010; Shier, 2015). Ethical and practical issues abound (Bradbury-Jones & Taylor, 2015; Flynn et al., 2019) but the proliferation of participatory action research and emerging patient engagement directives and initiatives constitute the needed groundwork for meaningfully and ethically engaging children/adolescents as co-researchers from inception to dissemination; research not for or with children/adolescents. Now is the time for research by children and adolescents (Clavering & McLaughlin, 2010).

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