Research in Developmental Disabilities 55 (2016) 100–113

Contents lists available at ScienceDirect

Research in Developmental Disabilities

Caregiver needs and stress in caring for individuals with fetal alcohol spectrum disorder

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ARTICLE INFO

Article history:
Received 29 August 2015
Received in revised form 11 January 2016
Accepted 3 March 2016

Keywords:
Fetal alcohol spectrum disorder
FASD
Caregiver
Needs
Stress

ABSTRACT

Objective: Individuals with FASD experience neurodevelopmental impairments and adverse outcomes, which can result in stress on the caregiver. However, there is little research on the needs of caregivers supporting individuals with FASD and whether they are associated with caregiver stress.
Method: 125 caregivers of individuals with FASD completed a survey with questions adapted from the Family Caregiver Survey and the Perceived Stress Scale.
Results: Caregivers reported a range of needs and concerns, and high levels of stress. In many areas of caregiver well-being concerns tended to be higher among caregivers with adolescents and adults compared to those with children. Foster parents reported fewer well-being concerns than biological/kinship and adoptive parents. Caregivers who cared for the individuals for longer periods of time reported the most well-being concerns and lowest satisfaction with supports. Caregivers with the lowest income reported higher levels of stress than those with higher incomes. Higher reported stress was highly correlated with more needs/concerns.
Conclusions: Caregivers of individuals with FASD have multiple areas of need and concern, and experience high levels of stress. Reducing demands on caregivers and providing resources may help reduce caregiver needs and stress, particularly for those caring for adolescents and adults, and those with lower incomes.

1. Introduction

Fetal Alcohol Spectrum Disorder (FASD) refers to individuals who have physical, cognitive, behavioral, and/or learning disabilities related to prenatal exposure to alcohol (PAE; Chudley et al., 2005). In Canada, FASD is estimated to occur in 1% of the population (Alberta Alcohol & Drug Abuse Commission, 2013; Health Canada, 2008; Stade, Unjar, Stevens, Beyene, & Koren, 2006), and in the United States of America the rate is 2–5% (May et al., 2009). Individuals with FASD frequently

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http://dx.doi.org/10.1016/j.ridd.2016.03.002
0891-4222/

require extensive support services with significant economic costs. In Canada, an estimated $5.3 billion is spent annually on supporting individuals with FASD, equivalent to $14,342 per individual (Stade et al., 2006).

Individuals with FASD experience a number of neurodevelopmental impairments in the areas of learning, memory, executive functioning (e.g., inhibition, decision making, flexible thinking), attention, intelligence and language, as well as behavioral problems (Kodituwakku, 2007), including elevated rates of inattentive, hyperactive, and aggressive behavior (Mattson & Riley, 2000; Nanson & Hiscock, 1990; Paley, O'Connor, Kogan, & Findlay, 2005). Streissguth et al. (2004) found high rates of adverse outcomes in children and adults with FASD, including mental health issues, delinquency, legal troubles, and confinement. Protective factors against these adverse outcomes include an early diagnosis, receiving services for disabilities, no exposure to abuse or domestic violence and living in a stable home environment. Given the variety of impairments and adverse outcomes associated with FASD, the types of services and supports needed are extensive and span health, social, education, and justice sectors.

Providing care for children with disabilities involves significant time and energy, disruption to family activities and routine (Plant & Sanders, 2007; Seltzer & Heller, 1997; Shultz & Quittner, 1998), and, not surprisingly, resultant increased levels of personal stress in caregivers. Plant and Sanders (2007) found that caregiving tasks and advocating to professionals on behalf of their child contributed to caregiver stress among families of pre-school aged children with developmental disabilities. Moreover, the difficulty of the caregiving task, the child behavior problems during these caregiving tasks, and the extent of the child's disability contributed most significantly to caregiver stress.

