

# Commentary: The Psychological Impact of Pediatric Cancer Hardiness, the Exception or the Rule?<sup>a</sup>

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This commentary was written as a result of our participation in the Symposium on the Psychosocial and Neurocognitive Consequences of Childhood Cancer in honor of our colleague, Raymond Mulhern, who was a major leader in the field. The commentary has two purposes: (a) to briefly review research findings regarding psychosocial functioning of children and adolescents with cancer and other severe chronic illnesses; and (b) to propose a theoretical rationale that could account for an increasingly compelling and consistent body of research that consistently does NOT identify psychopathology or dysfunction in these children despite exposure to major challenges and trauma.

Since much of our research (R.B.N./M.J.K.) has already been published, we simply wanted to refer to the studies whose results suggest that most children with cancer adapt well in comparison to normative data; we have reported similar findings for other medical conditions such as sickle cell disease (Noll et al., 1996; Noll, Reiter-Purtill, Vannatta, Gerhardt, & Short, 2007), juvenile rheumatoid arthritis (Noll et al., 2000), and hemophilia (Trzepacz, Vannatta, Davies, Stehbins, & Noll, 2003). We also found this to be true in our longitudinal follow-up studies of these children and families (Bingen et al., 2004; Gartstein, Vannatta, & Noll, 2000; Kupst & Schulman, 1988; Kupst et al., 1995, 2002; Reiter-Purtill, 2004; Reiter-Purtill, Gerhardt, Vannatta, Passo, & Noll, 2003a; Verrill, Schafer, Vannatta, & Noll, 2000).

We do not minimize the multitude of challenges facing children with pediatric cancers or other severe chronic conditions of children. Despite the obvious challenges and trauma, the prevalence of psychosocial dysfunction (i.e., psychopathology or social dysfunction) is similar to that found in the general population or appropriate comparison groups, such as age and gender

matched peers (Gartstein et al., 2000; Noll, Ris, Davies, Bukowski, & Kootz, 1992; Noll et al., 1999; Reiter-Purtill, Vannatta, Gerhardt, Correll, & Noll, 2003b; Verrill et al., 2000). We have found that many other studies supported these findings; either low levels of significant problems or levels similar to controls or comparisons (see reviews: Eiser, Hill, & Vance, 2000; Grootenhuis & Last, 1997; Marsland, Ewing, & Thompson, 2006; Reiter & Noll, 2003; Stam, Grootenhuis, & Last, 2001).

In addition, more recent results, presented by many of the authors in this special issue (Phipps, in press) support these findings (Table I). Our table is not all inclusive—for that readers should consult the reviews listed earlier. We sought studies that included prevalence figures, but where these did not exist; we selected studies that allowed comparison with comparison groups or normative data.

Cancer survivorship research has increasingly suggested that cancer survivors exhibit remarkable psychological resilience despite multiple challenges (Phipps, 2006; Robison et al., 2005; Rowland & Baker, 2005). Why would this be?

We propose that these data suggest **HARDINESS** in children and adolescents with cancer. Our clinical observations of children and adolescents at the time of diagnosis have not suggested a period of time where psychopathology or social dysfunction typically occurs, unless the child is feeling physically ill.<sup>1</sup> The term

<sup>1</sup>We believe making a diagnosis of depressive disorder or anxiety disorder (American Psychiatric Association, 1994) in a child who is physically sick and hospitalized is an exceptionally challenging enterprise even for the most experienced behavioral health specialist. We acknowledge that the diagnostic criteria may be met (i.e., anhedonia, fatigue, loss of appetite, etc.), but question the labeling of psychopathology during this timeframe. This speaks to a broader issue with the nosology of DSM-IV (see McHugh, 2005).

