Children’s Perspectives on Visits to the General Practitioners’ Office

by

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ABSTRACT

CHILDREN’S PERSPECTIVES ON VISITS TO THE GENERAL PRACTITIONER’S OFFICE

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The purpose of the current study was to understand children’s positive and negative perspectives of visits to the general practitioner (GP), and their preferred level of participation during these visits. One hundred sixty-seven children (female \( n = 82 \), male \( n = 85 \); ages 7-10, \( M_{\text{age}} = 8.07, SD = .82 \)) were recruited from four local schools. Data were collected through 15-20 minute individual interviews. Children reported they were fearful of needle procedures, pain and the unknown. Children indicated they like receiving rewards, interactions with doctors, and improving their health. Two-thirds of participants did not want increased choice or preparatory information. Children’s fear ratings for experiences during GP visits were positively associated with their preference for more participation. This study demonstrated children are capable of communicating their perspectives of GP visits. The current results can inform the development of interventions to promote positive experiences and reduce procedural distress during GP visits.
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Children’s Perspectives on Visits to the General Practitioners’ Office

Canadians rely on general practitioners or family doctors (herein GPs) for regular preventative health assessments, such as recommended in the Rourke record for infants (Rourke, Leduc, & Rourke, 2011), and the Greig record for children and adolescents (Greig et. al, 2010), as well as for treatment of acute illness and injury. Visits to the GP are fairly common for Canadian children; the Rourke record recommends children attend well-child visits on at least 12 occasions by the age of 5 while the Greig record recommends yearly well-child visits from ages 6-18 (Greig et al., 2010; Rourke et al., 2011). Research that seeks to understand children’s perspectives on their GP appointments could lead to improvement in these visits: the identification of both positive and negative aspects would elucidate factors to target in intervention programming. Unfortunately, pediatric health research on GP visits has trailed behind investigations of topics seen as more urgent or severe, such as chronic illness or hospitalization (Walco & Goldschnieder, 2008). Currently, most research regarding patient perspectives of pediatric medical services is specific to hospitalization, rather than visits to a GP (e.g. Coyne & Kirwan, 2012; Corsano, Majorano, Vignola, Cardinale, & Izzi, 2013). Furthermore, research regarding children’s medical care typically relies on the opinions of healthcare providers and parents as opposed to asking children for their perspectives of their own medical care (Coyne & Kirwan, 2012).

The objective of the current study was to understand children’s perspectives on visits to the GP, including negative and positive experiences as well as their participation during these encounters. In order to set the stage for understanding children’s medical perspectives regarding GP visits, the following issues will be reviewed in the introduction. First, the healthcare experiences children report as negative and/or fear inducing will be reviewed followed by a brief
outline of aspects that children enjoy. Next, the benefits of providing children with information regarding the procedures that occur during medical experiences will be summarized. Lastly, the importance of including children’s perspectives in child-centered care, as well as the developmental challenges of including children in healthcare decisions, will be explored. For this thesis, visits to a GP were inclusive of meeting with a GP for the purposes of: a well-child exam, healing acute illness, injury-related visits, and preventative care (e.g. vaccinations).

**Aspects of GP Visits Children Find Aversive and/or Fear Inducing**

Some research suggests that children across grades 1, 4, and 7 are generally fearful of visits to the GP (Aho & Erikson, 1985). Moreover, many children ages 4-18 feel scared before a medical procedure (Hedtrom, Haglund, Skolin, & Von Essen, 2003), and children ages three and older often report a fear of experiencing pain in medical settings (Broome & Hellier, 1987; von Baeyer & Spagrud, 2007). This fear is likely connected in part to their belief they will not be informed of upcoming procedures (Coyne & Kirwan, 2012), negative previous experience with medical procedures (von Baeyer, Marche, Rocha, & Salmon, 2004; Noel, McMurtry, Chambers, & McGrath, et al., 2010; Noel et al., 2012), and that they may not receive satisfactory relief from pain when they require it (Forsner, Jansson, & Soderberg, 2009; McMurtry et al., 2015; Taddio et al., 2009). Notably, unmanaged distress during childhood procedures can result in exacerbated fear and pain during subsequent procedures for children as young as 6 months old (Taddio, Katz, Ilersich, & Koren, 1997), as well as avoidance of medical care in adulthood (Noel et al., 2010; Pate, Blount, Cohen, & Smith, 1996; McMurtry et al., 2015; Taddio et al., 2012). Children are particularly afraid of needles (Aho & Erikson, 1985; McMurtry et al., 2015; Taddio et al., 2009; Taddio et al., 2012); as children often receive their immunizations at the GP, this fear is important to consider when understanding children’s perspectives of GP visits. Children’s fear of
needles is likely based in part on their experience of pain during needle procedures, which is inadequately managed by parents and healthcare providers (McMurtry et al., 2015; Taddio et al., 2009).

Non-painful procedures classified as non-invasive or minor by healthcare professionals and parents may be considered fear inducing by some children. Broome and Hellier (1987) found that children were least fearful of having a nurse look in their ear, listen to their heart, or take their temperature; however, a small subset of children were still fearful of these experiences. In fact, Aho and Erikson (1985) determined that purportedly minor procedures - such as throat cultures, ear checks, and heart checks - were reported as fear inducing by 10-20% of a sample of elementary school aged children. Additionally, children are also fearful of separation from their parents and other family members during hospitalization (Coyne, 2006; LaRosa-Nash, Murphy, Wade, & Clasby, 1995). This issue is so pervasive that it became a foundational argument for the promotion of family-centered care, a movement that promotes the participation of the whole family in children’s medical care to minimize emotional trauma (Shields, Pratt, Davis, & Hunter, 2007).

The first objective of the study was to determine aspects of visits to the GP children dislike, including aspects children report as aversive and fear inducing. Information about children’s fears is particularly important to understand the aspects of the medical experience for which children require intervention to manage their distress, as procedural fear experienced in childhood can relate to procedural pain and coping in adulthood (McMurtry et al., 2015; Pate et al., 1996). Currently, there is limited knowledge of what specific aspects of GP visits children find fear inducing, as existing studies regarding children’s medical fears have been conducted in the context of general fears (including non-medical fears; Ollendick, 1983; Muris
& Ollendick, 2002), or in the context of hospitalization (e.g. (Broome & Mobley, 2003, Coyne, 2006, Forsner et al., 2009; Foster & Park, 2012), with few exceptions (Aho & Erikson, 1985; Broome & Hellier, 1987). In contrast, the current study focused exclusively on procedures that occur during a visit to the GP, and explored children’s negative perspectives in more detail, including fear of pain, specific medical equipment, separation from parents, and fear of the unknown.

**Aspects of GP Visits Children Find Positive**

Research regarding positive aspects of visits to the GP is scarce, but understanding the aspects of GP visits that children enjoy is essential for the improvement children’s healthcare. It is likely children feel both positive and negative emotions during medical experiences; for example, hospitalized children have reported feeling both fearful of procedures as well as taking pride in facing their fears (Forsner et al., 2009). Many hospitalized children ages 6-17 have reported their relationship with health professionals (particularly nurses) as positive (Corsano et al., 2013; Coyne & Kirwan, 2012; Norena Pena & Cibanal Juan, 2011). More specifically, children expressed gratitude toward healthcare professionals who were empathic, caring, and readily available to children during their hospitalization (Coyne & Kirwan, 2012; Norena Pena & Cibanal Juan, 2011). Importantly, children enjoyed when healthcare providers listened to them and answered their questions (Corsano et al., 2013; Coyne & Kirwan, 2012). Furthermore, children aged 5-10 reported being in a hospital was associated with such advantages as watching TV, missing school, and having visitors (Eiser & Patterson, 1984). Lastly, children identified the hospital as a place in which they can be healed and recover (Coyne & Kirwan, 2012).

It is clear children feel positively about certain aspects of their medical experiences. However, the aforementioned studies involved hospitalized children, and research is needed to
determine which aspects of GP visits children view positively. The second objective of the study was to address this gap in the research. Through understanding what children enjoy about visits to the GP, interventions to promote these positive aspects can be developed.

**Children’s Perspectives of Preparatory Information Provided by GPs**

Belief in the importance of communicating with and actively involving patients in their own medical care has become widespread with the movement of patient-centered care (Ontario Medical Association, 2010). In order to treat children within a patient-centered care model, children must be provided developmentally appropriate information regarding medical procedures and involved in conversations regarding their medical care. In qualitative interviews regarding children’s experiences during hospitalization, children aged 7-17 reported they felt unsafe due to being unaware of what procedures would occur, and therefore felt fear of both the unknown and fear of being hurt (Coyne & Kirwan, 2012; Forsner et al., 2009). Information provision likely has implications for parents as well; for example, parents were more satisfied with well-child visits when doctors took the time to provide preparatory information to families (Halfon, Stevens, Larson, & Olson, 2011; Lewis, Pantell, & Sharp, 1991).

It is considered good practice to ensure children have the opportunity to learn about medical equipment and procedures (Anderzen-Carlsson, Kilhgren, Skeppner, & Sorlie, 2007). Providing information to children regarding upcoming medical procedures has resulted in more positive emotional and physical outcomes (Jaaniste, Hayes, & von Baeyer, 2007). Lewis et al. (1991) completed an RCT intervention, which aimed to increase children’s participation in their healthcare through improving child-physician communication. The intervention was successful in improving children’s rapport with their GP, the amount of information provided to children,
and the children’s inclination to take a more active role in their healthcare without any increase in the child’s anxiety (Lewis et al., 1991).

Depending on their coping style, some children may experience increased distress as a result of information provision (Melamed, Siegel, & Ridley-Johnson, 1988). However, as children age, they are more likely to demonstrate an information seeking coping style in medical situations (compared to an information avoiding coping style; Melamed, Siegel, & Ridley-Johnson, 1988). Upon reviewing the information provision literature, Jaaniste et al. (2007) concluded that: 1) most children want to be provided with developmentally appropriate preparatory information, and 2) children who received preparatory information before a medical procedure report lower distress, increased belief in their ability to cope, as well as more ideal treatment outcomes and recovery times. In fact, when children and adolescents are not provided with adequate preparatory information, it seems to result in more emotional and physical distress during procedures and negatively impacts the appraisal of future medical experiences (Coyne, 2006; Jaaniste et al., 2007).

In summary, it is well documented that 1) children as young as 5 years of age prefer to be provided information regarding their medical care using developmentally-appropriate language, 2) children currently report they are not provided with sufficient preparatory information regarding medical procedures, and 3) this lack of preparatory information results in feelings of fear and/or sadness (Coyne & Kirwan, 2012; Coyne, 2006; Cosano et al., 2013; Jaaniste et al., 2007; Wilson et al., 2010). However, while the importance of information provision has been demonstrated in hospitalization literature (Jaaniste et al., 2007; Jipson & Melamed, 2007), research regarding the impact of information provision regarding GP visits is needed. The third objective of the study was to determine children’s perspectives of the information provided to
them by doctors during GP visits. Specifically, children’s preference for more preparatory information was explored, as well as descriptions of the type of preparatory information children would like to receive. It should be noted that in the current study, preparatory information refers to information provided any time before an actual procedure occurs; for example, preparatory information regarding needle procedures could occur during the GP visit but would occur before the actual needle procedure.

**Children’s Perspectives of Their Participation in GP Visits**

Children’s participation during GP visits is associated with the quality of preparatory information provided to them, as it is difficult for children to take an active role in their healthcare if they have inadequate knowledge of what occurs at GP visits. According to the principles of patient-centered care, children have the prerogative to receive preparatory information as well as voice their own questions and/or opinions to ensure communication with doctors is reciprocal. Children’s participation in their care during GP visits may help to increase their understanding of health concepts, which in turn acts as preparation for making more serious medical decisions in the future (King & Cross, 1996; McCabe, 1996). Furthermore, school-aged children’s participation in their healthcare may also have intrinsic value if they feel competent and autonomous regarding their health (Coyne, 2006; Forsner et al., 2009; Runeson, 2002). Runeson et al. (2002) found that children and adolescents who were included in discussions during their hospitalization reported reduced pain and distress, and also required less time from healthcare providers during medical procedures.

Guidelines created by Hart (1992) for UNICEF promote a “ladder of participation” for children, with four levels of increasing participation based on the child’s competence and cognitive development, as follows: 1) simply providing information about medical procedures
and the child’s health; 2) listening to children’s views; 3) taking their views into account to make decisions; and 4) allowing competent adolescents to be the primary decision maker for their healthcare. Hart’s ladder of participation demonstrates children can and should always be active participants in their healthcare; of course, children’s degree of participation will vary based on their level of cognitive development, the parent’s preferences, and the children’s own preferences for their participation. Importantly, as children’s cognitive development increases, their perception of their ability to take an active role in controlling their health also increases (Bibace & Walsh, 1980; Neuhauser, Amsterdamn, Hines, & Steward, 1978).

According to the principles of patient-centered care, it is essential for children to feel acknowledged when they communicate with parents and healthcare professionals. Hospitalized children aged 7-10 years reported wanting a more active role in decision-making and believed parents and doctors inhibited their efforts to participate in their healthcare (Coyne & Gallagher, 2010). Children aged 7-14 have reported they have little control over the procedures performed on them during hospitalization, which makes them feel powerless (Coyne & Kirwan, 2012; Forsner et al., 2009). When children experience lower perceived levels of procedural control, this exacerbates their distress and experience of pain (Coyne, 2006; Forsner et al., 2009). Unfortunately, children aged 7-14 have indicated that they did not receive help or acknowledgment when they searched for protection or comfort from pain and distress (Coyne & Kirwan, 2012; Forsner et al., 2009). Specifically, children have reported that adults disregard their signals for distress, and when they directly ask for help in managing fear and pain they feel ignored (Forsner et al., 2009). It is troubling that children’s subjective experiences during medical procedures are not always acknowledged or addressed by parents and healthcare providers. Parents and healthcare providers need to truly understand the perspective of children
during visits to the GP, as this will inform interventions to promote children’s development of healthcare knowledge and their ability to take an active role in managing their health.

