

**EXPLORATION OF MOTHERS' EXPERIENCES  
OF HAVING A CHILD WITH  
DOWN'S SYNDROME  
AND THEIR QUALITY OF LIFE: A MIXED  
METHOD STUDY**

**CHAN KIM GEOK**

**THESIS SUBMITTED IN FULFILMENT OF THE  
REQUIREMENTS FOR THE DEGREE OF DOCTOR OF  
PHILOSOPHY**

**UNIVERSITI MALAYA  
KUALA LUMPUR**

**2012**

## **Abstract**

Mothers of child with the unexpected diagnosis of Down's syndrome (DS) were reported to be dealing with an on-going, chronic situation in supporting their child's various needs throughout their life. They were reported to perceive lower quality of life. There are little published studies related to experiences of mothers in Malaysia, particularly in the Borneo state of Sarawak with its diverse socio-economic, cultural and geographical background. The effects of having a child with DS on the quality of life (QOL) of mothers are little known. The purpose of the study is to understand the experiences of mothers having a child with DS and their QOL in the local context. It also aims to examine the relationship between mothers' selected background variables and their perceived QOL. Parallel mixed research design approach was utilized. Qualitative interviews were conducted to explore the experiences of 26 biological mothers of child having DS aged  $\leq 18$  years old. QOL of another 161 biological mothers were assessed using the WHOQOL-BREF. These mothers were all accessed from the various institutions which provide interventional or educational programs for children with disabilities. These institutions were located within and nearby the capital city of Kuching and the rural region of Samarahan Division within the Borneo state of Malaysia (Sarawak). Audio-recorded interviews were transcribed and analyzed thematically. Quantitative data analysis was done using Statistical Package for Social Sciences 19.0. Mothers' experiences were represented in the five major themes and subthemes which emerged, namely the *various emotions*, *extra care demands*, *variation of supports*, *coping strategies* and *life impacts*. Experiences of positive life impacts of competence and growth, joy of parenting and excitement with child's development were evident though there were worries and extra care demands. The outcomes of mothering a child with DS are not completely negative among mothers, though this could be related to

their accessibility to family resources of various sources of supports and coping strategies. An overall QOL mean score of  $14.0 \pm 1.84$  was obtained. The relatively lower mean score for QOL of environmental supports domain (mean= $13.3 \pm 2.1$ ) indicates the existence and extent of gap in relation to their experience of difficulty in their access to environmental support in meeting the needs for care giving of their child. Selected background variables (locality, education and income levels, marital status) were significantly correlated with their perceived overall QOL, with  $\rho(161) = 0.22$  to  $0.28$  ( $p < 0.01$ ). Maternal age was found to be inversely correlated with their overall and QOL of physical health domain. Regression analysis shows that rural-urban locality, education and income levels, marital status and maternal age together accounted for 14.5% of the variance in the sample's QOL score. Mothers who have a lower education and income levels, living in the rural locality, older in age and as singles are more likely to perceive poorer overall QOL. Various recommendations for care professionals in their practice, policy, education and future research are presented.

## ABSTRAK

Terdapat jumlah bukti yang sedikit sahaja daripada kajian yang diterbitkan mengenai pengalaman para ibu di Malaysia (khususnya di Negeri Sarawak) yang mempunyai latarbelakang sosio-ekonomi dan kebudayaan tersendiri. Tujuan kajian ini adalah untuk memahami pengalaman para ibu yang mempunyai anak yang menghidap SD dan kualiti kehidupann (KK) mereka dalam konteks tempatan. Ia juga bertujuan menyelidiki hubungan antara perbezaan latarbelakang ibu yang terpilih dan tafsiran mereka terhadap KK. Kaedah kajian campuran selari (*parallel mixed research design*) digunakan untuk kajian ini. Temuduga kualitatif telahpun dijalankan untuk mengkaji pengalaman 26 orang ibu yang mempunyai anak yang SD. KK sejumlah 161 orang ibu yang mempunyai anak yang SD pun dinilai dengan menggunakan instrumen WHOQOL-BREF. Para ibu tersebut telah dihubungi melalui pelbagai institusi yang menyediakan program intervensi untuk kanak-kanak yang kurang upaya. Institusi ini berada di dua kawasan di Sarawak (Bahagian Kuching dan Samarahan di Malaysia (Sarawak). Temuduga yang dirakamkan melalui rakaman audio telahpun di transkripsi dan dianalisa secara tematik. Analisa data kuantitatif telah dijalankan dengan menggunakan ‘Statistical Package for Social Sciences’ (version 19.0). Pengalaman para ibu tersebut telah dibahagikan kepada lima tema utama dan subtema yang timbul, iaitu *keperluan penjagaan yang lebih*, *pelbagai emosi*, *perbezaan sokongan*, *strategi menangani dan impak terhadap kehidupan*. Pengalaman para ibu yang mempunyai impak kehidupan yang positif, kegembiraan dan keterujaan terhadap perkembangan anak, kekuatan dan kemajuan adalah ketara, walaupun terdapat pengalaman mengenai pelbagai kebimbangan dan keperluan penjagaan tambahan. Nampaknya, kesan penjagaan anak yang SD tidak semuanya negatif di kalangan para ibu, walaupun perkara tersebut berhubung-kait dengan aksesibiliti kepada sumber bantuan keluarga pelbagai

punca dan strategi-strategi untuk menanganinya. Skor 'mean' KK keseluruhan  $14.0 \pm 1.84$  telah didapati. Dapatan tentang KK berhubung dengan 'domain' 'sokongan alam sekeliling' (N=161) dengan skor 'mean' 'domain' yang agak rendah ( $13.28 \pm 2.11$ ) telah memberi gambaran tentang sejauhmana pengalaman ibu yang mengalami kesukaran mendapat sokongan alam-sekeliling. Analisa 'korelasi' beberapa 'variables' latarbelakang ibu yang terpilih (iaitu lokasi tempat tinggal, pendidikan, pendapatan, umur ibu, taraf perkahwinan) dan KK keseluruhan mereka menunjukkan keketaraan 'statistical' ( $p < 0.05$ ) dan koefisien korelasi rho di antara 0.17 ke 0.28. Umur para ibu didapati berkorelasi secara 'inverse' dengan KK keseluruhan dan KK 'domain' kesihatan fizikal'. Analisa 'regression' yang selanjutnya menunjukkan bahawa kombinasi 'linear' beberapa 'variables' latarbelakang yang terpilih ini menyumbang kepada 14.5% 'variability' KK dalam sampel. Para ibu daripada golongan yang kurang pendidikan and berpendapatan rendah, lokasi tempat tinggal di kawasan luar bandar, yang telah lanjut usia, sebagai ibu tunggal lebih tinggi kemungkinan menunjukkan KK yang kurang memuaskan. Beberapa cadangan untuk para profesional dalam bidang penjagaan, pendidikan, polisi dan kemungkinan kajian masa hadapan akan dikemukakan.