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**Table 1.** Psychosocial Functioning – Pediatric Cancer Patients: Adjustment and Social Competence

Study	Sample	Comparison	Prevalence of Problems	No Difference <sup>a</sup>
Brown et al. (1992)	Cancer (N = 55) R <sup>b</sup> = 2–17	Norms	Minimal psychopathology according to self, parent and teacher reports; 5.5% met criteria for DSM-III-R diagnoses	X
Gray et al. (1992)	Survivors (N = 62) R = 18–37	Non-chronically ill (N = 51)	No difference in self-reported emotional or behavior problems, self-esteem; survivors report more positive affect and less negative affect as well as more perceived control in life experiences; survivors report less satisfaction with personal relationships	X
Anholt et al. (1993)	Survivors (N = 62) R = 6–18	Non-chronically ill (N = 120)	No difference in global self-concept; more positive self-perceptions of their intellectual status, behavior and happiness-satisfaction	X
Carpentieri et al. (1993)	Brain tumor survivors (N = 40) R = 4–16	Non-CNS cancer survivors (N = 40); Norms	51% of survivors and 49% of comparisons with elevations in one or more CBCL scales; relative to comparisons, parents report less social competence for survivors, but also less internalizing problems	X
Olson et al. (1993)	Survivors (N = 20) R = 6–16	Non-chronically ill (n = 40)	No self-reported differences in self-esteem, social skills, and perceived control over health; survivors had lower social competence according to parents and teachers; more behavior problems according to parents	X
Madan-Swain et al. (1994)	Survivors (N = 25) R = 12–18	Non-chronically ill (N = 16)	No difference in self-report of social competence or overall coping or in teacher report of internalizing and externalizing behaviors; more self-reported body image concerns	X
Sloper et al. (1994)	Survivors (N = 31) R = 9–18	Non-chronically ill (N = 31)	No group differences in self-reported anxiety or self-esteem; teachers report lower scores in academics and peer popularity; teachers and parents report greater behavioral difficulties	X
Radcliffe et al. (1996)	Brain tumor survivors (N = 38) R = 6–18	Norms	Less anxious and depressed than norms according to self-report and no group difference in global self-worth; lower mother reported social competence and more social problems; no differences in behavior or social problems according to teachers	X
Phipps & Srivastava (1997)	Cancer (N = 107) R = 7–16	Non-chronically ill (N = 442)	Lower on self-reported depressive symptoms and anxiety, but higher on defensiveness than comparisons	X
Elkin et al. (1997)	Survivors (N = 161) R = 14–30	Norms	Lower levels of psychological distress than norms	X