While studies eliciting children’s perspectives on their own healthcare have increased in recent years (e.g. Corsano et al., 2013; Coyne 2008, 2012; Forsner 2009), research regarding children’s participation in decision making in the context of GP visits is scarce. The fourth objective of the study was to determine children’s perspectives of their participation in GP visits. Please note in the current study, the term “participation” will refer to children’s ability to ask questions, share their opinions, and make choices for themselves during GP visits. As quoted by Lewis et al. (1991) “The relatively passive role for children [in the context of medical settings] contrasts with the efforts to promote knowledge, healthy habits, and a sense of control over health that are at the heart of many recent health education interventions for children” (p. 351).

Children as young as five want to participate in conversations regarding their healthcare and wish to have their experiences of distress and pain acknowledged by healthcare providers (Corsano, 2013; Forsner et. al, 2009; Martenson & Fagerskiold, 2006; Taddio, Ilersich, Ilersich, & Wells, 2014). The knowledge of health concepts children develop through participation in their own healthcare could facilitate more competent healthcare decisions as adults.

Objectives and Hypotheses

The current study aimed to understand children’s perspectives of visits to the GP, as this information can be used to inform interventions designed to increase children’s health knowledge, correct children’s misperceptions, and/or promote children’s participation in their own healthcare. The specific objectives and hypotheses of the proposed study are described below:
1. The first objective was to determine what aspects of visits to the GP children dislike, including aspects they report as aversive and fear inducing. Specifically, it was hypothesized that children would be fearful of aspects of visits that include pain, needle procedures, separation from their family, and the unknown (H₁).

2. The second objective was to determine what aspects of visits to the GP children find positive. While there is some research regarding children’s positive medical experiences, there was not enough strong evidence to formulate an evidence-based prediction for this objective.

3. The third objective was to explore children’s perspectives of the information provided to them by doctors during GP visits. It was hypothesized children would report they received inadequate preparatory information from doctors (H₂). Additionally, exploratory sub-analyses regarding the relations between children’s age and fear and their desire for more preparatory information were conducted.

4. The fourth objective was to determine children’s perspectives of their participation during GP visits. It was hypothesized children would report believing they do not have a choice in what happens during GP visits (H₃) and would prefer more control over the procedures that occur (H₄). Additionally, exploratory sub-analyses regarding the relations between children’s age and fear on their desire for increased participation during GP visits were conducted.

**Methods**

**Participants**

Participants were recruited from four elementary schools in the Waterloo Region (Ontario, Canada). A total of 432 forms (18 forms x 24 classes) were distributed to grade 2-4
classes, and 178 parents gave consent for their children to participate in the study (response rate = 41%). A total of 167 children were included in this study, as 93% of children with parental consent to participate gave assent at the time of data collection. The sample was 49% female ($n=82$) and 51% male ($n=85$), and included children ranging in age from 7-10 years ($M_{\text{age}} = 8.07$, $SD=.82$). The sample included 55 students in grade two (33%), 55 students in grade three (33%), and 57 students in grade four (34%).

**Procedure**

The Research Ethics Boards at the University of Guelph and the Waterloo Catholic District School Board granted approval for this study. Data were collected through 15-20 minute, individual interviews between a research assistant and the participant in meeting rooms at the schools. The researcher read the questions to the child and recorded his/her answers to compensate for any difficulties the child may have had with reading and writing. Following the questionnaire, the child was given a pencil as a token of appreciation for participation in the study.

**Materials**

*Interview – General Principles.* The interviews with participants followed a structured questionnaire, designed to meet the objectives of the research study (Appendix A). Questions were asked using developmentally appropriate language. Typically, open-ended questions were followed by close-ended questions for each topic. As research in this area is limited, it was important to use open-ended questions so that children’s responses were not confined to assumptions made by researchers; more structured response options ensured capture of data needed to meet specific objectives.

As an introduction, children were told the purpose of the interview was to determine what
children like and dislike about GP visits. GP visits were explained to children as “doctors you might go to for check-ups, if you hurt yourself, if you feel sick, or if you need medicine” in order to differentiate GPs from other medical professionals (e.g. dentists, surgeons). The questionnaire began by prompting children to discuss their memories of what occurs during GP visits in order to encourage them to begin thinking about the subject matter of the questionnaire. Children were assured that there were no correct or incorrect answers, but merely to answer questions honestly based on their personal opinion.

Children’s cognitive and language development can create challenges for obtaining self-reported information; therefore, children should be screened for their ability to competently use self-report rating tools (Wooley, Bowen, & Bowen, 2004). Seriation tasks have been effective in screening school-age children’s ability to use faces scales to self-report levels of procedural pain (Besenski, Forsyth, & von Baeyer, 2007); therefore, it was inferred a seriation task would be a useful tool for screening whether children could use a faces scale to self-report fear. Thus, before answering questions regarding their fears, children were asked to place the five faces of the Children’s Fear Scale (CFS; McMurtry, Noel, Chambers, & McGrath, 2011) in order of increasing intensity. If children could not place the five faces used in the CFS in order, the children were asked to complete a seriation task with five measuring cups of increasing size, and answered questions regarding their fears with these measuring cups.

**Demographics.** At the beginning of the questionnaire, children’s age, sex, grade and school were recorded.

**Objective 1: Aspects of GP Visits Children View as Aversive and/or Fear Inducing.**

Children were asked an open-ended question about their negative experiences with GPs (Question 3b, 4b), as well as what they would like to change about GP visits (Question 5a).
Children were asked an open-ended question regarding what makes them feel worried or scared while visiting the GP (Question 8a), as well as how they communicate this fear with others (Question 8b). Children were then asked close-ended questions about their medical fears in what is herein referred to as the “structured fear questionnaire”. Specifically, this structured fear questionnaire included questions regarding 1) children’s fear of specific equipment and procedures with the aid of pictures; 2) children’s more abstract medical fears, including fear of pain, being uninformed about medical procedures, separation from parents, and contracting germs (Questions 9 & 10). These questions were adapted from the Children’s Medical Fear Scale (Broome & Mobley, 2003), the Fear Survey Schedule for Children (Ollendick, 1983) and other medical fear research (Aho & Erikson, 1985; Broome & Hellier, 1987; Forsner et al., 2009; Ollendick, 1983). For questions 9-11 (Appendix A), children were shown pictures of medical procedures in order to provide both verbal and visual information for each item; these pictures were child-friendly and involved neutral facial expressions.

Participants answered items on the structured fear questionnaire using the CFS\(^1\) (McMurtry et al., 2011), a one-item measure designed for use with children. The CFS consists of a series of five sex-neutral faces which express an increase in fear ranging from no fear (neutral face) on the far left, to extreme fear on the far right (McMurtry et al., 2011). An initial validation study for the CFS demonstrated construct validity as well as test-retest and inter-rater reliability (McMurtry et al., 2011). In the current study, participants responded by indicating which of the five faces best represented their level of fear, with scores ranging from 0-4 (0 = no fear, 4 = high fear) (McMurtry et al., 2011). Participants had a laminated copy of the scale that they could use to indicate their responses verbally or through pointing.

\(^1\) 8 children (5%) were not able to correctly order the CFS, but were able to correctly order the measuring cups, and therefore used the measuring cups to provide their fear ratings (same metric as the CFS [0-4; 0 = no
**Objective 2: Aspects of GP Visits Children View as Positive.** Through two open-ended questions, children were asked to describe their positive experiences when visiting their GP (Question 3a) and the aspects of GP visits they would like to stay the same (Question 5b).

**Objective 3: Children’s Perspectives of Preparatory Information Provided by GPs.** Children answered close-ended and open-ended questions regarding the information provided to them by their doctors during GP visits. Children were asked to indicate whether or not they believe their doctor provides sufficient information about what will happen at the GP (Question 6a), as well as indicate whether they would like their doctor to provide them with more preparatory information in regards to GP visits (Question 6b). Following this, children were asked an open-ended question regarding what information they would like their doctors to give them so they can feel adequately prepared for GP visits (Question 6c).

**Objective 4: Children’s Perspectives of Their Participation in GP Visits.** There is little information available regarding valid and reliable scales that could be used to assess children’s perspectives of their participation in GP visits (Hennessy, 1999; Lewis et al., 1991). In the current study, children were asked close-ended questions regarding whether or not they believe they have a choice in what happens during GP visits (Question 7a), and whether they wished for more of a choice during GP visits (Question 7c). Children were then asked to describe who makes decisions for them during GP visits (Question 7b), as well as describe aspects of GP visits in which they would like more participation (Question 7d). Due to the complexity of determining their agency during GP visits, children were asked close-ended questions, followed by open-ended questions, to provide scaffolding to aid in their understanding of questions.
Analysis

All data collected were entered into SPSS, version 22 and then checked for accuracy by two undergraduate research assistants. Participants were asked both close- and open-ended questions; both qualitative and quantitative analyses were used. Analyses are described below by type.

Data Coding for Content Analysis. Data obtained through open-ended questions were analyzed using content analysis, which is an objective and systematic approach for describing qualitative data in a quantitative manner by obtaining the frequency at which specific content emerges from the data (Elo & Kygas, 2007). A coding manual (Appendix B) was constructed using both a deductive (based on literature of medical fear, pediatric pain, and/or patient-centered care), and an inductive (open coding from the current data) content analytic approach to encapsulate the variety of responses given by participants (Elo & Kyngas, 2007). As outlined in Figure 1, data were coded following recommended procedures to ensure reliability (Chorney, McMurtry, Chambers, & Bakeman, 2015; Hruschka et al., 2004). All subcategories had a mean inter-rater reliability of at least Cohen’s $\kappa = 0.80$ (acceptable according Altman’s Kappa Benchmark Scale; Altman, 1991; Table 1).

Descriptive Analyses. Frequencies for children’s fear ratings for each item on the structured fear questionnaire were calculated, and can be found in Figure 2. Frequency analyses were also completed to explore children’s responses to open-ended questions regarding: their spontaneously reported fears (Figure 3); how children reported they express their fear (Figure 4); aspects of GP visits children would like to change (Figure 5); aspects of GP visits children enjoy (Figure 6); content of preparatory information children prefer (Figure 7); who makes choices for children during GP visits (Figure 8); and aspects of GP visits in which children want more of a
choice (Figure 9). Next, children’s indications of whether or not they receive preparatory information from their doctor, and whether or not they wanted more preparatory information, were analyzed through frequency analyses. Lastly, children’s indications of whether or not they have a choice during GP visits, and whether or not they wanted more of a choice, were analyzed through frequency analyses.

**Cochran’s Q Analyses.** Cochran’s Q analyses were used to determine the differences in proportions for selected coding categories within children’s *responses*; these were selected post-hoc. The results of the Cochran’s Q are outlined below by sub-objective, and include specifications regarding which coding categories were included in each Cochran’s Q analyses, as well as the criterion created from the Bonferroni correction ($\alpha = .05/\# \text{ of comparisons in the Cochran’s Q analysis}$).

**Pearson Correlations.** Pearson correlations were calculated to determine the relation of children’s age and their fear of 1) needles, 2) pain, 3) the unknown, and 4) separation from parents. Pearson correlations as children’s age and fear were continuous variables, and met assumptions for linearity and normality.

**Multinomial Logistic Regressions.** A forced-entry, multinomial logistic regression was conducted to predict children’s preference for more preparatory information during GP visits from their age and total fear score. Another forced-entry, multinomial logistic regression was conducted to predict children’s preference for more choice in what occurs during GP visits from their age and total fear score. Children’s total fear score was derived by summing each participant’s ratings of fear for the individual item on the structured questionnaire (minimum score 0, maximum score 64; higher score indicates higher total fear ratings). Effect sizes for
regressions were calculated using McFadden’s pseudo-R squared (Fields, 2013; Menard, 2000; Shtatland, Kleinmanm, Cain, 2002), and are reported in the regression tables (Tables 2 & 3).

Results

Objective 1: Children’s Negative Perspectives on GP Visits

1.1 Children’s Fears Regarding GP Visits

It was hypothesized that children would be fearful of aspects of visits that included pain, needle procedures, separation from their family, and feeling uninformed about medical procedures (H_1). Please note in the description of results below, “no fear” indicates the first face on the 5 point faces scale, “low fear” is the second face, “moderate fear” is the third face, and “high fear” indicates the fourth and fifth face on the 5 point scale. This study explored many types of medical fears, ranging from fears of specific procedures to more abstract fears. Therefore, results discussed below are based on the a priori hypotheses for Objective 1. Other frequencies regarding children’s spontaneously reported fears (i.e., in response to open-ended questions), as well as children’s fears as endorsed on the structured fear questionnaire (i.e., when asked specifically about a given procedure or experience), can be found in Figures 2 and 3, respectively.

Children’s Fear of Needles. As hypothesized (H_1), frequency analysis demonstrated that needle fear was pervasive in this sample. Over half of participants (57%) spontaneously reported needles as the most fear-inducing aspect of GP visits. The proportion of responses endorsing needles as a feared experience (57%) during GP visits was significantly higher than the proportion of responses indicating a fear of pain (13%; χ²[1] = 59.88, p < .001), fear of the unknown (12%; χ²[1] = 55.69, p < .001), and fear of separation from parents (1%; χ²[1] = 89.17, p < .001). Furthermore, spontaneous responses indicating a fear of needle procedures
were more frequent than fear of other medical procedures (21%), \( \chi^2 (1) = 38.30, p < .001 \). When asked specifically about their fear for needles, 61% of children indicated they felt highly fearful about receiving medicine through a needle; children’s fear ratings for needle procedures were also significantly correlated with age, \( r = -.226, p = .002 \) (a small effect; Cohen, 1988). Seventy-three percent of participants endorsed feeling highly fearful of getting blood taken out of their arm with a needle, and children’s fear ratings for blood draws were significantly correlated with age, \( r = -.214, p = .003 \) (a small effect; Cohen, 1988).

