CARE-GIVING CHILDREN HAVING DOWN SYNDROME – LIFE IMPACTS AND PSYCHO-SOCIAL EXPERIENCES OF MOTHERS

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ABSTRACT

This paper highlights the life impacts and psycho-social experiences of mothers who caregiving their children having Down syndrome in the Malaysian State of Sarawak. In-depth interviews were conducted with 26 mothers who were accessed and recruited via selected health clinics, schools and community-based rehabilitation centres. Bringing up children having Down syndrome had impacted upon mothers to some extent in term of their family functioning, increased competence in childcare and motivation to reach out to others. Psycho-social experience of mothers includes a range of difficult emotions, feeling unsupported, their worries and concerns about recurrence of Down syndrome. Integral to their experience was the excitement and joy with child’s progress. Care-giving children having Down syndrome did have some life impacts upon mothers though their experiences are not all negative. It augurs well for care professionals to be needs-sensitive and to provide timely supportive care to facilitate the mental well-being of mothers and an environment helpful for the optimal development of their children.

Key words: Children with Down syndrome, life impacts, Malaysian, mothers, psychosocial experiences

INTRODUCTION

Mothering children could be a challenging task with various concerns. The demands for bringing up children having Down syndrome (DS) who are disadvantaged in various developmental aspects could be even more in a developing country like Malaysia where resources are still limited. Children with DS are often associated with a variety of developmental delays and anomalies such as congenital cardiac or gastro-intestinal anomalies which often require hospitalization and subsequent follow-up (Kapoor et al., 2014). Most of the mothers would be involved in sending their children with DS to attend the various interventional programs in the community-based rehabilitation (CBR) centres or the Integrated Special Education Programs (Malaysia Social Welfare Department, n.d.). Health care professionals are often involved in the care of children with DS and their mothers either in the hospitals, clinics or in the community context.

Having a child with the diagnosis of DS has been reported to be emotionally overwhelming and stressful. Studies from the western and non-western contexts report about care givers who face a variety of challenges throughout their children’s life which may last for varying periods of time (Chang & McConkey, 2008; Norizan & Shamsuddin, 2010; Truitt et al., 2012; Marchal et al., 2013; Hsiao, 2014; Smith et al., 2014). Caregivers’ coping styles, including their strength, resilience and selflessness among parents have been reported (Chang & McConkey, 2008). The psycho-social aspect of mothers’ experience within the context of the Malaysian State of Sarawak has not been reported. Sarawak as a state has its own geographical features and diverse mix of ethnic groups mainly the Ibans (30.1%), Chinese (26.7%), Malays (23.0%), Bidayuhs, Melanau and the other smaller indigenous groups (Sarawak State Planning Unit, 2009). Many of them live in poverty in the rural, remote locations, each embracing own religion and cultural beliefs (Ling, 2007).

Findings related to life impacts and psycho-social experiences of mothers, which will be elaborated, constitute part of the main study guided by the research question ‘What are the experiences of Malaysian (Sarawak) mothers caring for children with DS?’ Another part of the main study related to care demands and mothers’ quality of life have been
published earlier in Chan et al. (2013) and Chan et al. (2015).

MATERIALS AND METHODS

Study design
A qualitative interview approach was adopted to explore experiences of mothers of children having DS. Specifically, the method of in-depth interviewing which seeks to value participants’ experience of social reality and to gain an understanding of their perspective in a language that is natural to them is the assumption which guided the entire data collection process (Minichiello et al., 1990).

Study setting
Purposive sampling approach was used to recruit mothers of various ethnicities from within one urban and one rural regions in the Malaysian State of Sarawak 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 recruit mothers of children with DS as participants.

Recruitment of participants
Altogether 26 mothers of children with DS below 18 years old were recruited. Sample size was determined by data saturation whereby interviews were stopped when data categories were established with any new data fit into categories already devised.

Data collection
Participants who consented were interviewed face to face in their own homes at their convenient time and the interviews were audio-recorded with prior consent. All interviews were 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 were verified by a multi-lingual language expert. Textual data were managed by the qualitative data analysis software NVivo 7.0. Thematic analysis was guided by Creswell’s six generic steps of data analysis (Creswell, 2003). Textual data was prepared, organized, read through and was coded to generate themes as represented with quotes of participants’ own words. This was followed by interpretation of participants’ experiences. During the coding process, units of information (data segments) that had been coded from within a single interview transcript were inspected and compared with the others within the data sources which also had been coded at. There was a repeated moving back and forth between parts of the data source to explore the context of certain coding references and the various textual data.