## **Acknowledgement**

I would like to express my special thanks and appreciation to the Director of the Sarawak State Planning Unit, Director of the Sarawak State Health Department, Director of the Malaysia Ministry of Education, Director of the Sarawak Education Department and Director of the Sarawak Social Welfare Department for their kind approval for me to access the various institutions as well as to access and recruit participants for this study. My sincere thanks and appreciation to Associate Professor Dr Khatijah Abdullah Lim (University Malaya) and Associate Professor Dr Ling How Kee (University Malaysia Sarawak) for their advice, assistance and strong support throughout the implementation of this study. Special thanks and appreciation are extended to the staff of the various community-based rehabilitation centers, child health clinics and schools for their support and assistance in facilitating the access to participants for this study. I would like to also thank University Malaya for the approval of the postgraduate research fund (grant no. IPPP/UPDiT/Geran (PPP)/PS171/2008C). My sincere thanks go to all the mothers for sharing their experiences, without them this study would not have been possible.

My special thanks and appreciation is extended to friends Doreen Tee, Chan Feng Kuan, Adrian Chung, Kui Choo and Janet Lee who rendered their helps in time of needs during the process of the study. I would also like to express my gratitude to Dr Ling Siew Eng, Dr Pauline Lai and Dr Mohammed Mizanor for their advice related to data analysis directly and indirectly. Not forgetting Deborah Wong, Victor Gonzales and Ruth Wong for their support and encouragement.

I am most grateful to my husband who has been very supportive in providing all the help without which I would not be able to proceed with the study. Last but not least, I must thank my three lovely children Esther, Hosanna and Samuel for their prayers, love, sacrifice and understanding throughout the period of the study.

<b>TABLE OF CONTENT</b>	<b>Page no.</b>
<b>Abstract</b>	ii
<b>Acknowledgement</b>	vi
<b>List of contents</b>	viii
<b>List of figures</b>	xv
<b>List of tables</b>	xvi
<b>Instrumentation</b>	xvii
<b>Glossary of terms</b>	Xvii
<b>List of appendices</b>	xvii
<b>List of Abbreviations</b>	xvii
<b>List of appendices</b>	xvii
 <b>List of contents:</b>	
<b>CHAPTER ONE: INTRODUCTION</b>	1
1.0 Background of the study	1
1.1 Background information about children with DS	1
1.1.1 Related health problems	3
1.1.2 Developmental delays and impairment	3
1.2 Problem statement	5
1.2.1 Statistics	5
1.2.2 Personal interest	5
1.2.3 Previous research studies	6
1.3 Main research questions which guide the study:	10
1.3.1 Specific research objectives	11
1.4 Outline of research design	11
1.5 Situating the research in context: the Borneo state of Sarawak	12
1.5.1 Location and population	12
1.5.2 Demographics	14
1.6 Significance of study	15
1.6.1 Influence practice	16
1.6.2 Expand knowledge base	16
1.6.3 Influence policies	16
1.7 The research framework	17
1.8 The focus and organization of the thesis	18
1.9 Summary	20



<b>CHAPTER TWO: LITERATURE REVIEW</b>	21
2.0 Introduction	21
2.1 Literature search strategy	22
2.1.1 Criteria for inclusion and exclusion	22
2.1.2 Sources of literature for review	22
2.1.3 Combinations of key-words	23
2.1.4 Key studies reviewed	23
2.2 Studies using qualitative approach	24
2.2.1 Care giving experiences and emotional responses	24
2.2.2 Emotional responses and Burden (1991)'s psycho-social transition model	27
2.2.3 Some positive parental experience	29
2.2.4 Parental concerns of child's future	30
2.2.5 Significance of supports and parental experiences	31
2.2.6 Summary	33
2.3 Studies using quantitative approach	34
2.3.1 Socio-environmental supports, parental background variables and parental well being	35
2.3.2 QOL as a quantitative measure	40
2.3.2.1 Definitions and uses	40
2.3.2.2 Choices of QOL measures	43
2.3.3 QOL related studies	44
2.3.4 Summary	49
2.4 Studies using mixed methods	49
2.4.1 Socio-environmental supports and parental well-being	49
2.4.2 Parental wellbeing and related family variables	51
2.5 Summary	55
<b>CHAPTER THREE: RESEARCH DESIGN AND METHODS</b>	60
3.0 Introduction	60
3.1 Development of mixed method research	60
3.1.1 Paradigmatic debate	62
3.1.2 Pragmatism	63
3.1.3 Strengths and limitation of MMR	64
3.1.4 Methodological considerations	65
3.2 Research design of the study	66
3.3 Methods and instruments	69
3.3.1 Qualitative in-depth interviews	69

3.3.1.1 Advantages	70
3.3.1.2 Use of interview guide	70
3.3.2 Use of questionnaire	71
3.3.2.1 Validity and reliability of WHOQOL-BREF	74
3.4 Ethical considerations	75
3.4.1 Institutional ethics approval	76
3.4.2 Information to participants and informed consent	77
3.4.3 Confidentiality and anonymity	77
3.4.4 ‘Do no harm’	78
3.5 Pilot study	78
3.5.1 Aims and conduct of pilot study	78
3.5.2 Lessons learnt from the pilot study	79
3.5.3 Summary of pilot study	83
3.6 Research sites	84
3.7 Research participants	85
3.7.1 Sampling criteria	85
3.7.2 Sampling technique, sample size	86
3.7.2.1 Qualitative study sampling technique and sample size	86
3.7.2.2 Quantitative study sampling technique and sample size	87
3.8 Data collection procedure	89
3.8.1 Qualitative interviews	89
3.8.1.1 Establishing rapport and making initial contacts	89
3.8.1.2 Accessing participants for interviews	91
3.8.1.3 Before the actual interview	93
3.8.1.4 During interviews	95
3.8.1.5 Subsequent interviews	98
3.8.2 Questionnaire administration	99
3.9 Data management and data analysis	101
3.9.1 Qualitative data management and data analysis	101
3.9.1.1 Data quality	106
(a) Procedural rigor	107
(b) Interpretive rigor	108
(c) Reflexivity/reflection on researcher’s role	112
3.9.1.2 Presenting the findings	113
3.9.2 Quantitative data management and analysis	114
3.10 Chapter summary	117
<b>CHAPTER FOUR: QUALITATIVE FINDINGS OF MOTHERS’ EXPERIENCES</b>	<b>118</b>

4.0. Introduction	118
4.1 Participants' background characteristics	118
4.1.1 Marital status, maternal and child's age and number of children	120
4.1.2 Ethnicity, locality, religions	121
4.1.3 Education, income, employment and transport	121
4.1.4 Background information of the children	122
4.2 Experiences of mothers having a child with DS	128
4.2.1 Various emotions	129
4.2.1.1 Shock and disbelief	130
4.2.1.2 Sadness	130
4.2.1.3 Anger	132
4.2.1.4 Difficulty in accepting child	133
4.2.1.5 Shame and self-blame	133
4.2.1.6 Worries	135
4.2.1.7 Excitement with child's developmental progress	140
4.2.1.8 Joy of mothering child	142
4.2.2 Extra care demands	144
4.2.2.1 Health-related extra care demands	144
4.2.2.2 Developmental delay-related extra care demands	145
4.2.2.3 Child behavior-related extra care demands	135
4.2.3 Variation of supports	151
4.2.3.1 Informal supports	152
4.2.3.2 Formal support	161
4.2.3.3 Environmental supports	164
(a) Financial constraints	165
(b) Limitation related to transports	167
(c) Inadequacy of basic public facilities	169
(d) Informational support needs and challenges	169
4.2.4 Coping strategies	171
4.2.4.1 Reframing perspectives	172
4.2.4.2 Maintaining hopefulness	173
4.2.4.3 Religious beliefs and convictions	174
4.2.5 Life impacts	175
4.2.5.1 Being stigmatized	175
4.2.5.2 Family role impacts	177
(a) Family tension	177
(b) Family cohesiveness	177
4.2.5.3 Personal growth and competence	178
(a) In advocating for child	179
(b) In handling child behavior	179