**Children’s Fear of Pain.** It was hypothesized participants would endorse fear of experiencing pain during GP visits (H1), and frequency analysis provided some support for this hypothesis. Fear of pain was spontaneously reported by 13% of participants when asked an open-ended question regarding their fears about GP visits. Children’s responses to specific questions regarding their fear of experiencing pain during GP visits was variable, as 24% of children endorsed low fear of pain, 20% of children endorsed moderate fear of pain, and 45% of children endorsed high fear of pain. Younger children were more likely to endorse higher fear of experiencing pain at the GP, as age and fear of pain were significantly correlated, \( r = -.171, p = .013 \) (a small effect; Cohen, 1988). It is important to note that 60% of children reported feeling moderate-high fear that that no one would help them if they were experiencing pain or hurt at the doctor’s, and this fear decreased with age, \( r = -.161, p = .019 \) (a small effect; Cohen, 1988).

**Children’s Fear of Separation from Parents.** In contrast with H1, very few participants (1%) spontaneously reported separation from parents was their most feared aspect of GP visits. When asked specifically about whether they were fearful of separation from their parents at GP visits, responses were quite variable as 29% of children endorsed having no fear
and 43% of children endorsed having high fear. Fear of separation from parent was correlated with age such that younger children endorsed higher fear ratings for separation, $r = -.181, p = .010$ (a small effect; Cohen, 1988).

**Children’s Fear of the Unknown.** It was hypothesized participants would endorse fear of the unknown during GP visits ($H_1$), and frequency analysis provided some support for this hypothesis as 12% of participants spontaneously reported this concern. There were no differences in proportions among children’s responses for reported fear of pain and fear of the unknown, $\chi^2 (1) = .111, p = .739$. When asked specifically about their fear of not receiving preparatory information from their doctor about upcoming medical procedures, most participants endorsed feeling no fear (28%), low fear (23%), and moderate fear (28%). Children’s responses followed a similar pattern when asked about their fear of not receiving preparatory information from their parents, as detailed in Figure 2. Interestingly, children’s fear of not being provided information by their doctor had no significant relation to age ($r = -.082, p = .146$; a small effect, Cohen, 1988), yet children’s fear of feeling uninformed by their parents was significantly correlated with age, such that younger children endorsed higher fear scores for parents not telling them what will happen during the appointment, $r = -.199, p = .005$ (a small effect; Cohen, 1988).

**Children’s Other Reported Fears.** Most children endorsed no fear (29%) or low fear (37%) when asked to rate their fear of going to the doctors in general. Twenty-one percent of participants spontaneously reported being fearful of non-needle related medical procedures such as throat checks, receiving bad tasting medicine, or getting a wart removed. Post-hoc comparisons using the Bonferroni correction ($\alpha = .05/3 = .017$) revealed there were equivalent proportions of children’s responses indicating fear of non-needle medical procedures, pain,
and the unknown, χ²(1) = 6.12, p = .047. Eleven percent of participants spontaneously reported being fearful of being diagnosed with an illness or an injury; when specifically asked, 40% of children reported feeling highly fearful of the doctor diagnosing them with an illness or injury. When asked to describe their fears, 10% of participants stated they had no fears regarding visits to the GP. There were equivalent proportions of children’s responses for no fears regarding GP visits to proportions of responses indicating fear of pain and fear of the unknown, χ²(1) = 1.02, p = .601. It is important to note when children were asked about specific fear items included in the structured fear questionnaire, all participants endorsed they were fearful of at least one item on the questionnaire.

**How Children Express their Fears.** Children were asked to describe how they would communicate their fear to people around them. As exemplified in Figure 4, the most frequently described methods were through facial expressions (40%; e.g. “I would have a frown”) and verbally expressing their fear (33%; “I would tell my mom I was scared”). Children also reported expressing their fear through body reactions (20%; e.g. “I would be shaking”) and avoidance (16%; e.g. “I would ask them off-topic questions”). The least frequently endorsed ways of communicating fear-included vocal affect (9%; e.g. “I would scream”) and seeking physical comfort from parents (3%; e.g. “I would hold my mom’s hand). Five percent of participants indicated adults in the room would not be able to tell if they were scared because they would not demonstrate their fear (e.g. “I would keep it inside”).

**1.2 Children’s Suggested Changes for GP Visits**

When children were asked to describe their wishes for what would change the next time they visit the GP, they frequently focused on medical procedures: 32% wished for fewer needle procedures, and 16% for fewer non-needle related medical procedures. Furthermore, 5% of
children mentioned they would prefer to receive medicine through a different delivery method (e.g. a cream, pill, or liquid) rather than through a needle. Fifteen percent of participants wished for reduced pain during GP visits. Shorter wait times were requested by 17% of participants, and 19% of children wished for more entertaining activities in the waiting room and more child-friendly décor.

**Objective 2: Children’s Positive Experiences at the GP**

The second objective was to determine what aspects of visits to the GP that children find positive. Many participants (32%) endorsed rewards as a positive experience, which included receiving toys, food, or privileges as a result of visiting the GP. Other positive experiences reported included activities available to children in the waiting room (14%), interactions with healthcare personnel (14%), undergoing medical procedures (13%) and improved personal health as a result of GP visits (16%). The proportion of children’s responses for enjoying rewards during GP visits was significantly higher than responses for other positive experiences, $\chi^2 (1) = 27.36, p < .001$; an omnibus Cochran’s Q test did not indicate any differences among the proportions of the aforementioned, non-reward related positive experiences, $\chi^2 (1) = .896, p = .826$. Frequencies regarding the aspects of GP visits children reported as positive are detailed in Figure 6.

**Objective 3: Preparatory Information Provided to Children**

The third objective was to determine children’s perspectives of the information provided to them by doctors during GP visits. It was hypothesized children would report they receive inadequate preparatory information from doctors ($H_2$). However, more than half of participants (60%) indicated their doctor provided them with enough preparatory information. Only 36% of

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Please note that the results of question 5b regarding the aspects of GP visits children would like to stay the same (see Appendix A) are not included to reduce redundancy as they were nearly identical to the results of what children like about GP visits.
all participants wished their doctor would tell them more about what will happen during the visits. Children’s summed fear scores on the structured fear questionnaire significantly predicted children’s preference for more preparatory information, such that higher total fear scores increased the probability children wanted more preparatory information from their doctor, $\text{Exp}B = 1.05$, $\text{Wald}^2(1) = 9.11, p = .003$ (95% CI = 1.02 – 1.08). However, age did not significantly predict children’s preference for more preparatory information, $\text{Exp}B = .995$, $\text{Wald}^2(1) = .00, p = .982$ (95% CI = .652 – 1.52) (Table 2 for regression statistics).

Participants who had specific requests for types of preparatory information most frequently expressed wanting general information about what will occur during the appointment (34%), as well as specific information regarding upcoming needle procedures (18%) and non-needle related medical procedures (19%; Figure 7). Thirteen percent of participants also reported wanting more information about their personal health, including diagnosis of illness and what they will need to do to get better. An omnibus Cochran’s Q test indicated no significant differences in the proportions of children’s responses for preferring increased information about needle procedures, information about other medical procedures, and information about their personal health, $\chi^2 (1) = 1.97, p = .373$. Interestingly, pairwise comparisons using the Bonferonni correction ($\alpha = .05/3 = .017$) revealed children were more likely to want preparatory information regarding needle procedures compared to preparatory information regarding pain ($\chi^2 [1] = 18, p < .001$); more likely to want preparatory information regarding non-needle medical procedures compared to information regarding pain ($\chi^2 [1] = 17.86, p < .001$); and more likely to want preparatory information about their personal health than information about pain ($\chi^2 [1] = 9.14, p = .002$). Furthermore, 9% of children reported wanting to know logistical information about the appointment, such as when the appointment is scheduled, what order procedures will
go in, and when the appointment will end. It is important to note that 8% of children indicated they would not want any preparatory information whatsoever, which was significantly lower in proportion than children’s responses for increased preparatory information about needle procedures ($\chi^2 [1] = 5.82, p < .016$), and non-needle related medical procedures ($\chi^2 [1] = 6.42, p < .011$) (Bonferroni correction $\alpha = .05/2 = .025$).

**Objective 4: Children’s Perspectives of their Participation in GP Visits**

4.1 Children’s Indications of Whether They Have a Choice During GP Visits

It was hypothesized that children would report feeling that they do not have a choice in what happens during GP visits ($H_3$). Sixty percent of participants endorsed this hypothesis by reporting they do not have a choice in what occurs during GP visits, and another 16% of participants stated they have a choice only some of the time. Interestingly, the proportions of responses indicating children make decisions for themselves during GP visits (15%) was only slightly (albeit significantly) lower than proportions of responses indicating their parents making healthcare decisions on their behalf (25%), $\chi^2 (1) = 3.88, p = .049$ (Figure 8 for frequencies). Children described several reasons for why parents make decisions for them including their parent’s authority, knowledge, and/or they trust their parents to make decisions for them. When participants expressed why they got to make their own decisions during GP visits (15%), they often indicated it was because their doctor or parent let them have a choice. Less frequently, 7% of children indicated their doctor would make choices for them, and 7% believed their doctor made choices in order to do what was medically necessary for their health (Figure 8).
4.2 Children’s Indications of Whether They Want More of a Choice During GP Visits

It was hypothesized children would wish for more control over the procedures that occur (H4); however, only 34% of participants reported this. Furthermore, when asked specifically to rate their fear that no one would listen to them during GP visits, 50% of participants endorsed feeling “no fear”. Children’s summed fear scores on the structured fear questionnaire significantly predicted children’s preference for more choice, such that higher total fear scores increased the probability children wanted more choice during GP visits, \( \text{ExpB} = 1.04, Wald^2(1) = 5.88, p = .015 \) (95% CI = 1.01 – 1.07). However, age did not significantly predict children’s preference for more choice, \( \text{ExpB} = 1.39, Wald^2(1) = 2.32, p = .135 \) (95% CI = .90 – 2.12) (Table 3 for regression statistics).

When participants were asked to articulate what they want more of a choice about during GP visits, 42% of participants were unable to provide a description\(^3\). When participants were able to describe the choices they would like to have during GP visits, 25% of participants wished to be able to ask the doctor questions or give the doctor instructions and 19% wanted a choice about whether or not they had to undergo needle procedures; there was no significant differences in proportions of responses for these two categories \( \chi^2(1) = 1.85, p = .174 \). Less frequently, 11% of children expressed wanting more of a choice regarding the occurrence of non-needle related procedures, and 8% of participants wanted more of a choice in appointment logistics (e.g. when appointments were scheduled, length of appointments).

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\(^3\) It should be noted this is not inclusive of children who stated there was nothing they wanted more of a choice about or they were satisfied with their amount of choice. Rather, “no response” refers to children who stated they could not remember their experience of choice, they did not know an answer, or otherwise demonstrated they did not understand the question.
Discussion

The current study aimed to understand children’s perspectives on visits to the GP in order to determine the aspects children find positive and negative. It is important to determine which aspects of GP visits lead children to require intervention for distress reduction; the current results provide strong support that children are fearful of needle procedures, and some support for children’s fear of pain, separation from parents and feeling uninformed about medical procedures. In order to inform when interventions to reduce distress should be implemented during GP visits, parents and healthcare providers must be able to detect when children are experiencing fear; the current results demonstrate children endorse communicating their fear through facial expressions and verbal statements. The promotion of positive experiences during GP visits can improve children’s healthcare experiences; children enjoyed receiving rewards, activities available in the waiting rooms, interacting with healthcare professionals, and improving their personal health. Preparing children for medical procedures is foundational in promoting children’s participation in healthcare. However, contrary to what was hypothesized, children did not wish for increased information provision from their doctors. Similarly, while the majority of participants reported they did not have a choice in what occurs during GP visits, most participants did not want to have more agency. Conclusions of the study and implications for improving children’s experiences during GP visits are outlined below, starting with what children liked about the doctor, followed by children’s aversive experiences, and then children’s participation during GP visits.
What Do Children Like About GP Visits?

Children’s positive medical experiences are not as frequently researched as aversive experiences, but the promotion of aspects children enjoy is important to improving children’s GP visits. Children were most likely to report they enjoyed the rewards they received as a result of visiting the GP, such as food, toys, or privileges. Parents and doctors should take note of children’s strong preference for receiving small rewards, as this may be a simple and inexpensive way to improve children’s attitudes towards GP visits. Furthermore, participants appreciated how visits to the GP resulted in cured illness, healed injuries, and/or confirmed they were healthy, demonstrating participants understood the reason for GP visits is to improve their health. Some participants described their doctors and nurses as having positive communication styles (e.g. funny, nice, welcoming), which led to interactions with these healthcare professionals being their most enjoyed aspect of GP visits. This finding is similar to research regarding 6-15 year old hospitalized children (Corsano et al., 2013), which found children’s relationships with healthcare professionals could increase children’s satisfaction with their healthcare.

Participants also expressed opinions about the activities available to them in the waiting room and the décor of GP offices. Specifically, children preferred the setting to have child-friendly décor and activities and stressed the importance of the built environment being appropriate for children of all ages, not just very young children. Interestingly, interviews with hospitalized children also found children prefer when there are décor and waiting room activities that are age appropriate for school age children and teenagers (Coyne & Kirwan, 2012). Similarity, Varni et al. (2004) found parent and staff satisfaction with the aesthetics and built environment of a hospital were associated with satisfaction of health care service. The current
results suggest children’s preferred aspects of GP visits are fairly straightforward and can be implemented to improve experiences at the GP.

