Who Cares for the Children?

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Recently, an article stating that a pesticide study that was to be have been conducted on children had been dropped (The Buffalo News, April 9, ?Pesticide Study of Children Dropped? by John Heilprin). Apparently, the Environmental Protection Agency (EPA) was anxious to get information regarding the effects of pesticides on children. The study group was allegedly to be comprised of low-income minority neighborhood in Florida who would receive, as entitlements for participating, $970.00, a camcorder, and children?s clothing for each of the sixty children participants.

The Acting Administrator of the EPA elected to cancel the proposed study. Why, you might ask? After it became apparent that his senate confirmation as administrator of the EPA was in jeopardy if the study had gone forward, the acting administrator apparently felt that the study was not such a good idea. Conflict of interest, to be sure. Who was to benefit?the children or the Acting Administrator?by the decision to stop the proposed study? It is unclear, but at least the children were spared the chemical and pesticide exposure. And perhaps the Acting Administrator was offered the new post. As a bioethicist, I shudder at the notion of such behavior.

Unfortunately, such a scenario involving our children is not rare. Beginning in 1956, medical luminaries deliberately infected mentally handicapped children at Willowbrook State School on Staten Island with the Hepatitis virus. The purpose of the study was to develop an effective vaccination for infectious hepatitis. Newly admitted child patients were deliberately infected with the virus after parental consent had been obtained under what is now considered coerced and manipulative situations. In at least some of the children?s cases, admission to the school was contingent upon the participation? of the child in the study. Fortunately, the experimental unit was soon shut down.

More recently, there have been allegations of wrongdoing by the Administration for Child Services in New York City concerning foster children who were HIV-positive and were entered into clinical trials for AIDS drug treatment between 1988 and 2001 (The Buffalo News, May 5, ?AIDS Drugs Tested Foster Children the Past 20 Years? by John Solomon). It appears that the
appropriate and necessary permission had not been obtained from the parents or guardians, and, if it was obtained at all, had been coerced. There were implications that non-participation might have triggered a discontinuation of social benefits. Apparently, the study did not include an independent advocate for the children involved. As a pediatrician, I tremble when I recount these stories. One of the lead researchers brushed aside the issues of informed consent and coercion opining that the study medications—the best currently available (although not approved for children)—were treatments that would otherwise not be available for these patients. So, again I ask, who cares for the children?

Perhaps the more important question is: Why do these things happen? The answer is relatively straightforward: doctors and scientists need information and data that is applicable for children. After all, children are not simply little adults. Children are different from adults in at least three fundamental ways: physically, mentally, and experientially. The ramifications of being physically different demands the development of pediatric dosing of medications heretofore used only in adults as well as knowledge of possible side effects of the medicines used in a pediatric population. Pediatric therapeutic trials are required to elicit this type of information and are often done through proposed trials carried out under the auspices of the Food and Drug Administration (FDA). These studies are at times frustratingly and necessarily slow because safety must be assured, controls must be in place, and scientific conduct must be professional.

Assuming that all the appropriate safeguards are in place, who is responsible for ensuring the well being of the children involved? If the medical study is attempting to obtain pediatric information, then pediatric patients must be used. Ethical concerns abound, and they are not limited to the twin questions of who gives consent, and how consent was obtained, as in the two actual medical studies mentioned above. Most young children simply do not possess the informational experience and the concrete reasoning capacity to make these decisions. As a consequence, parents and guardians must think for them and make decisions that are in the best interest of the child. In many cases, we must think for our children because many of them simply do not have knowledge base or the decision making ability to reason through the medical complications of a study. Not surprisingly, mature adults can do no better if proper informed consent has not been obtained (the lack of proper consent specifically makes the two examples presented earlier in the column so egregious).

Proper consent encompasses three aspects: adequate and proper information, the ability of the patient to decide, and the opportunity to decide without coercion. This procedure was not followed in the examples given above, and as a result, children were used and abused. This unethical process is a bell that peals from the past. The Nuremberg Code was adopted by the International War Crimes Tribunal in 1947 following the unethical and horrific atrocities carried out by the physicians and armies of Nazi Germany. Countless lives were taken and inhumane medical experimentation performed without the knowledge or consent of a marginalized group of people. While harm of this magnitude is extremely unlikely in these current examples, it remains that the foundation of protection and consent is being sacrificed at the altar of scientific research.

Our children are a gift and our heritage. They are not pawns in a power struggle. Let us protect them as they cannot, in many cases, protect themselves. The American Academy of Pediatrics has established a high standard of parental permission associated with pediatric assent, insofar as the child is able to understand and participate in the decision process. This standard of care is
useful, but still may be abused. Our standard of care should be no less than the words of Christ in the New Testament: allow the little children to come close to me, for paradise is for these precious ones (paraphrase Matthew 19:14).

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