Parental Knowledge of Potential Cancer Risks From Exposure to Computed Tomography

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KEY WORDS computer tomography, radiation, pediatrics, parents, radiology

ABBRévIATIONS CI—confidence interval
CT—computed tomography
ED—emergency department

All authors reviewed the manuscript, provided critical revisions and gave final approval of the submitted version.

Dr Boutis was the primary and responsible author. As such, she had full access to the data and has final responsibility for the decision to submit for publication. In addition, she primarily designed the work; oversaw all research operations in patient enrollment, data collection, and entry; was involved in the analysis and interpretation of results; and wrote most of the manuscript. Dr Cogollo was primarily responsible for patient enrollment, data quality checks, and data entry. Drs Fischer and Freedman were involved in the intellectual content of the research proposal and aided in survey question development. Ms Ben David was involved in ensuring accurate radiation risk estimates, fielded correspondence from parents during the study period, and assisted in preparation of the study parent handout on radiation risks from skull radiography and head computed tomography. Dr Thomas provided very comprehensive content expertise in risk estimates, review of pertinent literature, development of survey questions, and input into the research proposal and manuscript revisions; was the main author of the study parent handout.

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WHAT’S KNOWN ON THIS SUBJECT: Studies have highlighted a lack of patient awareness of potential increased cancer risks associated with computed tomography (CT) scans in adult patients and in nonurgent settings. However, little is known about parental awareness of these risks in an emergency setting.

WHAT THIS STUDY ADDS: Approximately half of parents were aware of the potential cancer risks from CT scans in an emergency setting. Although risk disclosure moderately reduced willingness to proceed with recommended testing, almost all parents preferred an informed discussion before CT imaging.

abstract

OBJECTIVE: Computed tomography (CT) imaging of children is increasing in emergent settings without an understanding of parental knowledge of potential cancer risks. In children with head injuries, our primary objective was to determine the proportion of parents who were aware of the potential of CT to increase a child’s lifetime risk of malignancy. We also examined willingness to proceed with recommended CT after risk disclosure and preference to be informed of potential risks.

METHODS: This was a prospective cross-sectional survey of parents whose children presented to a tertiary care pediatric emergency department with a head injury. Survey questions were derived and validated by using expert opinion, available literature, and pre- and pilot testing of questions with the target audience.

RESULTS: Of the 742 enrolled parents, 454 (61.2%) were female and 594 (80.0%) were aged 31 to 50 years. Importantly, 357 (46.8%) were aware of the potential for an increased lifetime malignancy risk from CT. Before risk estimate provision, the proportion of parents “very willing/willing” to proceed with head CT was 90.4%; after disclosure, willingness decreased to 69.6% (P < .0001), and 42 (5.6%) would refuse the CT. Of note, 673 (90.3%) wished to be informed of potential malignancy risks.

CONCLUSIONS: Approximately half of the participating parents were aware of the potential increased lifetime malignancy risk associated with head CT imaging. Willingness to proceed with CT testing was reduced after risk disclosure but was a significant barrier for a small minority of parents. Most parents wanted to be informed of potential malignancy risks before proceeding with imaging. Pediatrics 2013;132:305–311

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There has been a fivefold increase in the emergency department (ED) use of computed tomography (CT), which involves higher radiation doses than other diagnostic imaging modalities. Simultaneously, there are increasing concerns about the potential future malignancy risk associated with the exposure to ionizing radiation, especially in children because they are more radiosensitive than adults. The results of the first long-term follow-up study in pediatric patients undergoing CT reported a 1 in 10 000 increased incidence of leukemia and brain tumors.

Although researchers are working to achieve more precise estimates of the malignancy risk, clinical practice continues, and it is therefore important that we gain an understanding of parental knowledge and perceptions of the potential risks of ionizing radiation from imaging procedures. It has been suggested that parental desire for a rapid diagnosis is contributing to the increasing use of CT in children and is occurring without their full understanding of the potential risks. The latter may be particularly true in the ED where time for discussions is limited and CT has become a vital component of urgent diagnostic evaluation of pediatric patients. Whereas studies have highlighted a lack of patient awareness of the potential effect of ionizing radiation associated with CT scans, this research has been limited to adult patients and parents in a nonurgent setting. Thus, the extent of parental awareness of potential future malignancy risk associated with imaging procedures in a pediatric emergency clinical setting remains relatively unknown.