Autism Spectrum Disorder (ASD) is often cited as the most stressful disability for parents (Abbeduto et al., 2004; Pisula, 2007). Watson, Coons, and Hayes (2013) compared caregiver reported stress of families of children (aged 1–36 years) with ASD (n = 25) to families of children with FASD (n = 25) using two stress measures: the Friedrich version of the Questionnaire on Resources and Stress (QRS-F) and the Parenting Stress Index-Short Form (PSI-SF). No overall significant group differences were found on the QRS-F, although caregivers of children with FASD reported significantly more stress on the Pessimism subscale. However, on the PSI-SF, parents of children with FASD reported significantly more overall stress than parents of children with ASD. The authors then conducted a qualitative analysis to examine the issues faced by families of children with FASD and ASD. Four main themes contributing to parental stress in both groups emerged: (1) the need for a timely formal diagnosis in order to access services and supports; (2) the diagnostic process; (3) the need to deal with the behavioral issues in their children; and (4) the multiple roles of the caregiver to advocate for the best services and supports for their children. The FASD group had some unique challenges regarding the diagnostic process, including having to travel to see specialists, difficulty confirming maternal alcohol use during pregnancy, and the absence of phenotypic facial features. Additionally, although both groups of parents expressed concerns with behavioral issues, the parents raising children with FASD expressed concerns regarding delinquent behaviors and difficulties choosing appropriate friends (Watson, Hayes, Coons, & Radford-Paza, 2013).

Paley, O'Connor, Frankel and Marquardt (2006) used the PSI (Abidin, 1995) to measure caregiver stress related to parental characteristics (parent-related stress) and child characteristics (child-related stress), among children with FASD (aged 6–12 years). Internalizing and externalizing behaviors, executive and adaptive functioning difficulties, and being an adoptive parent were all associated with more child-related stress. Biological parent custodial status and fewer family resources were the only significant predictors of increased parent-related stress (Paley et al., 2006).

There is a growing amount of literature regarding experiences and impact on families and caregivers in parenting individuals with FASD, and subsequent perceived familial needs (Olson, Oti, Gelo, & Beck, 2009). Morrissette (2001) performed a narrative analysis on interview data about the experiences of caregivers (n = 6) raising foster and adoptive children with FASD in the United States. Seven predominant themes emerged from this data: (1) the need for constant vigilance to ensure the child's well-being; (2) the effect of stress and strain on marriages; (3) child management concerns including manipulative and unmanageable behavior, their children's attempts to disguise their disability, and the importance of sequence and routine; (4) parental issues including a feeling of inadequacy and subsequent adjustment; (5) interactions with the professional community such as physicians, teachers and social workers; (6) medical implications secondary to FASD; and (7) transition and emancipation concerns.

Recently, a needs assessment was conducted to inform the development of an online intervention for families affected by FASD in Canada (Green et al., 2014). The number and extent of challenges reported by caregivers made it clear that there were many unmet needs that impacted the quality of life for caregivers, their children, and their families. Caregivers reported that the most challenging behavior categories were "Externalizing Behaviors" (ex. rule breaking/aggressive behavior), "Cognitive Difficulties" (ex. memory/attention/language/learning difficulties), and "Social Difficulties/Maladjustment" (ex. issues with attachment and getting along with others), whereas the most successful parenting strategies were "Parental Reflection" (ex. remaining calm, having realistic expectations, learning from past experiences), "Routine/Structure/Consistency" (ex. visual schedules, timers, prompts), and "Environmental Modification" (ex. leaving/avoiding a particular situation, changing the child's personal space). The authors concluded that parenting programs must provide a family-centered approach to training, education and support for children with FASD and their families (Green et al., 2014).

Adverse outcomes in FASD could be potentially prevented or lessened by better understanding, appropriate interventions and stable caretaking environments, and caregiver education or training about FASD has been identified as an important element for successful interventions for children with FASD (Bertrand, 2009). Leenaars, Denys, Henneveld, and Rasmussen (2012) evaluated a mentoring program for caregivers raising children with FASD, which helped families connect with various