



## Parents' perspectives on involving young children in neuroimaging studies

K. Schibli, A. D'Angiulli, T. Thomson

*Carleton University, Department of Neuroscience, Canada*

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### Abstract

**Purpose:** Media reporting of neuroimaging research is increasingly frequent, yet public perceptions of neuroimaging research, especially involving children, is scarcely documented. Semi-structured interviews were conducted to determine parents' understanding of neuroimaging and their feelings about young children participating. The goal of this study is to incorporate parent feedback in order to devise strategies to improve recruitment outcomes.

**Methods:** 12 parents (five fathers, seven mothers) with at least one child were asked a series of open-ended questions to determine what they know, and how they feel about children participating in neuroimaging research. To prompt verbalization, parents were presented with a photo of a young child undergoing electroencephalography (EEG) which was shown with limited explanation and lacking context, as often done in the media.

**Results:** Qualitative analysis revealed three category themes: (1) *fear*, (2) *a perceived lack of humanity* within the field of neuroscience, and the neuroscientists themselves, and (3) *practical suggestions* on how to move forward and improve the recruitment process. Neuroimaging was considered as synonymous of diagnostics of ill children. Parents also felt that neuroscientists lacked humanity, as they were unable to identify contributions to the lives of their families other than the aforementioned diagnostics. Additionally, concern was expressed over whether neuroscientists have adequate training for working with children. Parents often referred to examples from the media when discussing their discomfort with neuroscientific techniques.

**Conclusions:** The present study suggests there are many misconceptions regarding research involving neuroimaging, which are likely influenced by media exposure.

**Advances in knowledge:** These findings highlight the importance of knowledge translation with families when involving their children in experimental procedures. Implications and recommendations are discussed detailing how participants' insights and suggestions offer the opportunity for integrating parents' views in the entire research process, and possibly improving it.

## Introduction

Neuroscience has allowed the exploration of the function and structure of the brain as it relates to a range of topics, including child development. The rapid advancement of neuroscientific techniques has led to an exhaustive reporting of neuroscience research in the media, which is often lacking in critical content and accuracy. In particular, reporting of studies involving functional magnetic resonance imaging (fMRI) and neurostimulation have been on the rise in newspapers, and often underreport essential aspects of scientific research, such as sample size and details of the technique used.<sup>1, 2</sup> Neuroimaging refers to the use of images for capturing and displaying functional and structural brain activity. Common techniques reported in popular media include electroencephalography (EEG) and fMRI.<sup>3</sup>

EEG is a non-invasive technique with effective temporal resolution providing an accurate measurement of when processing occurs in the brain. To determine the influence of a particular stimulus on electrical brain activity, event-related potentials (ERPs) are measured. ERPs refer to a change in brain activity following an internal or external sensory stimulus and are calculated by averaging the summed potentials following the repetition of stimulus presentation. They are characterized by their latency following stimulus presentation and by their polarity (negative or positive).

fMRI is also considered a non-invasive imaging technique which involves the analysis of blood oxygenation levels through the use of magnetic fields and radio frequency. Both EEG and fMRI, are commonly used with children in research.<sup>4, 5</sup> EEG was first discovered in the 1920s by Hans Berger and is known to be risk-free with children; whereas fMRI is relatively new with paediatric populations. However, research examining long-term effects on children's neurocognitive development and physical growth (i.e. BMI) has shown that repeated exposure to MRI has no effect over a 10 year period in these areas of development, suggesting minimal risk when using this neuroimaging technique with young, healthy children.<sup>6</sup> Determining how the general public perceives neuroimaging provides insight for researchers interested in recruiting families, particularly children, in their studies.

Encouraging family participation in studies that use neuroimaging techniques (henceforth, neuroimaging studies or research) can be challenging, especially with limited resources and support.<sup>7</sup> Furthermore, much of the research conducted in our

laboratory involves community samples and children from low-socioeconomic (SES) backgrounds which are often underrepresented in neuroscientific research due to recruitment challenges.<sup>8</sup> To our knowledge, there have been no published studies documenting parents' first-person perspectives regarding their children's participation in neuroimaging research (third-person account<sup>8</sup>). Studies aimed at investigating the ethical, legal, and social implications of neuroimaging may include interdisciplinary teams with experts representing various fields;<sup>9</sup> however, parents and participating children are rarely included as stakeholders. As a result, families are not usually given an opportunity to share their perspectives limiting existing knowledge. Research practice, especially recruitment practices, may be improved if the underlying issues parents perceive with involving their children in neuroimaging research are addressed.