We enrolled the parents of children who presented to an ED with an isolated head injury to determine the proportion of parents who were aware of the potential of CT to increase a child’s lifetime risk of malignancy. We also examined parental willingness to proceed with a physician-recommended head CT once provided with information about the potential risks and benefits.

METHODS
Study Design and Setting
This study was a prospective cross-sectional survey conducted in an urban, university-affiliated, tertiary care children’s ED.

Study Population
“Parent” in this study applied to an adult who accompanied the child and was the child’s mother, father, or primary guardian. We enrolled 1 parent per child who presented to the ED with a chief complaint of an isolated head injury (ie, no other body parts were injured). Head injuries were selected because CT of the head is the most common CT examination performed in children in the ED, and the risks of significant brain injury must be weighed against those from ionizing radiation. We excluded parents who could not speak English sufficiently to understand the questions and responses and those whose children received a Canadian Triage Acuity Scale score of 1, those who presented outside study enrollment hours, and/or those who had contact with a physician before survey completion. The study was approved by the study institution’s research ethics board.

Survey Content
The survey was developed in accordance with the methods advocated by Burns et al and Streiner and Norman. The questions and estimates of radiation exposure and respective potential risks were based on information from the relevant literature, institutional dose estimates, and input from an expert panel of 3 pediatric emergency medicine physicians with survey expertise and 1 pediatric radiologist with survey and content expertise. Radiation dose information used to derive equivalent time periods of background radiation was based on 2011 institutional effective dose estimates of 0.024 mSv for a 3-view skull radiograph series on a 5-year-old child, 1.5 to 2.0 mSv for a single-phase (noncontrast) pediatric head CT, and an annual background radiation exposure of 3 mSv. Potential future excess malignancy risk estimates were based on Biological Effects of Ionizing Radiation VII data and Image Gently, the international pediatric radiation safety awareness campaign. Whereas the “most correct estimate” of malignancy risk estimates used were ~1 in 100 000 for a skull radiograph series and 1 in 10 000 for head CT, the authors acknowledge that risk will vary according to age and gender. In addition, the estimates of radiation exposure reported here account for a broad range of available imaging technology.

Items for the survey were generated until no new items emerged, distributed over 5 consensus-based sections. Pairings of anchors with numerical estimates were based on expert consensus from the radiology team at the study site. Potentially unfamiliar terms were defined before use, and all language in the survey was revised to a grade 6 level. The survey was distributed to 5 pediatric emergency physicians distinct from those who participated in the survey design and a convenience sample of 20 parents of varied educational and socioeconomic backgrounds to pretest for content, comprehension, and time required to complete. Finally, the survey was pilot-tested on 20 consecutive parents whose children presented to the ED with a head injury. At the pre- and pilot-testing phases, parents were asked to inform
the research staff of their interpretation of each question. Survey questions were removed or modified in accordance with feedback from all testing phases. In its final form, a total of 18 questions limited data collection time to ∼10 minutes per parent. The final survey (Supplemental Information 1) addressed the following domains (with the respective number of questions): demographic characteristics (4 questions), imaging expectations from current ED visit (3 questions), and knowledge of potential risks associated with ionizing radiation from skull radiographs and head CT (6 questions), and potential impact of knowledge of risks (4 questions). Although skull radiographs are infrequently performed in modern clinical practice, radiation exposure from this imaging type is similar to other frequently ordered plain films; in children with head injuries it is the most clinically relevant plain film, and many parents expect that this imaging be performed. Before the questions relating to impact of knowledge of risks, parents were informed of the following: “Although we are not sure, it has been estimated that a head CT scan in a child may carry an increased lifetime cancer risk around 1 in 10 000. It is very important to remember that the information from a CT scan may help a doctor decide how to best care for a child.”

In addition, after completion of the survey, parents were provided with an informative handout about balancing the benefits and potential risks of imaging in head-injured patients and describing the dose reduction methods used at our institution (Supplemental Information 2).

