

# Acceptability by Parents and Children of Deception in Pediatric Research

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**ABSTRACT:** *Objective:* Deception has been used to investigate the role of developmental and behavioral factors in child health; however, its acceptability for use in pediatric research has received little empirical attention. This study examined the acceptability of deception in a pediatric pain research study as assessed through participating children's and parents' long-term perceptions of its use. *Method:* Ninety-four children (52 boys; mean<sub>age</sub> = 12.77 yr) and their parents (86 mothers, 8 fathers) completed a structured interview that assessed perceptions of various aspects of deception in a pediatric pain study, 2.5 years after participating. *Results:* A minority of parents (25.5%) and children (13.8%) spontaneously recalled that deception was used. Overall, parents and children reported positive experiences with research participation, felt comfortable with the debriefing process, and deemed the research to be of societal importance. Opinions about researchers and psychologists were not negatively impacted, and most reported willingness to participate in research involving deception again. *Conclusion:* When thoughtfully planned and disclosed, deception in pediatric research seems to be acceptable to parents and children. Future research should further examine the acceptability of deception and alternatives (e.g., authorized deception) among pediatric samples.

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## ACCEPTABILITY OF DECEPTION IN PEDIATRIC RESEARCH

There is growing interest in consideration of ethical issues associated with conducting research with children.<sup>1,2</sup> For nearly 50 years, the use of deception in behavioral research has been frequently practiced and continues to be a source of great controversy.<sup>3–5</sup> Indeed, institutional review boards have imposed restrictions on

the use of deception in social science research.<sup>6</sup> In studies examining the role of various developmental and behavioral factors in child health, deception is often used. For example, deception has been used to examine the impact of anxiety on children's memories for pain,<sup>7</sup> achievement orientation on responses to success and failure in pediatric patients with cancer,<sup>8</sup> and ostracism and social connectivity on adolescents' eating behaviors.<sup>9</sup> Nevertheless, in the midst of this debate, the voices of the child participant and their parents in deception are almost unheard.

Deception involves intentionally withholding information from participants or misinforming them about the purpose of research, the nature of the experimental design, and/or the roles of researchers, with the purpose of answering important research questions that could otherwise not be answered. Therefore, deception interferes with one's ability to make fully informed decisions about participation in research. In this way, it has been argued that deception violates the principle of respect for the dignity of persons by compromising individuals' autonomy, which may also violate the principle of non-maleficence (i.e., do no harm).<sup>10–12</sup> However, deception has been justified on the basis that it increases methodological control and the likelihood of capturing spontaneous responses to experimental manipulation, thus often resulting in valuable scientific discovery.<sup>3,13</sup>

When deception studies are carefully designed to avoid or minimize harm, pose no greater than minimal risk to participants, and when it is otherwise impossible/impractical to answer the research question, its use has

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been deemed to be ethically appropriate and justified by national regulatory bodies. However, the research should not involve a therapeutic, clinical, or diagnostic intervention, and adequate debriefing is crucial.<sup>14,15</sup> Moreover, deception is often justified on the basis that the research is of societal importance, and researchers will be able to adequately prevent or reverse any potential harm afterwards. The Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans (TCPS2) provides little guidance for researchers who use deception specifically with children. For participants of all ages, full debriefing is considered to be critical for maintaining trust in the research community and should involve researchers providing details about the importance of research, explaining the necessity of having to use deception and expressing concern about participants' welfare. Specific to using deception with children, the TCPS2 states that it may be more appropriate to debrief parents, guardians, or third parties rather than the children themselves.

Unfortunately, literature in this area has primarily focused on adults and has been philosophically, rather than empirically based. Very little empirical research has examined the acceptability of deception in research during earlier developmental periods. This is problematic in that individual IRBs are left to base decisions about what constitutes harm in this context on principled arguments and evidence extrapolated from adults. The use of deception with children is particularly complex given inherent power differentials between children and adults, and between researchers and surrogate decision makers, as well as children's lack of autonomy and inability to independently provide consent. Furthermore, children's developing cognitive abilities may limit their capacity to understand the rationale for deception in research and its potential long-term implications.<sup>16</sup>

In addition, the use of assent and debriefing in pediatric research involving deception has been questioned.<sup>17-19</sup> Some have argued that conveying such information after research participation may foster distrust in adults and generate feelings that they were taken advantage of by individuals they believed they could trust.<sup>16</sup> Given that parents, but not children, are often aware of deceptive aspects of research before providing consent, it is unknown whether this "risk" is magnified in such circumstances given familiarity with, and attachment to, caregivers. Moreover, some have posited that the use of deception could introduce the risk of developing a lack of trust in research that could generalize beyond the current context.<sup>10</sup> Somewhat reassuring in this regard are findings demonstrating that trust in researchers by children is not negatively impacted by deception and immediate debriefing.<sup>18</sup> However, this previous research was limited in not assessing both children's and parents' perceptions of deception after a longer interval after participation.