Ethical considerations
Prior ethics approvals from gatekeepers for recruitment of participants were obtained. Clear information regarding study’s objectives and method of data collection were conveyed; written informed consent was obtained from the potential participants prior to their participation in the study. They were informed that their choice to participate was voluntary and that they were free to withdraw from participating, if they desired. They were assured of anonymity and confidentiality of data as collected. In instances where participants became emotional as they shared their experiences, an attitude of being concerned but not overly reactive was maintained. Local counselling services’ contact details and parent support groups details were available to be offered to participants if needed.

RESULTS

Participants’ background characteristics
The 26 participants who were recruited came from diverse socio-economic and cultural backgrounds. They were the ethnic Ibans, Chinese, Malays and Bidayuhs, with 38.4% (n=10) attained primary school education or less. Their age ranged from 22 to 58 (mean=42.4; SD=8.3) years. These were mostly married and lived with their spouses. Among them, three engaged stay-in helpers due to their out of home employment. More than two-third reported a monthly household income of RM 2000 and below. Refer to Table 1.

Themes of life impacts and psychosocial experiences and their sub-themes are illustrated in the participants’ own quotes for readers to judge the data interpretation. Refer to Table 2. The names as used are pseudonyms.

Theme 1: Life impacts
As mothers went through the process of bringing up their children with DS, various impacts on their lives, including family functioning, level of competence in childcare and motivation to help others were evident.

Subtheme 1.1: Family functioning impacts
The family functioning impacts upon mothers within the context of care giving children with DS range from family tension on some to increased family cohesiveness on the others.
Table 1. Participants’ background characteristics

<table>
<thead>
<tr>
<th>Characteristics (N=26)</th>
<th>n (%)</th>
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<tbody>
<tr>
<td>Maternal age (years)</td>
<td></td>
</tr>
<tr>
<td>Mean = 42.4 (SD=8.3); Range (22–58)</td>
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</tr>
<tr>
<td>Ethnicities</td>
<td></td>
</tr>
<tr>
<td>Malays</td>
<td>9 (34.6)</td>
</tr>
<tr>
<td>Chinese</td>
<td>9 (34.6)</td>
</tr>
<tr>
<td>Ibans</td>
<td>5 (23.1)</td>
</tr>
<tr>
<td>Bidayuhs</td>
<td>3 (7.7)</td>
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<tr>
<td>Religions</td>
<td></td>
</tr>
<tr>
<td>Islam</td>
<td>9 (34.6)</td>
</tr>
<tr>
<td>Christianity</td>
<td>11 (40.7)</td>
</tr>
<tr>
<td>Buddhism</td>
<td>6 (22.2)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>24 (92.3)</td>
</tr>
<tr>
<td>Single</td>
<td>2 (7.7)</td>
</tr>
<tr>
<td>Highest educational level</td>
<td></td>
</tr>
<tr>
<td>Primary school education and below</td>
<td>10 (38.4)</td>
</tr>
<tr>
<td>Secondary school education</td>
<td>13 (50.0)</td>
</tr>
<tr>
<td>Tertiary education</td>
<td>3 (11.5)</td>
</tr>
<tr>
<td>Employment status</td>
<td></td>
</tr>
<tr>
<td>Unemployed (housewife)</td>
<td>15 (57.7)</td>
</tr>
<tr>
<td>Employed</td>
<td>11 (42.3)</td>
</tr>
<tr>
<td>Household income</td>
<td></td>
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<tr>
<td>Less than RM500</td>
<td>4 (15.4)</td>
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<tr>
<td>RM 501–1000</td>
<td>8 (30.8)</td>
</tr>
<tr>
<td>RM 1001–2000</td>
<td>6 (23.1)</td>
</tr>
<tr>
<td>More than RM2000</td>
<td>8 (30.8)</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
</tr>
</tbody>
</table>

Table 2. Themes and subthemes

<table>
<thead>
<tr>
<th>Theme 1: Life impacts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subtheme 1.1: Family functioning impacts</td>
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<tr>
<td>Subtheme 1.2: Competence in childcare</td>
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<tr>
<td>Subtheme 1.3: Motivation to help others</td>
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<td>Theme 2: Psycho-social experiences</td>
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<td>Sub-theme 2.1: Difficult emotions</td>
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<td>Sub theme 2.2: Felt unsupported</td>
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<td>Sub theme 2.3: Worries for the now and the future</td>
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<td>Sub-theme 2.4: Excitement and joy with child’s progress</td>
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While mothers had other children at their schooling age besides the one with DS, the pressure on them was high due to the care demand involved. Experience of tension could be child’s behaviour-related, as was described below: “In the morning, my husband would scold me (for being not prepared). The child (with DS) was the one who threw tantrum; Because of this, it is becoming 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 together; otherwise the school teacher will mark her (the other elder daughter) for being late” (Kay).