Continued

Table I. Continued

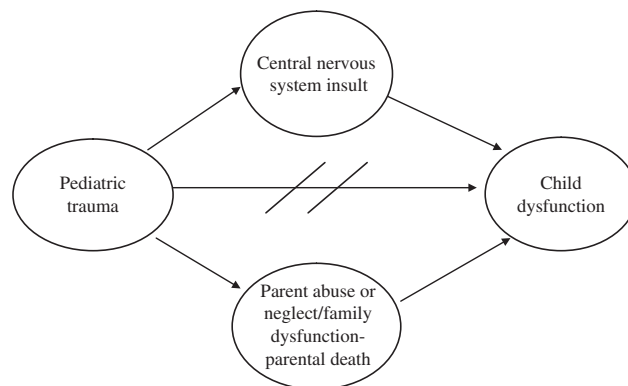
Study	Sample	Comparison	Prevalence of Problems	No Difference <sup>a</sup>
Zeltzer et al. (1997)	Survivors (N = 580) R = 18–33	Siblings (N = 396)	More self-reported mood disturbance (greater negative mood, and more tension, depression, anger and confusion) than sibling controls but not in the psychiatric range	
Boman & Bodegard (2000)	Survivors (N = 30) R = 18–29	None	Semi-structured interviews indicated 27% of survivors had poor coping; 40% good coping	
Sawyer et al. (2000)	Survivors (N = 39) R = 6–16 at 4 year follow-up	Non-chronically ill (N = 49)	Higher parent reported internalizing problems at diagnosis, but no differences at later measurement occasions	X
Mackie et al. (2000)	Survivors (N = 102) R = 19–30	Non-chronically ill (N = 102)	No differences for DSM-IV disorders but more self-reported difficulties with romantic relationships, friendships, social contacts, and coping	X
Maggiolini et al. (2000)	Survivors (N = 70) R = 12–20	Non-chronically ill (N = 70)	Survivors report more positive self-concept in several domains (psychologic, social, family, and coping); greater emotional stability relative to comparisons	X
Zebrack et al. (2002)	Survivors (N = 5736) R = 18–48	Siblings N = 2565	Survivors report more depressive symptoms and somatic symptoms than siblings; DSM-IV disorders not significantly different from population rates	X
<b>Post-traumatic Stress Disorder (PTSD) and Symptoms (PTSS)</b>				
Stuber et al. (1996)	Survivors (N = 64) R = 7–19	None	12.5% met criteria for PTSD	
Butler et al. (1996)	Cancer (n = 30) and Survivors (n = 42) R = 3–16	Epidemiological Norms	21% met criteria for PTSD according to parent report; relative to the general population, slightly greater incidence of PTSD during treatment, but no difference for survivors	X
Barakat et al. (1997)	Survivors (N = 309) R = 8–20	Non-chronically ill (N = 219)	No group differences in self-reported PTSD and most anxiety sub-scales	X
Kazak et al. (1997)	Survivors (N = 130) R = 8–20	Non-chronically ill (N = 155)	No group differences in self-reported PTSS; 1.6% survivors in severe PTSS range (1.4% for comparisons); 12.6% survivors in moderate PTSS range (14% for comparisons)	X
Erickson & Steiner (2000)	Survivors (N = 40) R = 12–35	None	Interviews indicate 10% met full criteria for PTSD; 78% met partial criteria	
Hobbie et al. (2000)	Survivors (N = 78) R = 18–40	Norms	20.5% met criteria for PTSD; significantly greater self-reported anxiety relative to norms	
Meeske et al. (2001)	Survivors (N = 51) R = 18–37	Norms	22% met full criteria for PTSD and these survivors experienced poorer quality of life and clinically elevated levels of psychological distress relative to survivors without PTSD who were similar to normative values	
Phipps et al. (2006)	Cancer (n = 81) and Survivors (n = 40) R = 7–17 Adult Survivors (n = 41) R = 18 and older		14.3% met criteria for PTSD	

<sup>a</sup>No difference from comparison group or norms<sup>b</sup>R = age range in years

resilience suggests a bouncing back after a period of time where psychological functioning is impaired. Especially for children and adolescents, we do not believe this occurs. We recognize the intense impact for children, parents, and treatment teams when a child is diagnosed; however, our focus is on the lack of psychopathology or social dysfunction. We believe that the cancer experience may have a subclinical impact on multiple domains of a child's life and can change developmental trajectories. Regardless, this is NOT the focus of this work. Given the extreme challenges, stressors, and trauma, posed to children and their families by the diagnosis of cancer (and other devastating diseases of childhood such as sickle cell), our focus is on outlining a theory to account for the lack of data demonstrating overt psychological dysfunction.

We suggest that the remarkable lack of social dysfunction and overt psychopathology in the face of cancer's challenges is a logical human response when the lens utilized to understand behavior uses an evolutionary viewpoint (Buss, 1995). We will present the framework for a comprehensive Human Evolutionary Response to Trauma/Stress (HEART) to examine human responses to randomly occurring traumatic or stressful life events in pediatric behavioral health, not pediatric psychology (Fig. 1). Our word choice, behavioral health, reflects our desire to present this model independent of professional guilds (American Psychological/Psychiatric Associations, American Medical Association, nursing, social work, etc.)—an evolutionary model for understanding children's responses to randomly occurring traumatic life events. Our theoretical model has the potential to extend outside of the realm of pediatrics or psychology and into broader settings where children face challenges. While the primary focus of our article has been pediatric cancer, the conceptual model we present encompasses any randomly occurring pediatric medical problem, even when the disease occurs in populations of children with fewer resources (i.e., sickle cell disease). In addition, we posit that the decision making of children and adolescents that is commonly associated with poor judgment, bad choices, and elevated risk taking behavior, may provide additional protection (Geary & Bjorklund, 2000). Finally, we will focus on the role of coping (broadly conceptualized as behavioral or pharmacological) and empirically supported therapies within this evolutionary framework.

