Informing Parents About CT Radiation Exposure in Children: It's OK to Tell Them

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OBJECTIVE. The purpose of our study was to determine how parents' understanding of and willingness to allow their children to undergo CT change after receiving information regarding radiation dose and risk.

MATERIALS AND METHODS. One hundred parents of children undergoing nonemergent CT studies at a tertiary-care children's hospital were surveyed before and after reading an informational handout describing radiation risk. Parental knowledge of whether CT uses radiation or increases lifetime risk of cancer was assessed, as was willingness to permit their child to undergo both a CT examination that their child's doctor recommended and one for which their doctor thought observation might be equally effective.

RESULTS. Of the 100 parents who were surveyed, 66% believed CT uses radiation before reading the handout, versus 99% afterward ($p < 0.01$). Before reading the handout, 13% believed CT increases the lifetime risk of cancer, versus 86% afterward ($p < 0.01$). After reading the handout, parents became less willing to have their child undergo CT given a hypothetic situation in which their doctor believed that either CT or observation would be equally effective ($p < 0.01$), but their willingness to have their child undergo CT recommended by their doctor did not significantly change. After reading the handout, 62% of parents reported no change in level of concern. No parent refused or requested to defer CT after reading the handout.

CONCLUSION. A brief informational handout can improve parental understanding of the potential increased risk of cancer related to pediatric CT without causing parents to refuse studies recommended by the referring physician.

Keywords: CT, pediatric imaging, radiation

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Utilization of CT continues to steadily increase in the pediatric population [1–3]. Although CT examinations make up approximately 11% of the number of radiologic procedures, radiation from CT delivers approximately 70% of the medically related radiation dose to the general U.S. population [4].

Even small doses of radiation may pose an increased risk of cancer [5–7], and children are thought to be at increased risk compared with adults [2, 8–10]. However, the risk remains theoretic and has generated considerable attention and controversy in both the medical literature and the lay press [11–13]. Regardless, because of the potential risk, established as-low-as-reasonably-achievable (ALARA) principles have been the standard in the radiology community for many years and are especially applicable in the case of pediatric CT [14].

The U.S. Food and Drug Administration (FDA) has outlined a three-pronged strategy to minimize avoidable pediatric CT radiation dose: optimize CT settings for pediatric patients, minimize multiple phases in contrast-enhanced studies, and minimize inappropriate CT referrals [15]. The first two elements rely almost completely on imaging professionals, whereas the third element relies more heavily on referring clinicians. Studies have shown that clinicians usually underestimate CT-related radiation dose and associated risk of cancer [16, 17]. Furthermore, some experts believe that as many as 30% of all pediatric CT examinations are unlikely to benefit the individual or could be easily and effectively replaced by a nonionizing imaging technique [18]. Acting on these findings, at least one institution has shown that educating clinicians can help stem the increase in CT referrals [3].

Patients also generally have a poor understanding of the radiation dose and risk associated with CT [16]. Some experts believe that parents may contribute to the increasing demand for CT as they seek rapid diagnosis without understanding the potential risks [4].