(c) In helping child to be more independent	181
4.2.5.4 Motivated to reach out to help others	181
4.3 Chapter summary	183
<b>CHAPTER FIVE: QUALITY OF LIFE RELATED FINDINGS</b>	<b>185</b>
5.0 Introduction	185
5.1 Participants' background characteristics	185
5.1.1 Ethnicities, age of mothers and child	187
5.1.2 Education, employment, income, transport and locality-related differences	188
5.1.3 Religions and marital status	190
5.1.4 Child care related information	190
5.1.4.1 communication with child	190
5.1.4.2 Supports in care giving	191
5.1.4.3 Service provisions for child with DS `	192
5.1.4.4 Child development and health related background	193
5.1.5 Child care related information sources	194
5.2 QOL-related findings	195
5.2.1 Overall and domain-specific QOL	195
5.2.3 Single-items (Q. 1 and Q. 2)	197
5.3 Relationship between selected background variables and QOL	198
5.3.1 Exploratory data analysis	199
5.3.2 Correlation analysis between selected background variables, overall and domain-specific QOL	200
5.3.2.1 Rural-urban locality, education and income	200
5.3.2.2 Maternal age	201
5.3.2.3 Marital status	202
5.3.2.4 Linear regression analysis	202
5.3.2.5 Religion, ethnicity and employment	203
5.3.2.6 Child and family-related variables	203

5.4 Chapter summary	203
<b>CHAPTER SIX: DISCUSSION</b>	205
6.0 Introduction	205
6.1 Discussion of mothers' experiences	206
6.1.1 Making sense of the various emotions	206
6.1.1.1 Feelings of shock, difficulty in accepting, anger, sadness and shame	207
6.1.1.2 Worries	210
6.1.1.3 Feelings of excitement, joy and acceptance	215
6.1.1.4 Summary	215
6.1.2 Extra care demands	216
6.1.3 Variation of supports	220
6.1.3.1 Variation with access to informal supports	220
6.1.3.2 Problems with access to informal supports	220
6.1.3.3 Issues with professional service provisions	222
6.1.3.4 Issues with environmental supports	226
6.1.3.5 Barriers in accessing informational resources	227
6.1.3.6 Mismatch between care demands and supports, the 'double jeopardy'	228
6.1.3.7 Summary	229
6.1.4 Coping strategies	230
6.1.4.1 Reframing perspectives	230
6.1.4.2 Maintaining hopefulness	231
6.1.4.3 Religious beliefs and convictions	232
6.1.4.4 Summary	233
6.1.5 Life impacts	234
6.1.5.1 Being stigmatized	234
6.1.5.2 Not all negative experiences	236
6.1.5.3 Summary	238
6.2 QOL of mothers	239
6.2.1 Correlation of background variables with mothers' QOL	241
6.2.2 Summary	246
6.3 Discussing themes of mothers' experiences and QOL	247

6.4 Interrelatedness among the themes and QOL	249
6.5 Summary of major findings of mothers' experiences and QOL	252
<b>CHAPTER SEVEN: CONCLUSION</b>	256
7.0 Introduction	256
7.1 Implications for practice, policies and education	257
7.2 Limitations and strengths	258
7.2.1 Limitations	258
7.2.2 Strengths	260
7.3 Recommendations	262
7.3.1 Recommendations for practice in relation to findings	262
7.3.2 Recommendations for policies	268
7.3.3 Recommendations for education	269
7.3.4 Recommendations for future research	270
7.4 Closing reflections	272
7.4.1 Research with mothers as participants	272
7.4.2 Conducting research that empowers mothers	270
7.4.3 Lessons learnt using MMR study design	274
7.5 What this study adds to the existing literature	275
7.6 Conclusions	275

## LIST OF FIGURES:

Figure 1.1	Map of Malaysia showing Sarawak located on the Borneo Island	13
Figure 1.2	Part of the Sarawak administrative divisions	14
Figure 1.3	Research framework	17
Figure 2.1	The WHO's four dimensions of quality of life	41
Figure 3.1	Research design framework	67
Figure 3.2	Four domains of the WHOQOL-BREF	72
Figure 3.3	Road map accessed from <a href="http://www.google.maps.com">www.google.maps.com</a>	92
Figure 3.4	Outline of the generic steps of data analysis (modified from Creswell, 2003)	102
Figure 3.5	Coding from one document	365
Figure 3.6	Review the context of segments coded	366
Figure 3.7	Select a node to be merged with another node	367
Figure 3.8	Merging one node into another node	367
Figure 3.9	Uncoding	363
Figure 3.10	Writing memo to be linked to a selected tree node	368
Figure 3.11	Memo with file name 'support' written and linked to tree node 'support network'	368
Figure 5.1	Correlation between maternal age and QOL of physical health	202
Figure 6.1	Framework of discussion of inter-relatedness among themes and with QOL	252

## LIST OF TABLES:

Table 1.1	: Statistics of Down's syndrome (new cases) over three years	306
Table 3.1	Internal consistency reliability of WHOQOL-BREF	83
Table 4.1	: Mothers' background characteristics	119
Table 4.2	: Sites accessed and numbers of participants (N=26)	120
Table 4.3	: Child-development related information	122
Table 4.4	: Child-health related information	123
Table 4.5	: Attendance to service provisions	123
Table 4.6	Individual mothers' background characteristics	124
Table 4.7	: Outline of major themes and subthemes	128
Table 5.1	: Summary of mothers' background characteristics	186
Table 5.2	: Selected background characteristics by localities	189
Table 5.3	: Mothers' communication with child	190
Table 5.4	: Family support by ethnicity	191
Table 5.5	: Family supports by marital status	191
Table 5.6	: Attendance to service provision	193
Table 5.7	: Child-development related information	193
Table 5.8	: Child-health related information	194
Table 5.9	: Information sources accessed by locality	194
Table 5.10	: Overall QOL and domain-specific QOL	195
Table 5.11	: Distribution of domain (DOM) and item means	196
Table 5.12	: Single-item (Q. 1 and Q. 2)	198
Table 5.13	: Tests of normality of overall and domain-specific QOL	199
Table 5.14	: Spearman's rho correlations between selected background variables and QOL	200
Table 5.15	: Linear regression analysis	381



## **INSTRUMENTATION:**

Instrumentation A: Interview guide	278
Instrumentation B: Questionnaires	281
Instrumentation C: Computer software NVivo 7.0 for computer assisted qualitative data analysis	300

<b>GLOSSARY OF TERMS</b>	302
--------------------------	-----

## **List of Abbreviations**

CP: Cerebral palsy

DS: Down's syndrome

CBR centre: Community-Based Rehabilitation centre

MOH: Ministry of Health

NECIC: National Early Childhood Intervention Council

## **LIST OF APPENDICES:**

Appendix A : Statistics of Down's syndrome (new cases) over three years	306
Appendix B : Sarawak Facts and Figure 2009	307
Appendix C : Keyword combinations used for the literature searches	309
Appendix D : Summary of key articles reviewed	310
Appendix E : Verification of translation of key interview guide	327
Appendix F : Verification of translation of questionnaires Section I and II	330
Appendix G : Request for permission to use the WHOQOL-BREF	333
Appendix H : Information to the mothers (in three languages)	336

