Journal of Adolescent Health 59 (2016) 716–721

ELSEVIER

JOURNAL OF ADOLESCENT HEALTH

www.jahonline.org

Original article

Comparison of Positive Youth Development for Youth With Chronic Conditions With Healthy Peers

Gary R. Maslow, M.D., M.P.H. [a,b], Sherika N. Hill, Ph.D., M.H.A. [b], and McLean D. Pollock, Ph.D., M.S.W. [b,*]

[a] Department of Pediatrics, Duke University School of Medicine, Durham, North Carolina
[b] Department of Psychiatry and Behavioral Sciences, Duke University, Durham, North Carolina

Article history: Received February 22, 2016; Accepted August 3, 2016
Keywords: Adolescents; Young adults; Childhood-onset chronic condition; Chronic illness; Positive Youth Development

A B S T R A C T

Purpose: Adolescents with childhood-onset chronic condition (COCC) are at increased risk for physical and psychological problems. Despite being at greater risk and having to deal with traumatic experiences and uncertainty, most adolescents with COCC do well across many domains. The Positive Youth Development (PYD) perspective provides a framework for examining thriving in youth and has been useful in understanding positive outcomes for general populations of youth as well as at-risk youth. This study aimed to compare levels of PYD assets between youth with COCC and youth without illness.

Methods: Participants with COCC were recruited from specialty pediatric clinics while healthy participants were recruited from a large pediatric primary care practice. Inclusion criteria for participants included being (1) English speaking, (2) no documented intellectual disability in electronic medical record, and (3) aged between 13 and 18 years during the recruitment period. Univariate and bivariate analyses on key variables were conducted for adolescents with and without COCC. Finally, we performed multivariable linear regressions for PYD and its subdomains.

Results: There were no significant differences between overall PYD or any of the subdomains between the two groups. Multivariable linear regression models showed no statistically significant relationship between chronic condition status and PYD or the subdomains.

Conclusions: The findings from this study support the application of the PYD perspective to this population of youth. The results of this study suggest that approaches shown to benefit healthy youth, could be used to promote positive outcomes for youth with COCC.

IMPLICATIONS AND CONTRIBUTION

While most youth with childhood-onset chronic condition do thrive, they are at increased risk of psychological distress and are known to struggle with educational and vocational transitions. The results of this study suggest that approaches shown to benefit healthy youth could be used to promote positive outcomes for youth with childhood-onset chronic condition.

Approximately 15% of adolescents have some form of childhood-onset chronic condition (COCC), such as cancer, diabetes, seizures, or sickle cell disease [1,2]. This group of adolescents is at increased risk for physical and psychological problems, ranging from symptoms such as pain and fatigue to a twofold to threefold increased risk of depression [3,4]. In addition, adolescents with COCC sometimes struggle with their peer relations, and as they become adults they are at greater risk of low educational attainment and unemployment [5]. Still, even though they are at greater risk and may have to deal with traumatic experiences and uncertainty, the majority of adolescents with COCC do well across many domains. For example, high

Conflicts of Interest: The authors have no conflicts of interest or financial disclosures to report.

* Address correspondence to: McLean D. Pollock, Ph.D., M.S.W., Center for Developmental Epidemiology, Duke University, Box 3454 DUMC, Durham, NC 27710.
E-mail address: mclean.pollock@dm.duke.edu (M.D. Pollock).

1054-139X/
http://dx.doi.org/10.1016/j.jadohealth.2016.08.004

school graduation rates and marriage rates for young adults with and without chronic illnesses are equivalent [6].

The notion of adaptation or adjustment to chronic illness is often presented as a negative concept. Doing well with an illness is defined by not having depression or some other major problem. However, recently the notion of adaptation to chronic illness has taken on a more positive perspective, particularly in studies examining adults with cancer, HIV, and myocardial infarction [7]. Developmental science models offer an opportunity to extend this perspective to youth with chronic illness.

The Positive Youth Development (PYD) perspective is a developmental science model that focuses on the developmental strengths of youth and how they align with growth promoting resources in their environment [8]. The PYD perspective provides a framework for examining thriving in youth and has been useful in understanding and promoting positive outcomes for at-risk youth. The Five Cs model of PYD postulates that youth with greater developmental assets including character, confidence, competence, connection, and compassion will have fewer maladaptive or risk outcomes and greater contribution in their communities [9–11]. This model has been empirically validated through a large longitudinal study of youth from 5th through 12th grades which found that youth with higher scores on a measure of these five PYD assets had lower rates of depression and at-risk behavior and higher rates of contribution to their communities [12].