Survey Administration

Research assistants were present in the ED from 0900 to 2300 daily, and they screened the ED electronic tracking system regularly to identify children who presented with a head injury. Research assistants approached parents before the physician assessment to avoid contamination of parental baseline knowledge and assessed for eligibility. If eligible, the research assistant obtained full informed consent and administered the survey. The questions and responses were read to the parents by the research assistant with the script in full view of the parent, and respective responses were recorded by the research assistant.

Outcomes

The primary outcome was the proportion of parents who were aware that a head CT may increase a child’s lifetime risk of malignancy. We also examined a priori selected parental demographic characteristics (age, gender, educational level, ethnic background, and child with previous ionizing imaging exposure) that may be independently associated with knowledge that CT potentially increases a child’s risk of malignancy. Ethnic origins of survey participants were relevant because those with a family background in geographic areas exposed to serious nuclear/radiation exposures may have a heightened awareness of radiation exposure and potential consequences. The other secondary outcomes were as follows: the proportion of parents with correct best estimates of ionizing radiation from head CT and skull radiographs to determine parental perception of the magnitude of exposure/potential risks from a head CT and how this compares with a plain radiograph, the change in proportion of families who were “willing/very willing” to undergo head CT testing after being informed of risks, and the proportion of families who would prefer to know the potential risks associated with diagnostic imaging that exposes children to ionizing radiation before proceeding with testing.

Data Analyses

On the basis of previous research, ∼15% of parents are aware of the potential future malignancy risk associated with ionizing radiation from CT. Thus, we estimated that a sample size of 700 completed surveys would enable us to determine with 95% certainty and a 2.5% confidence margin, the proportion of Canadians (assuming population base = 30 million) who are aware of the risk of ionizing radiation from the performance of a head CT scan (PASS 2008, version 08.0.2, NCSS, LLC).

Descriptive statistics were used to summarize responses. Proportions were compared by using a χ² test. Logistic regression was used to determine associations between parental demographic variables and the primary outcome. All variables were entered into a full (ie, saturated) multivariable logistic regression model. Goodness-of-fit of final model to the data was tested by using the Hosmer-Lemeshow test. All analyses were completed by using SPSS for Windows (version 13; IBM SPSS Statistics, IBM Corporation, Armonk, NY).

RESULTS

Enrollment and Demographic Characteristics

Of the 987 eligible families whose children presented to the ED with head trauma during the study period, 742 (75.2%) were enrolled in the study (Fig 1), and all of the participants completed every question in the survey. Sixty percent of participants were female, and ∼85% reported postsecondary education (Table 1). In addition, whereas the median age of the children was only 4.4 years, 12% had already had a history of a previous CT examination, and 97% of children were diagnosed with a minor head injury/concussion (Table 2).
Parental Knowledge of Potential Malignancy Risks and Radiation Exposure

Of the 742 respondents, the percentage (95% confidence interval [CI]) who believed that there is an increased lifetime malignancy risk later in life after having a head CT (primary outcome) was 46.8% (43.2%–50.4%). However, 62.9% (59.4%–66.4%) underestimated the current best risk estimate (Table 2). Knowledge that CT was associated with a potential for increased lifetime malignancy among parents was not significantly associated with parental age (P = .8), gender (P = .8), ethnic background (P = .9), history of previous imaging in their child, or educational level (P = .2) (goodness of fit P = .7, area under the curve of 0.62 [95% CI: 0.58–0.69]).

When asked to compare the radiation exposure from a head CT with background radiation exposure, 51.1% (47.5%–54.7%) underestimated CT radiation dose (Table 3). In contrast, 32.8% (29.4%–36.2%) of the parents overestimated the radiation dose and 44.8% (41.2%–48.3%) overestimated potential malignancy risk associated with skull radiographs, with 18.5% of parents choosing a risk estimate the same or above the level associated with head CT (Table 2). The results of statistical comparisons between CT and radiograph response proportions (Tables 2 and 3) were not reported because all of the comparisons achieved statistical significance but the differences did not appear to be clinically meaningful.

Of the 496 (66.8%) respondents who reported having some previous knowledge about radiation exposure in diagnostic imaging, information sources were as follows: health care workers, 197 (26.5%); paper media, 161 (21.7%); radio/television, 123 (16.6%); Internet, 119 (16.0%); communication with a friend/family member, 97 (13.1%); and/or formal education courses, 61 (8.2%).