Few studies have examined the lasting impact of debriefing on youth following participation in research

studies involving deception. In one exception, adolescents' self-perceptions about their performance persevered after a debriefing procedure, even after being told that their test results were invalid.<sup>20</sup> Furthermore, although older children were found to understand the content of debriefing (i.e., how they were deceived), the majority of younger children (aged 8 yr) exhibited difficulty comprehending this information and their misunderstanding persisted after the debriefing process.<sup>18</sup> Given that the majority of pediatric research involving deception concludes immediately after debriefing, children's and parents' perceptions of its use over a prolonged period of time are currently unknown.

Analysis of acceptability of pediatric research involving deception necessitates not only consideration of adverse events, minimization of harm, and respect for individuals' autonomy by IRBs/REBs and researchers but it is also important to examine participants' (i.e., parents' and children's) own perceptions of its use.<sup>21</sup> Despite growing controversy in this area, this has rarely been examined. Preliminary findings demonstrated that children and parents generally report positive perceptions of participating in research involving deception and the debriefing process did not make them skeptical of future research participation; rather, it increased the children's impressions of how valuable the research study was.<sup>22,23</sup> Nevertheless, a more in-depth analysis of specific aspects of deception and the debriefing process is needed to determine the appropriateness of deception procedures in pediatric research.

In response to ethical concerns about deception in research, alternative methods have been proposed and used. One such method, called "authorized deception," involves informing participants that deception will be used in the research before they agree to participate, without fully disclosing the details of deception.<sup>11,24-26</sup> This enables potential participants to freely permit the use of deception before deciding to participate in research. This method has been used with adults and offers a way to increase agency to the individual; however, it may not be developmentally appropriate for use with children given the sophistication of cognitive abilities it requires. Moreover, it is unclear how parents and children themselves perceive authorized deception and whether it would be preferable to traditional deception.

To address these gaps in the literature, parents and children were contacted approximately 2.5 years after taking part in an REB-approved pediatric pain study involving anxiety induction and the use of deception<sup>7</sup> to assess their perceptions of its use. Specifically, their perceptions of the use of deception and debriefing, their resulting view of psychologists and researchers, and the likelihood of future research participation were assessed. We hypothesized that parents and children would report long-term positive perceptions of participation in research that involved deception independent of the nature of the experimental manipulation, thereby providing support for its acceptability.

## METHOD

This study is a follow-up of a larger study that examined the influence of anxiety on children's memories for pain<sup>7</sup> and the influence of pain memories on subsequent pain experience.<sup>27</sup> The present Deception Impact study examined the acceptability of deception based on parents' and children's perceptions after participation in the larger study. The methods reported below contain only those details relevant to the current research question. Full details of the larger study protocol are published.<sup>7,27</sup> Description of the original study is included below. Ethical approval was obtained from the IWK Health Centre's Research Ethics Board.

### Participants

The original sample that completed the initial phase of this research consisted of 110 healthy children aged 8–12 years and one of their parents/guardians. Of these, 94 children (52 boys, 42 girls; mean<sub>age</sub> = 12.77 yr, SD = 1.42) and the same parents/guardians (86 mothers, 8 fathers) participated in the current follow-up study 2.5 years later. By parent report, during the original study, the majority of children were identified as "white" (89.4%; *n* = 84). The self-reported educational breakdown of the parents was as follows: (1) graduate school/professional training (*n* = 27), (2) university graduate (*n* = 35), (3) partial university (i.e., at least 1 yr) (*n* = 4), (4) trade school/community college (*n* = 17), (5) high school graduate (*n* = 9), and (6) some high school (*n* = 2). Of the 15 eligible children and parents from the original study who did not participate in the follow-up, 5 were not contacted because they did not provide permission to be contacted about future research, 7 could not be reached after 6 to 10 attempts, 2 children preferred not to participate, and 1 had recently been diagnosed with a serious medical illness and felt unable to participate.

Inclusion criteria for the original study included children between 8 and 12 years of age who were accompanied by a parent/guardian. Participants were excluded if they did not speak English as a first language and/or had developmental delays or significant hearing or vision impairments. Exclusion criteria also included diagnosis of an anxiety disorder or attention-deficit hyperactivity disorder, and/or chronic illnesses or health-related medical conditions. Previous completion of the experimental pain task was among the exclusion criteria. Finally, children were excluded if they experienced pain on a regular basis that was typically of moderate or severe intensity that interfered with school or social functioning and/or for which they took medication. No families withdrew during the original study, and no adverse events were reported after enrollment.

### Original Study with Deception

The original study involving deception had 3 phases: an initial laboratory visit (Lab Session 1), a telephone interview 2 weeks later, and a second laboratory visit 1

month after the initial visit (Lab Session 2). Of the 110 children who enrolled in the study, only 1 child discontinued participation before completing Lab Session 2.