**What Do Children Dislike About GP Visits?**

While children reported little to no fear of visiting GP’s in general, children did describe the specific aspects of GP visits they found to be fear inducing. These specific components should be targeted for intervention to reduce child distress during GP visits. In order to determine when interventions are necessary, the current results suggest parents and doctors should be aware that children report expressing their procedural fear most frequently through facial expressions and verbal statements.

The current study provides further evidence that children identify needle procedures as aversive; the most commonly endorsed fear in this study was undergoing a needle procedure, including both injections and blood draws. Participants spontaneously reported fear of needle procedures when asked about their fears when visiting the GP, therefore it is clear participants associate visits to the GP with needle procedures. This finding is interesting, as the sample included in the current study is not scheduled for mandatory vaccinations; yet, these children are fearful of receiving needles during GP visits despite the reduced probability they will receive one. This demonstrates the importance of understanding children’s personal perspectives of GP visits, as intervention to reduce procedural fear may be necessary for both anticipated and actually-occurring medical procedures.

As predicted, children endorsed feeling fearful of experiencing pain during GP visits. Furthermore, 46% of children felt no one would help them if they were experiencing pain or hurt

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4 Based on provincial immunization schedules for children in grades 1-12 in Ontario, [http://healthycanadians.gc.ca/apps/schedule-calendrier/index-eng.php](http://healthycanadians.gc.ca/apps/schedule-calendrier/index-eng.php). While children in this age group may receive flu shots annually, these are not mandatory for school attendance.

5 Assuming they are otherwise healthy children or do not require travel-related vaccinations.
at the doctor. Children would benefit from learning the options available to them to manage pain, and that pain can and hopefully will be managed during their appointment. Unfortunately, children and parents may need to advocate for procedural pain relief as previous research has indicated healthcare providers often inadequately manage children’s pain (McMurtry et al., 2015; Taddio et al., 2009); the current study indicates children are concerned about this pain relief deficit. Children were equally likely to fear the unknown and pain in the context of GP visits; this provides further support for the supposition that fear of upcoming medical procedures cannot be exclusively explained by fear of being hurt (Dalley, Creary, & McMurtry, 2014).

Reduction of children’s procedural pain may not be sufficient to reduce children’s procedural fear if children also feel uncertain about what medical procedures will occur while they are at the doctors.

Fear of separation from parents during GP visits was variable across participants; unsurprisingly, younger children were more likely to endorse fear of being without their parents at GP visits. While very few children spontaneously reported fear of separation from parents, it was rated as highly fear inducing by almost half of participants. According Muris and Ollendick’s (2002) study on the validity of fear measurement, events that are unlikely to occur may still be rated as highly fear inducing following a targeted question (e.g. questions about death in FSSC-R; Ollendick, 1983), yet these fears are not spontaneously reported by children following an open-ended question. This would also explain why fear of separation from parents seems to be more frequently endorsed in hospitalized children compared to children visiting their GP (Coyne, 2006, Forsner et al., 2005), as GP visits are typically shorter in duration and therefore separation from parents in this context would be very uncommon. Additionally, this study provided further evidence that purportedly minor procedures could be fear inducing for
some children. For example, consistent with Aho and Erikson’s (1985) findings, a small but meaningful subset of the participants were fearful of throat swabs, ear checks, getting checked with a stethoscope, and/or having a tongue stick put in their mouth. Most children endorsed feeling low amounts of fear for these types of procedures; therefore, interventions to reduce distress for these procedures would likely be different than interventions to reduce high levels of acute fear, as the latter would likely involve more intensive, exposure-based interventions (McMurtry et al., in press).

**Do Children Wish for More Participation in GP Visits?**

In contrast to the hypothesis, the current data suggest children are generally content with the amount of participation they have during GP visits. However, a considerable minority (approximately a third of participants) wished for more choice during medical procedures. For those children who wanted increased participation, they sought the opportunity to ask the doctor questions or share their personal opinions, in addition to having more of a choice about the needle procedures they undergo. Children had some difficulty answering questions regarding who made choices on their behalf during GP visits, which suggests the concept of agency during medical experiences may be difficult for 7-10 year old children to understand and discuss. When children provided an answer regarding who makes choices on their behalf, they were more likely to report their parents made decisions for them, rather than reporting they made decisions for themselves.

As expected, many children reported their doctor does not provide them with preparatory information during GP visits. However, more than half of children did not want more preparatory information, which was in contrast to what was hypothesized and evidence from child healthcare literature. Qualitative interviews with hospitalized children consistently find children report fear
of the unknown; specifically, distress is based on feeling uncertain of what procedures will happen during their stay (Coyne, 2006; Coyne & Kirwan, 2012; Forser et al., 2009). Research advocating for children’s increased participation in their own healthcare has generally focused on hospitalized children, and perhaps fear of the unknown is not as prevalent in the context of GP visits. Certainly, visits to a hospital are likely more novel compared to GP visits, as the latter is more frequent for healthy Canadian children. Children may feel they have an adequate understanding of what occurs during GP visits, which may therefore reduce feelings of uncertainty and accompanying distress.

Interestingly, younger children were especially fearful of their parents not telling them what will happen at a GP visit, rather than fear of not receiving information from doctors. It could be speculated this is because children may rely on their parents for information regarding how to evaluate and react to medical experiences through both observations and explicit statements; for example, there is ample evidence that parental reactions during children’s medical experiences can impact children’s procedural distress and pain, as well as children’s experience of chronic pain (for some examples, Bush & Cockrell, 1987; Chambers, Craig, & Bennett, 2002; Evans et al., 2008; McMurtry, Chambers, McGrath, & Asp 2010). The current study suggests children believe their doctors provide them with enough preparatory information, which could explain why many children not endorse fear of feeling uninformed by doctors.

Children who endorsed higher ratings of fear on the structured fear questionnaire were more likely to want increased participation in GP visits as well as more preparatory information. Previous literature has explored how children’s coping style and trait anxiety can impact whether information provision will reduce or increase their anxiety (e.g. Melamed et al., 1988). In adult hospitalization literature, pre-operative distress was inversely associated with pre-operative
information provision (Nigussie, Belachew, & Wolancho, 2014; Teasdale, 1995). Previous literature has demonstrated information provision can be effective in reducing procedural distress in children as well (Jaaniste et al. (2007). Therefore, information provision may be most useful as an intervention to reduce distress for fearful children, as opposed to an educational program for all child patients. However, this study was exploratory, and empirical research is needed to determine if information provision interventions are is particularly effective for highly fearful children in the context of GP visits.

Strengths, Limitations, and Future Research

A particular strength of this study was its novel focus on children’s perspectives on GP visits, rather than hospitalization and/or surgery. Unfortunately, pediatric health research on GP visits is not as common as research regarding chronic illness or hospitalization (Walco & Goldschnieder, 2008), despite the fact visits to the GP likely occur frequently for Canadian children and play an important role in children’s health and development. Through exploring the aspects of GP visits children enjoy and dislike, the current results could inform the development of interventions aiming to improve children’s healthcare services in this context. This study included detailed interviews with 167 girls and boys in grades 2 through 4, providing rich information regarding how GP visits can be improved.

Another major strength of this study was that interviews were conducted with children directly in order to obtain their unique perspectives on GP visits. Children’s perspectives are rarely elicited in the creation and implementation of healthcare improvement programs, as this research has typically relied on information from healthcare providers and parents (Curtis et al., 2004). Historically, children’s cognitive and emotional development was seen as a barrier for

6 Assuming the child has access to a GP (Gutmann et al., 2010) and caregivers are following the Rourke Record’s or Greig Record’s recommendations for assessment (Rourke, et al. 2011; Greig, 2010)
their inclusion in research regarding improving children’s healthcare (Corsano et al., 2013). Children in the concrete-operation stage, which is the developmental stage of children in the current study, have demonstrated understanding of concepts related to health and illness in previous research (Eiser & Kopel, 2013). Additionally, most children in the current study were able to discuss abstract healthcare concepts such as being provided with preparatory information and their degree of participation during GP visits. While this research is specific to the context of GP visits, it may also provide further support for children’s ability to participate in healthcare research in general. Children are capable of providing suggestions for how their healthcare can be improved, and their perspectives should be considered in combination with those of parents and healthcare professionals in efforts to improve GP visits.

As there was little past research to guide the creation of interview topics, it was important open-ended questions be used so children’s responses were not confined based on assumptions made by the researchers. Open-ended questions were followed by targeted questions in order to meet study objectives. This was particularly important for investigating children’s fears, as Muris and Ollendick (2002) outlined the importance of differentiating between children’s spontaneously reported fears and fears children endorse when asked specific questions, as specific fear questions often lead to higher reported levels of fear for a given stimulus compared to levels of fear children spontaneously report in open-ended fear questions7. This could be interpreted to mean that higher ratings do not reflect children's actual level of fear (i.e., are artificially inflated); however, it is unlikely children’s fear ratings in the current study were artificially inflated, as 1) children’s fear ratings for items were consistent with expectations based on previous literature; and 2) fear ratings were internally consistent throughout the current study.

7 Interestingly, most standardized fear questionnaires ask children to provide ratings after a targeted question (FSSC-R, Ollendick, 1983; STAI-C, Speilberger & Edwards, 1970).
such that children more frequently endorsed high fear for the same items that were spontaneously
reported in the open-ended fear question. Additionally, children appeared able to correctly use
the CFS to rate their fear as 1) they had to pass a CFS seriation task before fear questions were
asked; and 2) different participants endorsed all five faces for each fear item (vs. only endorsing
the "extreme" faces), showing children’s fear was variable and they were able to express this
variability using the CFS.

This exploratory study is a first step in the development of programs to improve pediatric
health services in collaboration with children. While this study details aspects of GP visits that
should be continued or changed, there is no guarantee that implementing these suggestions will
actually result in outcomes such as reduced procedural distress and fear, increased satisfaction
with healthcare services, and adherence with medical recommendations. Furthermore, research
must be conducted to determine the feasibility of incorporating the findings from exploratory and
intervention research into practice during GP visits.

This study had several limitations; namely, several other variables could have been
investigated to explain variability in children’s fears, preference for preparatory information, and
preference for increased participation during GP visits. Research has demonstrated a number of
other factors can impact children’s procedural distress, pain, and preference for information
provision for example, children’s trait anxiety, attachment style memories of previous medical
procedures and coping styles. (Noel et al., 2010; Noel et al., 2012; Jaaniste et al., 2007; Melamed
et al., 1988; Tremblay & Sullivan, 2010). As the impact of these variables has been explored
elsewhere, they were not measured in the current study in order to decrease the length of the
interview with children.
While this study focused on close-ended questions regarding children’s interactions with doctors, children’s interactions with parents during medical situations are equally important to understand and often arose in children’s responses to open-ended questions. In fact, children in the current study were more likely to endorse feeling fearful that their parents would not inform them of upcoming medical procedures, compared to fearing their doctors would neglect to provide preparatory information. Determining parent anxiety, coping style, and interactions between children and their parents would be informative to understanding children’s perspectives on GP visits. Lastly, including a sample of children within a wider age range may have resulted in enhanced information regarding the impact of age specifically on children’s medical fears; however, a strength of the current study was its rich detail on children’s negative and positive perspectives of GP visits within a narrow age range. Future research integrating the aforementioned confounding variables and children of other age groups should be conducted in collaboration with GP’s, parents, and children as each has unique priorities and perspectives in the context of children’s healthcare.

**Conclusion**

This study demonstrated that visits to the GP are a complex, multi-faceted experience for children that involve both positive and negative aspects. Children expressed being fearful of several aspects of GP visits, including needle procedures and pain, and likely require intervention for distress management during these experiences. Children appreciate when they receive rewards, are treated kindly by medical professionals, and when the built environment of the GP office is age-appropriate. Many children were content with their participation during GP visits; notably, children with higher levels of medical fears were more likely to prefer more participation in GP visits. Children are capable of articulating their perspectives on GP visits, and
therefore their views should be considered in the development and implementation of healthcare improvement programs. Findings from the current study can inform the development of programs to improve children’s experiences at GP visits.
References


*and Adolescent Development, 14*, 31-48.


### Table 1.

**Inter-Rater Reliability for Coding Categories (Cohen’s kappa)**

<table>
<thead>
<tr>
<th>Question From Coding Manual</th>
<th>Mean Inter-Rater Reliability ($\kappa$)</th>
<th>Range of Inter-Rater Reliability ($\kappa$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>3a) What children enjoy about GP visits</td>
<td>0.89</td>
<td>0.73-0.97</td>
</tr>
<tr>
<td>3b) What children dislike about GP visits</td>
<td>0.83</td>
<td>0.78-1</td>
</tr>
<tr>
<td>5a) What children want to change about GP visits</td>
<td>0.85</td>
<td>0.75-0.97</td>
</tr>
<tr>
<td>5b) What children want to keep the same about GP visits</td>
<td>0.89</td>
<td>0.72-0.97</td>
</tr>
<tr>
<td>6c) What children want more preparatory information about</td>
<td>0.98</td>
<td>0.85-1</td>
</tr>
<tr>
<td>7b) Who children believe make choices during GP visits</td>
<td>0.92</td>
<td>0.84-0.97</td>
</tr>
<tr>
<td>7d) What children would like more choice about during GP visits</td>
<td>0.96</td>
<td>0.84-1</td>
</tr>
<tr>
<td>8a) Children’s fears in the context of GP visits</td>
<td>0.96</td>
<td>0.88-1</td>
</tr>
<tr>
<td>8b) Children’s expression of fear during GP visits</td>
<td>0.91</td>
<td>0.56-1**</td>
</tr>
</tbody>
</table>

**Note:** According to Altman’s Kappa Benchmark Scale (1990), mean inter-rater for all of the above questions demonstrated “Very Good” strength of agreement ($\kappa > 0.81$). Additionally, according to Altman’s Kappa Benchmark Scale (1990), inter-rater reliability ($\kappa$) within the range of 0.41-0.60 is classified as “Moderate”, inter-rater reliability ($\kappa$) within the range of 0.61-0.80 is classified as “Good”, and inter-rater reliability ($\kappa$) within the range of 0.81-1.00 is classified as “Very Good”.