One important aspect of our theory is an emphasis on randomness and traumatic. We are not using the word random in a statistical sense; we selected this word



**Figure 1.** Human evolutionary response to trauma/stress (HEART).

to emphasize that we are exclusively focusing on events that occur in the lives of children that are not a result of parental neglect or pathology, or a result of a child's personality or behavior. Cancer, sickle cell, and rheumatoid arthritis, occur in ways that are not related to previous psychological or familial functioning. Bad things can randomly happen to very good people. In addition to our focus on randomness, these pediatric conditions are considered challenging, even traumatic, by a vast majority of people. Divorce, or the break up of a family, is often considered stressful or challenging, but in the right circumstances it can be viewed as being a stress relieving event. It is very difficult to find a life circumstance where the occurrence of pediatric cancer, or repeated pain crises occurring in a child with sickle cell disease, is viewed as a stress relieving event. Two fundamental advantages to the utilization of an evolutionary perspective to understand human responses to trauma/stress are: (a) the evolutionary perspective cuts across disciplines of behavioral health; and (b) this framework provides the opportunity to create testable hypotheses. The evolutionary perspective for examination of the emergence of stranger anxiety in infants provides an example of how the evolutionary lens cuts across disciplines. The emergence of these behaviors in infants can be examined from the perspective of cognitive, developmental, clinical, family, neuroscience, or social systems theory. An evolutionary model of human response to stress/trauma will hopefully bring a scientific behavioral health perspective to this issue across disciplines (i.e., psychiatry, pediatrics, neuroscience, psychology, social work, and sociology) and within the science of psychology. We present this model with a clear expectation that this perspective will promulgate the advancement of behavioral health science by allowing research to examine testable hypotheses focusing on the impact of traumatic life events on children.

Pediatric behavioral health has an unfortunate history of providing theoretical models that are extremely challenging to test (Holmbeck, 1997). We are hopeful that our HEART model for understanding the impact of traumatic life events will foster research that empirically examines our theory.

HEART is based upon our desire to construct a theory that is congruent with findings from the pediatric oncology and broader pediatric behavioral health literatures suggesting hardiness in children during and subsequent to exposure to devastating pediatric events (Bonanno, 2004). We welcome continued debate in the behavioral health literatures about the impact of these types of events on subclinical domains of functioning, but our focus is on overt psychopathology and/or dysfunction. Why don't these overwhelming medical events lead to overt psychopathology and dysfunction for children, even children from families with fewer fiscal resources as is often the case for children with sickle cell disease?

We posit that the pathway between exposure to a random traumatic medical event(s) and dysfunction does not occur unless the trauma involves the child's central nervous system (i.e., brain tumors, closed head injury, and neurofibromatosis) or if the trauma for the child is directly related to their family (i.e., death of parent(s), abuse, or neglect) (Fig. 1). We posit that trauma or insults that occur to the central nervous system disrupt functioning as a result of biologic vulnerability, rather than psychological reactions or responses (Ross et al., 2003). This article will focus on the application of general evolutionary theory to pediatric behavioral health for trauma/stress that does not have primary brain involvement or significant family disruption or dysfunction. Our model would predict no increased prevalence of dysfunction for children with chronic illness not involving their central nervous system compared to appropriate community comparison children.

General evolutionary theory (Darwin, 1859) is widely regarded by biologists as an established theory that guides the broad field of biology. The basic assumption underlying this theory is that evolution has occurred as a result of natural selection. Contemporary writers discuss evolution by natural selection as a theory to understand the mechanisms underlying the reasons for behavior in all animal species, including humans. From this perspective, human behavior is examined from the perspective of how does the behavior ensure survival of the individual and species? When a behavior regularly occurs, "How does it maximize the adaptation of the individual and the species? What is the function of the behavior?"