#### Original Study: Lab Session 1

At Lab Session 1, children were randomly assigned to either an experimental or control group. Children assigned to the experimental group completed a modified version of the Trier Social Stress Task for Children.<sup>28</sup> Children in this group were told they would be asked to prepare and deliver a speech and do a difficult arithmetic task in front of judges who would be evaluating their performance, while videotaped. Children in the control group were told that they would be asked to watch an interesting nature video. Children in the experimental group reported significant elevations in state anxiety from baseline as compared with the control group.<sup>7</sup>

While children anticipated having to complete either task, they completed an ethically acceptable experimental pain task, the cold pressor task,<sup>21</sup> in which they submersed their nondominant hand in 10°C water. After the cold pressor task, a research assistant told the children that they did not have to complete the speech or watch the video.

#### Original Study: Two-Week Memory Interview

Approximately 2 weeks later, children were contacted over the telephone to conduct the memory interviews. Children were asked to recall their experience completing the pain task, and then their memories of pain and expectancies of future pain were elicited.

#### Original Study: Lab Session 2

At a second laboratory visit that took place 1 month after Lab Session 1, children again completed the cold pressor task. No anxiety inducing manipulation of the environment occurred. After this, children were fully debriefed in the presence of their parents.

The deceptive manipulation was only present during Lab Session 1, and there was no manipulation during the 2-week memory interview and Lab Session 2.

#### Consent, Assent, and Debriefing of Deception in the Original Study

Parents and children were separated from each other during each laboratory visit. Parents provided full and informed consent at the outset of Lab Session 1. They were fully aware of the nature of deception being used with their children before consenting to participate. Children provided assent at Lab Session 1 but were not fully informed about the deception involved in the study. Specifically, they were not fully informed about the nature of the experimental or control conditions (i.e., that they would not be required to complete the tasks). Children were aware that a research assistant would call them; however, they were not aware that their memories of the pain experience would be elicited. At the end of Lab Session 2, children were fully debriefed in the presence of their parents. They were told about the nature of the study and the specific reasons why they were deceived about the experimental task and the memory

interviews. Specifically, children were told that they were falsely led to believe that they would have to give a speech or watch a video to induce a mild-to-moderate degree of state anxiety in the speech group. Researchers explained that this was done so that they could examine the impact of anxiety on memory. Children were also told that they were not informed about the memory interviews at Lab Session 1 to avoid biasing their recall. During debriefing, parents and children were given a handout outlining strategies for positively reframing pain memories that could be used to reduce distress and anxiety at future painful experiences.

### **Deception Impact Study: Procedure**

Approximately 2.5 years (mean = 2.735 yr, SD = 0.10) after Lab Session 2, a research assistant contacted parents who had participated in all 3 aspects of the original study and who consented to being contacted about future research ( $n = 104$  of 109). This research assistant was not involved in the original research. At the beginning of the telephone interview, the researcher obtained verbal consent from the parents after reviewing the full consent form with them over the telephone. Parents were then asked to conduct the parent telephone interview out of earshot of their children so as not to bias their recall. After the parent interview, children completed the child interview after providing assent. After completing the interview, parents and children were mailed a gift card to thank them for their participation.

### **Deception Impact Study Interview**

The deception interview protocol was designed by the study authors specifically for use in this follow-up study. The protocol included separate parent and child interviews that consisted of a free recall portion followed by questions assessing probed recall. Questions were based on critiques and commentary cited in the literature surrounding the use of deception in research.<sup>10,16,26</sup> A copy of the interview protocol can be found in Appendix 1.

Parents and children were first reminded about the general nature of the original research study and were then asked open-ended questions to elicit their memory of the original study. This enabled examination of parents' and children's spontaneous and unbiased recollections of their experiences taking part in the research study and whether they spontaneously recalled that deception was even used. Participants then transitioned to the probed recall portion of the interview in which they were asked a series of specific questions to assess their perceptions of the positive and negative aspects of their participation in the study, their memories of the deception aspect, parents' degree of comfort withholding information from children, perceptions of the adequacy of the debriefing process in facilitating children's comfort and understanding, perceptions of researchers and psychologists, the societal benefit of research, and their research preferences and likelihood of participating in

research in the future. Parents and children separately rated the majority of probed recall questions on 0 to 10 numerical rating scales. The language and phrasing of the questions and anchors were designed to be developmentally appropriate for parents and children aged 10 to 14 years.

For open-ended questions assessing free recall of deceptive aspects of the study, taped interviews were transcribed verbatim and subsequently coded by a study author. Codes indicated whether participants recalled that deception was used and the specific aspect that was remembered (experimental task, memory interview, or both). A different study author independently coded 20% of transcripts for reliability. Any disagreements (<5%) were discussed until consensus was reached. All other interview questions were rated on Likert scales and therefore did not require coding.

## **RESULTS**

### **Parents' Memories/Perceptions of Deception**

The results pertaining to the parent interview are shown in Table 1. During the free recall portion of the interview, 24 of 94 parents (25.5%) spontaneously recalled that any aspect of deception was used in the research. A logistic regression analysis revealed that child age did not significantly predict whether parents spontaneously recalled the deceptive aspect of the research. Of those parents who recalled that deception was used, 16 (66.7%) recalled the experimental task, 1 (4.2%) recalled the memory aspect, and 7 (29.2%) did not recall any specific details outside of vague recollection that children were not fully informed about the details of the study.

