Care-giving children having Down syndrome - life impacts and psycho-social experiences of mothers

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Caregiving children with DS

Figure

• One in every 800 live-born infants globally. Around 600 annually in Malaysia;

Anomalies

• Associated with congenital cardiac or gastrointestinal anomalies;
• require hospitalization and subsequent follow-up;

Intervention program for developmental delays

• in the community-based rehabilitation centres or the integrated special education programs;
Challenges, coping styles, their strength and resilience, selflessness and less materialism of caregivers have been reported,

The psycho-social aspect of care giving within the context of the Malaysian state of Sarawak with its own geographical features and diverse mix of ethnic groups has yet to be highlighted.

Findings as elaborated constitute a part of the main study guided by the main research question:

‘WHAT ARE THE EXPERIENCES OF MALAYSIAN (SARAWAK) MOTHERS CARING FOR children with DS?’
Methodology

Design - an explorative, qualitative approach; Semi-structured questions were used to guide the face-to-face interviews.

Sample and setting - Purposive sampling approach was used to recruit participants of various ethnicities from within two regions in the Malaysian state of Sarawak - one urban and one rural for maximum variations of their perspectives. Three selected community-based rehabilitation centres, three child health clinics, one government school and one non-government school were accessed to identify children diagnosed with DS and subsequently their mothers.

26 mothers of children having DS aged 18 years and below were recruited.
**Ethical consideration** - Medical research ethics committee and director of the Sarawak Health Department & informed consent from the participants; in instances where participants became emotional as they shared their experiences, as researcher, I maintained an attitude of being concerned, listening attentively to them while I tried not to be overly reactive to their expressions. Contact details of local counselling services and parent support groups were readily at hand so they could be offered to participants if necessary.

**Data collection** - Those who consented were interviewed face to face in their own homes at their convenient time and the interviews were audio-recorded with prior consent; conducted in the language as chosen by the participants and which the researcher was able to understand, either in English, Mandarin, Bahasa Malaysia, the local Iban language or the Hokkien dialect.

**Data management and data analysis** - Translated verbatim transcripts verified by a multi-lingual language expert; analysed thematically;
RESULTS

Participants’ background characteristics:

- 26 participants: Ibans, Chinese, Malays and Bidayuhs;
- More than one third of them had attained < primary school education.
- Age ranged from 22 - 58 years, with a mean age of 42 years; children with DS mean age = 7 years;
- Mainly within the urban region and a rural region about 40 km outside of Kuching
- Mostly married and lived with their spouses, except for two who were single mothers who lived with their extended families.
- Three employed with live-in domestic helpers;
- 17.9% (n=5) with household income <RM 500 (US $159.6)
THEMES AND SUB-THEMES:

**THEME 1: LIFE IMPACTS**
- Family functioning impacts
- Childcare competence
- Motivated to help others

**THEME 2: PSYCHO-SOCIAL EXPERIENCES**
- Difficult emotions
- Felt unsupported
- Worries for the now and the future
- Excitement and joy with child’s progress
THEME 1: LIFE IMPACTS
- Family functioning impacts:

They were subject to tension which could be child’s behavior-related as was described:

“in the morning, the father would scold me and said a lot of things (for being not prepared). The child was the one who threw tantrum; because of this child, it has become an issue in the family almost every morning. I wanted to put clothes on her, she didn’t want to cooperate; insisted to wear a different one and she cried; by around 6.40 am, we must all leave the house; otherwise the school teacher will mark her (the other elder daughter) for being late” (Kay).
Family functioning impacts

Several others described how their families had experienced increased *family cohesiveness*, more supportive and appreciative of one another as a result of the needs to pull family resources together:

“*I see that everybody is working very hard towards helping him, our family is actually very well knitted together; my husband is also very supportive*” (Julia). “*My children are all very understanding, very protective of her. My eldest daughter will not go to the friend’s party if she is not allowed to bring her sister (with DS) along to the party*” (Kua).
THEME 1: LIFE IMPACTS:
- Childcare competence

“One evening, we came out of the car, he still wanted to stay inside... didn’t want to come out, his father had to turn off lighting inside the house, closed the door and left him outside... then only he came out from the car; we must not give in to him; he didn’t behave (like that) after that. We disciplined him consistently...I also smacked him if he did something wrong ... use a wooden spoon, follow the same way I did to the other children. When he showed his anger by throwing things, I will punish him; would not allowed him to go away from his chair unless we told him to do so” (Julia).
This mother Kua who was very committed and motivated in helping as volunteer in a parent support group center spent much of her after working hour for the group. Her commitment to serve was clear as she motivated the other parents during one of the parent group meetings:

“There should be no turning back with our involvement in the parent support group for the sake of our children and others’ children in the Centre” (Kua).
Middle of the night i walked to the nursery where my baby was, i saw one sign board so nicely hung up at the side of the cot, ‘down syndrome’, i was extremely shocked” (Julia). “At first, as mother you just could not accept...You also didn’t have idea about what is DS ... have not seen before...very sad, i only knew how to cry in the hospital” (Tan).

“Other people have a normal child, but i have one like this...felt ashamed to mix with the Other people who said this and that” (Nor). “I just kept child’s condition a secret; I didn’t Tell anyone. During the Chinese New Year celebration, when people came over to our House for visiting, I would move the baby walker further away from them” (Kay).
“My parents-in law asked, ‘is it because when you were pregnant you did not eat proper tonic food? Why deliver this type of child? Is it because during pregnancy you were ‘disturbed’ by something?’ I cried; did not know what to do; just felt numbed” (Tan).

“When i gave birth to this son, his grandparents weren’t very supportive...very frustrated, they did not even touch him... they said they have pain here, pain there, gave all the reasons unable to help in care giving” (Jen)
Among the mothers who were still at child-bearing age, their worries about the risk of another child with DS had influenced their decision about their pregnancy, especially for those whose children with DS was the first-borns.

“Earlier i did plan to have another child of my own, (but) I have decided to adopt the boy (the younger brother)” (Mok). Another mother mentioned: “I was pregnant earlier on... now no more, I have aborted the pregnancy” (Kay).

“The only thing that bothers me: i’m worried that when i grow old, other family members may not take good care of her” (Rose).
THEME 2: PSYCHO-SOCIAL EXPERIENCES
- Excitement and joy with child’s progress

Mothers’ excitement and joy with their children’s progress could be something that others take granted as illustrated below:

“She can help herself to put on her sandals; can dress up herself; arrange her shoes neatly...can behaved well, independent. I can bring her to go anywhere, know how to feed herself. When she spoke any words it is clear. What we have done is worth it” (Kay).

“She is very compassionate, full of love and caring. She is a blessing and motivation to us... she is our comfort, enjoy being with her” (Kua).
Tension within family could occur; more so when mothering a child with additional needs due to the need to meet the needs of family and also child-related care demands;

Increased *family cohesiveness* within their families was evident, due to their needs to pull their family resources together to help their children

Of concern are the issues underlying the various psychosocial-related experiences of mothers with their perceived feeling unsupported, stigmatized;

*Confidence in childcare* and *motivation to help* others, the *joy and excitement with child’s progress* constitute as a part of the experiences of mothering their children having DS though there were other psychosocial concerns;
Findings point to the needs for care professionals in their practice to provide needs-sensitive and timely supportive care to promote mothers’ mental well-being and to facilitate an environment which encourages optimal development of their children.