**All subcategories for this question had an inter-rater reliability of $\kappa > .80$m, with the exception of the “Other” sub-category, which had a final inter-rater reliability of $\kappa=.056$**
Multinomial regressions determining if 1) age and 2) total fear score can predict children's preference for more preparatory information during GP visits

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<th></th>
<th>B</th>
<th>SE Waldχ²</th>
<th>Exp(B)</th>
<th>95% CI for Exp(B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>-1.62</td>
<td>1.89</td>
<td>.74</td>
<td>.65</td>
</tr>
<tr>
<td>Child Age</td>
<td>-0.01</td>
<td>.22</td>
<td>.00</td>
<td>1.00</td>
</tr>
<tr>
<td>Total Fear Score</td>
<td>.05</td>
<td>.02</td>
<td>9.11*</td>
<td>1.05</td>
</tr>
<tr>
<td>Intercept</td>
<td>-0.05</td>
<td>0.22</td>
<td>-0.01</td>
<td>1.00</td>
</tr>
<tr>
<td>Total Fear Score</td>
<td>1.05</td>
<td>0.49</td>
<td>1.11*</td>
<td>1.00</td>
</tr>
</tbody>
</table>

Note: * indicates p > 0.05, ° indicates a small effect (Field, 2013).

2. Total Fear Score

Note: * indicates p > 0.05, ° indicates a small effect (Field, 2013).
Table 3. Multinomial regressions determining if 1) age and 2) total fear score can predict children's preference for more choice during GP visits.

<table>
<thead>
<tr>
<th></th>
<th>B</th>
<th>SE</th>
<th>Wald</th>
<th>Exp(B)</th>
<th>95% CI for Exp(B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children's Preference for More Choice vs. Having Enough Choice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intercept</td>
<td>-4.14</td>
<td>1.93</td>
<td>4.62</td>
<td>1.39</td>
<td>[0.90, 2.12]</td>
</tr>
<tr>
<td>1. Child Age</td>
<td>0.33</td>
<td>0.22</td>
<td>2.32</td>
<td>1.39</td>
<td>[1.04, 1.46]</td>
</tr>
<tr>
<td>2. Total Fear Score</td>
<td>0.04</td>
<td>0.02</td>
<td>5.88*</td>
<td>1.04</td>
<td>[1.01, 1.07]</td>
</tr>
</tbody>
</table>

Note: * indicates p < .05, ° indicates a small effect (Field, 2013).

\[ R^2 = 0.03 \]

\[ \chi^2 (2) = 8.94 \]

Note: \( \chi^2 \) indicates a small effect (Field, 2013).
**Figure 1.** The process for creating a coding manual to categorize qualitative data in order to analyze for frequencies. This flowchart is adapted from Hruschka et al. (2004) and the process was informed by recommendations of Chorney et al. (2015).
Figure 2. Response proportions (%) for children’s fear ratings using the CFS (McMurtry et al., 2011) in response to items on the structured fear questionnaire. Items are listed in the order in which they were asked on the questionnaire.
on the structured fear questionnaire. Items are listed in the order in which they were asked on the questionnaire.

Figure 2 (continued). Response proportions (%) for children’s fear ratings using the CFS (McMurray et al., 2011) in response to items.

Parents
Fear of Feeling Uninformed by

Fear of Blood Draws

Fear of Throat Swabs

Fear of Injections
Figure 2 (continued). Response proportions (%) for children’s fear ratings using the CFS (McMurry et al., 2011) in response to items on the structured fear questionnaire. Items are listed in the order in which they were asked on the questionnaire.

Parents
Fear of Separation From

Doctors
Fear of Seeing Blood

Fear of Feeling Uninformed by
on the structured fear questionnaire. Items are listed in the order in which they were asked on the questionnaire.

Figure 2 (continued). Response proportions (%) for children’s fear ratings using the CFPS (McLarnity et al., 2011) in response to items...
Figure 3. Frequencies for participants’ spontaneously reported fears in the context of GP visits (n = 167). PA = Pain; NP = Needle Procedures; MMP = Medicine, Medical Procedures and Tools; MP = Medical Personnel; SP = Separation from Parent; II = Illness and Injury; UN = Feeling Uninformed and the Unknown; WT = Waiting; NON = No Dislikes; OTN = Other Negative Aspects; NR = No Response. Children’s responses could be coded in multiple categories (categories were not mutually exclusive); the bars represent frequency in which the categories were coded as “present” across all participant responses for this question.
Figure 4. Frequencies for participants’ expressions of fear (n = 167). FE = Facial Expressions; BA = Body Actions; VAE = Vocal Affect Expression; VE = Verbal Expression; PCP = Seeks Physical Comfort from Parents. AV = Avoidance; DND = Does Not Demonstrate Fear; OTI = Other Indications of Fear; NR = No Response. Children’s responses could be coded in multiple categories (categories were not mutually exclusive); the bars represent frequency in which the categories were coded as “present” across all participant responses for this question.
Figure 5. Frequencies for aspects of GP visits participants would like to change in comparison to frequencies for aspects of GP children dislike. PA = Pain; NP = Needle Procedures; MMP = Medicine, Medical Procedures and Tools; WT = Waiting; NON = No Dislikes; OTN = Other Negative Aspects; NR = No Response. Children’s responses could be coded in multiple categories (categories were not mutually exclusive); the bars represent frequency in which the categories were coded as “present” across all participant responses for this question. This bar graph includes only categories common to Questions 3b and 5a (see Appendix B for full coding manual).
Figure 6. Frequencies for aspects participants report enjoying about GP visits (n = 167). RW = Rewards; BH = Being in Better Health; MMP = Medicine, Medical Procedures and Tools; IPH = Receiving Information about Their Personal Health; HPS = Having Health Care Professional Support; PS = Having Parent Support; AW = Activities While Waiting; EA = Ending the Appointment; DEC = Décor of Office; NOP = No Positive Aspects; OTP = Other Positive Aspects; NR = No Response. Children’s responses could be coded in multiple categories (categories were not mutually exclusive); the bars represent frequency in which the categories were coded as “present” across all participant responses for this question.
Figure 7. Frequencies regarding children’s preferences for content of preparatory information ($n = 167$). PA = Pain; NP = Needle-Related Procedures; MMP = Medicine, Medical Procedures and Tools; GAL = Receive General Appointment Logistics; IPH = Information about Their Personal Health; GI = General/Unspecified Information; NOI = No Information; OTI = Other Information; NR = No Response. Children’s responses could be coded in multiple categories (categories were not mutually exclusive); the bars represent frequency in which the categories were coded as “present” across all participant responses for this question.
Figure 8. Frequencies for participants’ beliefs regarding who makes choices during GP visits (n = 167). PC = Parent Makes Choice; DC = Doctor Makes Choice; PCC = Parent & Child Make Choice; CC = Child Makes Choice; CNC = Child Does Not Have Choice; MN = Medically Necessary Choice; NP = No Response. Children’s responses were coded as mutually exclusive for this question; the bars represent frequency in which the categories were coded as “present” across all participant responses.
Figure 9. Frequencies for what participants would like more of a choice about \((n = 167)\). PA = Pain; NP = Needle Procedures; MMP = Medicine, Medical Procedures and Tools; AL = Appointment Logistics; RW = Rewards; DI = Degree of Involvement; OTC = Other Choices; NOC = No Choice; NR = No Response. Children’s responses could be coded in multiple categories (categories were not mutually exclusive); the bars represent frequency in which the categories were coded as “present” across all participant responses for this question.
Appendix A: Questionnaire - Children’s Perspectives on Visits to the General Practitioners’ Office

The following questions will be read to participating children. List all of the child’s responses verbatim in the space provided. Some open-ended questions have prompts in order to ensure participants give complete responses. All questions and prompts (which are in **bold** print) must be read to all participants, regardless of how extensive their previous responses are. Fill out the below demographic information before the questionnaire begins (you will likely have to ask the student for their age).

Child’s Age (years): _____________________________________
Child’s Grade: _______________________________________
Child’s School ________________________________________
Child’s Sex (circle one): Male  Female

Today I am going to ask you some questions about visiting a doctor. These questions are about visiting a type of doctor called a general physician. General physicians are the doctors you might go to for check-ups, if you hurt yourself, if you feel sick, or if you need medicine. These questions are not about doctors you would see at a hospital or in an emergency. Do you have any questions about the type of doctors we will be talking about? There are no right or wrong answers to the questions I’m going to ask you, I just want to know what you think. For some of the questions, you might have a lot to say, and for some questions you might not have an answer. You may need to take some time to think about your answers. That is fine to do, because I am really interested to hear what you have to say about visiting a doctor’s office.

1. I want to introduce you to a boy/girl your age named John/Jane. John/Jane is going to the doctor’s office today.
   a) What do you think will happen to John/Jane in the doctor’s office? Tell me all the things you can think of that will happen at the doctor’s office. 
   **Further prompts, if needed: What will happen first? What will happen next? What will happen last?**

Now, I want to know about specific people are doing when John/Jane is at the doctor’s office. Ask the following three prompts, pausing after each to allow the child to answer:

b) What will John/Jane be doing during the appointment? *If child answers “sitting/laying down on the bed”, write that answer down and further prompt: “And what will John/Jane do during the appointment after they settle on the bed?”*

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Now I want to know about John/Jane’s mom or dad: What will John/Jane’s mom or dad be doing during the appointment?
d) What will the doctor be doing during the appointment?


e) How do you think John/Jane will feel at the doctor’s office? Write down the child’s response, and then proceed to the prompts below. If the child says one of the prompts below, simply circle “Y” and move on to the next prompt. If the child responds “sick”, write down that answer and further prompt: “Do you think John/Jane will have any other kinds of feelings at the doctor’s office?”


f) I’m going to say some feelings, and I want you to tell me if John/Jane will feel that way. Do you think he/she will feel (circle “S” for sometimes or maybe):

<table>
<thead>
<tr>
<th>Feeling</th>
<th>Y</th>
<th>N</th>
<th>S</th>
</tr>
</thead>
<tbody>
<tr>
<td>Happy</td>
<td></td>
<td></td>
<td>S</td>
</tr>
<tr>
<td>Sad</td>
<td></td>
<td></td>
<td>S</td>
</tr>
<tr>
<td>Worried or Scared</td>
<td></td>
<td></td>
<td>S</td>
</tr>
<tr>
<td>Angry</td>
<td></td>
<td></td>
<td>S</td>
</tr>
<tr>
<td>Surprised</td>
<td></td>
<td></td>
<td>S</td>
</tr>
<tr>
<td>Just Normal/Just Ok</td>
<td></td>
<td></td>
<td>S</td>
</tr>
</tbody>
</table>

Set the context for the following questions by prompting the participant to think about their previous experiences at the doctor’s office: I’d like you to think about a time you went to the doctor’s office.

2. a) Can you remember a time you went to the doctor’s office?

   Yes
   No
   I don’t know

b) What has happened when you have been to the doctor’s office?
If the child answers yes, ask question 3. If the child answers no or I don’t know, skip to question 4. The child will only answer one of question 3 or 4.

3. Okay, good, now I’m going to ask you some questions about when you have gone to see the doctor.

   a) What were some things that you liked or made you feel happy when you went to the doctor’s?

   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

   b) What were some things that you didn’t like or made you feel unhappy when you went to the doctor?

   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

4. That’s ok. I’m going to ask you about visits to the doctor, and do the best you can to remember what happens at doctor’s visits.

   a) What do you think are some things that you might like or might make you feel happy when you go to the doctor’s?

   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

   b) What do you think are some things that you might not like, or that might make you feel unhappy when you go to the doctor’s?

   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
All participants will answer all of the following questions.

5. a) If you could change anything about going to the doctors office, meaning if you wished anything would be different or changed, what are some things you wish would be different or be changed the next time you go to the doctor’s office?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

b) What are some things you wish would stay the same the next time you go to the doctor’s office?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

6. I want to ask you a few more questions about what going to the doctor has been like for you. Are you thinking about a time you went to the doctor? Good. Sometimes doctors tell kids about what will happen to them when they are at the doctor’s office, and other times kids don’t know what will happen when they go to the doctor’s office.

a) Does your doctor tell you about what will happen while you are at the doctor’s office? You can say yes, no, or I don’t know.

   Yes No I don’t know

b) Some kids wish their doctor would tell them more things and other kids think their doctor tells them just the right stuff before they go to the doctor. Do you wish your doctor would tell you more about what will happen, or do you think the doctor tells you enough?

   Tell More Enough I don’t know

What are some things you would like your doctor to tell you more about during your next visit to the doctor’s office?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
7. a) When visiting the doctor, sometimes kids like you get a say or a choice about things and other times adults take charge and don’t ask kids what they think. Do you feel that you have a say or a choice about what happens to you at the doctor’s office? You can say yes, no, or I don’t know.

Yes  No  Sometimes

b) Based on above answer: Tell me why you think you do/do not have a say or a choice in what happens at the doctor’s office.

