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LIVED EXPERIENCE AND FUTURE CAREGIVING EXPECTATION IN SIBLINGS OF PEOPLE WITH DOWN SYNDROME

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Abstract

Having siblings with down syndrome may give both positive and negative experiences in life. Those experiences will differ from each other due to the wide variations of developmental and intellectual disabilities characteristics and level of severity in DS cases. Moreover, as siblings might have the longest relationship with their brothers or sisters compared to parents, siblings of people with DS are more likely to take a role as the main caregiver in the future, especially when their parents can no longer play that role. From that basis, this study aims to get understanding about the lived experience in siblings of people with down syndrome and to know their expectation about taking a role as caregiver for their DS sibling in the future. This study uses phenomenological qualitative research methods with data collection methods using semi-structured interviews. Data were analyzed using Interpretative Phenomenological Analysis (IPA). The findings revealed that experiences as siblings of people with DS intersect with many people both with family and other people outside the family. This causes both positive and negative feelings. In dealing with negative feelings, there are ways to cope with the situation includes acceptance, relating the DS sibling's condition with religious values, perceived benefits from the situation, and participating in the down syndrome community. Finally, all the lived experiences that happened influenced thoughts of DS sibling's condition in the future as well as the possible role as the future main caregiver including the possibility of DS sibling's functioning as an adult, willingness to be the future main caregiver, and possible caregiving style to be implemented,

Keyword: *down syndrome, siblings, lived experience, future caregiving expectation, interpretative phenomenological analysis*