Qualitative research in the social sciences has shown that an effective method for identifying opinions through the exploration of personal and social experiences is holding open ended, individual interviews.<sup>10</sup> Conducting interviews, as opposed to questionnaires, is a methodological outlet that is able to elicit individuals' complex answers.<sup>11, 12</sup> Accordingly, the present study implemented parent background information surveys followed by individual interviews.

The aim was to discover what parents think about neuroimaging research and, partly, explore how media may have shaped their perspectives on involving children in these types of studies. The goal of the present study is to incorporate parent feedback to devise strategies that could improve recruitment.

## Method

To defend the chosen methodology from onset, a discussion of its contextual grounding and why it was appropriate is required. First of all, explicit knowledge about issues in this specific field and the targeted population (young children between six to eight years of age) are very scarce. The present study was purposefully exploratory to create a ground base of knowledge on which research on recruitment processes in the specific field and population can move forward – particularly in our own laboratory where EEG is the neuroimaging technique applied.

The interviews were grounded in phenomenology<sup>13</sup> as the aim was to provide parents an opportunity to express their thoughts regarding issues

they may have when it comes to hypothetically involving their children in neuroimaging research. Their responses were recorded and transcribed to identify common themes. The goal of having this information was to be able to enhance the recruitment strategies for neuroimaging-based studies to better suit the expressed needs of parents. Additionally, this study aligned itself with the view that it is the researcher's responsibility to empower participants to be a part of reducing the power differentials that exist in societal contexts such as human experiments,<sup>14</sup> in this case, between the neuroscientists and the families they work with.

This study, which aimed to uncover reasons behind recruitment issues, paradoxically faced some of the same challenges. That is, it was extremely difficult recruiting parents and families! The irony of this situation serves as an indirect, further source of evidence to show the dire need for more knowledge in this area, which is the most concrete and practical motivation underlying the present study.

### *Participants*

This study was approved by our institution's human research ethics review board. Recruitment was mainly from the department offering a bachelor degree in Child Studies in our institution; a proportion of Child Studies students also have children, making them eligible to participate. Additionally, participants from previous studies in our laboratory from the same institution (therefore, falling under the same ethics review board) who agreed to be contacted for follow up research were e-mailed and invited to participate. Advertisement was done through posters and institutional mass email lists.

To be eligible, participants self-identified as having at least one child between the ages of six to eight years old. The ages of the participants ranged from 24 to 56 years of age. All of the 12 participants (five fathers; seven mothers) had at least a college diploma. Although socioeconomic status was heterogeneous (ranging from undergraduate student to professional), the sociocultural family background of the participant could be defined as fitting the typical Eastern Canadian middle class Caucasian family (the range of annual income was CND\$ 55,000-100,000, with approximately 5-10% of estimated disposable income; the range of education level for both parents combined was few years of university-level of education to completed Bachelor degree). All participants were native English speakers.

### *Materials & Procedure*

Parents participated in individual interviews following completion of a background information survey. The background information survey and interview questions were read out-loud by the interviewer in conjunction with being shown on paper. The detailed protocol and questions, including the prompt photograph, and their sequence as seen by the participant can be found in Appendix 1.

The selected photograph prompting verbalization was considered from a set of 20 photos taken in our laboratory during ongoing EEG neuroimaging studies with young children. It was judged as the best to prompt a response since no consistent emotion could be reliably discerned in naïve judges. The selected photograph was intended to provoke a similar response one would expect from an image presented in the media with limited explanation and lacking context.