______________________________________________________________________  
______________________________________________________________________  
______________________________________________________________________  
______________________________________________________________________  

8. a) Sometimes when kids are at the doctor’s office, they feel worried or scared. When you go to the doctor’s office, what are the kinds of things that make you feel worried or scared?

______________________________________________________________________  
______________________________________________________________________  
______________________________________________________________________  
______________________________________________________________________  

b) How can someone tell if you are worried or scared at the doctor’s office? If needed, prompt: How would you let someone know that you are worried or scared at the doctor’s office?

______________________________________________________________________  
______________________________________________________________________  
______________________________________________________________________
Introduce the CFS and screen for self-report ability. If the participant does not answer correctly the first time, repeat the instructions for a second time and repeat the screening question. If the child fails the task for a second time, use cups scales instead. These are 5 faces that show different amounts of being scared. The faces should go from showing no fear at all to the most fear possible but they are out of order. I would like you to put these faces in order from what you think is the least amount of scared up to the most scared possible.

![Faces](Image)

Note whether child completed the seriation task on the first or second trial, and whether the cups or CFS were used for the following questions:

If the child does not successfully complete the task, the child will use different sized cups to answer the questions. Introduce the cups by saying: Let’s try something different. These cups are different sizes. I would like you to put these cups in order from the smallest cup to the biggest cup. If the child cannot complete this task, conclude the questionnaire. If the child successfully completes this task, use the cups scale to answer questions 10 and 11. Place the CFS faces underneath the ordered cups in corresponding order (smallest cup matched with face showing “no fear at all” largest cup with face showing “most scared possible”). Child used (circle): CFS or cups

9. Great job! Let’s start with a question about going to the doctor.
   If using CFS: Remember, point to this face [point to the left-most face] for not scared at all, this face is a little bit more scared [point to second face from left], a bit more scared [sweep finger along scale], right up to the most scared possible [point to the last face on the right]. Using these faces, can you tell me how worried or scared you feel about going to the doctor? Circle below.

   If using Cups scale: Remember, point to this cup [point to the smallest cup] for not scared at all, this cup for is a little bit more scared [point to second smallest cup], a bit more scared [sweep finger along cups], right up to the most scared possible [point to the biggest cup]. Using these different sized cups, can you tell me how worried or scared you feel about going to the doctor? Circle below.

   0  1  2  3  4
10. You are doing a great job! There are different things that happen at different times when you go to the doctor. I am going to list some of those things, and I want you to use these faces to tell me how worried or scared you would feel. Take out the pictures out of the box, and place them in a stack face up. The pictures should be placed in order, with the letters on the back of the pictures corresponding with order of the letters in the chart. When you are done showing the child a picture, flip the picture over so it is not longer visible and put it back in the box. When the picture task is finished, put the pictures away. I will show you some pictures of things that happen at the doctor. You can look at these pictures to help you think about if you find these things scary or not, and we will put them away when we are done with each one. Check the box that corresponds with the face/cup the child points to. Repeat the instructions for the CFS or cups if necessary.

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) I am worried or scared of the doctor putting a tongue stick in my mouth to check my throat.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) I am worried or scared of sitting in the waiting room at the doctor’s office.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) I am worried or scared of the doctor checking my ear.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) I am worried or scared of the doctor listening to my breath with a stethoscope.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>e) I am worried or scared of getting medicine put into my arm with a needle (injection).</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) I am worried or scared of getting blood taken out my arm or hand with a needle.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) I am worried or scared of the doctor using a throat swab on the back of my throat.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

11. Thank you for telling me what you think! There are no more pictures left, but I want to ask you about a few more things that could happen at the doctor’s office. We do not have pictures for these questions, but I would still like you to use these faces to tell me if you find these scary or not. Some of these may sound the same, but each one is actually a little bit different so please pay attention. Remind children of CFS or cups instructions if necessary. Check the box that corresponds with the face/cup the child points to.
<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>a) I am worried or scared my parents will not tell me what is going to happen at the doctors.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>b) I am worried or scared the doctor and nurse will not tell me what they are going to do to me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) I am worried or scared of seeing blood come out of me at the doctor’s office.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) I am worried or scared the nurse or doctor will tell me something is wrong with me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) I am worried or scared of being alone without my mom or dad when I go to the doctor.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) I am worried or scared of feeling pain or hurt when I go to the doctor.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) I am worried or scared I will get germs if I go to the doctor.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h) I am worried or scared no one will listen to what I have to say when I go to the doctor.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i) I am worried or scared no one will help me if I am feeling pain or hurt when I go to the doctor.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

12. We want to help make needles less scary and hurt less for kids. So we need to figure out the best way to teach kids about how to make needles better. I’m going to list some ways that we could teach kids about how to make needles less scary and less painful, and I want you to tell me what you think.

a) Would you want to learn information about how to make needles better from:

- [ ] Youtube video  
- [ ] Educational movie  
- [ ] Storybook  
- [ ] Activity in your class at school  
- [ ] From parents  
- [ ] From doctor or nurse  
- [ ] Internet  
- [ ] From other kids  
- [ ] An app  
- [ ] A game  
- [ ] Brochure or pamphlet  
- [ ] Any other ways?: __________________________

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What do you think is the **best** way?

______________________________________________

b) Now, I want to know **where** we should teach kids about making needles less scary and painful. Would you want to learn about how to make needles better at:

- School
- Home
- Doctor’s office
- Computer or phone
- TV
- Other place: __________________________________________

What do you think is the **best** way?

______________________________________________

13. Thank you for talking to me about some of the things at the doctor’s office that make you feel worried or scared. I just have a few more questions to ask you.

a) **What is your favourite thing about visits to the doctor’s office?**

_______________________________________________________________________

_______________________________________________________________________

_______________________________________________________________________

_______________________________________________________________________

b) Thank you for helping us to understand what kids like you think about going to the doctor’s office. Is there anything you liked about helping with this study? Can you tell me some of the things you liked about helping with this study?

_______________________________________________________________________

_______________________________________________________________________

_______________________________________________________________________

_______________________________________________________________________

c) Is there anything you didn’t like about helping with this study? Can you tell me some of the things you didn’t like about helping with this study?

_______________________________________________________________________

_______________________________________________________________________

_______________________________________________________________________

_______________________________________________________________________
Appendix B: Children’s Perspectives on Visits to the General Practitioners’ Office - Coding Manual

Materials:
- SPSS data file corresponding to this study (different SPSS data file for each coder)

Location of files
1. Open PPHC Lab Drive
2. Go to “GP Study” folder
3. Open GP Study SPSS spreadsheet (different spreadsheets for different coders)

Instructions:
- Code the participant responses, as found on the SPSS data file, according to the classification outlined below.
- The coding scheme is organized so that each individual question on the questionnaire falls under one of the study objectives. The questions listed below are the only questions that will require qualitative coding for analysis.
  - Objective 1: Questions 3b/4b, 5a, 8a
  - Objective 2: Questions 3a/4a, 5b, 14a
  - Objective 3: Questions 7b, 7d
  - Objective 4: Question 6c
  - Objective 5: no coding for this objective
  - Objective 6: no coding for this objective

- When coding the data, the coder should code the responses to the questions by objective (e.g. completing coding for all questions of Objective 1, followed by Objective 2, etc).
- On the SPSS data sheet, each response can be coded “0”-Child did not give a response that falls within this category or “1”- Child gave a response that falls within this category.
- The SPSS data file is set up so that every coding category for a given question receives a code of either “0” or “1”. Each response should get a minimum of one code assigned, and all responses can be given multiple codes. If multiple codes are required, each code and accompanying part of the response should be in its own column in the SPSS data file. The only exception to this rule is question 7b under Objective #3, as the coding categories for this question are mutually exclusive and therefore only one category should be coded as present.
- For example, for Objective 1, Question 3a/4a, the response “I don’t know how long the needle will hurt” would be coded as the following, as the response includes reference to expected pain, needle procedure, and feeling uncertain.

<table>
<thead>
<tr>
<th>Pain</th>
<th>Needle Procedures</th>
<th>Other Medical Procedures</th>
<th>Medical Personnel</th>
<th>Medici ne</th>
<th>Separat ion from Parents</th>
<th>Illnes s and Injury</th>
<th>Feeling Uninfor med</th>
<th>No Fears/ Dislike s</th>
<th>No Response</th>
</tr>
</thead>
</table>

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• The response category “No Response” includes 1) responses indicating the child does not know an answer, 2) responses indicating the child cannot remember or an answer stating they don’t know the answer or 3) responses that are off-topic and do not provide an answer to the question asked, or 4) absence of any response from the child.
  o The coding categories of “No Response” should only be indicated as present (“1”) when no other codes can be given for a participant’s response. For example, the response to Question 3b/4b “I don’t know... I’m afraid of getting sick” would be coded as follows. Coding the response as “No Response” would be inaccurate as the child’s answer did provide information regarding what the child dislikes and/or is fearful of at the doctor’s office.

<table>
<thead>
<tr>
<th>Pain</th>
<th>Needle Procedures</th>
<th>Other Medical Procedures</th>
<th>Medical Personnel</th>
<th>Medicine</th>
<th>Separation from Parents</th>
<th>Illness and Injury</th>
<th>Feeling Uninformed</th>
<th>No Fears/Dislikes</th>
<th>No Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

• The explicit wording of the question asked to the children is listed at the top of each table. If the child gives a response that is off-topic and does not answer the question asked of them, it should be coded under the “No Response” category. For example, the response to Question 3b/4b “I like eating the lollipops” would be coded as follows, as that response is off-topic and does not provide information regarding what the child dislikes and/or is fearful of at the doctor’s office.

<table>
<thead>
<tr>
<th>Pain</th>
<th>Needle Procedures</th>
<th>Other Medical Procedures</th>
<th>Medical Personnel</th>
<th>Medicine</th>
<th>Separation from Parents</th>
<th>Illness and Injury</th>
<th>Feeling Uninformed</th>
<th>No Fears/Dislikes</th>
<th>No Response</th>
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<tbody>
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<th>No Response</th>
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</tbody>
</table>
**Objective 1**

3b/4b) What were some things that you didn’t like or made you feel unhappy when you went to the doctor?

8a) Sometimes when kids are at the doctor’s office, they feel worried or scared. When you go to the doctor’s office, what are the kinds of things that make you feel worried or scared?

<table>
<thead>
<tr>
<th>Category Name</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
</table>
| 1. Pain       | The child’s response references experiencing pain or hurt. Their response must specifically mention the words “pain” or “hurt,” (or another synonym such as “ouch” or “stung”). | - The throat swabs really hurt my throat *(This response would also be coded as present in Category 3)*
|               |            | - I didn’t like that it was really painful
|               |            | - Because it always hurts at the doctor’s office |
| 2. Needle Procedures | The child’s response references needle related procedures, including the mention of blood draws, shots, or needles. | - When he got a needle
|               |            | - Sometimes taking a blood test
|               |            | - Needles, that’s it
|               |            | - Taking blood |
| 3. Medicine, Medical Procedures and Tools (non-needle related) | The child’s response references medical procedures, medical tools, or medicine other than a needle or needle-related procedures. Other medical procedures include, but are not limited to, surgical procedures or check ups. References to medicine can include the taste, the delivery method [pill, inhaler, liquid], and/or overall dislike of having to take medicine. This category does not include mention of a needle or a needle-related procedure, which would fall into Category 2. | - They used the light to look into my eye
|               |            | - All those scary tools
|               |            | - If I need surgery
|               |            | - If I had to take medicine
|               |            | - When I got a check up |
| 4. Medical Personnel | The child’s response references the medical personnel they interacted with, including nurses and doctors. The child’s response must explicitly reference the word doctor and/or nurse, and the child’s belief regarding their interaction with the doctor. This | - There was a different doctor and I liked my old doctor better
<p>|               |            | - The nurse was not nice |</p>
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Separation from Parent</td>
<td>The child’s response references being separated from a parent, guardian, or other caregiver.</td>
<td>- If my mom and dad aren’t there</td>
</tr>
</tbody>
</table>
| 6. Illness and Injury | The child’s response references having an illness at or outside the doctor’s office, obtaining germs at or outside the doctor’s office, or having an injury at or outside the doctor’s office. | - Worried I have a really bad cold  
- If I’m going to die  
- Getting more sick because there are germs there  
- If there is something wrong |
| 7. Feeling Uninformed and the Unknown | The child’s response references feeling uncertain about what will occur during GP visit. More specifically, the child must mention not knowing something or feeling unsure, or doing something they have not done before. | - Not knowing what they are going to do to me  
- I don’t know if the needle will hurt *(This response would also be coded as present in Category 1&2)*  
- What’s going to happen |
| 8. Waiting | The child response references something they disliked about waiting at the doctor’s office, or consequences of waiting (e.g. led to them missing an activity such as school, a sports game). | - I had to wait so long  
- Missing school  
- I can’t play my favourite game  
- The waiting room had too many people |
| 9. No Fears/Dislikes | The child’s response references there is nothing they fear or dislike about GP visits. | - Nothing  
- I’m not scared or worried about anything |
| 10. Other Negative Aspects | The child’s response indicates an aspect of GP visits not included in the aforementioned categories. This category does not include answers that are not a direct and valid response to the question of what a child dislikes about the doctors office, as off-topic responses are categorized as No Response, Category 11. | - I was bored  
- Nothing to do  
- I bleed a lot |
| 11. No Response | The child is unable to provide a response. This response category | - I don’t know  
- I forget |
exclusively includes 1) responses indicating the child does not know an answer, 2) responses indicating the child cannot remember an answer, 3) responses that are off-topic and do not provide an answer to the question asked, or 4) absence of any response from the child. If the child follows any of these statements with a response that can be coded in another category, this category cannot be coded as present. This category can only be coded as present if all other categories are coded as “0”.  