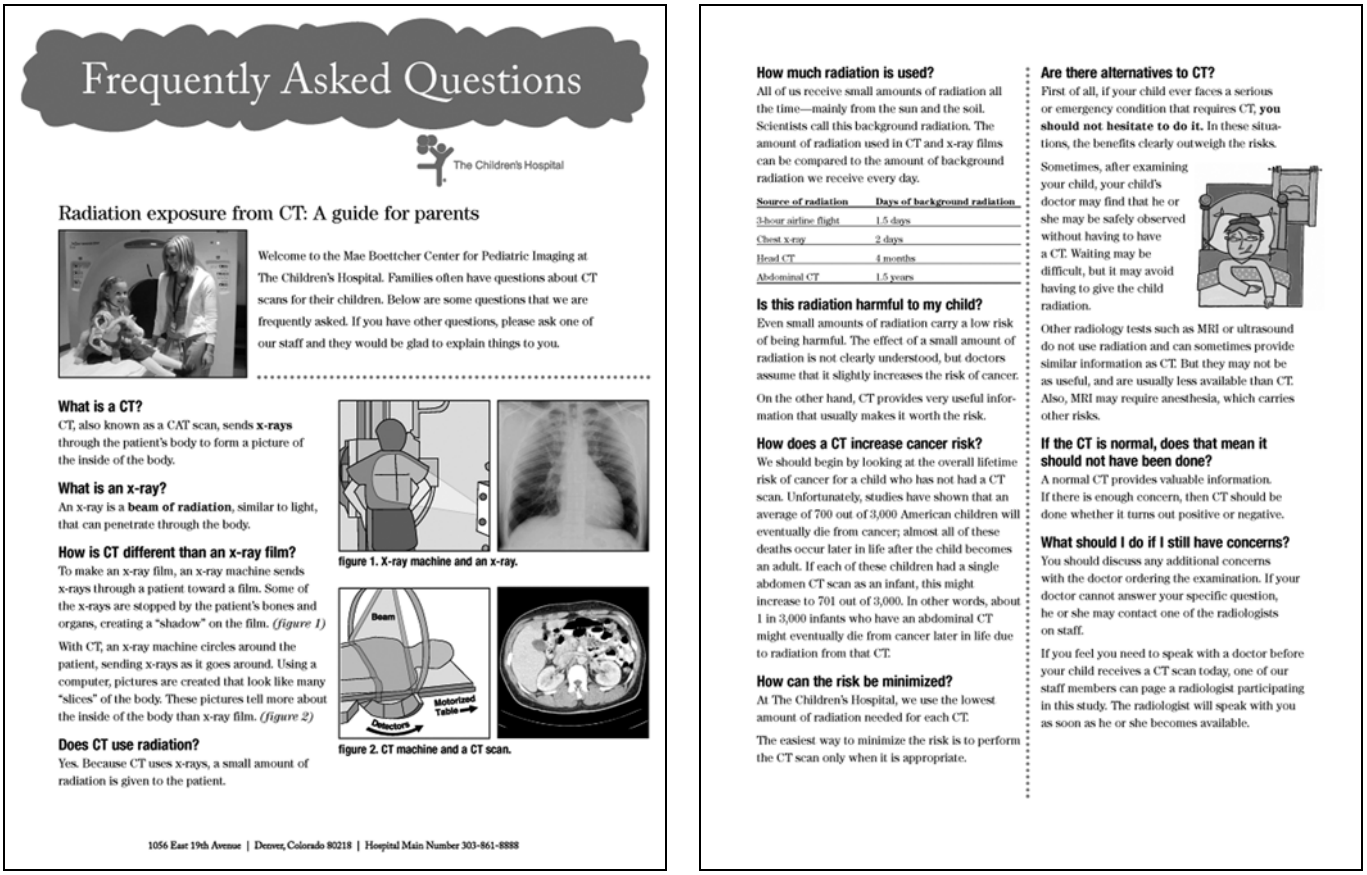

Fig. 1—Informational handout describing radiation risk provided to parents of children referred for CT. Parents read the handout after taking the initial survey and before the final survey. Reprinted with permission from The Children's Hospital, Denver, CO.

If this is true, better informing parents of the radiation dose and risks might help to decrease the demand for pediatric CT.

On the other hand, some authors have suggested that radiation exposure is not an issue for individual patients and parents, but rather for radiologists and clinicians [19–22]. Specifically, concern exists that parents may be unnecessarily upset by such information and may be reluctant to allow their children to undergo CT in instances when CT is appropriate. The purpose of this study was to determine whether a brief informational handout regarding CT-associated dose and risk improves parental understanding or changes their willingness to allow their children to undergo nonemergent CT examinations.

Materials and Methods

Participants

An informational handout regarding CT-related radiation dose and risk was prepared for parents and guardians of pediatric outpatients (18 years old and younger) referred to the imaging department of a tertiary-care children's hospital for nonemergent CT. Over a 2-month period, parents were asked if they would be willing to fill out a survey while waiting in the reception area for the child's CT scan. An initial survey was completed by each participant before reading the handout, and a final survey was completed after reading the handout. The handout and final survey were not given to the parent until the initial survey was submitted.

Parents of children undergoing major trauma, children with emergent conditions requiring immediate care, and suspected victims of nonaccidental trauma were excluded from the study. To minimize attention bias, referring clinicians were not alerted to the existence of the study. Before the initiation of the study, the institutional review board (IRB) reviewed the study protocol, including the handout and surveys, and granted the study exempt status from further direct IRB supervision. The study met the guidelines established by the Health Insurance Portability and Accountability Act.