Directed question and photograph selection was based on extensive simulation pilot work which involved students in small-group workshop activities in a third-year undergraduate course in applied developmental science at our institution. An assessment of the minimal sample size required to give relatively reliable information was determined by independently and sequentially gathering and analyzing answers from six groups of five students which simulated the same scenario of the present study. Saturation of content was reached after workshops were conducted with two groups. The preliminary assessment of measure of reliability in coding the simulated interview responses involved double-coding of a randomly selected sub-sample 25% of the responses by three raters. Percent inter-rater agreement across assessments in the responses of two versus all-inclusive six groups varied only slightly (79% vs. 81%) and was not significantly different (estimated Fleiss's  $K_{15} > 0.50$  for all categories). The three category themes extracted were: (1) fear, (2) a perceived lack of humanity within the field of neuroscience, and the neuroscientists themselves, and, lastly, (3) practical suggestions for improving the recruitment process.

Following the pilot work, the interviews with parents were audio-recorded and transcribed verbatim. Thematic qualitative analysis was conducted on a rolling basis focusing on the three themes identified in the pilot simulation study, and recruitment was stopped as soon as saturation point of extracted

contents was reached. The measure of reliability in coding the interview responses was based on double-coding a randomly selected sub-sample 60% of the all verbal responses from the parents by three raters, which resulted in 87% inter-rater agreement for the three individual categories, with a Fleiss'  $K_{15} = 0.73$  for the overall taxonomy.

## Results & Discussion

The parents interviewed appeared to have reflected on many current concerns in neuroethics.<sup>9</sup> In line with existing research,<sup>16</sup> they often expected neuroimaging research to focus on identifying medical conditions related to the brain which would be informed by a medical physician. Media reports involving neuroimaging studies focused on health tend to be more accurate and neutral in tone<sup>2</sup> rather than overly optimistic. While this is promising in terms of informing the general public, parents may assume that neuroimaging is only applied when there is a health concern. Accordingly, the expectation of neuroimaging research being diagnostic seemed to cause a great deal of fear. No parent could identify an alternative purpose for neuroimaging studies beyond medical diagnosis, which may indicate an implicit reason why parents are apprehensive to involve their children in neuroimaging research. Additionally, parents expressed concerns that neuroscientists were not trained to work with children. The findings will be discussed through the three themes identified: (1) fear, (2) a perceived lack of humanity within the field of neuroscience, and the neuroscientists themselves, and, lastly, (3) practical suggestions for improving the recruitment process. Each quote from the individual interviews which are reported here are verbatim quotes corresponding to a different (non-overlapping) parent.

### *Fear*

The parents interviewed expressed a desire to protect their children and stated that fear was the main reason they would avoid involving their children in a neuroimaging study. Specifically, parents identified being scared of: side effects, namely risks of exposure to radiation, the perceived invasiveness of the machinery involved, and the lack of ability to be genuinely informed of proceedings as parents. Upon seeing the prompt image for the interviews (see photo in Appendix 1), a parent responded: "Well, it looks

like you'd have to be a bit of a bad parent to sit back and watch your child go through that!"

The most pressing concern expressed involved whether or not neuroimaging technologies posed risks for children. Four out of five parents cited concerns over radiation. For example, one father voiced his concerns over radiation: "A CT scan has the same amount of radiation as 175 X-Rays! And exposure to radiation never fades away. Radiation accumulates throughout the life of an individual. Exposing a child to radiations can significantly increase the risk of him or her having cancer later on in life ... Obviously, I would like some research data to be available to help my child if he developed a brain condition. But how many cancers will develop, how much suffering will be caused, in order to obtain this data?"

This is unfortunate as most neuroimaging technologies would present very low if any radiation risks, for example, EEG and MRI neuroimaging techniques are non-invasive and pose no risk of radiation exposure unlike CT scans or X-rays. It is possible that media descriptions of the risks of radiation exposure, especially when discussing medical practice, influenced parents' perceptions. Another misconception surrounding neuroimaging seems to be that it is seen as an invasive procedure rather than as an observational tool. Only one of the parents interviewed seemed to recognize that these tools serve to observe children's brain activity in response to presented stimuli or at passive rest. Other parents expressed concerns through the use of words associated with equipment and procedures: injecting, inserting, shocking, electrocuting, and deceiving were identified as the verbs typically associated with neuroimaging.