<table>
<thead>
<tr>
<th>Category Name</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
</table>
| 1. Pain       | The child’s response references experiencing pain or hurt. Their response must specifically mention the words “pain” or “hurt,” (or another synonym such as “ouch” or “stung). | - No more needles because they are pointy and they hurt *(This response would also be coded as present in Category 2)*  
- There wouldn’t be stuff that hurt |
| 2. Needle Procedures | The child’s response references any aspect of needle-related procedures, including the mention of blood draws, shots, or needles. | - Needles wouldn’t hurt *(This response would also be coded as present in Category 1)*  
- Needles wouldn’t be so sharp  
- There would be no flu shots, there would be liquid you can pour on a part of your body (also coded as Category 3) |
| 3. Medicine Instead of Needle | The child’s response explicitly references preferring to receive medicine through a different delivery method (e.g. cream, liquid, pill) other than a needle. **Any response coded as “present” in this category should also be coded as “present” in Category 2.** | - Maybe the needles less painful, like a tiny laser in my bone get the medicine in a different way, like a pill (also coded as Category 1 and 2)  
- The shots wouldn't hurt, it was just something I could take medicine and it would go away pill (also coded as Category 1 and 2) |
<p>| 4. Medicine, | The child’s response references | - That thing they use to take your blood |</p>
<table>
<thead>
<tr>
<th>Medical Procedures and Tools (non-needle related)</th>
<th>medical procedures, medical tools, or medicine other than a needle or needle-related procedures. Other medical procedures include, but are not limited to, surgical procedures and check ups. References to medicine can include the taste, the delivery method [pill, inhaler, liquid], and/or overall dislike of having to take medicine. This category does not include mention of a needle or a needle-related procedure, which would fall into Category 2.</th>
<th>pressure with wouldn’t be so tight - I got a check-up - I wish there was something they could so rather than burning it off which wouldn’t hurt so much (also Category 1) - When she runs a lot of tests and puts lots of things on us or makes us get needles (also Category 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5. Reward</td>
<td>The child’s response references wanting to receive awards during or after visits to the GP. This includes, but is not limited to receiving toys, food, stickers or privilege during or after visits to the doctor’s office. This response category does not include references to activities in the waiting room (e.g. better toys, video games in the waiting room), which are coded in Category 8.</td>
<td>- To get three stickers - I wish we could get more candy. At the end the doctor says just go and the kids just been sitting there the whole time. It should be more entertaining He would give us toys and there would be a TV in the waiting room. And you could play x-box on it. (Also coded as Category 8)</td>
</tr>
<tr>
<td>6. Improved Communication Between Doctor and Child</td>
<td>The child’s response references the communication, or lack thereof, between the doctor and the child.</td>
<td>-Doctors would ask me more questions, instead of tools ask me about how I feel (also Category 4) - I wish I could get the doctor to say words I actually understand</td>
</tr>
<tr>
<td>7. Décor of Office</td>
<td>The child’s response references their negative evaluation about the physical space in the doctor’s office, including the entire building or specific rooms.</td>
<td>- I would make the room bigger - I would make the walls look nicer for kids -A bouncier bed, no more needles (also coded in Category 2)</td>
</tr>
<tr>
<td>8. Activities while Waiting</td>
<td>The child’s response references their negative evaluation of the activities available to them in the waiting room, including but not limited to toys, books, TV, and/or video games.</td>
<td>- I would want more toys for kids my age - Better waiting room for kids</td>
</tr>
<tr>
<td>9. Wait Times</td>
<td>The child’s response explicitly references how long they wait before their appointment begins, or that their appointment takes too</td>
<td>- I would not want to wait so long - My mom and I had to wait 30 minutes - They took a very long time to Call me, the service wasn't quick.</td>
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long.

<table>
<thead>
<tr>
<th>Category Name</th>
<th>Definition</th>
<th>Example</th>
</tr>
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</table>
| 10. No Changes                       | The child’s response references there is nothing they would change about GP visits | -Nothing  
- I would not want to change anything  
- Now I do like having needles they make me healthy, I change how many times I go there, so I can go there a lot |
| 11. Other Changes                    | The child’s response references an aspect of GP visits not included in the aforementioned categories. This category does not include answers that are not a direct and valid response to the question of what a child would like to change about the doctor’s office, as off-topic responses are categorized as No Response, Category 10. | - All the sick people wouldn’t have to sit together  
- I had to wear this boy gown with Elmo on it, they should have one for girls |
| 12. No Response                      | The child is unable to provide a response. This response category exclusively includes 1) responses indicating the child does not know an answer, 2) responses indicating the child cannot remember an answer, 3) responses that are off-topic and do not provide an answer to the question asked, or 4) absence of any response from the child. If the child follows any of these statements with a response that can be coded in another category, this category cannot be coded as present. This category can only be coded as present if all other categories are coded as “0”. | - I don’t know  
- I forget  
- I don’t remember  
- No  
- (response referring to dentist)  
- give me something that would make me fly (or other non-sensical response) |

8b) How can someone tell if you are worried or scared at the doctor’s office?

<table>
<thead>
<tr>
<th>Category Name</th>
<th>Definition</th>
<th>Example</th>
</tr>
</thead>
</table>
| 1. Facial Expressions                | The child’s response references a facial expression, including but not limited to expressions shown through the child's eyes. The child’s response can be | - My face would turn red  
- The look in my eyes  
- I would have a frown  
- Look on my face and I would tell them (also Category 4) |
given through a verbal statement or by non-verbally miming a facial expression.

| 2. Body Actions | The child’s response references a body reaction (other than a facial expression). The child’s response can be given through a verbal statement or by non-verbally miming a body reaction. This includes body reactions, including but not limited to, shaking, shivering, being tense, fidgeting, etc. | - I might be shaking  
- (mimes bawling up fists)  
- I would be shivering  
- Sometimes I just breathe really heavy  
- Butterflies in my stomach  
- Mimes biting my nails  
- I would move around a lot |

| 3. Vocal Affect Expression | The child’s response references a vocal expression of affect, specifically crying or screaming. This does not include verbal expression of pain using words, which would fall under Category 4. | - If you’re crying  
- I would be screaming  
- I would be loud  
- Gulp |

| 4. Verbal Affect Expression | The child’s response references verbalizing, through words, their emotions to an adult (they said something out loud about fear). This response does not include crying or screaming, which would fall under Category 3. | - I would let them know I am worried or scared  
- I would tell whoever is with me  
- I raise my hand to let them know I’m scared (also body reaction)  
- I would just let them know  
- I would tell them |

| 5. Seeks physical comfort from parents | The child’s response references seeking the physical comfort of their parents. This category does not include verbal conversations with parents about fear (Category 4). | - I go to my parents and sit on their lap or you can tell by the face I’m making (also Category 1)  
- Hold my mom’s hand  
- Hold my mom’s arm  
- I’ll ask my parents to come sit beside me |

| 6. Avoidance | The child’s response references avoiding the aversive situation either through covert methods (see first two examples) or by directly telling someone they don’t want to do something. This includes, but is not limited to responses referring to mentions of stalling, trying to not go to the doctor, and trying | - I would hide underneath the car  
- Usually I start asking off topic questions  
- I would tell them I don’t want to do it  
- I wouldn’t want to go  
- Turning my head  
- I ask my parents if I can go home  
- I would tell them I don’t want to do it (also coded in Category 4) |
<table>
<thead>
<tr>
<th>Objective #2</th>
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<tbody>
<tr>
<td>3a/4a) What were some things that you liked or made you feel happy when you went to the doctor’s?</td>
</tr>
</tbody>
</table>
5b) What are some things you wish would stay the same the next time you go to the doctor’s office?

<table>
<thead>
<tr>
<th>Category Name</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
</table>
| 1. Rewards                                        | The child’s response references receiving awards related to their attendance of GP visits. This includes, but is not limited to receiving toys, food, stickers or privilege during or after visits to the doctor’s office.                                                                                   | - Getting a lollipop  
- I got angry bird stickers  
- I get a new app on my iPad                                                                                     |
| 2. Being in Better Health                         | The child’s response references feeling better, being healed, or being healthier as a result of visiting the doctor’s office. This category does not include 1) learning new information about personal health, which would be coded in Category 4; or 2) learning new information about medicine, medical procedures, and tools, which would be coded in Category 3. | - That you are all better when it’s done  
- No wart anymore  
- Nothing wrong anymore  
- The doctor’s keeps you healthy  
- After everything is ok                                                                                         |
| 3. Medicine, Medical Procedures and Tools         | The child’s response references a positive evaluation of medical procedures, medical tools, or medicine including, but not limited to, a needle or needle-related procedures and check ups. This includes their positive evaluation regarding undergoing a medical procedure or learning about medical procedures.  
The child must explicitly reference they like certain medical tools, procedures, or medicine. Responses referring to medicine or medical procedures children dislike are not a direct answer to this question and are therefore not coded in this category. | - The doctor told me there was nothing wrong and I was just having a check up (also coded as Category 4)  
- When I got a needle, I was happy  
- I like the feeling of what they do the blood pressure finger thing  
- I like looking at all the tools  
- While we’re waiting, I get to look at all the tools and ask about them |
| 4. Receiving Information about Their Personal Health | The child’s response references receiving information about and/or increasing their understanding of their own health or illness as a result of visiting the doctor’s office. This includes learning something about their health or illness, which may include confirmation of health, diagnosis of illness or injury. This does not include simply undergoing a medical procedure, which is not coded in this section. This does not include learning about medicine or medical tools, which would fall in Category 3 “Understanding the Purpose of Medical Procedures/Tools” | - When I had strep throat the doctor showed me what it looks like  
- I found out what was happening and what I had to do to get better (also coded as category 2)  
- Happy nothing was wrong with you  
- Knowing I was healthy |
| 5. Having Health Care Professional Support | The child’s response references their doctor’s presence and/or help with coping during visits to the doctor’s office. The child’s response should reference the word doctor and/or nurse (or other health care professional), and the child’s belief regarding their interaction with the individual. The response must reference the child’s positive evaluation of their health care professional. This response does not include descriptions of the child undergoing a medical procedure performed by the health care professional. | -The doctor told me I would be ok  
-My doctor is funny  
-He is nice and he welcomed us  
- The nurse told me jokes  
- He was going to help me, he wasn’t going to hurt me |
| 6. Having Parent Support | The child’s response references their parent’s presence and/or help with coping during visits to the doctor’s office. The response must reference the child’s positive evaluation of their parent’s presence and/or help. | - My dad comforted me when I was getting a wart removed  
- My mom and dad were with me so I wasn’t scared |
| 7. Activities While Waiting | The child’s response references activities available to them in the waiting room and/or while they are waiting for the doctor in the examination room. The child’s | - I like playing with the toys in the waiting room  
- I liked waiting because I was relaxed  
- Watching the computer, when |
<table>
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<tr>
<th>Category</th>
<th>Description</th>
<th>Example Responses</th>
</tr>
</thead>
</table>
| 8. Ending the Appointment | The child’s responses explicitly reference that their favourite thing about the doctor’s office is when the appointment is over and/or they get to leave the appointment. | - Going home after  
- My favorite thing about going to the doctor is when everything is done and I’m leaving |
| 9. Décor of Office | The child’s response references their positive evaluation about the physical space in the doctor’s office, including the entire building or specific rooms. This response category does not include responses referring to the examination bed, which are coded as “Other” (Category 11). | - The view of the grandriver hospital  
- I liked seeing the fishies  
- I see Star Wars stuff at the doctors and I like looking at it |
| 10. No Positive Aspects | The child’s response reference there is nothing they like about visiting the GP. | -Nothing  
-I don’t like anything |
| 11. Other Positive Aspects | The child’s response indicates they like an aspect of GP visits not included in the aforementioned categories, including but not limited to feeling that the seats/beds were comfortable, and not waiting for a long time. This category does not include answers that are not a direct and valid response to the question of what a child likes about the doctors office, as off-topic responses are categorized as *No Response, Category 12.* | - The seats were comfy  
- Sitting on the bed  
- The doctor didn’t take long to come in the room  
-Everything |
| 12. No Response | The child is unable to provide a response. This response category exclusively includes 1) responses indicating the child does not know an answer, 2) responses indicating the child cannot remember an answer, 3) responses that are off-topic and do not provide an answer to the question asked, or 4) absence of any response from the child. If the child follows | - I don’t know  
- No  
- I don't remember  
- (response referring to dentist)  
- I don’t like getting the popsicle stick or needles. I don’t like getting medicine  
- I don’t remember anything that made me happy but I’m sure there was something |
any of these statements with a response that can be coded in another category, this category cannot be coded as present. This category can only be coded as present if all other categories are coded as “0”.

- When it was my first time I thought I would be happy

### Objective 3

#### 6c) What are some things you would like your doctor to tell you more about during your next visit to the doctor’s office?