Informational Handout

The English-language informational handout was titled "Radiation exposure from CT: A guide for parents" (Fig. 1). After the handout briefly described CT and its associated radiation, it provided a table comparing radiation exposure from several activities with that of background radiation, based on effective whole-body dose. The comparison table included the following sources of radiation and was based on the following dose estimations: daily background radiation with dose estimated at 0.01 mSv [23]; a 3-hour airline flight, at 0.015 mSv [24]; a chest radiograph, at 0.02 mSv [25]; head CT, at 1.11 mSv; and abdominopelvic CT, at 5.57 mSv. The effective doses for head and abdominal CT were calculated from the dose–length product data obtained from the most common scanning protocols at our institution and converted to a whole-body effective dose using body region-specific normalized effective dose conversion factors (0.0021 for head CT and 0.014 for abdominal CT) [26].

The handout emphasized that although the long-term effects of CT are controversial and incom-

pletely understood, the low levels of radiation exposure from CT are assumed to slightly increase the risk of cancer [2, 6, 9]. We estimated the lifetime risk of fatal cancer attributable to radiation from a single abdominal CT examination in infancy to be about one in 3,000 (0.03%). Brenner et al. [2] estimated the attributable risk to be approximately 0.23%, using unadjusted adult settings. Our estimation reflected an adjustment based on the typical 50 mAs used at our institution, versus the 404 mAs used by Brenner et al., and assuming a linear correlation between mAs and fatal cancer risk. The concept of risk was further illustrated in the handout by showing that the lifetime risk of fatal cancer for a North American child younger than 15 years would increase from a baseline of approximately 700 in 3,000 (23%) [2] to about 701 in 3,000 after undergoing an abdominal CT examination as an infant.

Alternatives to CT were listed in the handout, including observation in some circumstances. Specific alternatives were not offered to parents on an individual basis. Parents were advised that if they had any questions or concerns regarding the information in the handout, a staff radiologist would be available for discussion before their child underwent CT.

The handout was 757 words long and scored at an eighth-grade readability level according to the Flesch-Kincaid method, using Microsoft Word word-processing software. Assuming an average eighth-grade reading speed of 150 words per minute [27], most parents would be able to read the handout in fewer than 5 minutes.

Surveys

Initial and final surveys were provided to each study participant to be completed before and after reading the informational handout, respectively (Appendix 1). The first four questions of the initial survey were identical to the first four questions of the final survey. These questions assessed parental knowledge regarding the use of radiation and the increased risk of cancer, their willingness to have their child undergo CT recommended by the child's doctor, and their willingness to have their child undergo CT in a hypothetic scenario in which their child's doctor thought that observation would be just as valuable. Parents were also asked the age of their child in the initial survey and their perceived change in level of concern and understanding after reading the handout in the final survey.

Surveys and handouts were administered by the secretarial staff during business hours. Physicians were involved only in that a radiologist needed to be available to answer questions that parents might have. Both surveys were completed before the child underwent CT. Only one parent or guardian was asked to complete the initial and final survey for each child undergoing CT.

Statistical Analysis

Responses to questions of whether radiation uses cancer and increases the risk of radiation (before and after reading the handout) were paired and tested for statistical significance using the two-sided McNemar chi-square test. Ordered categoric responses to questions assessing willingness to allow the child to undergo CT were also paired and tested for statistical significance using the Stuart-Maxwell test, which tests marginal homogeneity for all categories simultaneously. If one of these questions was not answered, the pair was excluded from the calculation of statistical significance. No significance test was performed on responses to questions included only in the final survey. All calculations were performed using Excel 2002 (Microsoft). A change was considered to be statistically significant at $p < 0.01$.

Sample size was determined with special attention given to the proportion of parents who might become unwilling to allow the child to undergo CT after reading the handout. With a sample size of 100 parents, if no parents refused the study, the test had 80% power to exclude a proportion of less than 1.6%. After the study was completed, a 95% exact binomial confidence interval was applied to the observed proportion.

Results

Understanding of Radiation and Risk

One hundred two parents were surveyed. Two parents did not return the final surveys so the initial surveys were also discarded. A total of 100 initial and 100 final surveys were included in the results. Two respondents left one question unanswered; thus, the number of responses does not total 100 for every question. The average patient age was 7.4 years old (SD, 5.3 years), ranging from less than 1 year to 17 years.