On the other hand, several mothers described how their families had experienced increased family cohesiveness, more supportive and appreciative of one another due to the needs to pull family resources together: “I see that everybody is working very hard towards helping him; our family is actually very well knit together; my husband is also very supportive” (Julia). “My children are all very understanding, very supportive 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).

Subtheme 1.2: Competence in childcare

Mothers’ competence and strength in childcare as they went through the process of care giving their children provide useful insights which could be emulated by the others. Julia, a mother perceived that her child should not be given any special treatment but should be disciplined firmly if he misbehaved: “One evening, we came out of the car but he still wanted to stay inside...didn’t want to come out, his father had to turn off the 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, the same way as I would do to my other kids. When he showed 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).

“It is challenging...we regard him like any other child...only that we need to be patient, we must not give up...he’s a bit slow, unlike other children, I push myself to continue to teach, like teaching other children...if I pity him, dress-up for him, I will cause him to be stunted in his development. If he is always waiting for me to help him... until when are we going to continue to help him? Yes, we are forced to teach him the same way (like for other children... if we love him, we should have less pity for him” (Zuriah).

Subtheme 1.3: Motivation to help others

The motivation to help others though they faced various challenges is evident among mothers. They assumed such roles as peer counsellor, motivator, leaders in non-governmental organization and other parent-support group. The various roles involved sacrifice of their time and effort but they were committed and determined to help. This mother Kua who was very committed and motivated in helping as volunteer in a parent support group 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” (Kua).

Theme 2: Psycho-social experiences

The psycho-social experiences as a theme and its subthemes in this section provide a picture of mothers’ experience within the context of family in relation to care giving of their children having DS. Many experienced the initial difficult emotions, felt unsupported; worries for the now and the future were apparent. At the same time, their excitement and joy with child’s new progress were evident.

Sub-theme 2.1: Difficult emotions

Emotions of disbelief, sadness, anger intertwined with feelings of shame and guilt were shared among mothers, with several who recounted their feelings of being humiliated and stigmatized.

Being told that their child has DS was emotionally overwhelming to mothers and had affected their ability to provide care to their child: “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). “I felt SO ANGRY at that time. If she (baby) cried, the nurse would feed her. I did not want to go there (hospital nursery) to see her. I had no mood to breastfeed her. After discharged home...I kept crying in my bed, kept looking at the words ‘Down syndrome’ on the baby card” (Kay).

These different emotions did not occur in a linear manner or progressively one after another. “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).

Some mothers suspected the child’s condition may have been caused by what they drank or some deeds they had committed. A sense of guilt was evident: “I did drink a lot of green tea during my pregnancy. I suspected it might have caused the DS” (Chara).

For some mothers, the sense of being humiliated and stigmatized was perhaps the most hurting to them, not confined to any one particular ethnic group: “There was once a stage performance by our children from the Centre in the shopping complex; no one from among the crowd clapped their hands after the performance. One parent even asked me, ‘these children are “cacat” (disabled) can they perform?’ I felt like my heart was ‘bleeding’” (Kua).

Whenever this mother Kua brought her daughter who had DS to the wedding dinner, she would be extra cautious due to her concern that other guests may not be happy; she may be blamed for bringing bad luck. Mother Aziah talked about her encounter in a clinic: “I overheard an elderly lady nearby who told her pregnant daughter, ‘don’t look at the child over there, otherwise, yours (child) MAY also become like that’. That’s why, if there’s anyone pregnant in the house, I wouldn’t dare to go there...felt lonely and alienated but I just kept quiet”.

Sub theme 2.2: Felt unsupported

Some mothers felt they were not supported by their spouses or extended families emotionally or practically, in particularly among the Chinese mothers. “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). From another mother Jen: “He (husband) went out most of the evenings...seldom at home at night. He did his own thing, I did my child care”. Julia’s experience of lack of access for support from her in-law is evident, “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).

