Commentary: Contexts and Challenges in Pediatric Psychosocial Oncology Research: Chasing Moving Targets and Embracing “Good News” Outcomes

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Pediatric oncology provided one of the most impressive medical success stories of the latter half of the twentieth century. As recently as the mid-1960s, malignant diseases such as acute lymphocytic leukemia (ALL) were still almost universally fatal. For the parents of a child diagnosed with ALL, doctors could offer little more than palliative measures, and the tragic end often came quickly. By the early 1990s, an initial remission was obtainable for virtually all children with ALL, who now had a 75–80% chance of long-term survival. As we follow this story, we can only marvel, applaud, and be thankful. This incredible progress was achieved through a focused national effort and through the establishment of cooperative groups that allowed for treating nearly all children with cancer via large-scale clinical trials. Someone entering the field today might have a hard time appreciating just how rapid and dramatic such progress has been and, although survival rates have plateaued somewhat, how new approaches to resistant disease and significant advances in supportive care continue to be made.

The rapidity of these medical advances, as wonderful as they are, have posed a challenge for the psychosocial researchers in this arena—namely, that of just keeping up. Our work is yoked to that of our medical colleagues, and, like it or not, we follow. However proactive we may wish to be, rarely are we in the position of setting the agenda. In truth, our primary recourse is to hitch our research wagons to the shooting star of the prevailing medical advances and follow where it leads. To do so is not easy. Psychosocial research takes time to develop, and having a moving target does not help. From this perspective, the accomplishments reviewed by Patenaude and Kupst (2005) and Kazak (2005) are all the more impressive. It is a testament to the alacrity, creativity, and adaptability of the early researchers in this area, one perhaps augmented by the occasional good luck of being in the right place at the right time. These two papers aptly review the brief history of pediatric psycho-oncology to date, the advances that have been made, the methodological obstacles that have been faced, and the challenges now on the horizon for future investigators. What perhaps is not fully appreciated is the context in which this work has taken place. In this paper, I add my impression to some of the contexts behind this history, not the least of which has been the challenge of chasing a rapidly moving target. This impression may be best illustrated by a once-common problem that was not addressed at length in either review: nausea and vomiting (NV).

Today, when someone new to the field walks through a medicine room full of children receiving chemotherapy, they may fail to be impressed by the relative calm and by the absence of distress. Yet, over a decade ago, the sounds of retching were ubiquitous and accompanied by an unmistakable odor. The gallows humor of the day was all about vomit; “puke jokes” were in. The antiemetics at the time were not effective, and NV were a source of much suffering. This was clearly an area for psychology to make a significant contribution.

When I began as a postdoctoral fellow, I worked on a study for Lonnie Zeltzer and Sam LeBaron, comparing hypnotic and nonhypnotic behavioral interventions for NV. Another mentor at that time, Michael Dolgin, was working on identifying correlates of anticipatory NV, such as motion sickness or sensitivity to odors. Likewise, when I began at St. Jude, this area was the primary research focus of my colleague Vida Tyc. Behavioral study of the problems of NV was indeed at the forefront of psycho-oncology research. Then, in the early 1990s,
problem? Not necessarily. But it does raise legitimate questions regarding the limits, if any, of our follow-up, and it may require us to seek consultants from outside of pediatric psychology. We will eventually have to address some boundaries in this process as well as question whether this is still our domain or whether it would be better served by others. This issue is one for our medical colleagues as well, as there has been some discussion that it may call for the development of a new subspecialist, one who has training in pediatric and adult oncology. This is an issue that may also promote a natural collaboration between pediatric and adult psycho-oncology researchers.

A related issue, one viewed from the perspective of the scientist–practitioner model, is that the problems of long-term survivors are not those that we typically address in our clinical work, save for neurocognitive issues. The majority of clinic referrals and consultations involve patients on active therapy. Survivors more than a couple of years beyond completion of treatment infrequently return to our cancer centers. Our contact with the long-term survivor population is maintained primarily through research. Again, this is not necessarily a problem, but it is a context that should be appreciated. Research in this area is not driven by a recognition of the problems we see in our clinic every day; rather, research brings to our attention a number of issues of which we might have been otherwise unaware. To some extent, research with survivors is about finding problems rather than responding to those who are brought to us.

