**THE NEXT GENERATION OF CAREGIVERS: WHAT SIBLINGS OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDER WANT US TO KNOW**

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**Objectives:** With the advent of deinstitutionalization in Canada, siblings are becoming likely caregivers of brothers and sisters with Autism Spectrum Disorder (ASD). Yet, parents do not typically involve children in the process of planning for future care. Consequently, siblings can potentially be left unprepared anticipated challenges associated with caregiving. Therefore, the purpose of the current study was to explore the lived experiences of siblings of individuals with ASD as they encounter the likelihood of becoming full-time caregivers in the future.

**Method:** To examine the experiences and perspectives of individuals who have a brother or sister with ASD, a qualitative approach, informed by basic interpretative inquiry was employed. A semi-structured interview guide consisting of 19 questions was used to elicit responses about both positive and negative experiences. All interviews were transcribed verbatim and scripts were analyzed using Interpretative Phenomenological Analysis (IPA), to understand the meanings of their personal experiences (Smith, Flowers & Larkin, 2009). Inclusion criteria for participation included being a brother or sister of an individual with ASD, but who themselves had not been diagnosed with ASD. In total, 17 individuals, ranging in age from 18 to 53 years old, participated in interviews.

**Results:** Concerns of future caregiving became a collective worry amongst all participants. With the use of IPA, four sub-themes representative of future concerns were elicited from interviews: *Uncertainty*, *Expectations of Care*, *Preparing for the Future* and *Finding a Balance*. Specifically, siblings felt highly uncertain about challenges associated with future caregiving. Participants dwelled on how their futures would look once parents could no longer provide care and how to explain parental loss to their brother or sister with ASD. They also referred to the perceived expectations of care by siblings (without ASD) and parents. Additionally, participants frequently discussed the expectations that they imposed on themselves in terms of providing support for their loved one. Furthermore, they reported struggling with preparations for anticipated responsibilities. Although some participants described feelings of denial about future duties, others discussed involvement in establishing care plans, in order to feel prepared for potential challenges. Lastly, participants expressed concerns about the ability to effectively manage duties of caregiving in addition to their lifestyle, and how to decipher a balance between their needs and desires (i.e., starting a family, travelling, moving away for a job) and those of their brother or sister with ASD.

**Discussion/Conclusions:** Due to a recent movement towards deinstitutionalization, agencies within communities may be unprepared to meet the increased demands of families seeking support for their loved one. As a result, the burden of full-time care is often placed on siblings of individuals with ASD. Results of the present study highlight the need for tailored supports to ensure an uninterrupted transfer of care. Accordingly, consideration should be given to ways in which the burden can be eased for siblings as they embark on new journeys as caregivers. Thus, the findings of the current study can inform practice by raising awareness of salient concerns voiced by the future caregivers in order to generate an impetus for tailored resources and services.

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