

Background: Rett syndrome is a rare neurodevelopmental disorder that affects mainly females and results in severe physical and intellectual disability. The management of Rett syndrome often requires resources such as equipment and respite although the extent of their use is not known. In addition, research suggests that parents of a child with a disability experience lower levels of well-being than parents of a child with no disability. The effect of resource use on the well-being of parents with a daughter with Rett syndrome is also not known.

Aims: This study described the relationships between characteristics of the girl/woman with Rett syndrome and her family, the use of equipment and respite, and parental well-being.

Methods: The population-based Australian Rett Syndrome Database was the source of data. Data from 2004 and 2006 parent questionnaires described the girl/women with Rett syndrome and her family. Univariate and multivariate logistic regressions and linear regressions were used to analyse relationships between participant characteristics (age, clinical severity, mobility and behaviour), family characteristics (socio-economic status, family size and the place of residence), the use of equipment and respite, and parental well-being.

Results: A total of 170 families with girls and women aged 2-28 years participated in this study. Preliminary assessment suggests that wheelchairs, shower chairs and hoists were commonly used. The majority of girls and women had accessed respite services at some point in time. Further findings will be presented in relation to implications for occupational therapy practice.

Conclusion: Understanding the relationships between characteristics of the girl/women and her family, use of resources, and parental well-being can influence the therapeutic management of girls and women with Rett syndrome.