Impact of Disclosure of Potential Risks

At the start of the survey, 671 of 742 (90.4%) parents would be very willing/willing to proceed with a head CT if the emergency physician thought it was necessary, but this number was reduced to 517 (69.7%) after current risk information was provided (P < .0001). Figure 2 shows the degree of change in category of willingness to proceed for each respondent. Of note, 346 (46.6%) parents did not change category of willingness, whereas 363 (48.9%) decreased their willingness, with 204 (56.2%) of these parents decreasing willingness by only 1 category.
Importantly, 262 (35.3%) would not have any further thoughts about recommended CT testing if the doctor thought it was important, whereas 311 (41.0%) wanted further discussion with a physician, and 42 (5.6%) would refuse CT testing. Of the 42 who stated that they would refuse CT testing, head CT was subsequently recommended by the physician in 8 cases; CT imaging was completed successfully in all 8 cases. The vast majority of parents, 673 (90.7%), preferred to know the potential malignancy risks of diagnostic tests that expose children to ionizing radiation before proceeding with testing.

### DISCUSSION

Our study revealed that ~50% of the parents who participated in this survey were aware that ionizing radiation from a CT of the head may potentially increase a child’s lifetime malignancy risk. Although the provision of risk information reduced parental willingness to proceed with theoretical CT testing, almost all parents were willing to discuss with the doctor the need for CT imaging if it was recommended. Finally, >90% of families preferred to be informed of potential risks before proceeding with recommended ionizing diagnostic imaging.

We found a greater prevalence of parental awareness of the potential risk associated with CT than previously reported. In 2004, Lee et al. reported that only 3% of adult patients who received an abdominal CT in the ED believed there was an increased malignancy risk. In parents of children who were scheduled to undergo non-urgent outpatient CT, Larson et al. found that 13% of respondents were aware of possible malignancy risks. Although there are differences between studies in clinical setting, geographic region, and potentially, parental demographic characteristics, our finding of almost 50% parental awareness suggests that there has been a substantial interval increase in public awareness over the past 8 years. In 2006, a survey of pediatricians reported a sustained increase in parent questioning regarding radiation doses since 2001. The recent expansion of media coverage is probably the most influential contributing factor toward increasing parental awareness, with 54% of our study parents reporting knowledge gains from the media/Internet. However, increased communication and discussion from physicians, imaging technologists, or nurses with patients is also becoming more commonplace, with ~25% of respondents receiving their information from health care providers. As in previous studies, our respondents generally underestimated the radiation exposure and risk associated with CT. However, quite unexpectedly, they selected similar dose and risk estimates when assessing skull radiographs as for CT, which implies that parents have a limited sense of the relative difference in the radiation dose of skull radiographs (60–80-fold less) compared with CT of the head. The latter could result in an inappropriately equal level of concern about radiation exposure and potential malignancy risks when a physician recommends radiographs or CT, which may affect how often parents raise verbal conversations about potential risks from CT. Clinicians may therefore have a greater responsibility to initiate conversations with families about the risks/benefits of CT rather than do so only when prompted by the patient.

We found that parental willingness to proceed with physician-recommended CT testing decreased by ~20% after being provided with current risk estimates. This finding differs from the only comparable study by Larson et al. in which risk disclosure had no impact on willingness to proceed with CT testing in their respective children. However, the latter study involved parents attending a clinic with their children for a previously scheduled CT, and the concern around their child’s current clinical condition may have outweighed any new information about

### TABLE 2 Parental Knowledge of Potential Cancer Risk From Imaging Tests That Use Ionizing Radiation

<table>
<thead>
<tr>
<th>Potential Malignancy Risk</th>
<th>Skull Radiographs (n = 742)</th>
<th>Head CT (n = 742)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Almost no risk at all (&lt;1:1 000 000)</td>
<td>282 (38.0)*</td>
<td>271 (36.5)</td>
</tr>
<tr>
<td>Very small risk (1:1 000 000)</td>
<td>195 (26.3)</td>
<td>196 (26.4)</td>
</tr>
<tr>
<td>Small risk (1:10 000)</td>
<td>91 (12.3)</td>
<td>105 (14.2)*</td>
</tr>
<tr>
<td>Moderate risk (1:1000)</td>
<td>40 (5.4)</td>
<td>38 (5.1)</td>
</tr>
<tr>
<td>Large risk (1:100)</td>
<td>6 (0.8)</td>
<td>8 (1.1)</td>
</tr>
<tr>
<td>I do not know</td>
<td>128 (17.3)</td>
<td>124 (16.7)</td>
</tr>
</tbody>
</table>

Data are presented as n (%).
* Most correct estimate.