Appendix I	: Consent form (in three languages)	340
Appendix J	: Institutional ethics approval letters	344
Appendix K	: Response slip	353
Appendix L	Preparation for conducting interview	354
Appendix M	: Email from a participant	355
Appendix N	: A sample of journaling	357
Appendix O	: NVivo 7.0 data analysis illustrations (Figure 3.5 - 3.11)	365
Appendix P	Coding summary report	369
Appendix Q	: Verification of translation of transcripts	374
Appendix R	: SPSS syntax (for data checking and computing domain mean scores)	377
Appendix S	: Descriptive exploratory data analysis	378
Appendix T	Table 5.15 Linear regression analysis	381
<b>REFERENCES</b>		<b>382</b>

# CHAPTER ONE

## INTRODUCTION

### 1.0 Background to the study

For many mothers, their experiences as mothers have brought them not only happiness and joy but also respect from their immediate families and general community (Mbekenga, Christensson, Lugina & Olsson, 2011). To some others, motherhood experience is perceived as a challenging task with endless concerns (Liamputtong, Yimyam, Parisunyakul, Baosoung & Sansiriphun, 2004). There are others who struggle with the care demands and challenges while trying to juggle between their paid job and motherhood even though their child is developing normally or non-disabled (Lupton & Schmied, 2002). Question arises as to what it is like for mothers to have a child with disability<sup>1</sup> such as Down's syndrome (DS) who is disadvantaged in various developmental aspects (social, language, self-help, cognitive and motor)? The demands on motherhood for having a child with DS could be even more challenging in a developing country context like Malaysia where resources are still limited or lacking.

In order to facilitate our understanding of the experiences of mothers having a child with DS, the sections that follow provide some background contextual information about child with this condition.

---

<sup>1</sup> Various other terms have been used to describe a child with DS, such as a child with special needs, a child with additional needs, a disabled or special child. In this study, 'child with a disability' is used.

## **1.1 Background information about children with DS**

Children with DS could be born to mothers irrespective of religions, ethnic background and socioeconomic status. It is reported that condition of DS occurs approximately one in every 800 among live-born infants (Baum, Nash, Foster, Spader, Schaub & Coury, 2008). An earlier Malaysian study (Boo, Hoe, Lye, Poon & Mahani, 1989) reported the incidence of DS as one in every 1000 live births. About 95% of which are attributed to an extra chromosome 21 due to disjunction, hence the name trisomy 21, while 3-4% are caused by translocation of chromosomes 15, 21 or 22, and one to two percent demonstrate mosaicism where cells could have both normal and abnormal chromosomes (Baum, et al., 2008; Wong, 1993).

DS is the most recognizable and well-described genetic (chromosomal) syndrome encountered in pediatrics (Baum, et al., 2008). It can usually be diagnosed at birth by their clinical manifestation alone or through chromosome study. Various clinical features which are often observed in child with DS include 'small round skull with a flat occipital region, inner epicanthal folds, upward outward slant of the eyes, small nose with a depressed bridge, protruding tongue, hypoplastic mandible, high-arched palate, short, thick neck, hypotonic musculature with protruding abdomen, hyper-flexible and lax joint, broad short and stubby hand and feet' (Wong, 1993, p. 559). The term 'Mongoloid' was once widely used to describe individuals with these features due to similarity of these features to that of the Asian or Mongolian race. However, this term was no more in use since the 1970s and was replaced by the term 'Down's syndrome', named after the doctor John Landon Down who first described the various features in the year 1866 (Baum, et al., 2008).

### **1.1.1 Related health problems**

A child with DS is often born with other congenital anomalies involving the cardiac conditions (Wells, Barker, Finley, Colvin & Finley, 1994), gastro-intestinal or other organ systems which required various urgent care and treatments in the hospital immediately after delivery, and subsequent medical follow-up for their health conditions (Baum, et al., 2008; Schrojenstein, Lantman-de Valk, Haveman & Crebolder, 1996). A child with DS is also associated with a higher mortality rate due to infections, and a higher risk of developing malignancies, especially leukemia (Schrojenstein, et al., 1996).

### **1.1.2 Developmental delays and impairment**

Besides the child's congenital anomalies, parents having a child with DS are reported to have been frequently confronted with various challenges during the process of their care-giving due to their child's extra care giving needs associated with developmental delays and impairments in the aspects of personal-social and psychomotor skill development. A child with DS also commonly has problems of expressive language-communication (Laws & Bishop, 2004). Besides these, individuals with DS form the largest group of persons with intellectual disability (Schrojenstein, et al., 1996). They perform less well than appropriately matched comparison groups on tests of verbal short-term memory, despite performing relatively well on non-verbal short-term memory tasks. A child with DS also often suffers from visual and auditory sensory impairments (Schrojenstein, et al., 1996). In term of personal-social aspect, a child with DS might be predisposed to behavior such as being disruptive, non-compliant, over active and autistic characteristics (Laws & Bishop, 2004; Malaysia, Ministry of Health, 2004). Characteristics such as being sociable and upbeat to their parents, friendly, lovable and cheerful have been reported in Hodapp, Ly,

Fidler & Ricc (2001) and Stewart, Law, Burke-Gaffney, Missiuna, Rosenbaum, King, et al. (2006).

In relation to child's developmental delay, most parents would be involved in sending their child with DS to various interventional programs and therapies in various settings such as hospitals, child health clinics or community-based rehabilitation centers (CBR). These interventional activities are reported to be helpful in promoting the child's development, including prevention of modifiable risk factors to the child's speech-language learning (Buckley, 2000; Malaysia, Ministry of Health, 2004).

To summarize, a child with DS is often born with congenital anomalies and has associated delays and impairments in personal-social and psychomotor skill developments.

Furthermore, there are frequently problems with expressive language-communication with differing levels of disabilities with his or her unique behavioural characteristics. This might pose some impacts on the parents after delivery of their child due to care giving of child (Flaherty & Glidden, 2000; Gatford, 2001; Plant & Sanders, 2007). They were reported to experience more challenges due to child's limited ability to function independently as compared to those who have non-disabled or typically developing children during their day to day care-giving (Baum, et al., 2008; Glidden & Schoolcraft, 2003).

## **1.2 Problem statement**

### **1.2.1 Statistics**

At the national level, in average, more than 600 new reported cases of children with DS are added to the statistics of children with special needs (new cases) annually, according to the available annual reports over three consecutive years (for years of 2004, 2005 and 2006) (Table 1.1 in Appendix A) from the Ministry of Health (Malaysia, MOH, n.d. a, b, c). The just-mentioned figure could be actually lower due to under reporting. The annual reports indicate that DS constitutes as one of the main categories for children with disabilities, besides autism, cerebral palsy (CP) or attention deficit hyperactive disorders. It constitutes almost a quarter of the total number of the children (below twelve years old) with newly reported disabilities. Sarawak is one of the few Malaysian States with a relatively high percentage of children with this disability due to DS (Sarawak, Health Department, 2007a; Malaysia, MOH, n.d. a, b, c). This indicates that children having DS, in particular, their parents are considered of significance as a group in Sarawak, so as to be given the research attention.

