

✧ RESEARCH PAPER ✧

Care demands on mothers caring for a child with Down syndrome: Malaysian (Sarawak) mothers' perspectives

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This paper examines the experiences of mothers caring for a child with Down syndrome in the Malaysian (Sarawak) context. Qualitative interviews were conducted with 26 biological mothers of children with Down syndrome aged 18 years and below. They were accessed through selected child health clinics, community-based rehabilitation centres and schools using purposive sampling within two regions in Sarawak, one of the two Borneo States of Malaysia. Major themes emerging within the context of care demands were children's health, developmental delays, daily needs and behaviour issues. The insights obtained into the care demands experienced by mothers of children with Down syndrome have several implications for practice by care professionals.

Key words: behaviour, care demands, child, Down syndrome, experiences of mothers.

INTRODUCTION

Mothering a child has widely been described as a challenging task.^{1–3} The question thus arises as to what it is like for

a mother to have a child with a disability. Motherhood of a child with a disability such as Down syndrome (DS) can be especially challenging and demanding. DS, a common genetic disorder, is caused by an extra 21st chromosome.⁴ Children who are born with this condition are often affected by congenital cardiac, gastrointestinal or other anomalies that require urgent care and treatment in the hospital immediately after delivery and subsequent medical follow-up.⁵ Besides this, DS in children is frequently associated with a variety of developmental delays and impairments (social, language, self-help, cognitive and psychomotor).⁶

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