

Treatment challenges in childhood cancer

Letter to editor

One of the major issues at hand in rural West Virginia is the lack of importance and impact that is given to childhood cancer, because our hospitals can make more money treating adults. Economically, families of children with cancer often cannot afford even gas, food, and lodging. I am the founder of Walking Miracles Inc, a 501(c)(3) nonprofit organization located in West Virginia, that provides supportive services for these families. Our biggest issue to access of care is travel. The other is the cost of drugs and other treatments. Children's hospitals also suffer due to the lack of funding from the NCI, which also affects the number of clinical trials and treatments available. Therefore, our families often have to be sent out of state to more advanced childhood cancer treatment centers for some treatments as well. Finally, because the same drugs are being used to treat adults, if there is a shortage, children are the ones that experience delays in treatment.

As a two-time childhood cancer survivor of leukemia and non-Hodgkin's lymphoma during the 1970s and 1980s, I know first-hand that there were times when we had challenges with getting the drugs we needed, due to shortages or non-availability. We often needed to go to another facility to get the chemotherapy we needed for my treatments.

As highlighted in the Viewpoints published in the May issue of Journal of Clinical Pathways,^{1,2} this has become a major issue: first, because of high drug costs; second, because no new drugs are being made now for childhood cancers; and third, because the same drugs that are being used for adults are used in newly diagnosed childhood cancer patients. In the last 20 years, only two new drugs have been approved that were specifically developed to treat children with cancer. According to statistics and research, the development for new drugs from pharmaceutical companies comprises 60% of funding for adult cancer drugs and close to zero for childhood cancers.³ The National Cancer Institute (NCI) spends 96% of its budget on adult cancers and only 4% of its budget on childhood cancers.³

The reason for this is income; childhood cancer does not produce the revenue adult oncology does. Pharmaceutical companies do not commit resources to childhood cancer research, because the adult cancer drug business is viewed as more profitable and less risky to them. Today, profit margins for generic drugs have limited the incentive to produce them. Other reasons for the lack of new drugs

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include the limited number of manufacturers, increased worldwide demand, shortages of raw materials, production problems, aging production plants, stockpiling, and long timelines for approval.

Another reason is the small number of cases of children diagnosed. In 2016, an estimated 10,380 children in the United States will be diagnosed with cancer.⁴ While that number may seem small, that is 10,380 lives and the futures for a lot of families. So what if, as an administrator, board member or director of a children's hospital or NCI, your child was diagnosed with childhood cancer? How would you feel if someone told you they can't treat your child as effectively as we should because investing in this area really doesn't justify the cost? This is not patient centered care; it is greed.

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Conflict of interest

Author declares that there is no conflict of interest.

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