### **1.2.2 Personal interest**

Personally, the interest in exploring mothers' experience of having a child with DS in the local context has been influenced by my personal background. My earlier role as a paediatric nurse provided me the experience of nursing children with DS in the paediatric wards in the government referral hospital. These children were often referred from other nearby district hospitals and were admitted to the ward for various diagnostic and therapeutic procedures due to their congenital medical or surgical conditions. Having seen the mothers of these children giving care to their children, resting on arm-chairs next to

their children's cots in the ward day and night, it dawned on me the challenges related to having a child with DS.

My enthusiasm in exploring mothers' experiences grew more intense after listening to a mother who testified in a public meeting her experience of various challenges in helping her child with disability to achieve her potential in development. The question that dawned on me then was 'how much do I understand the experiences of mothers having a child with DS in the local context?' I also wondered whether these mothers' experiences affect their quality of life (QOL). I believe that understanding both their experiences and measuring their QOL would give us some reference as to what is valued and desired from the mothers' perspectives.

### **1.2.3 Previous research studies**

Though a substantial amount of studies related to experiences of mothers having a child with DS in the last two decades were cited, much of these were however conducted in the context of the western developed countries. Fewer studies were conducted in developing countries such as Malaysia.

In relation to having a child with DS, mothers were likened to be dealing with an on-going, chronic situation in supporting their child's various needs throughout their life (Chou, Pu, Lee, Lin & Kroger, 2009). Having a child with the unexpected diagnosis of DS was reported as emotionally overwhelming and stressful for some families, affecting their parental function due to depression, sorrow or marital dissatisfaction (Gatford, 2001; Glidden & Schoolcraft, 2003; Hedov, Anneren & Wikblad, 2000; Lam & Mackenzie,



2002). Furthermore, an increased risk for stress, exhaustion and more negative effects and poor health as a result of having a child with disability was cited in McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri (2008). There was also a concern of possible relinquishment of child, especially during the early period after mothers delivered their child (Roger, 2007).

Previous studies have highlighted the need to examine to the multi-dimensional, holistic concept of QOL to determine the well-being and needs of mothers of child with various disabilities (Schalock, 2005; Danielle, 2003). From several studies across different socio-cultural contexts, parents of child having disabilities were reported to perceive lower QOL in relation to their psychological well-being and physical health, as compared to mothers who had children who were non-disabled or 'typically' developing due to increased care demands (Hasanah & Razali, 1999; Hatton & Emerson, 2009; Hedov, et al., 2000; Mugno, Ruta, D'Arrigo & Mazzone, 2007). These studies highlight the significance of perceived lower QOL and decreased level of well-being of mothers which could potentially impact on the optimal growth and development of their child with disability.

The lack of family economic or material resources and its strong association with dissatisfaction with life, higher levels of psychological stress and decreased level of well-being among mothers of child with disabilities were reported in Hatton & Emerson (2009). Furthermore, significant association of mothers' employment, education level and ethnicity with mothers' stress index is also cited in Ong, Afifah, Sofiah & Lye (1998) and Ong, Chandran & Peng (1999). Insights into mothers' perceived QOL in relation to different life domains could serve to influence policy makers in developing care priorities and strategies

to be put in place, or improving the necessary service provisions and supports in the community (Sarawak State Planning Unit, 2009).

It is to be acknowledged that much of the cited studies which explored aspects of experiences of parents included those of children with various intellectual disabilities apart from DS. There are significant differences between the different types of disabilities, as compared to children with DS.

### **Needs for research**

Many of the studies related to parents' or mothers' experiences and perceived QOL were conducted in the western developed countries (Van Riper, 2007). Whilst this does not negate the findings, there are fundamental differences in term of the cultures and health care systems of these countries as well as the greater availability of public transportation. Findings of these studies may not be relevant to a culturally diverse country such as Malaysia. Furthermore, the geographical characteristics and the relatively less developed infrastructure such as the public transport system, and the inaccessibility of many rural communities to service provisions which are available in the bigger cities becomes an issue of concern.

Several of the disability-related studies from the non-western developing countries, in particular from the Peninsular States of Malaysia examine some related aspects of experience of disabilities (Minder, 2007; Moyle, Iacono & Liddell, 2006; Norisan & Shamsuddin, 2010; Ong, et al., 1998; Ong, et al., 1999). Study by Minder (2007) focuses on language-communication problems of children with DS in the Malaysian context while

study by Moyle, et al. (2006) explored the traditional beliefs related to having children with disability. Norisan & Shamsuddin (2010) examine the coping styles and parental stress among 147 mothers of children with DS age 2-12 years in the Malaysian State of Kedah using self-administered questionnaires. Experience of mothers of children having disabilities were reported in Ong, et al. (1998), however, the study focus was on those having children with CP, a diagnosis unlike that of DS (DS is apparent immediately after birth with some variation in child characteristics) (Baum, et al., 2008).

The above cited studies which were conducted in the Peninsular States of Malaysia provide some insights into some aspects of experience of mothers of child with disabilities.

However, none of these was conducted in the Borneo State of Sarawak which has its geographical, physical infrastructure, ethnic, religious and socioeconomic contexts. Within the same country itself, as a result of these variables, mothers could be adapting differently to the presence of a child with disability due to DS (Norisan and Shamsuddin, 2010).

Study which reports about care experiences of mothers (or parents) bringing up children who are 'normally developing' or children with no Down's syndrome in the local Sarawak context has yet to be cited. There may be unique characteristics of bringing up children in Sarawak - a land with vast geographical distances, as compared to experiences of those from a different socioeconomic or cultural background.

It is also to be acknowledged that generally, both parents play significant roles in the care giving process of their child, whether their child is normally developing or not. While they both play important, complementary roles towards the growth and development of their child, however, their experiences could be different from each other.

Furthermore, as shown from the pilot study which would be elaborated in section 3.5.2, that it is more feasible to recruit mothers into the study. Hence, within the scope of this study, the focuses would be to look into mothers' experiences and their QOL within the context of the Borneo state of Malaysia (Sarawak).

### **1.3 Main research questions which guide the study:**

#### *1. What are the experiences of mothers having a child with DS?*

The focus is directed at exploring the experiences of mothers related to having a child with DS, with his or her child characteristics, health condition and developments within the local social-cultural, environmental context, in order to generate a rich data which would provide a broadened understanding.

#### *2. What is the QOL of mothers having a child with DS?*

In order to explicate further understanding of the QOL of mothers, the study adopts the World Health Organization's conceptualization of QOL, defined as the "individuals' perceptions of their position in life in the context of the culture and value systems in which they live, in relation to their goals, expectations, standards and concerns". It is regarded as "multi-dimensional", incorporating the individuals' perceived physical health, psychological well-being, social relationship with others, and their relationship to salient features of the environment. It is further viewed as a "subjective evaluation which is embedded in the individual's social, cultural and environmental context" (The WHOQOL

Group, 1996, p. 5). The focus is directed at determining the QOL of different life domains and the influence of the various background variables.

Research question no. 1 was answered using the qualitative method whereas research question no. 2 was answered using the quantitative method.

### **1.3.1 Specific research objectives**

1. To identify the experiences of mothers having a child with DS.
2. To determine the overall QOL of mothers having a child with DS.
3. To determine the QOL of mothers having a child with DS in relation to their physical health, psychological well-being, social-relationship with others and the environmental domains.
4. To examine the relationship between selected background variables of mothers (i.e. rural-urban locality, education, income, maternal age, marital status, religion, ethnicity and employment) and their perceived QOL.

