Commentary: Traversing Hurdles: The Future of Collaborative Pediatric Oncology Research

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The authors contributing to this section have identified a number of strengths, struggles, and future directions for research in the broad area of pediatric oncology. In their paper, Armstrong and Reaman focus on the past, present, and future of multicenter cooperative groups, which, in the United States, have primarily culminated in the formation of the Children's Oncology Group (COG). Last, Grootenhuis, and Eiser focus on reviews of childhood cancer research published between 1985 and 2000 and consider mainly English-language contributions made to the literature from three primary geographic areas: North America, Europe, and Australia. Much can be learned from both of these papers about where the field has been with respect to collaboration, as well as where we might be headed.

As a young investigator, I find myself entering the field at a time when medical science has experienced many successes with respect to increasing survivorship among children diagnosed with cancer. Much of this success can be attributed to cooperation among collaborative groups in sharing knowledge gleaned first through clinical experience and then through solid scientific research. We have arrived at a time in which we are beginning to see childhood cancer survivors complete postgraduate education. Whereas 30 years ago many of these children would not have survived their initial diagnosis and treatment, survival rates have increased so that the majority of children diagnosed with cancer now meet or exceed the 5-year standard for survivorship. Although this increased survivorship is certainly something to celebrate, we must bear in mind that survivorship does not translate into absence of consequences of these illnesses and their treatments.

Collaborative research helps us address the acute and ongoing needs of childhood cancer survivors on a much larger basis and allows us to ask a much broader range of questions. In doing so, we are able to better identify similarities, differences, and disparities among children who come from various geographic locations, ethnic and racial groups, and socioeconomic backgrounds. Large cooperative groups help by providing an infrastructure on which member institutions can capitalize. As addressed by Armstrong and Reaman, sometimes the networking that is provided through this framework leads to broadly based and widely disseminated research efforts (i.e., groupwide trials), and other times it leads to smaller, more narrowly focused, yet equally important (and often foundational) studies (e.g., limited-institution studies, rapid pilot intervention studies). In addition, present-day technology such as e-mail, teleconferencing, and videoconferencing enhances our abilities to collaborate with others within the cooperative groups and around the globe. Considering data on published studies, such as those provided by Last, Grootenhuis, and Eiser, we are better able to identify successes and failures in taking advantage of these technological opportunities. The bottom line appears to be that we can still work to improve our global collaboration efforts a great deal; through enhanced collaboration, perhaps we can help alleviate or even eliminate many of the disparities that occur across groups and across the world. We can, and I believe have an obligation to, better utilize technology available to us to ensure that the work we are doing can be accessible worldwide. We truly have the opportunity to create multicenter, multinational, and transdisciplinary research agendas, but we must get past certain hurdles, each of which I will illuminate briefly.

The “Publish or Perish” Hurdle

One of those hurdles is the “publish or perish” ideology so prevalent among academic researchers and research institutions. As alluded to by Armstrong and Reaman,
large cooperative studies often lead to authorship issues that are difficult to resolve. It goes without saying that individual researchers must be attentive to meeting their own career needs in order to sustain those careers, but simply saying that the system exists the way it does is not an excuse to disregard competition for authorship as a barrier to true collaborative research efforts. In order to better serve the public good, we, as research professionals, must advocate for shifts in tenure and promotion policies that recognize the value not only of individual authorship, but also of individual contributions to larger cooperative efforts and dissemination of information through group authorship.

**The Isolationist Hurdle**

We must also overcome a tendency to allow ourselves to become isolated with our specific populations, in our own institutions, or in our existing cooperative groups, particularly as they can lead to the possible exclusion of other groups. The formation of COG, as outlined by Armstrong and Reaman, seems to have occurred in response to addressing this phenomenon. Although there is a wide array of groups and organizations dedicated to oncology and psycho-oncology research, these are often viewed as competitive entities rather than collaborative ones. Among these organizations are the American Cancer Society, Candlelighters, the Children's Brain Tumor Foundation, the Leukemia and Lymphoma Society, the Pediatric Brain Tumor Foundation of the United States, and the list goes on and on. In working toward better collaboration, we can also work to better utilize these groups as partners in our common goals. Additionally, we can partner with agencies beyond the National Cancer Institute in seeking better ways of addressing the needs of childhood cancer survivors. These include focusing on developing partnerships with other government entities that share common concerns for childhood cancer survivors, such as the Department of Education and the Department of Labor. Another way is to establish or enhance relationships with influential organizations such as the American Academy of Pediatrics.

We can work to improve collaboration with researchers investigating other illness groups that demonstrate similar neurocognitive consequences. For example, many of the long-term and late effects of childhood cancers and their treatment are similar to the neurocognitive and psychosocial effects experienced by those with sickle cell disease, HIV/AIDS, epilepsy, poorly controlled diabetes, and other chronic childhood illnesses. We may also be able to learn through comparative studies of children treated for cancers and those who experience more acute events that lead to long-term consequences, such as experienced by victims of traumatic brain injury and stroke.