The following results pertain to the probed recall questions that all parents responded to.

#### **Overall Experience or Comfort Withholding Information**

Parents rated their overall experience participating in the research very positively. The lowest rating was 5/10 and was endorsed by 1 parent (1.1%). They reported generally being very comfortable allowing their child to participate in a study that he/she did not know everything about. Only 1 parent (1.1%) rated their comfort as 1/10; all other parents gave comfort ratings of 7/10 and above.

#### **Debriefing**

In terms of parents' perceptions of the overall debriefing process, they reported believing that the debriefing process was very important and being very comfortable with the manner in which the research assistant explained to the child the reasons why deception was used. Only 2 (2.2%) parents believed that debriefing was not important (i.e., ratings of less than 5 of 10). Overall, parents indicated that they believed that their children left the debriefing process with a good degree of understanding of the reasons why deception was used. Parents reported that their child was not angry or upset when she/he learned that deception was used (only 1 parent rated their child's degree of anger as >5/10); in

**Table 1.** Summary of Results Pertaining to the Parent Interview

|  | Mean | SD   | Range (0–10) |
|--|------|------|--------------|
| Overall research participation experience  | 9.62 | .86  | 5–10         |
| Comfort with withholding information from child  | 9.40 | 1.22 | 1–10         |
| Importance of debriefing process   | 9.23 | 1.76 | 0–10         |
| How comfortable parents were with debriefing process   | 9.71 | .87  | 5–10         |
| Degree to which parents believed their child understood the reasons for withholding information            | 8.33 | 1.48 | 5–10         |
| How angry or upset child was when finding out the researchers used deception                               | 0.76 | 1.37 | 0–6          |
| How clever or fun parents believed it was that the researchers had used deception                          | 6.95 | 2.56 | 0–10         |
| Similarity of this use of deception to other times adults withhold information from child in everyday life | 5.95 | 3.27 | 0–10         |
| How useful/important parents think this research is to society   | 8.96 | 1.24 | 5–10         |
| Degree to which use of deception influenced parents' willingness to take part in future research studies   | 0.86 | 2.29 | 0–10         |
| Likelihood of participation in future research that involved deception                                     | 9.35 | 1.26 | 4–10         |
| Degree to which parents would have preferred authorized deception  | 1.59 | 2.73 | 0–10         |
| Degree to which withholding information from child negatively changed their opinion about researchers      | 0.13 | .64  | 0–5          |
| Degree to which withholding information from child negatively changed their opinion about psychologists    | 0.22 | 1.04 | 0–8          |
| Degree to which withholding information from child reduced their trust in researchers                      | 0.14 | .56  | 0–3          |

fact, some parents reported that the deception was moderately “clever/fun.” Parents reported that the researchers’ withholding of information was moderately similar to other times that adults’ withhold information from their child in everyday life (e.g., such as believing in Santa Claus or the Easter bunny).

#### Societal Importance

Similar to previous experimental research involving the experimental pain task used in this study,<sup>21</sup> parents reported believing that the research involving deception was of great societal importance.

#### Future Research/Authorized Deception

Overall, parents indicated that the use of deception in this research did not influence their willingness to participate in research studies in the future. Six parents (6.4%) reported that the deceptive aspects of the research had a high degree (i.e., ratings of >5/10) of influence on their willingness to participate in future research. Moreover, they indicated that it was highly likely that they would participate in research studies that involved deception again. One parent (1.1%) reported a low likelihood (i.e., ratings of less than 5 of 10) of participating in future deception studies. In terms of authorized deception, parents did not indicate a moderate or strong preference for their child to be informed that deception would be used at the outset of participation; however, 80.9% of parents believed that their child would have still decided to participate had authorized deception been used.

#### Generalizability to Researchers and Psychologists

Parents reported that the use of deception in the research did not negatively change their opinions of researchers or psychologists nor did it reduce their trust in researchers. One parent (1.1%) reported that our use of deception negatively changed their opinion about psychologists to a considerable degree (i.e., ratings of >5/10).

#### Children’s Memories/Perceptions of Deception

The results pertaining to the child interview are shown in Table 2. During the free recall portion of the interview, 13 of 94 children (13.8%) spontaneously recalled that any aspect of deception was used in the research. A logistic regression analysis revealed that child age was not a significant predictor of whether children spontaneously recalled the deceptive aspect of the research. Of those children who recalled that deception was used, 12 (92.3%) recalled the experimental task and 1 (7.7%) did not recall any specific details outside of vague recollection that they were not fully informed about the details of the study. None of the children recalled the memory aspect of the deception.

The following results pertain to the probed recall questions that all children responded to.