Parents also expressed that they felt unable to provide informed consent when it came to signing up for neuroimaging-based studies. One father said: "You need a translator, something to convert your field's jargon to something everyone can understand... this seems like a lot of gibberish." One mother said: "I would want to prepare my child ... even though I am quite sure it is safe, I feel a bit unnerved ... If I can't understand, how can I prepare them?" It is clear that the creation of an environment that allows parents to develop a clear understanding of what the study will involve prior to visiting the research facility is necessary, so that they may prepare themselves and their children. However, it may not be enough to simply explain the process of the experiment. The purpose of developmental neuroimaging research in

clinically healthy children is a topic that needs to be made much more concrete to parents.

### *Lacking Humanity*

None of the parents interviewed could provide an example of how the field of neuroscience contributes to society outside of helping to diagnose sick children. The conception that neuroscience is directly linked with the medical world appeared to be the main reason why parents did not want to involve their children in neuroimaging research. It was expressed repeatedly that neuroscience and neuroscientists lacked a connection to humanity and lacked the experience required to work with children.

Parents described how they imagined the setting for the hypothetical neuroimaging study would appear. They all felt that the primary recruitment method would involve a medical doctor referring a very ill child for additional tests. The setting described was of a hospital or clinic, and it was believed the studies would be conducted by a real doctor, meaning that they were trained in medicine. Neuroimaging studies appear to be perceived as a diagnostic process rather than as a field of academic inquiry. The medical setting provoked fear for many parents as they felt that enrolling their child in a study likely meant they would find out their child was ill. Furthermore, parents expressed an association between neuroimaging studies and the discovery of tumours.

Two parents expressed concern that neuroimaging research may identify vulnerabilities to future illnesses, as described by one mother: “I feel like we only hear about neuroscience and how it can help identify kids as sick. Or like how it can say your child isn’t sick now, but look! They probably will be! What kind of contribution is that? I wouldn’t want to know if I were going to be very sick when I get older if there’s nothing I can do about it. And it would be heart breaking to get news like that about my kids ... It seems to me that they (neuroscientists) mostly look up sickness. It’s a hard reputation to shake isn’t it?” This parent expressed current ethical concerns regarding neuroscientific research, including the need for effective protocols regarding incidental findings and caution when predicting illness based on brain and gene mapping.<sup>17</sup>

Parents cited media influences as contributing to these perceptions of neuroscience as an inhumane discipline. They voiced concern that this was a field

that studied “dead brains and people,” “animals,” and “electrocution of the brain.” Two parents recalled the lobotomy from Ken Kesey’s *One Who Flew over the Cuckoo’s Nest*<sup>18</sup> as coming to mind when the topic of neuroscience was mentioned. One father expressed that he felt that the media made it seem that neuroscience as a field was ignoring important issues such as brain privacy, lie-detection, and life support. These are common issues raised in neuroethics, including how research in neuroscience may influence how free will is viewed<sup>19</sup> and concern regarding the use of neuroimaging for forensics and the law.<sup>2</sup> Parents also shared that they felt the design of neuroimaging studies relied heavily on deception. This led to three parents expressing distrust in the people organizing the studies as they felt they may not be “upfront” about their true research goals.

Mistrust in neuroscientists was a primary issue expressed by parents for reluctance with involving their children in neuroimaging research. Parents were concerned that neuroscientists lacked training for working with children. In particular, parents described their perceptions of the scientists as being “elitist” and in an “esoteric” field of study. One parent expressed concern that if neuroscientists were exposed to laboratory conditions all the time, they may have grown desensitized to working with humans. “When I think of a laboratory, I think of mice. But I’m not an animal, nor are my children. We’re human beings ... I don’t want them to feel like they’re being abducted by aliens for no reason.”

While overturning the way parents perceive neuroscience and neuroscientists may seem like a daunting task, parents also offered several suggestions on how to increase the likelihood of families participating in neuroimaging research.

### *Practical Suggestions*

Parents expressed that neuroscience may be in need of advertising to convey the purpose for this field of research. They suggested that neuroscience laboratories partner with local child care centres to host “A Day in the Life of a Neuroscientist” type events. Under the guidance of professionals in education, neuroscientists could host these days which might include: discussions of the purpose of being a neuroscientist, what’s involved in becoming a neuroscientist, games that demonstrate typical tasks in a neuroscience laboratory, and holding a fun and interactive mock study where teams of children investigate their theory.