**The Traditionalist Hurdle**

We must also be careful not to become so strongly rooted in tradition and comfortable with existing paradigms that we fail to ask what we might still be able to do better. For example, although we must continue to conduct research looking at how to address the late effects in our existing populations, we cannot be satisfied with accepting these late effects as given outcomes. We must continue to conduct research focused on reducing or eliminating late effects of treatment. This may include educational/neurocognitive interventions, psychomotor therapies (e.g., physical or occupational therapy), and/or pharmacological treatments (including examinations of possible additive, combinative, or reductive effects of traditional medications as well as of experimental, complementary, and alternative therapies). In investigating these areas it will also be important to consider the timing of the interventions and whether or not we can define specific windows of opportunity at which targeted interventions may have the strongest influence on outcomes.

With respect to psychosocial research, we must not only consider the neurocognitive effects of treatment, but also issues related to quality of life, social interactions, and behavioral functioning. We must seek to identify better means of measurement for these constructs, but also better (and different) means of creating therapeutic change for them. Costs of providing psychological services in a managed care era where mental health needs are inadequately covered leaves us needing to develop innovative and more cost effective means of service delivery. We must consider and test models based on technologically driven and delivered services through use of the Internet, videos, print, and other media. We must also consider and test the therapeutic value of models of group intervention in settings such as camps and other recreational/educational programs, school-based programs, hospital-based programs, and community-based programs. We can, again, partner with organizations and existing programs in helping to accomplish these goals, as well as with large umbrella groups, such as the Children's Oncology Camping Association and the National Association of School Psychologists. Again, we must be willing to think outside of our traditional models and paradigms toward other potentially valuable, and
possibly more cost effective, ways of promoting positive change in the lives of childhood cancer survivors.

The Policy and Bureaucracy Hurdle
From personal experience, some of the most challenging policy-based and bureaucratic hurdles (beyond the initial questions of access to appropriate medical and psychosocial care) occur in the arena of academic/career outcomes. We must challenge traditional systems to recognize not only the special needs of childhood cancer survivors, but also the special strengths these children can offer. These may include, for example, strengths in such areas as creativity, oral language abilities, logic and problem-solving abilities, and applied social skills. Additionally, we must help better identify ways in which these strengths can be accentuated through academic and occupational settings. As noted by Armstrong and Reaman, “Psychological testing has traditionally been considered a function of the schools and has thus not been covered by many insurance programs” (p. 89–97). This often leads families who are already facing great financial hardship to depend upon services offered through the public school system. However, there is a lack of appropriate understanding/training of the special neurocognitive considerations these children face, and as a result, inadequate assessment and intervention often follow. We must “educate the educators” and be advocates to the schools and educational policymakers to help them understand that it is inappropriate to attempt to package the needs of these children into strict templates, formulas, and discrepancy models, and to guide them in better understanding how to most appropriately assess and educate these children.

The Transitions Hurdle
Existing systems are inadequate in providing systematic and appropriate support from diagnosis through long-term follow-up, particularly as childhood cancer survivors become young adults. Research focused on improving (or in many cases creating) comprehensive transition services for these young adults is much needed. These services should include not only medical and psychosocial care, but also educational and career planning. Additionally in this area, better research and continued support of families who have lost a child to cancer are needed. Currently, services for these families are not consistently available, nor are they of consistent quality when they are available. Large, collaborative, prospective studies to develop better ways of addressing the needs of these families are also much needed, yet often forgotten.

The Funding Hurdle
In order to conduct large, multicenter, multinational, transdisciplinary research, funding must be made available. If we are to make this happen, we must engage in better advocacy for improved funding of psycho-oncology research. We must also forge partnerships and collaborations with other organizations and institutions as identified above, thus better promoting the common goals we are all working toward.

The Dissemination Hurdle
Finally, all of the work we do through collaborative research efforts is of little consequence if we are unable to disseminate the information we learn in effective and widely available ways. Translational research—taking the science from the lab into the community—is vital if we are going to truly be able to improve the lives of childhood cancer survivors and their families. It is not only important for us to share what we learn with other professionals through professional publications, conferences, and media, but it is also imperative that we make this information available in a publicly accessible way so that it reaches the childhood cancer survivors and their families directly. Through these efforts we can better ensure that best practices are put into place and that these are more accessible to a greater proportion of this population.

Conclusions
We've come quite far in creating infrastructures that support collaboration—among researchers, among disciplines, among institutions, and even among people on different continents. Still, there is much work to be done. We have many hurdles to traverse, but we are in a better position to do that today because of the dedication and foresight of medical and psychosocial researchers who have been building foundations of support. I look forward to being part of this journey in the years to come.

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