Caring for Youth with Co-occurring Developmental Disabilities and Behavioral Health Issues when Caregivers Face Additional Health-Related Stressors

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Background

Approximately 15% of children and adolescents in the U.S. experience a developmental disability (DD) and approximately 30% of these youth also have a diagnosable mental health condition (Boyle et al., 2011; National Association for Persons with Developmental Disabilities and Mental Health Needs, 2016). Studies show that caregivers of youth with co-occurring DD and behavioral health issues experience the highest levels of caregiving strain (Mantorell, Gutierrez-Recaha, Irazabal, Marsa, & Garcia, 2011). In addition, many of these caregivers must also deal with their own or another family member’s chronic health condition, stressors which may place them at even greater risk for poor outcomes (Gallagher & Hannigan, 2015; Grinstead, Leder, Jensen, & Bond, 2003; Pinquart & Sorensen, 2007).

The aims of this study are to: (1) Provide a descriptive “snapshot” of caregivers of youth with co-occurring DD and behavioral health issues; (2) identify similarities and differences in risk and protective factors among these caregivers and those caregivers with graduated levels of health-related stressors (i.e., those focused on providing care for the target youth with DD; without additional health-related stressors with which to contend; those contending with minor health-related stressors; and, those contending with major health-related stressors); and, (3) examine the relative contribution of risk and protective factors to objective, subjective internalized, and subjective externalized caregiving strain in this DD caregiver population.

Methods

Design and procedures. We conducted a secondary analysis of baseline (at program enrollment) and 6-month follow-up data from family caregivers participating in SAMHSA’s Longitudinal Child and Family Outcomes study (see Mantorell, Stephens, Brashares, Kryelova, & Fisher, 2008). Determination of youth DD status was based on caregiver report of youth “having an Individualized Education Plan” (N = 3,819) for the primary reason of “developmental disability” (n = 600). Caregivers were stratified into groups based on self-reported “recurrent or chronic physical health problems” for themselves or another household member and the degree to which these problems affected their ability to provide care for the youth with DD. The final sample consisted of family caregivers without additional health-related stressors (n = 202), with minor additional health-related stressors (n = 304), and with major additional health-related stressors (n = 94).

Measures. 1) Revised Caregiver Information Questionnaire (CMHS, 2005), 2) Family Life Questionnaire (CMHS, 2005); 3) Child Behavior Checklist-1.5 (Achenbach & Rescorla, 1997), 4) Multi-SCIENCES, 62B, 126-137. 5) Youth Services Survey for Families and Multi- Sector Services Contacts Questionnaire (CMHS, 2005) and 6) Revised Youth Information Questionnaire (CMHS, 2005).

Analysis. Analyses were conducted using SPSS version 22 (IBM Corp., 2013). One-way Analysis of Variance (ANOVA) tests (i.e., for continuous variables) and chi-square tests (i.e., for categorical variables) were used to explore caregiver group differences in risk and protective factors at program enrollment. Hierarchical linear regression with 6-month follow-up caregiving strain subscale scores as the dependent variables was used to identify predictors of objective, subjective internalized, and subjective externalized caregiving strain. The sample for the regression analyses included caregivers for whom 6-month follow-up data on the strain outcomes were available.

Results

Table 1. Overall, caregivers were predominantly female (92%), white (66%), relatively well-educated (81.2% with at least a high school diploma), and living at or below the poverty level (71%).

A comparison of risk factors by caregiver group is presented in Table 2. Significant group differences were found on a variety of risk factors including current unemployment, recent problems with depression and other mental health issues, caregiver ratings of youth internalizing and externalizing behaviors, objective, subjective internalized, and subjective externalized caregiving strain, and family history of substance abuse problems, depression, and other mental illness.

Table 3. Predictive factors between the three caregiver groups. Lower proportion of caregivers with additional health-related stressors reported having “time for self or friends” at least “half of the time.” Marginally significant group differences were also found on the factors of behavioral health literacy and empowerment and family quality of life, with the major additional health-related stressors group reporting lower levels of each characteristic.

Discussion and Implications

This study is among the first to explore risk and protective factors in a national sample of caregivers with co-occurring DD and behavioral health issues. There were several striking features in the overall sample (e.g., 71% were living in poverty compared with a 15% poverty rate in the U.S. adult population). Significant differences were also found between groups (e.g., 70% of caregivers with major health stressors with recent depression compared with 37% in the group without health stressors). Although predictors of caregiving strain in this sample were similar to populations who do not experience DD, it is noteworthy that experiencing a minor health stressor appeared to be protective against strain. Findings showcase the need for healthcare providers and DD service providers to conduct brief health, mental health and service needs assessments to determine not only the child’s but also the family’s information and referral needs so that the family receives appropriate services and support.

This study illustrates the challenges that caregivers who deal with health issues and take care of youth who have co-occurring developmental disabilities and behavior health challenges face. Community-based service systems such as medical, mental health, and developmental disabilities services need to take a more holistic approach to serving youth who have co-occurring issues. In addition to providing services to the youth, they should also assess the family caregivers’ needs and refer them to appropriate resources and services if warranted. Taking a more coordinated and comprehensive service approach will lead to better outcomes for patients/clients and their families. This is particularly important in light of the current and future changes to the DD services field in terms of the new Home and Community Based Services rule and in particular, the increased emphasis on community-based service delivery and living for people with disabilities.

Select References