#### Overall Experience

Similar to their parents and other laboratory-based research involving use of the cold pressor task with children,<sup>21</sup> children rated their overall experience participating in the research very positively. The lowest rating was 4/10 and was endorsed by 1 child (1.1%); 3.3% of children gave ratings of less than 7/10.

#### Debriefing

In terms of children’s own perceptions of the overall debriefing process, children indicated that they left the debriefing process with a moderate degree of understanding of the reasons why deception was used and felt very comfortable with the research assistant after

**Table 2.** Summary of Results Pertaining to the Child Interview

|   | Mean | SD   | Range (0–10) |
|---|------|------|--------------|
| Overall experience of taking part in the study  | 8.57 | 1.28 | 4–10         |
| Importance of debriefing process  | 7.01 | 2.50 | 0–10         |
| Comfort with research assistant during debriefing   | 8.14 | 1.82 | 0–10         |
| Extent to which child understood the reasons why deception was used                                     | 6.67 | 2.83 | 0–10         |
| How angry/upset child was when he/she learned the researchers had used deception                        | 1.23 | 1.76 | 0–9          |
| How clever or fun child thought it was that the researchers used deception                              | 7.15 | 2.06 | 0–10         |
| How big this “secret” was compared with other secrets children keep or that other adults keep from them | 2.89 | 2.37 | 0–10         |
| How useful/important child thinks this research is to other children (societal importance)              | 8.44 | 1.78 | 2–10         |
| How willing child is to take part in research studies again in the future                               | 9.13 | 1.39 | 5–10         |
| Likelihood that child would participate in future research involving authorized deception               | 8.57 | 1.56 | 3–10         |
| How positive child currently feels about researchers  | 8.56 | 1.49 | 2–10         |
| How positive child currently feels about psychologists  | 8.61 | 1.63 | 0–10         |
| How much child currently trusts researchers   | 8.44 | 1.60 | 1–10         |

deception was revealed and explained. Sixteen children (17%) reported a poor understanding (i.e., ratings of <5/10) of why deception was used. Children believed that the debriefing process was moderately important; 13 children (13.9%) believed that debriefing was not important (i.e., ratings of <5/10). Children did not report being even mildly angry or upset when they learned that deception had been used; in fact, they reported thinking in retrospect that it was moderately “clever/fun” that the researchers “kept the secret.” Three (3.3%) children rated their anger as >5/10; 7 (7.5%) children did not consider the deception to be “clever/fun” (i.e., ratings of less than 5 of 10). Overall, children reported that the researchers’ withholding of information was mildly similar to other times that adults’ withhold information from them in everyday life.

### Societal Importance

Similar to previous experimental research involving the experimental pain task used in this study<sup>21</sup> and similar to their parents, children reported believing that

the research involving deception was of great societal importance. Four children (4.2%) rated the societal importance of the research as low (i.e., ratings of less than 5 of 10).

### Future Research/Authorized Deception

Overall, children indicated being extremely willing to participate in research studies in the future. In terms of authorized deception and consistent with parental report, children indicated that it was highly likely that they would participate in research studies in the future if they were informed from the outset that deception would be used. Two children (2.2%) reported a low likelihood (i.e., ratings of less than 5 of 10) of participating in research studies involving deception in the future.

### Generalizability to Researchers and Psychologists

Children reported that they currently felt very positive about researchers and psychologists and indicated that they have a high degree of trust in researchers. One child (1.1%) rated their feelings about researchers as not positive (i.e., ratings of less than 5 of 10); 2 children (2.2%) rated their feelings about psychologists as not positive. Two children (2.2%) reported a low degree (i.e., ratings of less than 5 of 10) of trust in researchers; 91.6% of children provided trust ratings of  $\geq 7/10$ .

### Differences in Perceptions Based on Nature of Deception

To examine whether the specific nature of deception is important for subsequent perceptions, we examined ratings of participants assigned to the anxiety induction (believed they would have to give a speech) and control (believed that they would have to watch a nature video) groups using a series of independent samples *t* tests. Given the relatively large number of interview questions and subsequent analyses (16 for parents; 14 for children), only analyses significant at the .01 alpha level were retained. For all of the perceptions assessed, there were no significant differences in perceptions between experimental groups. Moreover, parents and children in both the anxiety induction and the control groups were equally likely to spontaneously recall that deception was used; however, as described above, this comprised only a minority of parents and children.

## DISCUSSION

The results of this study revealed that approximately 2.5 years after participating in a research study involving deception, parents and children generally found their experience of participating to be positive. Overall, parents felt very comfortable with their children participating in a study that involved deception, were satisfied with the debriefing process that occurred, and believed that debriefing was important. Children reported leaving the debriefing session with a moderate understanding of the deception that occurred in the study and believed that being debriefed was of moderate

importance to them. Both children and parents felt that the study was of great societal importance and indicated that they would participate in research again in the future. Contrary to arguments made against deception in the literature<sup>10</sup>, but consistent with other pediatric research<sup>18</sup>, having participated in a study involving deception did not seem to negatively influence children's and parents' positive views of and trust in researchers.

