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# Research in Developmental Disabilities

journal homepage: [www.elsevier.com/locate/redevdis](http://www.elsevier.com/locate/redevdis)

## Types of strain among family members of individuals with autism spectrum disorder across the lifespan



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### ARTICLE INFO

#### Keywords:

Autism spectrum disorder  
Family  
Strain  
Caregiving  
Lifespan

### ABSTRACT

**Background:** Although increased caregiver strain is often found among family caregivers of individuals with autism spectrum disorder, it is still unclear as to how different types of strain relate to amount and types of caregiving across the lifespan.

**Aims:** The present study examined different types of strain (i.e. subjective internalized strain, subjective externalized strain, and objective strain) and how such strain relates to the amount of caregiving responsibilities.

**Methods:** Data was collected via online survey from a sample of 193 family caregivers of individuals with ASD from the United States, Canada, and the Republic of Ireland. Participants completed measures of strain and caregiving responsibilities, as well as coping, demographics, and services needed and received by the individual with ASD.

**Results:** Caregivers reported higher levels of objective strain than subjective, and caregiving responsibility was related to objective and subjective internalized strain. Coping style was strongly correlated with all types of strain, and unmet service needs were significantly related to objective and subjective internalized strain. Caregiving behaviors were only related to objective strain.

**Conclusion:** The present results indicate that, although caregiving responsibility is related to objective and subjective internalized strain, the relationship is perhaps not as strong as the relationship between coping mechanisms and strain. Future research is needed to understand different types of strain and develop strategies to help caregivers.

### What this paper adds

Many studies have shown increased strain among family caregivers of individuals with autism spectrum disorder (ASD), but it is not yet clear how caregivers perceive strain, particularly different types of strain, during different developmental periods. Additionally, researchers do not yet know how much objective responsibility relates to perceived strain. The current study expands on the extant literature by relating perceived caregiver strain to objective responsibility across the lifespan of the individual with ASD. Analyses illustrate not only how strain and responsibility relate to age, but whether or not the relationship between strain and responsibility may differ based on the age of the individual with ASD. Additionally, regression analyses show how responsibility relates to different types of strain when taking into account unmet service needs of the individual with ASD and personal coping styles of the family caregiver.

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<http://dx.doi.org/10.1016/j.ridd.2017.07.003>

Received 27 February 2017; Received in revised form 28 June 2017; Accepted 10 July 2017

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## 1. Introduction

Autism spectrum disorder (ASD) currently has a prevalence rate of 1 in 68 children in the United States (Center for Disease and Prevention; CDC, 2015). In addition to core deficits in social communication and restrictive and repetitive behaviors (American Psychiatric Association, 2013), individuals with ASD can exhibit impairments in daily living skills, lower levels of educational and career achievement (e.g., Holwerda, van der Klink, Groothoff, & Brouwer, 2012; Migliore, Timmons, Butterworth, & Lugas, 2012), and internalizing and externalizing behavior problems (e.g., Chiang, Cheung, Li, & Tsai, 2013; Test et al., 2014; Wehman et al., 2014; Wehman et al., 2014). Caregivers of individuals with ASD deal with various challenges and responsibilities including, but not limited to, working with a relatively undeveloped and fragmented service systems to meet the needs of the individual with ASD (Friedmen et al., 2013) to having to support their adult children dealing with their maladaptive behaviors (Taylor & Seltzer, 2010; Volkmar, Reichow, & McPartland, 2014), and various physical and mental health and comorbidities (Anderson et al., 2013; Havercamp & Scott, 2015; Havercamp & Scott, 2015).

### 1.1. Caregiver strain

An important aspect of the caregiver experience is the perception of how the caregiver's life has been negatively impacted by caring for the individual with ASD; this perception is commonly referred to as "caregiver strain" or "caregiver burden" (Zarit, Reever, & Bach-Peterson, 1980). In general, caregiver strain can be categorized as objective – the degree to which caring for the individual with ASD affects work, finances, or routine – and subjective – the degree to which caring activities impact the caregiver emotionally (Hoinig & Hamilton, 1966). Understandably, the perception of caregiving strain is very important; studies show that self-reported caregiver strain relates to poorer mental health-related quality of life (Khanna et al., 2011).

Numerous studies have shown that family caregivers of individuals with ASD across the lifespan report high levels of stress and strain, even compared to family members of individuals with other intellectual and developmental disabilities (e.g. Estes et al., 2009; Jellett, Wood, Giallo, & Seymour, 2015; Lee et al., 2009; Lee et al., 2012; Montes & Halterman, 2007; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Although objective and subjective strain have been examined more extensively in other caregiving populations, the differences in types of strain among ASD caregivers are not well understood. Many extant studies of strain in ASD caregivers either use a measure that does not differentiate between subjective and objective strain (e.g. De Andrés-García, Moya-Albiol, & González-Bono, 2012), or combine the subjective/objective subscales into a single score (e.g. Stuart & McGrew, 2009). Because subjective and objective strain focus on different aspects of strain – e.g. negative feelings for subjective strain and negative external consequences for objective strain – the types of strain may relate to different outcomes. Therefore, it is important to study both subjective and objective strain among caregivers.

### 1.2. Potential correlates of caregiver strain

Although overall increased strain in caregivers of individuals with ASD has been well-established, researchers are still working to determine the factors that most strongly contribute to parent and caregiver strain in this population. In particular, it is not yet known how objective factors, such as amount of caregiving and unmet service needs uniquely contribute to a caregiver's feeling of both subjective and objective strain, especially when taking into account personal coping strategies.

#### 1.2.1. Objective responsibility

One factor that can contribute to caregivers' perceptions of strain is how much caregiving is actually being done. In a study of children with ASD, Tehee, Honan, and Hevey (2009) found that parental involvement (i.e. how much parents participate in various caregiving activities) was positively correlated with parenting stress, although the smaller sample size prevented the researchers from examining whether the more objective measure of caregiving predicted stress above and beyond coping strategies. In contrast, Sawyer et al. (2010) found that the number of hours mothers spent engaged in caregiving activity, as measured by time diaries, did not significantly predict maternal depression symptoms or overall mental health problems. Such mixed results may arise from different perceptions of the strain of amount of caregiving, as well as caregivers' various coping mechanisms.

It is important to distinguish between objective caregiving and objective strain. Although measurements of objective strain share face validity with reports of objective caregiving, strain, as mentioned above, refers to the perception of impact (Brannan, Heflinger, & Bickman, 1997). Therefore, although caregiving behaviors, such as personal care (bathing, dressing, toileting, etc.) and coordinating interactions with the service system, may directly impact objective strain (disruption of family social activities, interruption of personal time), objective caregiving and objective strain are different aspects of caregivers' lives. The present study aims to quantify just how much perception of objective strain relates to objective caregiving.

#### 1.2.2. Needs

An important factor in caregiver strain is the level needs of the individual with ASD and the family. Service needs range from obtaining a diagnosis and various medical services and therapies (e.g., behavioral therapy, occupational therapy, mental health) to respite services for the family (Anderson et al., 2013; Myers & Johnson, 2007; Taylor & Seltzer, 2010) and transition services when the child leaves the high school setting (e.g., Crane, Chester, Goddard, Henry, & Hill, 2015; Friedmen et al., 2013; Myers & Johnson, 2007; Shattuck et al., 2012). Many families struggle with the service system, experiencing problems not only finding appropriate service providers, but completing the necessary administrative steps to obtain funding for such services (Shattuck et al., 2012; Vohra,

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