Before reading the handout, 66 (66%) of 100 parents believed CT uses radiation, versus 99 (99%) of 100 after reading it ($p < 0.01$). Before reading the handout, 13 (13%) of 98 believed CT increases the lifetime risk of cancer, versus 86 (86%) of 100 after reading it ($p < 0.01$). Although only yes or no responses were elicited for this question, 10 participants answered yes to the question but then also indicated in the margin their understanding that the increase in cancer risk was slight. Parents indicated their perceived change in understanding of risks as listed in Table 1. Fifty-nine percent of the respondents reported that this information either was new to them or clarified their understanding. Of note, of the 41 parents who claimed they already knew the information, or that their doctor had explained all of it to them, 71% answered that CT does not cause an increased risk of cancer on the initial survey.

TABLE 1: Reported Change in Understanding of Risks

No. (%) of Parents	Response
28 (28)	I already knew this before visiting my child's doctor.
13 (13)	My child's doctor explained all of this to me.
30 (30)	My child's doctor explained some risks to me, but this information made it more clear.
29 (29)	All of this was new to me—my child's doctor did not explain any of it.
100	Total

TABLE 2: Willingness to Allow Child to Undergo CT Before and After Reading Handout

No. (%) of Parents Before	No. (%) of Parents After	Response
67 (67)	57 (58)	Willing to allow CT, no concerns
32 (32)	40 (40)	Willing to allow CT, some concerns
1 (1)	2 (2)	Willing to allow CT, strong concerns
0	0	Unwilling to allow CT
100	99	Total

Level of Concern

When asked both before and after reading the handout how willing they were to have their child undergo CT recommended by their doctor, parents responded as listed in Table 2. Willingness to have their child undergo CT did not change after reading the handout in 80 (81%) of 99 respondents. The level of concern increased for 14 (14%) of 99 and decreased for five (5%) of 99 respondents. This change was not statistically significant ($p = 0.10$). No parent reported unwillingness to do the study. One parent asked to speak to a radiologist for further clarification, but no parent (95% CI = 0–3.6%) refused or requested to defer the child's CT after reading the handout.

When asked how their concern about the risks associated with CT changed after reviewing the handout, parents responded as listed in Table 3. The reported change in level of concern was similar to the change in willingness to have the child undergo CT as described in the

TABLE 3: Reported Change in Level of Concern

No. (%) of Parents	Response
2 (2)	Much less concerned now
5 (5)	A little less concerned now
62 (62)	No change
29 (29)	A little more concerned now
2 (2)	Much more concerned now
100	Total

TABLE 4: Willingness to Allow Child to Undergo CT if Observation Is as Valuable as CT, Before and After Reading Handout

No. (%) of Parents Before	No. (%) of Parents After	Response
2 (2)	3 (3)	Willing to allow only CT
38 (38)	31 (31)	Would prefer CT
37 (37)	26 (26)	No preference between CT or observation
20 (20)	38 (37)	Would prefer observation
2 (2)	2 (2)	Willing to allow only observation
99	100	Total

Note—Percentages may not total 100% because of rounding.

preceding paragraph, with most parents reporting no change in level of concern.

Possible Alternative: Observation

When asked how willing they would be to have their child undergo CT if their doctor thought that observation would be just as valuable as CT, parents responded as listed in Table 4. Willingness to have their child undergo CT in this situation did not change after reading the handout in 73 (74%) of 99 respondents. The preference changed toward more willing to observe in 23 (23%) of 99 and toward more willing to use CT in three (3%) of 99 respondents. Overall, the average change toward more willing to observe was statistically significant ($p < 0.01$).

Discussion

Before receiving the informational handout, a moderate proportion of parents (66%) realized that CT uses radiation, whereas nearly all of them (99%) understood this afterward. Initially, only 13% of parents realized that CT might increase the risk of cancer. Although this constitutes a small minority, Lee et al. [16] reported that even fewer (3%) adult emergency department patients believed that an increased cancer risk is associated with CT. After reading the handout, most parents (86%) believed that CT increases the risk of cancer for their child. Therefore, although parents do not generally understand the potential increased risk of cancer associated with CT, a brief handout (which takes fewer than 5 minutes of parents' time to read and practically no physician time) can be effective in improving their understanding, at least on a basic level.

Providing parents with quantitative information regarding CT-related radiation dose and potential risk did not significantly change parents' willingness to allow their children to undergo CT and only slightly raised their self-reported level of concern. Furthermore, no parent refused to allow his or her child to undergo CT after reading the information, and only one parent asked to speak with a radiologist—merely to clarify a point made in the handout. These findings should assuage fears that providing such information will either dissuade parents from allowing their child to undergo CT recommended by the child's clinician or cause parents excessive concern.