Overall, there were no differences in perceptions of parents and children who were randomized to the anxiety-induction versus the control condition in the original study, which may imply that the form/outcome of the deception does not impact how salient it is to participants. Additionally, the specific context of deception may impact the extent to which participants recall it. Deception by omission (i.e., intentionally withholding information) is generally more common in research than deception by commission (i.e., intentionally misinforming participants). The majority of studies engage in some form of deception by omission by withholding the true purpose of the research study. The original study on which this follow-up study is based involved both forms of deception. Whereas a small percentage of parents (17%) and children (12.8%) remembered the experimental task aspect of the deception (deception by commission), only 1 parent and none of the children identified the memory interview (deception by omission) as being an aspect of deception in the study. This suggests that overt deception (i.e., deception by commission) may be more salient for children and their parents. Nevertheless, a relatively small percentage of parents (25.5%) and children (13.8%) spontaneously recalled that deception was even used.

Authorized deception seemed to be considered an acceptable alternative to full deception for parents and children; however, it was not considered by most families to be necessary for deception to be used in pediatric research. Martin and Katz<sup>26</sup> found that an authorized deception protocol used with adults did not have an impact on the effect of the placebo being investigated nor did it affect participant recruitment and retention or result in any adverse events. However, a similar protocol has not been examined among children, whose ability to understand what they are consenting to in a study involving authorized deception will invariably be impacted by their cognitive development.

It is important to consider that the conclusions drawn from this research are based on average responses of parents and children, and there was considerable variability in responses. For example, although the majority of parents reported being comfortable with the use of deception, this was not the case for all parents. Similar ranges of responses were found for several of the questions, highlighting individual differences in perceptions of the use of deception in pediatric research. As such, researchers cannot assume from the present results that

deception in research is considered to be acceptable by all families. Moreover, the parents in this study were fully informed about the nature of deception in the research from the outset of participation. It is possible that parental perceptions may be more negative in research contexts in which parents are also deceived throughout.

Pediatric researchers are encouraged to explore novel ways in which their research questions could be answered without the use of deception or with minimal use of deception. However, when deception is necessary, we consider it to be of paramount importance that procedures be fully explained to the parents of each individual child during the informed consent process, while emphasizing that the parent may withdraw their child's participation/data at any time and that the child may choose to have their data withdrawn after the debriefing process if they so wish. Researchers have suggested that few participants will refuse consent for the use of their data in the context of debriefing, and if a significant proportion refuses, this signifies that the nature of deception being used is likely problematic.<sup>10</sup> We concur with this position. We also recommend that researchers build into their studies ways to minimize any potential negative effects of deception on participants. For example, after debriefing in this study, children and parents were given a handout outlining evidence-based strategies to positively reframe negative pain memories and improve responses during future painful medical procedures.

Various aspects of cognition relevant to deception (e.g., theory of mind, ability to understand intentionality, hypothetical thinking) differ depending on the developmental stage of the child participant.<sup>29</sup> This poses challenges for researchers in developing uniform protocols for assent and debriefing, especially when research includes several developmental groups or spans a period during which rapid changes in cognitive development occur. In accordance with previous research,<sup>18</sup> several of the youngest participants (aged 8 yr) may have initially had difficulty comprehending the information presented to them during deception and debriefing. Moreover, given that perceptions of deception were elicited several years later, the current results may overestimate the degree to which children comprehended this aspect of the research. Although child age was not a significant predictor of whether parents and children spontaneously recalled the deceptive aspect of the research, future research should assess developmental differences in perceptions of deception at various points following the debriefing process and study participation. Indeed, the child's understanding of deception and its associated sequelae likely differ based on developmental stage and the degree to which their parents are involved in, and are comfortable with, the deception.

Understanding the impact of participating in pediatric research involving deception is also critical to inform decisions of both researchers and IRBs. In the absence of

empirical data regarding the impressions of parent and child participants involved in deception research, decisions will likely be made solely on theoretical principles and speculative assumptions regarding the potential consequences for participants.<sup>10</sup> A survey of IRBs regarding the importance of addressing various topics for ethics boards listed “research on children” as the second most important item and “research involving deception” as the fifth most important item.<sup>30</sup> Therefore, there is recognition of the importance of empirical research on deception with children, such as this study, to directly inform individuals who make decisions regarding the acceptability of its use.

These findings revealed generally favorable reactions to the use of deception in research with children; however, it is important to consider that the specific nature of the deception likely plays a role in its perceived acceptability in research with children. In this study, the nature of deception could be conceived of as relatively mild as compared with deception used with adults. Moreover, the outcome of the deception could also be construed as positive because half of the children believed that they would have to complete an anxiety-provoking task but were later informed that they did not have to. It is possible that children and parents feel differently about researchers and the use of deception in research depending on the perceived outcome of the deception (positive vs negative) or the relationship of the child to the deceiver (e.g., parent is involved vs researcher alone deceives). Additionally, given that participants in this study were debriefed after the final laboratory visit (i.e., approximately 1 month after they were deceived), future research should examine the relative acceptability of immediate versus delayed debriefing procedures. Researchers are encouraged to continue to include measures of parent and child perceptions and acceptability of research involving deception in their protocols. Future studies may consider the use of more anonymous methods of data collection to reduce the impact of potential social desirability effects on responding. Such bias was minimized in this study given that the research assistants were not involved in the original research involving deception.