Both reviews indicate that, as a whole, children with cancer adjust very well and that only a small percentage experience difficulties that approach pathological levels. This is good news, but it is news that researchers in the area have been reluctant to fully embrace. Rather, we have had an understandable tendency to question whether we are missing something. Thus, both Kazak and Patenaude/Kupst suggest that traditional measures of psychopathology may fail to capture the unique difficulties of children with cancer. However, when specific, alternative measures are used, children with cancer continue to look exceptionally well. The most commonly cited example of an alternative measurement approach involves assessment of posttraumatic stress symptomatology (PTSS). Yet, studies of PTSS in children with cancer consistently point to low levels of difficulties, typically no higher than those seen in the general population (e.g., Kazak et al., 1997). The same is not true when we study the parents of these children, particularly mothers, who show elevated levels of distress in a number of domains. But when the focus is on the child
patient, we have yet to find the instrument that documents a high level of adjustment difficulties, at least as far self-report measures are concerned. We will, of course, continue to look, and new instruments will undoubtedly be developed; but thus far, the “good news” holds the day.

One of the alternative assessment approaches suggested by Patenaude and Kupst involves a return to qualitative measures and to mixed, qualitative–quantitative methods that provide in-depth observation of the experiences of the cancer patient and family. To this I say, Amen! Unfortunately, few of us have had adequate training or experience with qualitative methods, and this scenario will need to be corrected. Graduate training in psychology remains firmly entrenched in quantitative methodologies and generally skeptical of qualitative approaches. This context may call for consultation with our colleagues in sociology, anthropology, and nursing. Patenaude and Kupst review some important early contributions to pediatric psycho-oncology that used qualitative methods. Here, there is a notable omission that I feel compelled to mention: the work of Bluebond-Langner (1978). Her observations of life on a pediatric cancer ward in the early days, when few survived, make for some of the most compelling reading ever produced in pediatric oncology and would serve as a model, perhaps an inspiration, for those considering incorporating qualitative methods into their work.

The positive adjustment of children with cancer poses another challenge for those interested in doing intervention research. To begin with, one might pose the question: If kids with cancer are doing so well, why do we need to intervene at all? No matter how we might answer, we cannot deny the question’s legitimacy. Kazak’s suggested framework of universal, selected, and targeted interventions provides a logical and helpful starting point. Likewise, her assertion is quite convincing that interventions should be framed to promote competence rather than reduce pathology. Nevertheless, there is a real sense in her paper that we are stretching to find targets with whom to intervene. Time and again, we hear the qualifiers “small subset of patients,” “most relevant subgroup in need of intervention,” and so forth. In light of Patenaude and Kupst’s discussion regarding the problem of small sample size in pediatric oncology research, targeting interventions to the small subsets most in need becomes even more problematic. Even the largest institutions are unlikely to provide sufficient numbers, so multi-institutional studies become obligatory. But whether an adequate sample size can be obtained begs the question of whether the intervention is really needed in the first place.

Kazak suggests that “the challenge in this area is the development of creative tools to document clinically relevant change in subclinical distress [italics mine] associated with cancer and its treatment.” What a challenge! Although one can always document statistically significant change in subclinical distress if the sample size is large enough, it is not clear whether it is even possible to document clinically significant change in a situation where a clinical-level problem does not exist. That is a stretch. Certainly, we strive to be creative, but in some instances it appears that the increased demands for creativity imply a diminished need for intervention in absolute terms. Pragmatically, even if one is successful in documenting a significant change in these circumstances, will the clinical imperative remain when the research ends? That is, will the intervention continue to be provided after the study is over? Will third-party payors be persuaded to reimburse for such treatments? Unfortunately, these questions must be asked, as they reflect on the ultimate relevance of our intervention research.

