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My Sibling and I: Exploring the experiences and coping strategies of younger siblings of individuals with Down syndrome

A thesis presented in partial fulfilment of the requirements for the degree of

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in

Psychology

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New Zealand.

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ABSTRACT

Down syndrome is a lifelong condition which impacts each family member in unique ways. Yet, with numerous studies focused on parental coping, little is known about the meanings siblings attach to the relationship they share. This study aims to investigate the personal experiences and coping strategies of younger siblings of individuals with Down syndrome. Three siblings aged between 17 and 22 years were interviewed to gather data on their experiences and coping strategies. The interviews were recorded and transcribed for analysis. Data was analysed using Thematic Analysis. Findings suggest four major themes and eight emotional states. The four themes identified are Blurred ordinal roles, Growth, Coping with society's perceptions and Future plans. The eight emotional states identified are feelings of Loss, Guilt, Uncertainty, Embarrassment, Protectiveness, Denial, Acceptance, Gratitude and Admiration. The results report an overall positive experience between siblings. Challenges related to the lack of public awareness, social stigma and functioning levels of siblings were raised. Siblings reportedly engaged in both, emotion-focused and problem-focused coping strategies. Variables such as family size and sibling's level of functioning were found to account for some of the differences across the case studies. The discussion provides suggestions on the practical application of findings, limitations and recommendations for future research.

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