### **1.4 Outline of research design**

Parallel mixed design as one of the mixed method research (MMR) approaches was utilized in this study. The use of this study design taps on the complementary strength of using qualitative study method which provides a more in-depth and comprehensive understanding about the life of mothers having a child with DS. Quantitative study yields a global view of mothers' perceived overall and domain-specific QOL, and the relationship of selected background variables and their QOL. Qualitative interviews which were conducted with a purposive sample of 26 mothers of child aged 18 years old and below in their natural

settings explored mothers' experiences in relation to having a child with DS. Quantitative study was undertaken using a cross-sectional approach, utilizing the WHOQOL-BREF (The WHOQOL Group, 1996) to assess the QOL of 161 mothers who were recruited from the various institutions which provide interventional or educational programs to children with various disabilities. These institutions were located within and nearby the capital city of Kuching and the rural region of Samarahan Division within the Borneo state of Malaysia (Sarawak) (Figure 1.1).

### **1.5 Situating the research in context: the Borneo state of Sarawak**

Some background information about the state of Sarawak is provided here in order to situate the research in context and to help in the subsequent interpretation of the findings. As the research context, the geographical vast spread of the Sarawak State, the relatively less efficient public transport and inaccessibility of the people in the rural regions to the service provisions (Sarawak State Planning Unit, 2009) which are only available in the urbanized regions, are issues of concern. Furthermore, the rural-urban locality difference provides further context/concern which is taken into consideration in interpretation and understanding of mothers' experience in the study.

#### **1.5.1 Location and population**

Sarawak State is the largest in Malaysia in term of its land mass over the other 13 States with an area of 124,449.53 kilometre squares, located on the island of Borneo (Figure 1.1) between latitude 0°50' and 5° N, and longitude 109°36'E and 115°40'E. It is separated from the Peninsular Malaysia by the South-China Sea (Sarawak Government Official Portal, 2010).



Figure 1.1 Map of Malaysia showing Sarawak located on the Borneo Island  
(Source: [http://www.epu.gov.my/c/document\\_library](http://www.epu.gov.my/c/document_library), retrieved 16 May, 2012)

The field work of this study was undertaken in the Kuching and Samarahan Divisions within the Borneo State of Sarawak (Figure 1.2). Kuching Division which comprises of Kuching as capital city of Sarawak and two smaller districts are predominantly urbanized areas with an estimated population of 623,660, and population density of 123.5 person/sq. km. Contrastingly, Samarahan Division and four other smaller districts are predominantly rural areas with a relatively sparsely populated with a population density of 38.7 person/sq. km (Sarawak State Planning Unit, 2009, p. 10) (Appendix B: Sarawak Facts and Figures 2009).

The State with an estimated population of over 2.4 million (Malaysia, Department of Statistics, 2010) has the least population density among the Malaysian states (Sarawak State Planning Unit, 2009). It has a population density of 17 persons per square kilometre

in comparison with the Federal Territory of Kuala Lumpur (capital city of Malaysia) of 5,678 persons per square kilometre (Sarawak Government Official Portal, 2010).



Figure 1.2 Part of the Sarawak administrative divisions

### 1.5.2 Demographics

The State has a diverse mix of different distinct ethnic groups in which the six major ethnic groups, according to descending order in number, are the Iban, Chinese, Malay, Bidayuh, Melanau and the other indigenous groups. Of these, predominantly the Ibans accounts for 30.1% of the State's population, while the Chinese and Malays contribute to 26.7% and 23.0% respectively (Lam, 2006; Sarawak State Planning Unit, 2009). Many of the Ibans who stay together as a communal group and maintain a strong tie to their ancestral 'longhouses' generally had a literacy rate which is still low (66 percent as in year 2000), much lower than the Sarawak average (Lam, 2006). Many of the local ethnic groups are living in poverty in the rural, remote locations of Sarawak (Berma, Shahadan & Gapor, 2006). The official language, Bahasa Malaysia which is used widely enables communication amongst the different ethnic groups locally. Besides this, the other main



languages used are English, Mandarin, Bahasa Iban and other local dialects (Sarawak State Planning Unit, 2009).

In term of religious affiliation, many of the Ibans are Christians in their faith due to missionary presence in the colonial years. Though animistic beliefs and rituals still exist (Bruton, 1993 in Ling, 2000, p. 27), the ‘conversion of many Ibans to Christianity has caused the abolition of many of these taboos and beliefs’ (Lam, 2006, p. 27). The Malays in Sarawak are synonymous with Muslims, whereas the Chinese could be Christians, Buddhists or a mix of animistic Taoist beliefs and ancestor worship (Ling, 2000, p. 29). There are however, some records of animistic beliefs or taboos related to pregnancy among the Malay and Chinese groups. The Chinese’s superstitions and practice which restrict pregnant women from taking certain types of food or superstitions of interference from evil forces have been cited (Queensland Government, 2011; Superstitions of Malaysian Chinese, n.d.). The Malay’s taboos in associating child’s disability to pregnant mothers who look at the moon has also being reported in EEM (2012).

## **1.6 Significance of study**

Major significant findings related to mothers’ experience in their perspectives and their perceived QOL in the local context in Malaysia (Sarawak) which are drawn out and obtained from this study highlight and draw one’s attention to their various issues of concerns. The various findings point towards a number of implications including for practice, education and policies.

### **1.6.1 Influence practice**

Study findings related to experiences of mothers having a child with DS and their perceived QOL highlight various issues of concerns. Findings point out to implications for care professionals towards care provision which is empathic and sensitive to their needs, and contribute towards a family environment which promotes optimal growth and development of their child with DS.

### **1.6.2 Expand knowledge base**

Study adds on to the knowledge base and insights in relation to mothering a child with DS within the local setting which is diverse in its ethnicity and socio-economic status which are different from that of the western developed countries. Further knowledge and insights as gained have implications for health care and social work's basic education curriculum, including aspects to be focused and expanded in preparation of their professional care provision.

### **1.6.3 Influence policies**

Findings serve to sensitize the governmental and non-governmental agencies towards the needs and challenges faced by mothers of child having DS. These contribute towards suggestions for related policies and service provisions which take into consideration the differences in relation to mothers' background socio-economic differences.

