

Caregiver Needs and Stress in Caring for Individuals with Fetal Alcohol Spectrum Disorder

Lay Summary

L. Baugh, S. Bobbitt, G. Andrew, J. Cook, C. Green, J. Pei, C. Rasmussen

Background

Individuals with Fetal Alcohol Spectrum Disorder (FASD) often present with a large range of strengths of difficulties making it difficult to identify capabilities and set goals with them. In addition, the areas of difficulty described in this population are often related to adverse outcomes such as delinquency and school conflict. This can have a significant impact on caregivers, contributing to high levels of stress in the caregiver role. However, there is little research on the needs of caregivers supporting individuals with FASD and associations with caregiver stress. Thus, in the current study we examined: 1) the needs of those caring for individuals with FASD, 2) whether their needs are met, and 3) whether caregiver stress is associated with these needs and other caregiver/child characteristics.

Participants included 125 caregivers of individuals with FASD from across Canada who anonymously completed a survey consisting of general demographic questions, an adapted version of the “Family Caregiver Survey” and the “Perceived Stress Scale”.

Key Findings

Caregivers reported:

- A wide range of needs and concerns, including: their role as caregiver, their relationship with their child with FASD, their relationship with family and friends, their financial situation/covering costs, the caregiver’s own health, stigma and discrimination, the safety of the individual with FASD, and the caregiver’s own safety.
- Many positive experiences of caregiving: learning about themselves, discovering strengths in themselves, contributing to others understanding of FASD, becoming more confident in dealing with others, and meeting helpful people.
- Varying degrees of satisfaction with the supports they were receiving. They reported higher levels of satisfaction with the information/advice given to them and the ways they were involved in treatment and care planning, and lower levels of satisfaction for support from medical and/or care staff.
- High levels of stress, specifically in the following areas: things happening unexpectedly, being unable to control important things, feeling generally “nervous” or “stressed”, and not feeling like things were going their way or like they were on top of things.
- Mixed experiences of well-being:
 - a. Caregivers of adolescents reported the highest levels of wellbeing concerns.
 - b. Overall, concerns tended to be higher among caregivers with adolescents and adults, compared to those with children.
 - c. Foster parents reported fewer well-being concerns than biological/kinship, and adoptive parents.
 - d. Caregivers who cared for the individual with FASD for longer periods of time reported more well-being concerns.

- Income was not significantly related to caregiver needs and concerns in terms of well-being and support, however, caregivers with lower income reported higher levels of stress.
- Finally, higher reported stress was highly correlated with more reported needs/concerns.

Implications for Policy and Practice

Caregivers of individuals with FASD have multiple areas of need and concern, and experience high levels of stress. This is particularly true as children age, and the transition to adulthood may be a time requiring higher supports. Efforts should be made to reduce caregiver stress by reducing demands on caregivers and providing resources that better meet caregiver needs. These efforts may be particularly necessary for those caring for adolescents and adults and those with lower income levels.