It was suggested that neuroscientists in these programs provide supplementary materials for the educators such as ideas for creating a neuroscience lab dramatic play area, along with reading materials that encourage children to explore science. Additionally, resources could be provided to the families through paper handouts detailing the children's day as a neuroscientist and links to additional information could be provided here as well. For example, it may be beneficial for neuroscience laboratories to have family friendly websites that convey what projects are currently being pursued while illustrating how these projects have concrete implications for children in their communities.

## Conclusions

The present study suggests there are many misconceptions regarding research involving neuroimaging, which are likely influenced by media exposure. These findings highlight the importance of knowledge translation with families when involving their children in experimental procedures. It is essential that researchers communicate to parents the meaningfulness of their research. Devising recruitment strategies that are founded on forming a trusting relationship with families through community programs that initiate a conversation of the real world applications of neuroimaging studies with children may enhance study participation.

## Implications and Recommendations

Based on the themes that emerged from the interviews, three areas must be addressed to encourage family participation in neuroimaging studies: (1) the purpose of the research and how it relates to families in everyday life must be made clear, (2) researchers need to indicate how they are qualified to conduct research with children, and (3) risk factors, or lack thereof, such as radiation and the potential for incidental findings related to health, must be clearly presented to parents and explained to children in an age-appropriate way. Since the focus of this study involved parents of children between the ages of six and eight years old, some suggestions for clearly communicating with this age group include role-playing with a toy or mannequin the procedure that will be used (e.g EEG capping procedure) or describing the study through the use of drawings (comic strip) or a brief video.

In light of the initial insight given by this pilot study, it may be argued that it is vital to incorporate the perspectives of parents as a top priority when developing research questions and recruitment strategies. It is quite an oversight that this has been overlooked for so long. Research such as neuroimaging should be held to a very high standard of ethics and even scientific skepticism.<sup>20</sup> Yet, this is not always the case. With this fast paced field, often reactive approaches are implemented rather than proactive approaches to ethical evaluations.<sup>2</sup> Hopefully through putting greater care into showcasing the human element behind neuroimaging studies and the neuroscientists behind these studies, the field of neuroscience can ease the minds of many worried parents. By working to build partnerships with child care centres, educators, and families, and then showcasing these efforts, it may be possible to create a future that is not plagued with recruitment issues when working with families.

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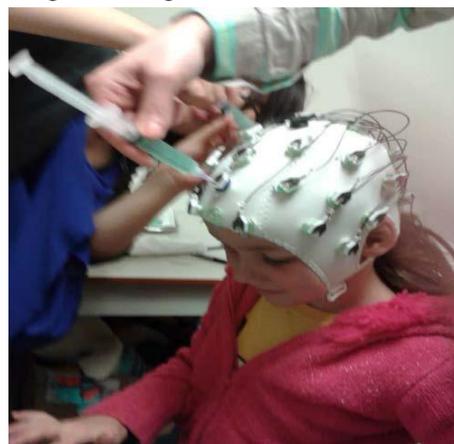
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## Appendix 1

### Interview Questions

1. Tell me about your understanding of neuroimaging?
2. I'd like to share an image with you (as seen below). Would you share with me your thoughts and emotions upon seeing this image?



3. Have you ever been approached to have your child(ren) participate in a study that uses some form of neuroimaging? (For example: EEG's, MRI's etc.?)

- If yes, could you describe what that experience was like? (Where, when, who, what, why)
- If no, could you describe what you imagine that process would look like? (where, when, who, what, why)

4. When you consider having your child(ren) participate in a neuroimaging study, what thoughts come to mind? (Any potential barriers? And potential motivating factors?).

5. What things would be helpful and useful for parents to know as they consider having their child(ren) participate in a neuroimaging study. (Information, demos, concrete materials, videos, etc.)

6. What role, if any, do you feel research involving children's neuroimaging plays in our society? To the lives of your immediate family members?