
Resilience in Youth and Families Living With Pediatric Health and Developmental Conditions: Introduction to the Special Issue on Resilience

Marisa E. Hilliard,¹ PhD, Elizabeth L. McQuaid,² PhD, Laura Nabors,³ PhD, and Korey K. Hood,⁴ PhD

¹Department of Pediatrics, Baylor College of Medicine, ²Bradley/Hasbro Children's Research Center, The Warren Alpert Medical School of Brown University, ³School of Human Services, University of Cincinnati, and ⁴Department of Pediatrics, Stanford University School of Medicine

All correspondence concerning this article should be addressed to Marisa E. Hilliard, PhD, Baylor College of Medicine, 1102 Bates Avenue, Suite 940, Houston, TX 77030, USA. E-mail: marisa.hilliard@bcm.edu

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Abstract

This special issue of the Journal of Pediatric Psychology showcases a growing area of research with a collection of 16 contemporary studies of resilience in youth with chronic medical or developmental conditions and their families. The research reported in this special issue covers a broad range of pediatric populations, including cancer, type 1 diabetes, and chronic pain, among others, ranging in age from early childhood through early adulthood. This introduction to the special issue reviews the various ways the articles' authors conceptualize and define risk and resilience; most analyze protective processes in relation to resilient outcomes, including both achievement of explicitly positive experiences and avoidance of dysfunction or disruption. Challenges with measurement of resilience-related constructs is reviewed. Finally, the special issue editors offer a definition of resilience in the context of pediatric and health psychology.

Key words: adjustment; chronic illness; resilience; risk.

Ann Masten describes youths' achievement of developmental milestones despite exposure to major adversity as not unusual or extraordinary, but rather "ordinary magic" (Masten, 2001). Indeed, a substantial body of developmental psychology research (e.g., Bonanno & Diminich, 2013; Masten, 2011) demonstrates that resilience is the modal outcome trajectory following major stressors or traumatic events. As pediatric psychologists, we too care a great deal about helping our patients and their families use their strengths and capacities to achieve resilience in the face of serious and often chronic challenges. Historically, the field of pediatric psychology has largely—though not exclusively—focused on the important work of characterizing the difficulties associated with living with and managing health conditions in youth and on evaluating deficits and risk factors to identify youth and families in need of reparative

intervention. At the same time, pediatric psychology research has long recognized the processes by which many youth with chronic or acute medical stressors and their families adjust well emotionally and behaviorally, have good health outcomes, and go on to live happy, healthy, productive, and satisfying lives (Hanson, Henggeler, & Burghen, 1987; Stewart, Reid, & Mangham, 1997; Wallander et al., 1989).

Recent Progress and Challenges in Pediatric Psychology Resilience Research

Over the past 15 years, research to identify strengths and protective processes that promote resilience related to pediatric health conditions has been mounting. One indication of this progress is the growing number of studies and publications that address resilience (Haase, 2004; Hilliard, Harris, & Weissberg-Benchell, 2012;

Koinis-Mitchell, Klein Murdock, & McQuaid, 2004; Landolt, Buehlmann, Maag, & Schiestl, 2009; Mullins et al., 2015; Phipps, 2007; Yi-Frazier et al., 2015). Further, conceptualization of how risk and resilience are related in the context of various pediatric health conditions has led to models of resilience within specific populations (e.g., Hilliard et al., 2012; Koinis-Mitchell et al., 2004; Landolt et al., 2009). Common definitions or frameworks that could apply across conditions remain elusive. Thus, while there has been progress, differing conceptualizations have resulted in variations in study design and methods and influence the clinical implications that can be drawn from the growing body of research. In addition, in the absence of appropriate instruments to assess resilience factors or outcomes, different variables (e.g., quality of life, low scores on risk or adverse outcome measures) have been substituted (e.g., Karlson et al., 2012; Landolt et al., 2009). This has advanced knowledge and considerably broadened the scope of resilience, but has also contributed to divergent definitions and difficulty synthesizing findings across studies.

Conclusions and possible clinical implications have depended on each study's working definition of resilience and measurement strategy. For example, strategies for resilience promotion differ if it is conceptualized as a stable personal characteristic or trait compared with adaptive behaviors or strategies that could potentially be modified or enhanced through intervention. A broad range of constructs have been used in previous studies of resilience, and various combinations of self-efficacy, optimism, coping style, religiosity, peer support, social competence, family connectedness, parental support, intellectual capacity, and school attendance, among others, have been identified as components (e.g., Alriksson-Schmidt, Wallander, & Biasini, 2007; Bachanas et al., 2002; Koinis-Mitchell et al., 2012; Yi-Frazier et al., 2015). Each of these constructs is likely relevant to living well with a health or developmental condition; yet, without a unifying theoretical framework, the core concepts of resilience remain unclear. This limits the degree to which clinical interventions can target the essential components of resilience promotion.