In summary, approximately 2.5 years after participation in an experimental pediatric research study involving deception, parents and children generally reported positive experiences participating in research and favorable impressions of research involving deception, although there was individual variability among participants. More research is needed to generalize across differing deception protocols and age groups. Further examinations of developmental differences in children’s understanding of deception and its sequelae are warranted. Researchers using deception in pediatric studies are encouraged to include measures examining the acceptability of deception in their protocols and to explicitly report how deception and debriefing was handled to provide models for other researchers.

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## APPENDIX 1. Deception Impact Study Interview Protocol

### Parent Interview

#### 1. Free Recall

First I would like you to tell me everything that you can remember about your experience taking part in (the) study about children's feelings and pain (at the research center). This was the study in which you (and child's name) came to our research center 2 times, he/she did the cold water task and also a memory interview on the telephone.

Allow time for parent to think and respond

Prompts: "What else happened?"

"Tell me more"

"Uh huh"

"What else?"

Repeat the last thing said.

When the parent is unable to provide more information, move on to the next phase.

#### 2. Specific Questions

- On a scale from 0 (very negative) to 10 (very positive), how would you rate your participation experience in our study overall?
- What was the most positive aspect about taking part in the study?
- What was the most negative aspect about taking part in the study?
- Did the researchers withhold any information or "keep any secrets" from (child's name) when he/she participated in the study? (Yes/No)
  - (If yes) What information did they withhold from (child's name)?

We are interested in hearing your thoughts about a particular aspect of the study. During your first visit to our research center, we told (child's name) that he/she would have to give a speech in front of judges or watch a nature video. Then, the research assistant told (child's name) that he/she would have to give a speech/watch

a video. After the first cold water task, the research assistant told (child's name) that he/she didn't have to give the speech/watch the video because the judge couldn't make it/the video equipment wasn't working. Although, you and the research assistant knew all along that (child's name) was never really going to have to give a speech/watch a nature video, he/she believed that he/she would really have to give a speech/watch a video. Then, at the end of the second lab visit, the research assistant told (child's name) this and explained the reasons why she kept the secret.

- Why did the researchers not tell (child's name) that he/she was never really going to have to give a speech/watch a nature video?
- On a scale from 0 (not at all comfortable) to 10 (extremely comfortable), how comfortable were you allowing (child's name) to participate in a study that he/she did not know everything about?
- On a scale from 0 (not at all comfortable) to 10 (extremely comfortable), at the end of the study, how comfortable were you with the way that the research assistant explained to (child's name) why they withheld information from him/her?
- What would have made you more comfortable?
- On a scale from 0 (not at all comfortable) to 10 (extremely comfortable), at the end of the study, how comfortable do you think (child's name) was when the research assistant explained to him/her the reasons why she withheld information from him/her?
- At the end of the study, to what degree do you think (child's name) understood the reasons why we withheld information from him/her on a scale from 0 (did not understand at all) to 10 (understood completely)?
- On a scale from 0 (not at all important) to 10 (extremely important), how important do you think it was to explain the reasons why we withheld information from (child's name) at the end of the study?
- On a scale from 0 (not at all similar) to 10 (extremely similar), how similar was our withholding of information during the study compared to other times adults withhold information from your child in everyday life (e.g., such as believing in Santa Claus or the Easter bunny)?
- In your opinion, would (child's name) have still decided to participate in the study if he/she had known from the very beginning that the researchers were keeping a secret or withholding information? (Yes/No/Don't Know)
- On a scale from 0 (not at all useful/important) to 10 (extremely useful/important), how useful/important do you think this research study is to society?
- To what degree does the fact that we withheld information from (child's name) about the speech/video influence your willingness to take part in

research studies again in the future on a scale from 0 (no influence at all) to 10 (extremely influenced)?