Humans are living fossils. From an evolutionary perspective, our understanding of behavior within our sheltered 21st century habitats misses the context where we are biologically adapted to thrive. Humans are biologically fit to flourish in small groups (Barkow, 1989). Given our relative lack of strength, modest endurance, speed, vision, smell, hearing, and so on, our survival has depended upon social bonds and strong community responses to threats (c.f., McHenry, 1994). Contemporary changes over the past 10,000 years would be expected to have very little impact on the biology that drives inclusive fitness. Within an environment where random trauma are rather likely to occur in the form of a random lion attack, unexpected adverse weather, or a host of events that might cause physical and emotional challenges, what mechanism(s) might maximize the opportunity for survival subsequent to exposure?

We posit that the "symptoms" of post-traumatic stress might be expected to maximize fit, as exposure to the trauma causes a series of reactions that include increased alertness, vigilance, and remaining closer to trusted significant others. We suggest that increased vigilance, alertness, and awareness of environmental cues that a repeat trauma might occur are excellent mechanisms to ensure survival. We also wonder about the adaptation of the child who does not manifest symptoms of post-traumatic stress after exposure to trauma. Within our model, the adjustment of a child with no symptoms may be concerning. In sharp contrast, social isolation, depression, excessive anxiety, hopelessness, chronic pessimism, withdrawal, etc. do not seem to be responses that would maximize fit or inclusiveness. What would be the natural function of such behavior? Our model would predict that children exposed to the challenges of cancer (or sickle cell) would demonstrate increased rates of symptoms of post-traumatic stress, but no changes in rates of dysfunction related to these distressing life events (i.e., no increased rates of post-traumatic stress disorder).

Our model would predict that the response of a child or adolescent to random challenges is withdrawal to primary attachment figures (proximity seeking, clinging) and increased vigilance directly related to potential repeated physical threats. While an observed response is typically seen to actual or perceived physical threats (i.e., IVs, lumbar punctures, and port access), new clinicians are often startled by the responses of children or adolescents to the news of a diagnosis of cancer. A common reaction of a school-aged child or adolescent is a lack of interest, no reaction, concern about missing school, or becoming upset when they see how upset their

parents have become. Children and adolescents focus on the here and now.

This short sightedness can be a significant liability. Considerable literature strongly demonstrates that while adolescence should be a time of relatively high physical safety and low probability of death, the lack of foresight by adolescents coupled with decreased parental monitoring results in a host of significant problems including tobacco use, alcohol use and abuse, unprotected sexual behaviors resulting in over 4800 new cases of HIV/AIDS each year, unhealthy diet, etc. (Danice et al., 2006). The leading causes of death among youth aged 10–24 years are unintentional injuries, suicide, motor vehicle crashes, and homicide. Dramatic changes are seen for adults aged 25 and above, where primary causes of death are cancer and cardiovascular disease (Danice et al., 2006). The focus on the present and difficulty providing appropriate weight to long range consequences of behavior results in a myriad of problems. While the risk taking behaviors of adolescents and parental acquiesce are rational within an evolutionary framework (it is the ideal time to propagate), the decision making of adolescents within contemporary society results in a host of problems (Reyna & Farley, 2006). We posit that cognitive immaturity has an adaptive role when children or adolescents must face the challenges of random trauma or stressors (Geary & Bjorklund, 2000).

Given the broad parameters of our evolutionary model, are children growing up today who live in more disadvantaged economic circumstances and are also exposed to random trauma (i.e., sickle cell disease) at higher risk to become dysfunctional? We note that except for a very small group of children in the US, disadvantage does not include exposure to chronic hunger or lack of shelter. Lack of these basic resources would be expected to increase reproductive risk; however, few children in the US face this extreme lack of resources. Our model would predict that children from disadvantaged environments in the US are not at higher risk to become dysfunctional, when exposed to these random medical trauma compared to other children living in similar conditions (Noll et al., 2007).