We chose to provide patients with quantitative dose and risk estimates. Although these estimates are subject to a large amount of variability (uncertainty in the dose–risk calculation, automatic adjustments in scanner settings, variability in patient characteristics, and so forth), they likely provide a closer estimation of the actual risk than what patients perceive when merely told the risk is "slight." Furthermore, criticism that these estimates overstate the risk would further support the conclusion that parents do not react adversely when given specific information regarding CT-related radiation. Although specific values of dose and risk may be open to debate, parents clearly better understood that CT uses radiation and increases the lifetime risk of cancer after reading the handout. Despite this knowledge, parents' willingness to proceed did not significantly change.

Limitations of this study include that the choice between scanning and observing the patient was presented as a hypothetic scenario. Furthermore, the information was given to parents when the child presented to the radiology department in a nonemergent setting; future studies should evaluate the effectiveness of providing such information to parents at the time the decision to order CT is made. That only nonemergent cases were included in the study may limit its external validity because the nonemergent indications for the study (e.g., neoplasm follow-up or congenital abnormality) may affect parents' attitudes differently than emergent indications (e.g., trauma or infection).

Another limitation was discovered after the study was underway: It became clear that the question assessing patients' perception of understanding of risk was misleading and the results difficult to interpret, because the questions did not adequately differentiate what the parent initially knew versus what the ordering clinician told them versus what they learned from the handout. Nevertheless, regardless of whether the parents' doctors had informed them of the risks, the data indicate that parents did not understand the risk at the time that their child was to undergo CT—only 13% of parents initially believed that CT increases the risk of cancer.

In the course of our study we found a conspicuous lack of clear and concise information regarding CT-related radiation risk that is conveniently available to clinicians, patients, or even radiologists. In order for risk information to be appropriately incorporated into the decision of whether to order CT, accurate information must be known or readily available to those involved in the decision at the time the decision is made [28]. We hope that such information will be further developed and disseminated to clinicians, parents, and patients.

When presented with the hypothetic alternative of observing their child rather than proceeding with CT, parents become more willing to observe after reading the handout. Whether providing such information to parents would actually reduce the number of marginally indicated pediatric CT examinations depends on many factors, including how often parents request CT examinations for their children, how strongly parents influence ordering clinicians, how often such influence leads to inappropriate CT examinations, the relationships between parents and clinicians, and the symptoms and clinical question in each case. Although further investigation into these questions is necessary, our findings indicate that parents are more willing to at least consider other options when they understand the risks associated with CT.

Even if providing CT-associated risk information to parents did not reduce children's exposure to radiation, we believe that informing parents of possible risks associated with CT fulfills the prima facie principle of respect for patient autonomy [29]. Improved parental un-

derstanding comes at the small cost of a slight increase in parental concern (which some might see as a benefit), but not to the extent that it dissuades parents when CT is indicated. Given the evidence that providing radiation dose and risk information to parents of children undergoing CT does not interfere with appropriate care, we believe that such information should be provided to parents routinely.

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APPENDIX 1: Initial and Final Parental Surveys

Initial Survey:

1. To the best of your knowledge, does a CT scan (Computed Tomography or CAT scan) use radiation? (*Yes / No*)
2. To the best of your knowledge, does a CT scan increase the risk of cancer? (*Yes / No*)
3. If your doctor recommends a CT scan for your child, how willing are you to have your child receive a CT scan? (*Willing to do CT, no concerns / Willing to do CT, some concerns / Willing to do CT, strong concerns / Unwilling to do CT*)
4. If your doctor felt that observation would be just as valuable as a CT scan, how willing would you be to have your child receive a CT scan? (*Only willing to do CT / Would prefer CT / No preference between CT or observation / Would prefer observation / Only willing to observe*)
5. What is the age of your child? (*Under 1 year of age / ___ years old*)

Final Survey:

1–4. Identical to questions 1–4 of Initial Survey)

5. After reviewing this information, how did your concern about the risks associated with CT change? (*Much more concerned now / A little more concerned now / No change / A little less concerned now / Much less concerned now*)
6. How well do you feel this pamphlet improved your understanding of the risks of CT? (*I already knew this before visiting my child's doctor / My child's doctor explained all of this to me / My child's doctor explained some risks to me, but this information made it more clear / All of this was new to me—my child's doctor did not explain any of it*)