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## Parents' of Child with Down's Syndrome: Their Care-giving Experiences, Parent - Child Communicative Pattern at Home and Perceived Quality of Life: A Pilot Study

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### **Abstract**

Background: children with Down's syndrome are frequently associated with physical problems such as congenital anomalies, a higher mortality rate caused by infections, a high risk of developing malignancies, visual and auditory impairment and disruptive behaviour disorders, and autism. They form the largest group of persons with intellectual disability commonly challenged by language impairment. At the national level, the latest available annual reports (for the year 2004 to 2006) from the Malaysia Ministry of Health (Information and Documentation System Unit) shows that around 600 new cases are reported year, a relatively common cause of disabilities for children (0-12 years age range). Objectives: to explore experiences of Malaysian parents with Down's syndrome child related to care giving, their communicative patterns quality of life. Methodology: This is a pilot study using cross-sectional, qualitative and quantitative methodological approach. Data collection was conducted with prior ethical approval and consent from two participants who were parents with Down's syndrome child of the Malay ethnic background, from the community -based rehabilitation (CBR) center. Prior appointment was made for in-depth interviews and participant observations at their individual homes. Participant-generated Index (PGI) of quality of life Instrument was also administered during the second visit to the home. Findings: identified main themes such as burden of care physically and emotionally; support socially, financially and from family; levels of understanding related to the future, resources for information and child's condition; developmental stimulation, emotional responses initially, acceptance; varying ways of communicative pattern with child; PGI of Quality of life which showed participants' QOL at the poorer end. Conclusion: further study of more participants' care giving experiences will yield better understanding of Malaysian parents with DS child. The pilot study indicated that rich data can be obtained. However, there was a need to improve on the interviewer questioning technique and duration of observation in the main study.