Sub theme 2.3: Worries for the now and the future

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). For many of the mothers, their concerns their child’s ability for self-care and future care provision were profound: “That’s 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). It is noteworthy to know how some of the mothers placed their hopes on the child’s siblings to take over the future care provision when they get too old to care: “I have delivered the younger brother (sibling); hope that he can help to look after her next time. We also plan to give her our house which will be secured under her name” (Wang).
Sub-theme 2.4: Excitement and joy with child’s progress

Mothers’ excitement and joy with their children’s progress could be something that others take granted. The quotes of the three mothers below are illustrative:

“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). Julia’s excitement with child’s progress was further expressed inside the journaling which she showed to me during the session I had with her in her house: “Such a joy and excitement Jo (the child) could speak more words. Today, he learnt to speak 3 words in a sentence, use more grammar and verbs” (Julia). “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).

The experience of joy during their mothering process was obvious among mothers who described their children as a blessing, and fun to be with. Apparently, their joy increased further especially as their children were able to be responsive and reciprocate.

DISCUSSION

Not all negative experiences

Motherhood experience has been described as challenging even when mothering a child who is normally developing. Findings Tension within family could occur; more so when mothering a child with additional needs due to the need to meet the various needs. Family functioning impacts such as increased family cohesiveness within their families was evident, due to their needs to pull their family resources together to help their children. To reiterate, 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 psycho-social concerns that they had experienced. Mothers’ resilience and positive experiences, including their role as activist mothers, working to effect change on behalf of their children with disability and for other disabled people should be highlighted to represent a more balanced perspective about family having a child with DS (Cuskelley et al., 2008). This is further substantiated in some studies across different cultural contexts, which highlighted mothers’ strength, competence, and resilience in their journey of care giving their children with a disability (Chang & McConkey, 2008).

Making sense of mothers’ psycho-social experiences

Of concern are the salient issues underlying the various psychosocial-related experiences of mothers with their perceived feeling unsupported, stigmatized and the associated isolation within a social context that is negative and critical. These could hinder their adjustment of their care giving role (Sheldon et al., 2007). It would do well for care professionals to recognize that mothers of children who have just been diagnosed with DS, their energy level and readiness to care for their child could be affected. There is a need to provide supportive care through home-visit follow-up and introduction to parent support group. Self-blame could be due to a lack of understanding about developmental disabilities. The feeling of shame and avoidance from socializing with others to escape unfriendly stares could disadvantage them in their social support network (Chang & McConkey, 2008). Sharing of relevant information with mothers could potentially reduce the occurrence of self-blame and misunderstanding. Mothers’ feeling humiliated and stigmatized could be related to the societal stereotyping towards children with DS as less able; they could be disabled by the same social barriers as the disabled people themselves.

Findings show that among the mothers of various ethnic groups, the cultural variations among them did not have obvious difference in term of their childcare competence bringing up children with DS. Similarly, their experience of difficult emotions were irrespective of their ethnicities or cultural differences. However, in term of family functioning impacts, apparently the few of the Chinese mothers had highlighted their daily experience of tension in the family coping with a child having DS. Predominantly, more Chinese mothers than other mothers who reported feeling unsupported and blamed, more so if the child with DS is a boy due to their in-laws’ expectation for boys in the family to carry the ‘family surname’. This could also be reflective of the Chinese traditional beliefs of disabilities being attributed to family curse or wrong acts of parents as reported among the Hong Kong Chinese mothers (Chang & McConkey, 2008, Chou et al., 2009).

Hope for another child was mixed with concerns of recurring DS. Care professionals may encounter situations giving rise to ethical dilemma such as request for termination of pregnancy due to DS diagnosis. Supports for mothers with previous history of child with DS for their concerns without judgment are warranted. As educational preparation for prenatal testing of developmental disabilities is not yet a norm, it is timely to include this component into the nursing training (Louise et al., 2016). Worries about future care provision appeared
to be compounded by the relatively under-developed formal support system locally which is apparently different from the developed countries (Chan, 2010). Much emphasis is placed upon familial support (Chang & McConkey, 2008, Chou et al., 2009). There was uncertainty as to the extent siblings could be depended on for a life-long continuum of care (Ling, 2007).

Drawing on the resiliency model of family adaption, family’s resiliency is the ability of a family to respond positively to an adverse event and emerge strengthened, more resourceful and confident (McCubbin & McCubbin, 1993). Resilience is fostered by protective factors such as the availability of better formal supportive care, besides the familial resources of immediate and extended families, other social supports, with a social context of acceptance with changes in public attitudes towards children with DS. These, together could facilitate mothers’ coping and wellbeing and the maximal development of their children with DS.

CONCLUSION

This indigenous study which uses qualitative interviewing on a purposive sampling of mothers from across different socioeconomic background provides important insights with much details and depth pertaining to the life impacts and the psychosocial aspect of care-giving children having DS in a developing country of Malaysia. 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.

ACKNOWLEDGMENTS

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