<table>
<thead>
<tr>
<th>Category Name</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
</table>
| 1. Receive Information about Pain         | The child’s response references information regarding if they will experience pain or hurt at the doctor’s office. Their response must specifically mention the words “pain” or “hurt,” (or another synonym such as “ouch”). This response category does not include 1) wanting to know if they will experience a needle which would be coded in the Category 2; or 2) wanting to know about other medicine, medical procedures, and tools, which would be coded as Category 3; or 3) wanting more information about what will happen when visiting the doctor’s office generally which is coded in Category 4. | - I want them to tell me about stuff that will hurt  
- Tell me if it is going to hurt or if the appointment will be calm |
| 2. Receive Information About Needle Related Procedures | The child’s response references information regarding needle related procedures, including the mention of blood draws, shots, or needles. This response category | - If I am going to get a needle or not  
- Are they going to give me a needle or something  
- If it’s a needle they should tell us |
| 3. Receive Information on Medicine, Medical Procedures and Tools (non-needle related) | The child’s response references learning about medical procedures, medical tools, or medicine other than a needle or needle-related procedures. Other medical procedures include, but are not limited to, surgical procedures and check ups. References to medicine can include the taste, the delivery method [pill, inhaler, liquid]. This response category does not include 1) wanting to know if they will experience pain which would be coded in Category 1; 2) wanting to know information about needles, which would be coded in Category 2; or 3) wanting more information about what will happen when visiting the doctor’s office generally which is coded in Category 4 or 3) children stating they do not want to know about getting a needle, which would be coded in Category 9. | - Do I need medicine  
- What’s inside the medicine  
- More in depth with names and what something is called  
- Maybe how the tool works  
- Tell me about the tools and what they do  
- I got a check up |
| 4. Receive General Appointment Logistics | The child’s response references wanting information regarding what will happen when visiting the doctor’s office generally. This includes where the appointment is, when the appointment is scheduled, when the child can leave, what order things will occur in, and/or choosing to not go to the doctor at all.

This response category does not include 1) wanting to know if they will experience pain which would be coded in *Category 1*; 2) wanting to know information about needles, which would be coded in *Category 2*; or 3) wanting to know about other medicine, medical procedures, and tools, which would be coded as *Category 3*.

- How long each thing is going to take, when will it end
- If I have to come back or something
- What time I gunna be done
- Maybe what’s going to happen next |

| 5. Receiving Information about Their Personal Health | The child’s response references receiving information about their own health or illness as a result of visiting the doctor’s office. This includes learning something about their health or illness, which may include confirmation of health, diagnosis of illness or injury. This does not include undergoing a medical procedure, or learning about medicine or

- She will never tell me if I’m sick or something
- How healthy I am
- If there is something wrong
- That like how your body is working
- Maybe if like, how many tools they use, and if I broke my leg or arm they would tell me that, how long it takes to do ear checks and mouth checks |
| 6. General/Unspecified Information | The child’s response refers to wanting to know what will happen or what the doctor will do without specifying the particular aspects of GP visits they want information about. | - What might happen  
- What’s going to happen when I’m there and stuff  
- What they will be doing to her  
- Just what’s going to happen in general or why I have to there (Also coded as Category 4)  
- I want to know exactly what’s going on |
| 7. No Information | The child’s response indicates they do not want to receive further information at the doctor’s office. **If this category is coded as “1”, all other categories should be coded as ”0”**. | - Nothing  
- I don’t want them to tell me if I am getting a needle  
- There isn’t really anything  
- Normally if they tell me what’s wrong with me it freaks me out  
- Sometimes if you hear too much or see too much it scares you  
- No, I don't want to know |
| 8. Other Information | The child’s response indicates they want more information about an aspect of visiting the doctor’s office not included in the aforementioned categories. This category does not include answers that are not a direct and valid response to the question of what a child would like more information about the doctors office, as off-topic responses are categorized as **No Response, Category 10**. | - How is my brother doing  
- I always ask if I'm going to get a needle. Also is there anything where my parents have to be out of the room because I don't like that (Also coded as Category 2)  
- Maybe more good news then bad news, like if there is bad news throw every piece of good news |
| 9. No Response | The child is unable to provide a response. This response category exclusively includes 1) | - I don’t know  
- I forget  
- I don’t remember  
- No |
responses indicating the child does not know an answer, 2) responses indicating the child cannot remember an answer, 3) responses that are off-topic and do not provide an answer to the question asked, or 4) absence of any response from the child. If the child follows any of these statements with a response that can be coded in another category, this category cannot be coded as present. This category can only be coded as present if all other categories are coded as “0”.

### 6c) What are some things you would like your doctor to tell you more about during your next visit to the doctor’s office?- does the child’s doctor communicate with them directly

<table>
<thead>
<tr>
<th>Category Name</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Communication Recipient - Child</td>
<td>The child’s response explicitly confirms their doctor communicates information directly to them.</td>
<td>This should include a statement like “they tell me, my doctor tells me, she tells me”.</td>
</tr>
<tr>
<td>2. Lack of communication with child</td>
<td>The child’s response explicitly confirms that their doctor does not communicate information directly with them, either some or all of the time.</td>
<td>- Sometimes he tells me but sometimes he only tells my mom</td>
</tr>
<tr>
<td>3. No mention of communication with child</td>
<td>The child’s response makes no mention of their evaluation of their doctor’s communication with them. This means the child does not make an</td>
<td>- Sometimes he tells me and sometimes he tells my mom</td>
</tr>
</tbody>
</table>

- (response referring to dentist)

Sometimes he tells me and sometimes he tells my mom

- She will only tell my mom not me
- The doctor never tells me anything
- She will never tell me if I’m sick or something (This response would also be coded as present in Category 5)
explicit statement that their doctor tells them things (belongs in Category 1) OR the child does not make an explicit statement that their doctor does not tell them things some or all of the time (belongs in Category 2)

Objective 4

7b) Tell me why you think you do/do not have a say or a choice in what happens at the doctor’s office.

For question 7b, the rule for coding multiple categories does not apply. For this question, only one category should be coded as present as these categories are mutually exclusive. If you feel that a response could be coded in multiple categories, defer to the order of the categories and code to the category with the highest rank (e.g. if you believe a response could be coded as Category 1 or 5, code to Category 1 as it is a higher rank). A reminder that, as with all other coding questions, if a child’s response does not specifically reference their beliefs regarding why they do or do not have a choice in what happens at the GP, code the response under Category 7 (“No Response”).

<table>
<thead>
<tr>
<th>Category Name</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
</table>
| 1. Parent Makes Choice        | The child’s response references their parent’s authority, their parent making choices for them, their **parent learning information from the doctor**, and/or their parent telling information to the doctor. | - My parents make decisions for me.  
- Because I might still be hurt my voice is mumbles and the parents will take charge or if parents remember and I forgot they can tell the doctor  
My parents know what is better if you don't get the needle you will get sick  
- Because if I had something wrong something could go wrong with me and the parents would know more about it
- I trust my father and he takes me, I trust him that it will be alright
- Well because the doctor just ask my mom questions and sometimes I have to get a needle but I don't want to |
| 2. Doctor Makes Choice        | The child’s response references their doctor’s authority and/or their doctor making choices for them. | - Because the doctor does everything, she chooses what to do or what not to do  
- Because we need to listen to the doctor and we don't get to do whatever we want  
- Because I think what the doctor says is what’s gonna happen |
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Example Responses</th>
</tr>
</thead>
</table>
| 3. Parent & Child Make Choice | The child’s response references that the parent and child both contribute to making choices or are somehow involved. The child’s response does not reference the doctor’s participation in making choices. | -My doctor doesn't talk to me about what's going to happen  
-My doctor talks to my mom about why I’m there but then he asks me sometimes I think I do because usually the doctor asks me questions, but usually my dad steps in and answers -The doctor talks to my parents but I listen and then I know what’s going on |
| 4. Child Makes Choice | The child’s response references their own autonomy and/or making choices for themselves, and/or a description of something about the child themselves that is the reason for the child having a choice (not a reason why the parent or doctor has a choice, which is coded as Category 1 and 2, respectively). | -It’s your appointment  
- The doctor asks me if I’m ready for a shot  
- Let me decide the toy or candy because I've been really good  
- Because I can say " I don't like the medicine" and they say "oh you can take this one"  
- Because I don't wanna have something in my arm that will hurt. |
| 5. Child Does Not Have Choice | The child’s response references that they do NOT have a choice, and/or a description of something about the child themselves that is the reason for the child NOT having a choice (not a reason why the doctor or parent has a choice). | -Sometimes I might be shy and I don’t know what to say at the doctors  
- I never get to say I don't want to get something or if I don't think I need it. My mom and dad say that I need it but I don't feel like I need it.  
- Sometimes they might think that they don't trust kids or there isn't a choice.  
- Because sometimes if we want to play with a toy there were not really allowed to because of all the germs |


6. **Medically Necessary Choice**  
The child’s response references that they do not have a choice because what happens at the doctor is medically necessary for their health and wellness.

<table>
<thead>
<tr>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Because you have to go</td>
</tr>
<tr>
<td>- If it’s really bad they need to fix it</td>
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<tr>
<td>- Because they always have something that will help me</td>
</tr>
<tr>
<td>- Because you have to have medicine when your sick</td>
</tr>
</tbody>
</table>

7. **No Response**  
The child is unable to provide a response. This response category exclusively includes 1) responses indicating the child does not know an answer, 2) responses indicating the child cannot remember an answer, 3) responses that are off-topic and do not provide an answer to the question asked, 4) absence of any response from the child, or 5) a response of “nothing”.

<table>
<thead>
<tr>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Nothing</td>
</tr>
<tr>
<td>- No</td>
</tr>
<tr>
<td>- I don’t know</td>
</tr>
<tr>
<td>- I forget</td>
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<tr>
<td>- (response referring to dentist)</td>
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<tr>
<td>- Because you have to wait patiently and a long time.</td>
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<td>- How did I get asthma</td>
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<td>- It's good because I get to know - What's going on</td>
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<tr>
<td>- What the problem is, where it - - Came from, how it happened</td>
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<td>- They should tell me things</td>
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</tbody>
</table>

**7d) Tell me some things you wish you could have more of a say or a choice about when you are at the doctor’s office?**

<table>
<thead>
<tr>
<th>Category Name</th>
<th>Definition</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Pain</td>
<td>The child’s response references wanting a choice about experiencing pain or hurt. Their response must specifically mention the words “pain” or “hurt,” (or another synonym such as “ouch” or “stung”).</td>
<td>- I don’t like being hurt</td>
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<td></td>
<td></td>
<td>- I wish I could have more of a choice if it could be less painful</td>
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<td></td>
<td></td>
<td>- I could play a game when it’s hurting</td>
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<tr>
<td>2. Needle Related Procedures</td>
<td>The child’s response references wanting a choice about needle related procedures, including the mention of blood draws, shots, or needles.</td>
<td>- I always ask if I am getting a needle (Also coded as Category 5)</td>
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<td></td>
<td></td>
<td>- No needles for me</td>
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<tr>
<td></td>
<td></td>
<td>- How big the needle is, how long the needle has to take</td>
</tr>
<tr>
<td>3. Medicine, Medical Procedures and Tools (non-needle related)</td>
<td>The child’s response references wanting a choice about medical procedures, medical tools, or medicine other than a needle or needle-related procedures. Other medical procedures include, but</td>
<td>- What order are things going in, check my ears first (Also coded as Category 4)</td>
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<td></td>
<td></td>
<td>- Getting my blood pressure checked</td>
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<tr>
<td></td>
<td></td>
<td>- The kind of medicine</td>
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<td></td>
<td></td>
<td>- Medicine that tastes good like jello</td>
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<td></td>
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<td>- I got a check up</td>
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<tr>
<td>4. Appointment Logistics</td>
<td>The child’s response references wanting a choice regarding the logistics of the appointment. This includes where the appointment is, when the appointment is scheduled, when the child can leave, what order things will occur in, and/or choosing to not go to the doctor at all.</td>
<td></td>
</tr>
</tbody>
</table>
|   | - I can pick where we go  
- What time it is because sometimes it’s in the middle of a fun activity at school  
- What will go first |
| 5. Rewards | The child’s response references wanting to receive awards during or after visits to the GP. This includes, but is not limited to receiving toys, food, stickers or privilege during or after visits to the doctor’s office. |
|   | - A toy, more lollipops  
- If I could choose a toy or a lollipop  
- Getting a slushie |
| 6. Degree of Participation and/or Control | The child’s response references the level of participation they have during GP visits, including participation in conversations and being involved in making choices. This category involves the child referencing their participation in what occurs at the doctor’s office, including telling the doctor things, asking the doctor questions, and/or making choices for themselves |
|   | - Maybe I could ask more questions about stuff  
- Talk to doctor more, tell them how I feel ask them questions on how it will go, whether it will hurt or feel weird (Also coded as Category 1  
- If I'm sick I wish he would tell me, or if I was hurt they would tell me, if I broke a bone or got a leg injury  
- Sometimes I can’t tell them things  
- I wish I could tell the doctor do this or do that  
- Sometimes they just do stuff without asking  
- If someone else in my family was sick - I wish I had more of a say in telling the doctor that  
-I would like to have a choice about what the doctor is going to do |
<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.</td>
<td>No Choice</td>
<td>The child’s response references nothing they would like to have a choice about.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Nothing</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- I don’t want more of a choice</td>
</tr>
<tr>
<td>8.</td>
<td>Other</td>
<td>The child’s response references other aspects not mentioned in the aforementioned categories. This includes, but is not limited to, general and non-specific statements of wanting a choice.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- I wish I had more of a choice</td>
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<tr>
<td></td>
<td></td>
<td>- I got to stay with my parents or not</td>
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<tr>
<td></td>
<td></td>
<td>- Do I want to have my mom or dad out of the room</td>
</tr>
<tr>
<td>9.</td>
<td>No Response</td>
<td>The child is unable to provide a response. This response category exclusively includes 1) responses indicating the child does not know an answer, 2) responses indicating the child cannot remember an answer, 3) responses that are off-topic and do not provide an answer to the question asked, or 4) absence of any response from the child. If the child follows any of these statements with a response that can be coded in another category, this category cannot be coded as present. This category can only be coded as present if all other categories are coded as “0”.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- My hospital doctor asked my parents if i wanted to have surgery so there aren't anymore soft spots in my head but he didn't ask me. Can't think of anything for my regular doctor</td>
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<td></td>
<td></td>
<td>- I don’t know</td>
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<td>- I forget</td>
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<tr>
<td></td>
<td></td>
<td>- I don’t remember</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- No</td>
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<td></td>
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<td>- (response referring to dentist)</td>
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