Finally, we posit a key role for behavioral therapies or medications within our model. An evolutionary model includes considerable room for variability in responses, as variation in species responses are expected to lead to a better fit dependent upon contextual factors. For example, Nettle (2006) notes that heritable variation occurs universally for all species. Traits within a species that optimize fit within one context can be a detriment

within another setting. Within this framework, a child who is exposed to the trauma of cancer and temperamentally was more emotionally liable prior to exposure to the challenges of pediatric cancer can be taught specific skills (Weisz, McCarty, & Valeri, 2006) or given medications (Glass, 2004) that would facilitate more adaptive responses. We hypothesize a key role for behavioral or pharmacological interventions, noting the numerous empirically supported treatments are available and fit into this framework (Weisz et al., 2006). It is noteworthy that even with normal variations of a child's temperament that clearly create greater challenges for adjustment when cancer occurs, we could locate no reports of increased rates of psychopathology or social dysfunction for youth with cancer during treatment or as late effects, except brain tumors (Vannatta, Gartstein, Short, & Noll, 1998). The HEART model would predict that even variability of affective responses (i.e., difficult temperament) within the context of the physical and emotional challenges posed by cancer is not associated with greater dysfunction.

Data demonstrating dysfunction for children with central nervous system trauma are consistently reported within the behavioral health literature, ranging from closed head injury (Yeates et al., 2004) to neurofibromatosis (Noll et al., in press) to cancer (Vannatta, Gerhardt, Wells, & Noll, 2007, Zebrack et al., 2004), and so on (Nassau & Drotar, 1997; Wade et al., 2006; Wallander & Thompson, 1995). It is striking how these groups of children are systematically segregated, when research on dysfunction is reported for pediatric health conditions (Table I). Our model would predict that these types of trauma will be associated with more behavioral, emotional, and social dysfunction than physical trauma that does not involve the central nervous system. Specifically our model would predict that, a middle class child exposed to one moderate closed head injury is at higher risk for dysfunction than an inner city child exposed to repeated episodes of severe pain as a result of sickle cell disease, when these children are compared to base rates of dysfunction in their communities.

For pediatric cancers, despite considerable effort across the past 30 years to identify domains of overt dysfunction, a sizeable body of work reports prevalence similar to that in the general pediatric population, or improved functioning (Rowland & Baker, 2005, for a review). Insofar, as family neglect and abuse on the one hand is associated with problematic functioning in children, it seems feasible that these contemporary

responses to pediatric cancer in the US may serve as a buffer. Our model would predict that the strong response from parents and community when a child is diagnosed with cancer may serve a protective function resulting in better functioning and perhaps less dysfunction.

In summary, we have attempted to provide a framework for understanding findings from numerous investigators working in pediatric behavioral health that has remarkably found minimal evidence for increased dysfunction in children when exposed to these exceptionally difficult events. HEART is offered as a lens to understand considerable research over the past 30 years and as a theory that can be empirically tested. Please note that we are not suggesting that all children with cancer or other chronic health conditions that do not involve the central nervous system are free of dysfunction. We are suggesting that the incidence and prevalence of dysfunction among these children is strikingly similar to the rates of difficulty found within the communities where they live. This can be empirically tested. Additionally, our model does not address subclinical changes that are not associated with dysfunction. It is a model to examine the responses of children to overwhelming events and to ask, when a child is diagnosed with cancer, are they risk for increased rates of dysfunction?

We welcome future work that refines, expands, and explores the utility of this theory. Our commentary represents an initial attempt to present a new theoretical framework. Clearly, our theory will require further refinements. HEART has a very circumscribed focus on the lack of overt linkages demonstrated between medical trauma and children's dysfunction. Regardless, we encourage further work that explores linkages between the trauma of childhood chronic illnesses such as cancer and subclinical effects on a host of psychological (i.e., relationship quality, career choices, quality of life, cognitive appraisal mechanisms, etc.) and/or biological (i.e., premature cell death, early health changes/vulnerabilities, etc.) factors. Work examining subclinical effects, especially in subjective domains, should attend to critical methodological factors such as the focusing illusion (Kahneman, Krueger, Schkade, Schwarz, & Stone, 2006; Smith, Schwarz, Roberts, & Ubel, 2006). We hope that our proposed theory improves our understanding of the adaptations of children with challenging health conditions.

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