Although interventions based on PYD models have been used to promote positive developmental outcomes for youth [11], there is limited evidence of the PYD approach being applied to program development for youth with COCC. A recent systematic review identified only three, community-based programs for youth with COCC that utilized major principles of the PYD approach [13]. Yet, thousands of youth with COCC participate in illness-specific programs each year such as summer camps [14]. To promote the application of the PYD perspective in future programming and interventions for youth with COCC, a better understanding of PYD among youth with COCC is needed.

According to the model by Lerner et al. [15], PYD assets of youth are shaped by the ecological context surrounding an individual, as well as by internal factors such as school connection or hope for the future. In this model, ecological and individual characteristics are mutually influential such that certain environmental factors influence the development of individual characteristics of youth and vice versa. Chronic illness in childhood can affect a child's environment by potentially altering their ability to participate in critical activities such as school or by changing the constellation of important adults with whom they interact. These changes could have a positive or negative effect. For example, many youth with COCC identify health care providers such as doctors, nurses, or physical therapists as important adults (G. Maslow, J. Lewis, C. Barrington, E. Fisher, unpublished data, 2016), which may be related to their experiences with receiving health care. To better appreciate the differences in individual characteristics that are shaped by their different experiences and environments, it is important to compare PYD between youth with COCC and those without as a first step.

To this end, this study aimed to apply the Five Cs model of PYD to a sample of youth with COCC and compare their levels of PYD assets to youth without illness. Based on studies that have found that youth with COCC are more isolated or have lower self-esteem than healthy peers [16], we hypothesized that youth with COCC would have lower levels of confidence, competence, and connection. We also hypothesized that youth with COCC would have higher levels of character and compassion based on anecdotal reports of youth with COCC often pursuing careers in helping professions. Finally, we hypothesized that youth with more physical limitations would have lower PYD scores.

Methods

Sample

This study used a noncategorical approach to define and recruit youth with COCC. Previous psychosocial studies have found that distinguishing between youth with COCC by specific biological illnesses is an arbitrary delineation that would be better understood by accounting for the burden of the illness such as chronicity or impairment [17,18]. Therefore, this study utilized a noncategorical approach to examine the relationship between COCC and PYD. Study participants were recruited from Duke University clinics in Durham, North Carolina, between August 2013 and March 2015. Healthy participants were identified from system-wide pediatric primary care practices, and participants with COCCs were recruited from specialty pediatric clinics including cardiology, cystic fibrosis, endocrinology, gastroenterology, hematology, muscular dystrophy, neurology, oncology, and rheumatology. Recruitment targets were set for each specialty clinic to ensure that there would be a variety of conditions represented among youth with COCC in sufficient numbers to allow for subgroup analyses. As a result, the clinical, convenience sample consisted of nine conditions (as listed in Table 1) that are known to cause impairment or lifestyle limitations; thereby, necessitating routine clinical monitoring and treatment unlike chronic conditions such as asthma and obesity.

Of the 465 subjects enrolled in the study, 51% with chronic conditions, 348 initiated surveys. Among these participants, 325 (95%) had complete data on surveys of interest to be included in the final analytical data set.

Procedure

A trained clinical research coordinator approached subjects who met study inclusion criteria during their scheduled clinical appointments. Inclusion criteria for participants included being between 13 and 18 years of age during the recruitment period and being able to speak and read English. Potential subjects were excluded if they had an intellectual disability documented in their electronic medical record or a severe learning disability as reported by the clinician or parent that would prohibit them from being able to independently complete an online survey.

The main additional exclusion criterion for healthy controls was that they could not have a documented COCC in their medical chart problem list or a new diagnosis during their clinical appointment. To ensure compliance, a second medical chart review was conducted of each healthy subject prior to data analysis to confirm that they did not have any of the 141 International Classification of Disease, Ninth Edition codes related to childhood-onset neuromuscular conditions, cardiac conditions, respiratory conditions (not including asthma), renal conditions, gastrointestinal conditions, hemetology conditions (not including sickle cell trait), congenital/genetic conditions, metabolic conditions (not including obesity), and malignant conditions. The complete list of International Classification of Disease, Ninth Edition can be obtained by contacting the corresponding author.