I hope that the preceding will not be taken as a general indictment of intervention research in pediatric oncology settings. On the contrary, intervention research is needed within a number of areas. For instance, I am currently conducting trials of interventions designed to reduce distress in children undergoing stem-cell transplant and have been involved in several trials of problem-solving interventions for mothers of newly diagnosed patients (by necessity, all of these are multisite studies). So, I can hardly suggest that there is no room for intervention work. My point is that we should not try too hard to look for opportunities to intervene for the sake of intervention in the absence of a clearly documented need. We should not have to struggle to find targets for intervention; they should be screaming out, demanding our attention. In the present zeitgeist, researchers in our area are feeling a pressure to do intervention research. Of course, funding agencies are more easily persuaded by intervention studies. But I believe much of this pressure is in response to our oft-repeated self-criticism that the majority of research in this area has been descriptive and correlational with only a small number of published interventions (e.g., Kazak, 2002). This situation is exacerbated by the well-known tendency for psychologists to be hard on one another (including ourselves). Thus, we beat ourselves up for this imbalance, and in the process, devalue the descriptive/correlational or survey research (these have become almost pejorative terms), while elevating intervention studies to something akin to the Holy Grail. However, a fair reading of the literature
suggests a limited number of areas in pediatric oncology where intervention is clearly needed. The ratio of correlation:intervention studies, though imbalanced, may not be that far out of line. Moreover, there is still important descriptive and correlational work to be done, a topic to which I now turn, concluding with what I see as a promising direction for the field in the coming years.

The excellent global adjustment of children with cancer may limit the need for some types of intervention research, but it opens a door for further inquiry into the nature and mechanisms by which these positive adjustment outcomes are achieved despite such significant stressors. This issue was not addressed at length in the reviews. It is not just that children with cancer do well but that, according to many studies, they do exceptionally well, functioning better than healthy peer comparisons. This finding is curious yet most remarkable. Just as curious is the fact that many investigators who report these findings seem to ignore them. Perhaps we are less inclined to highlight the positive outcomes, since funding agencies are more impressed by problems in need of fixing than they are with children who are coping with illness in a “superhealthy” manner. As a result, we have a number of studies examining the determinants of depression in children with cancer that neglect to mention that there is little or no depression to predict. On the other hand, a smaller number of investigators have acknowledged the positive outcomes more directly but have tried to explain them away as reflecting the inadequacy of the outcome measures or as a function of denial, avoidance, or repressive coping. The assumption is that the positive outcomes cannot be “real” but are made in error or are reflective of some type of illusion. I confess that I had fallen in the latter category.

Our attempt to understand the exceptionally good functioning of children with cancer has led to the adaptive style paradigm and to our studies documenting the high levels of a “represive adaptive style” in this population. But is represive adaptation really adaptive? I certainly did not think so at the outset of this work. There had to be something unhealthy to this repressive coping style in children, perhaps a “dark side.” There had to be a price to pay for such conspicuous well-being and avoidance of distress, perhaps in the physical domain, as has been shown in numerous studies of adult repressors.

Well, if there is a price to pay, we have yet to find it. Our efforts are ongoing, but I find myself beginning to reframe the question. It looks quite different from the perspective of positive psychology, and when you start with the assumption that our studies show these kids doing so well because they are doing so well. In a recent review that focused on bereavement, Bonanno (2004) reported that, contrary to widely held assumptions, the majority of bereaved persons show minimal levels of disturbance, which does not imply delayed grief or any other maladaptive response patterns. He labeled these individuals as resilient and indicated that resilience is the rule rather than the exception. Moreover, he suggested that people take multiple pathways to resilience (one of which is ‘represive coping’, a unique perspective on this construct). This model can be readily applied to the child with cancer.

We are ostensibly in the era of positive psychology. If so, then let us embrace the findings of low levels of distress in children with cancer, not run from them. Let us not fear that the observations of high functioning and low pathology will make funding our research more difficult. We still have an enigma to explain: Children facing a life-threatening, catastrophic illness with readily described multiple stressors are coping extraordinarily well, and we really know very little about how they do it. Understanding the pathways to resilience in children with cancer is an exciting prospect, and the potential significance extends well beyond cancer. If we can communicate our enthusiasm for this issue, funding agencies will listen. This issue comprises a potential mother lode of interesting research questions. Constructs providing potential starting points include optimism, hardiness, stress resistance, hopefulness, and repressive adaptation. Do children with cancer differ from healthy children on these variables? If so, how do these differences arise, and what are the mechanisms by which these traits lead to positive outcomes? Our studies will need to include measures of positive affect, both as an outcome and as a potential mediator of traditional outcomes. We are just beginning to scratch the surface, and the questions and opportunities for study are numerous. If I were a new researcher coming to this area, I would not be discouraged because the surprisingly positive adjustment of children with cancer reduces opportunity for intervention research. Opportunities for intervention are still plentiful, but exciting opportunities are also available for research examining the mechanisms and pathways to these positive outcomes. So choose your target and have at it, but be prepared for change.

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References