## 1.7 Research framework

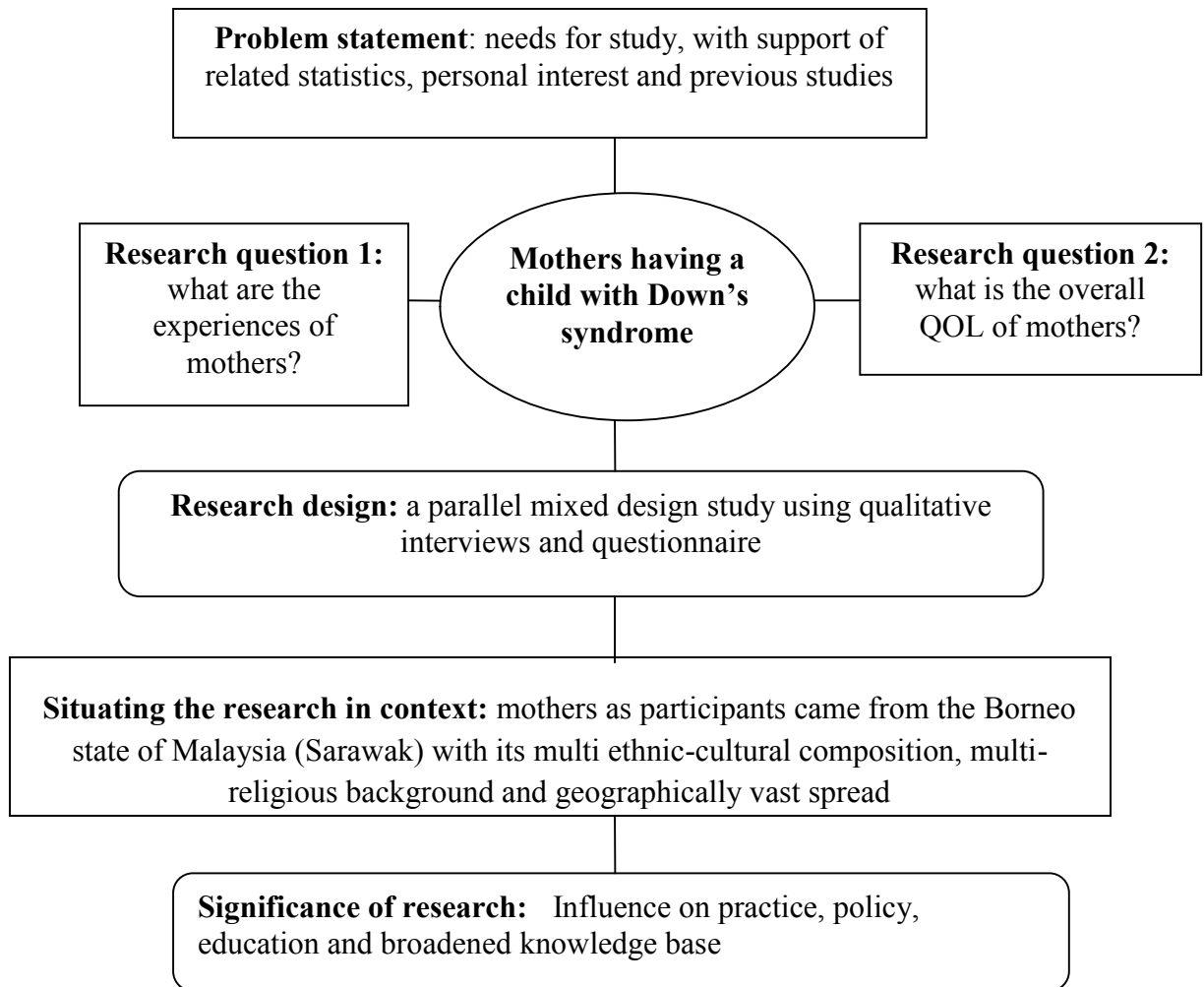


Figure 1.3 Research framework

The research framework in Figure 1.3 links together the different research components which were taken into consideration for the study. These include the problem statement, the research questions, the study design, the research context about Sarawak and significance of study. The framework clarifies the boundary and informs the direction of the study.

Subsequent section outlines the focus and organization of this thesis which is organized into seven chapters.

### **1.8 The focus and organization of the thesis**

The writing of this thesis is structured into seven chapters to facilitate clarity and ease of understanding of the study:

In this present *introduction chapter*, the area of research that the topic of study belongs to is established. Previous research is outlined in order to provide further background to the study, to define the research problem and to indicate the gap in research or justification for a study on the topic area in the local context. The research questions which guide the study and research objectives are made clear. An outline of study design is also included.

Research context and the significance of the study are elaborated.

*Chapter Two* is a critical review of literature which includes previous research carried out in the area of parental experiences and QOL to identify a gap in the existing knowledge, and to demonstrate a need for a new study with enhanced study design. Consequently, it enables a more comprehensive analysis and discussion of the data in the later chapters.

*Chapter Three* presents the parallel mixed design method which was used for the study. The pragmatic knowledge claim associated with the use of mixed method research is outlined. Procedural activities involved in the study which include ethical considerations, outcome of pilot study, data collection and data management are described. An outline of Creswell's six generic steps of data analysis activities (Creswell, 2003) which guided the qualitative data analysis is also included.

In *Chapter Four*, the main findings of mothers' experiences which were established from the analysis of the textual data are detailed. These are represented as the five major themes and sub-themes which are supported by mothers' own quotes. These are *extra care demands, various emotions, variation of supports, coping strategies and life impacts*.

Findings from the quantitative component of the parallel mixed design study which was to examine the perceived QOL of mothers are presented in *Chapter Five*. QOL means of mothers' four life domains, namely their physical health, psychological well-being, social relationship with others and their environmental support were obtained, with some variation among the different life domains indicated. Significant correlation findings of several background variables with their QOL were highlighted and detailed.

In *Chapter Six*, discussion and further analysis of findings are conducted in three sections. The first section discussed and further analysed findings of the mothers' experience as represented in the five major themes with their sub-themes. Conceptualizations of family resiliency model, psychosocial transition model and social model of disability were drawn upon in the discussion to make sense of mothers' experiences. Findings in relation to correlation of the selected background variables with the QOL are discussed in the subsequent section. Before ending the chapter, themes of mothers' experience and QOL findings are compared and contrasted in order to gain a broadened perspective and understanding of mothers' experience having a child with DS in the local region of Sarawak.

*Chapter Seven* draws together various issues that emerge from the analysis of findings. Implications and various recommendations in relation to practice, policy and education are forwarded. Some limitations and the strengths of the study which give further credibility and significance to the findings as derived from the study are elaborated. These include the use of the parallel mixed design study approach, the characteristics of participants as recruited and the multi-lingual use of the researcher in relation to conduct of the study within the multi-ethnic, multi-cultural background of the local context. The chapter ends with an overview of study findings.

### **1.9 Summary**

This introductory chapter lays the foundation for the thesis. It introduces the background of the study, outlines the research problem, research questions and study objectives. A brief outline of the study design and the research context are also included. An outline of the organization of thesis facilitates clarity and ease of understanding of the study.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.0 Introduction

This chapter provides a critical review of the existing literature relate mainly to the experiences and QOL (or well-being) of mothers of child with DS. Few studies which explored experiences of both parents are also included as these are thought to also lend some understanding to the topic of study. Two main approaches of understanding mothers' experiences were identified- one used the quantitative approach; the other main approach was the qualitative approach. Though generally there are views about the superiority of quantitative studies over the qualitative studies, both sources of evidence are equally important, especially when exploring experiences of mothers. Several other studies which utilized the third approach of mixed method design are also included in the review.

The majority of studies which have been reviewed adopted the quantitative approach. Numerical and summative scores which were generated from the quantitative approach provide a relatively limited understanding of the complex parental experiences and might not be comprehended adequately without further exploration. The fewer studies which used qualitative methods in-depth interviews, phenomenological or focus-group discussions provided the 'depth' and richness of data from the participants' point of views. The discussion of the existing studies according to qualitative, quantitative and mixed method research approaches helps to inform the present study design.

