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QUALITY OF LIFE AND EXPERIENCES OF MOTHERS OF CHILDREN WITH DOWN SYNDROME



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Background:

Mothering a child with Down syndrome (DS) could be stressful and emotionally overwhelming for some families. The mothers or care-givers were reported to perceive a lower quality of life. Children who are born with this condition are often associated with a variety of developmental delays and various congenital anomalies which require care in the hospital soon after delivery and subsequent medical follow-up. In Malaysia, the Ministry of Health reported an annual figure of more than 600 new cases of children with DS which constitutes almost a quarter of the total number of the children (below 12 years old) with newly reported disabilities (Ministry of Health Malaysia, n.d.). There have been only a few local studies with detailed accounts on children with DS and their parents, particularly in the Borneo state of Sarawak. Therefore, the purpose of this study was to investigate the experiences of mothers caring for a child with DS and their perceived QoL. The main research question which guided the study was 'What are the experiences of Malaysian (Sarawak) mothers caring for their DS child and their QoL?' This paper constitutes part of the main study which highlights some of the concerns faced by these mothers.

Methodology:

This study was conducted using a parallel mixed-method approach within the local ethnic and cultural context in two regions of Sarawak. Experiences of mothering their child were explored using qualitative interviews (N=26) whereas the WHOQOL-BREF instrument (WHOQOL Group, 1996) was used to determine their perceived QoL (N=161). Mothers of children having DS aged 18 years and below were accessed from either schools, Community-Based Rehabilitation centres or child health clinics where their children were attending the interventional or educational programs within and nearby the capital city of Kuching and the rural region of Samarahan Division. Textual data from interview transcripts were managed and analyzed with NVivo 7.0, a computer-assisted qualitative data analysis software program. Thematic analysis guided by Creswell's six generic

steps of data analysis was conducted. Quantitative data analysis was done using Statistical Package for Social Sciences 19.0.

Findings:

The overall QoL of the respondents (mean=14.0 ± 1.84) was found to be positively correlated with their locality, education, income and marital status with rho (161) = 0.22 to 0.28 (p < 0.01) but inversely correlated with the maternal age, with rho (161) = - 0.17 (p < 0.05). Those who had a lower education and income levels, living in the rural locality, older in age and as singles perceived poorer overall QoL. Regression analysis indicates that the combination of these variables together account for 14.5% of the QoL variability (Chan, Abdullah & Ling, 2013).

Two of the major themes which emerged were in terms of their *psycho-emotional aspect* of their experiences and *child-behavior-related care demand*. In the context of the *psycho-emotional aspect* of their experiences, these were related to feeling of shock, confusion, difficult to accept; feeling of shame and guilt which explained why some of the mothers were secretive about their child's condition and shielded their child away from public eye; their feeling of being stigmatized by others; feeling unsupported both emotionally and practically either from their spouses or extended families; various worries about recurrence of DS, child's inability for self-care and future care provisions for their affected child.

Child-behavior-related care demand as another major theme was due to their children's characteristics of tantrum, behaviors that were socially or age-inappropriate or of heightened active level. This was physically exhausting and added to their challenging experiences. However, a wealth of practical knowledge and wisdom could be learnt and emulated from several other mothers who exercised their firmness and competence in setting limits like for any other children.

Discussion and implications:

Mothering children with DS in the Sarawak context could be challenging as evident by the mothers' or care-givers' experiences in the psycho-emotional aspect and child behavior-related care. These were partly related to their children's characteristics, familial or societal attitudes. As stated earlier, regression analysis shows that the combination of the mothers' several background variables together account for only 14.5% of the QoL variability. Besides their background variables, familial and societal attitudes, and child characteristics could be possible factors which can impact on the QoL or well-being of mothers.

Resilience model (Van Riper, 2007) emphasizes the need for families to have access to protective factors in term of supports and resources to enable them to cope and adapt to having a child with disability. Care provision should aim to contribute towards a family environment which promotes mothers' QoL and facilitate the optimal development of their child with DS. Insights as gained point to implications for care professionals' practice. These include being anticipative of and sensitive to mothers' initial emotions; imparting relevant information to clear any misconception and unhelpful disability-related cultural belief; facilitating their access to various supports and resources. Health care and social work

professionals' educational preparation would do well to include disability-related element. Besides these, national policy-making needs to be more inclusive in supporting families and children with DS with their future in mind with greater focus to outreach service designed for rural areas.

References

- Chan, K. G., Abdullah, K. L., Ling, H. K. (2013). Quality of life among Malaysian mothers of child with Down's syndrome. *International Journal of Nursing Practice*, 19 (4): 381-389.
- Ministry of Health Malaysia (n.d.). Year 2004-2006 Annual Report, Family Health Development Division. Retrieved 4 August 2008, from http://fh.moh.gov.my/uploads/laporan_tahunan_kesihatan_keluarga.pdf.
- Van Riper, M. (2007). Families of children with Down's syndrome: responding to a change in plans with resilience. *Journal of Paediatric Nursing*, 22(2), April, 116-128.
- WHOQOL Group (1996). *WHOQOL-BREF: Introduction, administration, scoring and generic version of the assessment*. Geneva: Program on Mental Health, WHO.