To date, the study of resilience in pediatric psychology has captured the multidimensional nature of succeeding in the face of risk, yet the lack of specificity and commonality across studies has limited the precision of the conclusions that can be drawn. To advance this field, a cross-cutting definition of pediatric psychology resilience is needed to permit comparisons across studies and conditions and ultimately to establish a shared understanding of how positive outcomes are achieved in the face of the challenges that accompany pediatric developmental and health conditions.

Current Advances and Approaches to Resilience Research

This special issue of the *Journal of Pediatric Psychology* showcases the growing area of pediatric psychology resilience research with a collection of 16 contemporary studies of resilience in youth with chronic medical or developmental conditions and their families. The studies in this special issue address many of the issues encountered in previous pediatric psychology resilience research, including the challenges of resilience definitions, measurement, and clinical implications. The research reported in this special issue covers a broad range of pediatric populations, with the greatest representation in cancer (Germann et al., 2015; Phipps et al., 2015; Rosenberg et al., 2015; Sharp et al., 2015; Yi, Zebrack, Kim & Cousino, 2015), type 1 diabetes (Kichler & Kaugars, 2015; Lord, Rumburg, & Jaser, 2015; Monaghan, Clary, Stern, Hilliard, & Streisand, 2015; Rohan et al., 2015; Rosenberg et al., 2015), and chronic pain (Cousins, Cohen, & Venable, 2015; Cousins, Kalapurakkel, Cohen, & Simons, 2015; Kalapurakkel, Carpino, Lebel, & Simons, 2015). The age range is also wide, from early childhood (Monaghan et al., 2015; Wade, Madigan, Plamondon, Browne, & Jenkins, 2015) through early adulthood (Rosenberg et al., 2015; Yi et al., 2015). The following pages include systematic and topical reviews reflecting conceptual models of resilience (Cousins, Kalapurakkel, et al., 2015; Van Schoors, Caes, Verhofstadt, Goubert, & Alderfer, 2015), cross-sectional (Cousins, Cohen, et al., 2015; Germann et al., 2015; Kalapurakkel et al., 2015; Koinis-Mitchell et al., 2015; Monaghan et al., 2015; Phipps et al., 2015; Rohan et al., 2015; Sharp et al., 2015; Yi et al., 2015) and prospective (Lennon, Murray, Bechtel, & Holmbeck, 2015; Lord et al., 2015; Rohan et al., 2015; Wade et al., 2015) observational studies, and pilot intervention research (Kichler & Kaugars, 2015; Rosenberg et al., 2015). Clearly, resilience has relevance to all corners of the field of pediatric psychology, and attention to youth and family strengths can enhance all of our work.

The authors of the papers in this special issue conceptualize resilience in various ways, with definitions including resilience as *assets* or *resources* that predict or contribute to good outcomes (e.g., optimism, cohesive family), protective *processes* or adaptive *behaviors* that individuals and families engage in to overcome risk (e.g., acceptance, self-control, supportive communication), or the achievement of good *outcomes* despite exposure to risk and adversity (e.g., good quality of life, high adherence). Similarly, the definition of at-risk populations varies, from inclusive (i.e., all individuals with a particular condition) to specific (i.e., individuals with a health condition plus additional barriers)—either approach can be

appropriate. Most papers in this issue focus their analyses on protective processes in relation to *resilient outcomes*, consistent with the emphasis on adaptive behaviors to overcome risk in the developmental psychology literature (Rutter, 2012). For example, in two studies with youth with cancer, Germann and colleagues (2015) report on the use of hopeful thinking as a mediator between internalizing symptoms and quality of life in youth with newly diagnosed cancer, and Sharp and colleagues (2015) demonstrate that youths' active connectedness with friends and family is related to reduced risk for negative outcomes and greater likelihood of positive outcomes. Reflecting the social-ecological foundations of most resilience models (Mullins et al., 2015), several studies also address protective processes on the family level. For example, Wade and colleagues (2015) report on responsive parenting as a process to buffer the risks to language development associated with relatively low birth weight, and Koinis-Mitchell and colleagues (2015) demonstrate the protection afforded by family routines related to disease management and sleep hygiene in the context of risks experienced by urban children with asthma. Interventions, such as those described by Rosenberg and colleagues (2015) and Kichler and Kaugars (2015) for youth with diabetes and cancer, explicitly focus on enhancing adaptive behavioral skills to promote positive outcomes, such as positive appraisals of stressors, goal-oriented problem-solving, and seeking family and social support.