### TABLE 3 Parental Knowledge of Exposure to Ionizing Radiation From Diagnostic Tests Relative to Daily Background Radiation

<table>
<thead>
<tr>
<th>Relative to Background Radiation</th>
<th>Skull Radiographs (n = 742)</th>
<th>Head CT (n = 742)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than a day</td>
<td>124 (16.7)</td>
<td>104 (14.0)</td>
</tr>
<tr>
<td>A few days</td>
<td>157 (21.2)*</td>
<td>133 (17.9)</td>
</tr>
<tr>
<td>A couple of weeks</td>
<td>75 (10.1)</td>
<td>79 (10.6)</td>
</tr>
<tr>
<td>1 month</td>
<td>83 (11.2)</td>
<td>64 (8.8)</td>
</tr>
<tr>
<td>6 to 8 months</td>
<td>60 (8.1)</td>
<td>78 (10.5)*</td>
</tr>
<tr>
<td>3 to 4 years</td>
<td>25 (3.4)</td>
<td>49 (6.6)</td>
</tr>
<tr>
<td>I do not know</td>
<td>218 (29.4)</td>
<td>235 (31.7)</td>
</tr>
</tbody>
</table>

Data are presented as n (%).
* Most correct estimate.
small malignancy risks. In our survey, CT imaging was theoretical, leaving parents relatively uninformed about clinical need, and thus malignancy risks may have played a greater factor in reported willingness to proceed with imaging.

Approximately 90% of parents in this study would prefer to be informed about possible risks before their children undergo CT or radiographic examinations. There are limited data on current physician practice in this area, but a study published in 2004 reported a physician risk disclosure rate of 22% in an adult ED population scheduled for abdominal CT. In a 2012 survey of 126 Canadian pediatric emergency medicine physicians, 69% of the respondents reported discussing potential malignancy risk with families at least “most of the time” when they recommend a CT of the head (K.B., J.F., S.B.F., K.E.T., unpublished data). Whereas reported rates may be inflated, this finding does suggest that disclosure rates among emergency physicians are increasingly approaching parental expectations.

This research has limitations that warrant consideration. Because demographic characteristics were only available upon consenting to the survey, we could not compare our responder and nonresponder parent groups. However, our response rate was relatively high at 75%, which approximates the 80% target of a representative sample. In addition, we did not ask about the respondent’s experience with cancer, which may have been an important variable in knowledge of potential cancer risks from CT-related radiation. As with all surveys, it is not possible to know if some respondents may have provided what they perceived to be socially desirable answers rather than their true perceptions. The risk information given to parents was brief and without a personal or detailed clinical context, and therefore the impact of risk disclosure reported in this survey may not reflect what would happen in clinical reality. Our results reflected English-speaking parents, many of whom had postsecondary education, who presented to a pediatric ED located in an urban Canadian setting and included only children with relatively minor head injury. Thus, our findings may not be generalizable to other sociodemographic and clinical scenarios and a less-educated population may have less knowledge of radiation risks from imaging.

CONCLUSIONS
The evolving professional literature, media, and Internet coverage are influencing the environment in which physicians practice and the knowledge base of our patients and their families. This situation may especially be true in pediatric medicine, where concerns are often the highest, and a greater understanding of parental perceptions and desire to be informed of radiation risk is needed. We found that approximately half of participating parents were aware of the potential lifetime increase in malignancy risk associated with CT and most underestimated the risk of CT. In addition, despite many parents demonstrating a decreased willingness to proceed with CT imaging after risk disclosure, almost all were agreeable to pursuing a discussion with their physician in the face of clinical need. Because almost all parents expressed a preference to be informed of potential risks before
proceeding with recommended imaging, we strongly recommend that physicians be well informed of the benefits and potential risks of CT imaging.

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