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Research Paper

Correlates of wellness among youth with functional disabilities

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Abstract

Background: The literature is more informative on the impediments to wellness among youth with functional limitations and less instructive on the state of wellness for this population.

Objective: To explore overall wellness, and each sub-dimension of wellness, in a national sample of youth with functional limitations and to determine how demographic characteristics are associated with wellness.

Methods: Using a previously validated screening instrument, we identify youth with functional limitations aged 12 to 17 represented in the 2011/12 National Survey of Children's Health. Survey items were coded to operationalize an overall wellness score comprised of four sub-dimensions of wellness (i.e., physical, intellectual, emotional, and social).

Results: The mean overall wellness score was 26.7 (out of 40) and had an approximate normal distribution. Mean raw scores for each sub-dimension were as follows: social = 2.79 (out of 4; 69.7%); emotional = 4.09 (out of 6; 68.2%); intellectual = 3.79 (out of 8; 47.4%); and physical = 6.30 (out of 8; 78.7%). Lower wellness scores were associated with older age among youth, increasing number of chronic health conditions, lower income, single mother homes, and youth whose mother reported fair or poor mental health status (all $p < 0.05$). Higher wellness scores were positively associated with mother's education ($p < 0.001$).

Conclusions: Program planners should consider interventions that target youth with functional limitations shown to be at particular risk for lower overall wellness and promote family involvement and comprehensive supports, including maternal educational attainment, mental health screening, and referral.

Keywords: Youth with functional disabilities; Wellness; 2011/12 National Survey of Children's Health

Youth with special health care needs or disabilities are at higher risk for physical, developmental, behavioral, or emotional conditions and as a result require more health care services than their peers.[1,2] Youth with functional limitations due to health conditions expected to last 12 months or more are a unique subset of youth with special health care needs, accounting for an estimated 4.3% of youth in this group.[2] Successful health management of this population is multifaceted and includes quality improvement efforts within clinical practices and health systems, partnerships across the entire service team and related researchers, training and education for everyone involved, and advocacy for youth with functional limitations and their caregivers.[3]

Wellness is viewed as a holistic[4–6] and multi-dimensional[6–8] concept which encompasses more than the absence of disease.[9,10] Wellness relates to functional abilities as well as life balance,[4–6] thereby aligning well with other comprehensive frameworks for describing health, including the International Classification of Functioning, Disability, and Health (ICF).[11] ICF classifies health across multiple domains according to body structure and function, as well as an individual's capacity to perform activities and participate in society.[11] Similarly, wellness is commonly viewed as being comprised of various sub-dimensions, which can include social, emotional, physical, and intellectual wellness,[8,9,12–19] though the identification of the specific dimensions of wellness has varied in number and definition in the literature.[6–8] Wellness expands the traditional understanding of health and functioning to include a context of actively engaging in activities that build and support an individual's potential or capacity to be healthy.[12,14,20]

For youth without disabilities, wellness is often maintained at the population level in large part through mandated physical education programs in schools and federally-mandated school wellness policies required by the Child Nutrition and WIC Reauthorization Act of 2004 (Public Law 108–265). Given the recognition that wellness is an important component of healthy living, it is troubling

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that researchers have documented challenges when implementing wellness programs for children with disabilities[21] and children with functional limitations.[22] Moreover, researchers have reported disparities in the delivery of preventive health services for youth with functional limitations.[23] School wellness policies focus on physical activity, nutrition, and other school-based activities that promote student wellness.

Overall the literature is more informative on the impediments to wellness among youth with functional limitations and is less instructive on the state of wellness for this population. Children with functional limitations were more likely than other children with special health care needs to experience participation restrictions related to school attendance, participation in organized activities, working for pay, and volunteering.[22] Children with severe functional limitations experienced significantly greater odds of delayed health care, unmet health care and care-coordination needs, referral problems, dissatisfaction with care, difficulty using services, worse health insurance experiences and greater impact on family (financial problems, employment challenges, need to provide home care) than children with special health care needs who had some or no limitations.[24] Research has also indicated that functional limitation, family poverty, and being uninsured were significantly associated with greater caregiver burden and less preventative dental care.[25] Additionally identified impediments to the health of youth with functional limitations have included living in families with limited resources and experiencing greater exposure to secondhand smoke, less access to health care, and lower health status.[26] While we have indications that factors such as social disadvantage, restricted access, decreased participation, unhealthy home environment, and financial resources impact the health care needs and experiences of youth with functional limitations, we do not know their overall state of wellness.

The purpose of this paper is threefold. First, we operationalize a measure of wellness across multiple dimensions to determine the extent of wellness in a national sample of youth with functional limitations aged 12–17 years. Second, we calculate measures of the various sub-dimensions of wellness and determine which sub-dimensions are most prevalent in this population. Lastly, we explore how different characteristics of youth with functional limitations, their caregivers, or other demographic information are associated with wellness among this group. This information will be valuable to program directors, policymakers, and clinicians interested in understanding and improving the state of wellness for youth with functional limitations.

Methods

Consistent with the aims of the current study, we utilized nationally representative youth survey data that includes questions that allowed us to operationalize measures that represent the commonly cited sub-dimensions of wellness. Specifically, the 2011/12 National Survey of Children's Health (NSCH)[27] collected by the Centers for Disease Control and Prevention (CDC) was conducted via telephone interviews by trained interviewers, incorporating both landlines and cell phones and utilizing a sampling design focused on reaching U.S. households including at least one child aged 0–17 years at the time of the contact. Responses were given by the person in the household who knew the most about the child or youth's health. A total of 95,677 interviews were conducted between February 2011 and June 2012, with representation from all US states (Centers for Disease Control and Prevention, National Center for Health Statistics, State and Local Area Integrated Telephone Survey. 2011–2012 National Survey of Children's Health Frequently Asked Questions. April 2013. Available from URL: http://www.cdc.gov/nchs/slaits/nsch.htm). From the survey, youth with any special health care needs were, first, identified through the use of a validated screening instrument, which includes five items and follow-up questions related to consequences of ongoing health conditions.[28] From that group, youth with one or more functional limitations due to health conditions expected to last 12 months or more were selected for inclusion in this study (''yes'' to questions K2Q16, K2Q17, and K2Q18).

The strength of the National Survey of Children's Health is its utilization of a complex sampling design and population weights to be nationally representative of children and youth ages 0–17 years. There are a unique set of survey items for youth 12–17 years which fit our interest with the adolescent years. The survey design elements and analytical techniques allow for national-level generalizations.

This study was exempted from review by the university's Institutional Review Board as it utilizes a publicly-available, de-identified dataset.

Dependent variable

Based on extensive review of the wellness literature, we reviewed all questions on the NSCH and identified items relating to sub-dimensions of wellness that could reasonably be developed based on available data, including physical, intellectual, emotional, and social wellness. The NSCH did not contain survey items to operationalize other additionally common sub-dimensions of wellness (e.g., spiritual and environmental wellness). Based on definitions from the literature,[6–8,29–31] questions were identified from the NSCH survey that represented each of the sub-dimensions of wellness. (Domains, descriptions, questions and coding are presented in the Appendix.) We evaluated each survey item to determine if it operationalized wellness for 12–17 year olds. Then, each author presented questions for a unique sub-dimension of wellness and identified any sub-dimensions that could not be reasonably developed using this survey. The authors reached consensus through extensive discussion about overall question selection and