Several studies in this issue aimed to predict resilient outcomes. In line with the conceptualizations of resilience voiced by Masten (2011), Bonanno and Diminich (2013), and others (Kia-Keating, Dowdy, Morgan, & Noam, 2011; Luthar, 1993), the authors in this special issue selected a range of resilient outcomes, including outcomes that were notably positive or better than a comparison group/condition (e.g., without risk/adversity), that maintained normative trajectories, and/or that represented avoidance of a markedly poor outcome. Achievement of outcomes consistent with those that would be typically observed in the absence of risk/adversity is one essential aspect of resilience. Evaluating and demonstrating achievement of one or more positive outcomes (e.g., high quality of life, posttraumatic growth) is also critically important. Resilient outcomes in these studies include low levels of deficits, maintenance of developmental trajectories, and explicit benefits. For example, Phipps and colleagues (2015) report higher levels of posttraumatic growth and no elevations in posttraumatic stress in parents of youth with cancer compared with controls. Similarly, Monaghan and colleagues (2015) describe associations between young children's behavioral strengths (e.g., self-control, initiative) and resilient parent outcomes including lower distress and higher quality of life. In a longitudinal cohort of youth with spina bifida, Lennon and colleagues

(2015) document trajectories of benefits and deficits across childhood and adolescence compared with typically developing youth.

Measurement of resilience-related constructs is of primary methodological importance, and several authors in this special issue note challenges and gaps in this area. While some constructs have well-developed instruments, such as posttraumatic growth and benefit-finding in cancer, health- or condition-specific measures of positive constructs in other disease areas are by and large lacking. There is a need for psychometrically strong measures that explicitly assess strengths, protective processes, and resilient outcomes in pediatric populations. The studies in this special issue tended to use general measures of protective factors or positive outcomes, and several used observational coding methods. Using a combination of self-report and observation of adolescents' positive affect related to diabetes management, Lord and colleagues (2015) highlight the importance of multisource and multimethod assessment to ensure comprehensive measurement of the various aspects of resilience and protection.

A Definition of Resilience for Pediatric Psychology

The call for this special issue referenced a recent definition of behavioral and health resilience in the context of type 1 diabetes: "... achieving one or more positive outcomes despite exposure to significant risk or adversity" (Hilliard et al., 2012, p. 739). Studies in this issue, such as Rohan and colleagues' (2015) evaluation of various individual and family processes in relation to achieving in-range glycemic control in preadolescents with type 1 diabetes, provide empirical support for this definition. Building on this conceptualization, we propose a cross-cutting definition of resilience for pediatric psychology that expands on the previous definition with the varied components of resilience reflected in the studies in this special issue, which we hope can serve as a foundation for ongoing work in this field: *In the context of pediatric/health psychology, resilience is the demonstration of emotional, behavioral, or health outcomes that match or surpass normative developmental milestones, behavioral functioning, or emotional well-being, despite exposure to the substantial challenges of living with and managing a medical or developmental condition.* These resilient outcomes should first focus on *explicitly positive experiences* or the *maintenance of a typical trajectory*, but could also include the *absence of negative experiences*, such as low levels of distress or dysfunction. For youth with conditions that limit a particular area of functioning (e.g., intellectual/developmental disabilities), the determination of resilient outcomes should be made in comparison with

developmental milestones typical of the population with that condition. Both static factors (i.e., resilience resources or assets) and dynamic processes (i.e., adaptive behaviors or positive interactions) can be protective—that is, can reduce or eliminate the deleterious impact of risk factors. Though protective factors and processes may be unique to particular conditions or groups of people, this definition emphasizes protective processes that are relevant across populations. While this special issue focuses on resilience in children, adolescents, and young adults with medical or developmental conditions, this conceptualization of pediatric resilience likely also applies to health psychology and resilience across the lifespan.

As this special issue shows, resilience-related research is thriving in pediatric psychology and has great potential to guide strengths-based approaches to care. More research is needed to delineate the specific protective factors and processes that most effectively buffer a variety of risks in diverse populations. As this field continues to expand, we encourage an emphasis on protective processes that are potentially modifiable or able to be strengthened via intervention to move this literature even closer to practice. While the conditions that face pediatric patients and their families are relatively uncommon, resilience is not. We are optimistic that an emphasis on resilience in research, practice, and policy will shine a light on and support the “ordinary magic” of our patients and families as they live successfully with complex and demanding pediatric conditions.

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