- How likely is it that you would take part in a research study again in the future if you knew that researchers were going to withhold information from your child like they did in this study on a scale from 0 (not at all likely to take part in research again) to 10 (extremely likely to take part in research again)?
- Does the fact that we withheld information from your child change your opinion of researchers? (Yes/No)
- To what degree does the fact that we withheld information from your child negatively change your opinion about researchers from 0 (not at all negatively changed) to 10 (extremely negatively changed)?
- Does the fact that we withheld information from your child change your opinion of psychologists? (Yes/No)
- To what degree does the fact that we withheld information from your child negatively change your opinion about psychologists from 0 (not at all negatively changed) to 10 (extremely negatively changed)?
- How do you think your child felt when the research assistant told him/her that you and her were keeping a secret and that he/she was never really going to have to give a speech/watch a nature video?
- On a scale from 0 (not at all upset/angry) to 10 (most upset/angry possible), how upset or angry was (child's name) when he/she found out the researchers had kept a secret
- On a scale from 0 (not at all clever/fun) to 10 (most clever/fun possible), how clever or fun do you think it was that the researchers kept the secret?
- To what degree does the fact that we withheld information from your child negatively change your opinion about psychologists from 0 (not at all negatively changed) to 10 (extremely negatively changed)?
- To what degree does the fact that we withheld information from your child reduce your trust in researchers from 0 (does not reduce my trust at all in researchers) to 10 (completely reduces my trust in researchers)?
- On a scale from 0 (not at all prefer) to 10 (extremely prefer), to what degree would you have preferred that the researchers told your child that there would be a secret in the study from the very beginning?
- Is there anything else you would like to us to know about your and (child's name)'s experiences taking part in this research study?

## Child Interview

### 1. Free Recall

First I would like you to tell me everything that you can remember about your experience taking part in (the) study about children's feelings and pain at the (research center). Sometimes people don't remember everything

and that's okay! We just want you to tell us everything you can remember about when you took part in (the) study.

Allow time for child to think and respond

Prompts: "What else happened?"

"Tell me more"

"Uh huh"

"What else?"

Repeat the last thing said.

When the child is unable to provide more information, move on to the next phase.

## 2. Specific Questions

- On a scale from 0 (very negative) to 10 (very positive), how would you rate your overall experience taking part in the study?
- What was the most positive or best part about taking part in the study?
- What was the most negative or worst part about taking part in the study?
- Did the researchers "keep any secrets" or keep any information about the study from you when you took part in the study? (Yes/No)
  - (If yes) Do you remember what was the secret?
  - Were there any other secrets? (Yes/No)
    - What were the other secrets?

We are really interested in hearing your thoughts about a particular aspect of the study. During your first visit to our research center, the research assistant told you that you would have to give a speech in front of judges or watch a nature video. Then, the research assistant told you that you would have to give a speech/watch a nature video. After the first cold water task, the research assistant told you that you didn't have to give the speech/watch the video because the judge couldn't make it/the video equipment wasn't working. Although the research assistant and your mom/dad knew all along that you were never really going to have to give a speech/watch a video, you thought that you really would have to give the speech/watch the video. Then at the end of the second lab visit, the research assistant told you this and explained the reasons why she kept this a secret.

- How did you feel when the research assistant told you that she and your mom/dad were keeping a secret and that you were never really going to have to give a speech/watch a nature video?
- How upset or angry were you when you found out the researchers had kept a secret on a scale from 0 (not at all upset/angry) to 10 (most upset/angry possible)?

- On a scale from 0 (not at all clever/fun) to 10 (most clever/fun possible), how clever or fun do you think it was that the researchers kept the secret?
- During your second visit to our center, the research assistant explained everything to you at the end of the study. To what extent did you understand the reasons why we kept a secret about the speech/video on a scale from 0 (I did not understand at all) to 10 (understood completely)?
- Why did the researchers keep a secret/not tell you that you were never really going to have to give a speech/watch a nature video?
- How comfortable were you with the research assistant after she told you that you were never really going to have to give a speech/watch a nature video on a scale from 0 (not at all comfortable) to 10 (extremely comfortable)?
- How important is it to you that the research assistant explained the reasons why she kept a secret from you about the speech/video on a scale from 0 (not at all important) to 10 (extremely important)?
- How big is this secret compared to other secrets you keep or that other adults keep from you on a scale from 0 (not at all a big secret) to 10 (the biggest secret possible)?
- If you knew from the very beginning that the researchers were keeping a secret from you, would you still have decided to participate in the study? (Yes/No/Don't know)
- Would you rather the researchers tell you that there would be a secret in the study from the very beginning? (Yes/No)
- On a scale from 0 (not at all useful/important) to 10 (extremely useful/important), how useful/important do you think this research study is to other children?
- On a scale from 0 (not at all willing) to 10 (extremely willing), how willing are you to take part in research studies again in the future?
- How likely is it that you would take part in a study again in the future if you knew that researchers were going to keep a secret like this again on a scale from 0 (not at all likely to take part in this research) to 10 (extremely likely to take part in this research)?
- Does the fact that they kept a secret from you about the speech/video change how you feel about researchers? (Yes/No)
- On a scale from 0 (not at all positive) to 10 (extremely positive), how positive do you feel now about researchers?
- Does the fact that they kept a secret from you about the speech/video change how you feel about psychologists? (Yes/No)
- On a scale from 0 (not at all positive) to 10 (extremely positive), how positive do you feel now about psychologists?
- Does the fact that they kept a secret from you about the speech/video change how much you trust researchers? (Yes/No)
- How much do you trust researchers now on a scale from 0 (you don't trust researchers at all) to 10 (you trust researchers completely)?
- Is there anything else you would like to tell us about experience taking part in this research study?