The chapter begins with section 2.1 which is a brief description of the literature search strategy undertaken to identify and retrieve existing literature, including a brief outline of

articles reviewed. The subsequent sections from 2.2 present a critical review of various previous studies which were broadly categorized under quantitative, qualitative and mixed method studies.

## **2.1 Literature search strategy**

In an effort to search for relevant research articles for review, broad inclusion and exclusion criteria were defined to allow as many relevant articles as possible to be identified for analysis and review. Various sources of databases were accessed. This was followed by searches of articles from the databases using combinations of keywords.

### **2.1.1 Criteria for inclusion and exclusion**

The inclusion criteria of articles for review were those which are written in English, about experiences of mothers /parents of child having DS, excluding articles which were written in non-English. Articles included for review were further limited to those published during the last 10 years unless no newer publication were available.

### **2.1.2 Sources of literature for review**

Related articles for review were retrieved from on-line electronic databases such as the Medical Database @ EBSCOhost (which included Academic Source Premier, Psychology and Behavioral Sciences Collection, CINHAL Plus with Full Text, MEDLINE with full text), ScienceDirect and the internet Citation Database (Google Scholar). Besides on-line electronic databases, the university library's computer system, the Online Public Access Catalogue were accessed. Unpublished research studies from the library thesis collection



of the University of Malaya and subscribed journals in the university's library shelf were searched under 'title' and 'subject/key words' search.

### **2.1.3 Combinations of key-words**

Combinations of key-words were used in the searches from databases which included:

'mother/parents/families', 'care giving OR care provisions', 'emotional experience', 'child OR children', 'Down's syndrome', 'quality of life', 'WHOQOL-BREF', 'parental stress', 'positive perceptions', 'behavioral problems', 'parental coping'. Boolean logic (operators) (AND, OR), brackets which nested synonyms or equivalent concepts together with OR, and quotation marks were used to link these keywords concepts within the search (Appendix C).

Titles of items searched and retrieved from databases either in full text or abstracts was viewed on screen. Relevant full text articles searched and viewed were downloaded, saved and stored in the data management software 'Endnote' program for ease of retrieving. The searched articles' reference lists were also reviewed to search for further relevant article references.

### **2.1.4 Key studies reviewed**

Relevant full text articles were reviewed and pertinent information of main articles extracted, including the study aims, methodology and findings, tabulated and organized alphabetically for easy reference (Appendix D).

Key studies using qualitative, quantitative and mixed method research approaches which were considered relevant to mothers (or parents) of child with DS were retrieved and critically reviewed. Majority of these were published after the year 2000, though few of these were published since more than 10 years ago. Among studies which were retrieved, the majority of these studies were conducted in the western contexts, with the most number of studies from the United States of America (USA), followed by those from the United Kingdom (UK), and other western countries of Sweden, Canada, Australia and Italy. A few other cited studies were conducted in the Middle-Eastern and Asian countries.

Critique and the findings related to parental experiences which are identified from the previous studies and categorized according to the three broad methodological approaches are presented in the next few sections.

## **2.2 Studies using qualitative approach**

### **2.2.1 Care giving experiences and emotional responses**

A study was conducted by Rogers (2007) using qualitative interviews among a sample of 24 UK parents having children with various developmental disabilities, including those with DS who were recruited by snowball method. Parenting of child with disabilities was reported to produce changes in the parents' lives which involved practical and emotional challenges (Rogers, 2007). Some of the mothers described their experiences of disappointment, emotional pain in coming to term with the unexpected 'loss' of the child they dreamt of. Some of them experienced the psychosocial responses of shock, disbelief or denial which lasted for varying period of time with the unexpected diagnosis. They were able to accept the child's diagnosis, though some denied the severity of their child's

impairment. Furthermore, experiences of negative mental health impact were reported from among the parents who collectively had taken anti-depressants or beta-blocker medication; felt suicidal and had thoughts of either to harm or relinquishing child.

Focus group discussion among 36 mothers and four fathers of children with physical and intellectual disabilities in the USA by Resch, Mireles, Michael, Benz, Grenwelge, Peterson, et al. (2010) further indicated that some parents experienced distress and denial related to loss of a dream child related to child's disability.

A web-based questionnaire survey was conducted in the USA by Myers, Mackintosh & Goin-Kochel (2009) to explore responses of 493 parents of child with disabilities to an open-ended question 'how have your child affected your life and your family's life?' Themes such as difficult emotions of grief, depression, guilt and blame were identified. About half of the group of parents (48%) indicated their stress related to the time demands for various therapies for their child, the needs for constant care and supervision and child's challenging behavior.

The web-based questionnaire survey, using an open-ended question to collect qualitative data (Myers, et al., 2009) enabled participation of parents from various states of the USA, including few from other nationalities such as Australia, New Zealand, Canada, England and Ireland, but limited to only those who were English-speaking. It has the advantage of being relatively economical in accessing to a big number of participants, and able to give participants the convenience and flexibility of participating at their own pace, especially useful to those who were busy with various their work commitments. However, it had the

limitation of access to only those who were computer literate and had the access to internet facilities. Therefore, there would be an under-representation of the lower income parents and of ethnic minority parents in the study sample. The web-based, written response to an open-ended question as a form of data collection to collect qualitative data did not give the flexibility for further probing of participants for further idea or responses, unlike the use of face to face interview approach. Furthermore, the truthfulness of participants' responses to a web-based survey may need to be guarded as in other self-administered survey.

A study which was conducted by Lam & Mackenzie (2002) used semi-structured interviews to explore the experiences of 18 Hong Kong Chinese mothers of child with DS between two and six years old. It was reported that in some of the families their parental function were affected due to depression or sorrow in relation to child's diagnosis. Some mothers were reported to batter their own child, while some fathers were quoted by the participating mothers to have difficulties in accepting their child due to feeling of 'lose face' or shame; indifferent and not sharing in care responsibilities. Some of the parents were reported to attribute child's DS condition for the wrong food or medication taken by them or for having done the wrong thing. The initial period soon after the delivery of child and during the child's early age was described as the challenging and critical period, when parents struggled with acceptance of child and their own anxiety.

The inclusion of participants whose children aged between two and six years in Lam & Mackenzie (2002) implied that the experience of those mothers whose children who were older were excluded. It could be that parents' experience of care giving would vary with child's different stage of life and age range. However, it was unclear of the background

characteristics of the participants besides the brief report about them as the Hong Kong Chinese mothers of child with DS who were housewives. Hence, the extent of transferability of the findings to the local context which is socio-culturally diverse is cautioned.

The above studies reported parents' experiences of practical challenges and emotional reactions in relation to having a child with a disability. However, several other studies reported some what different experiences among mothers having a child with a disability diagnosis.

### **2.2.2 Emotional responses and Burden (1991)'s psycho-social transition model**

In a study which aimed to evaluate the services provided to three groups of mothers whose child had been diagnosed as suffering from some form of handicapping condition within the first six months of life (Burden, 1991), the *psycho-social transition model* was used as the framework of analysis. First group of the mothers (n=20) received the service of advice, treatment, playgroup, mothers' support group, overnight respite care and the service of a home-visiting 'befriender' therapist immediately after the diagnosis of the child's disability. Second group of mothers (n=12) were a comparison group of mothers whose children had been similarly diagnosed and who had received considerable early support from a consultant paediatrician but who did not have access to the service as the first group of mothers, except for the early support from a consultant paediatrician. The third group of mothers (n= 15) whose children's handicapping conditions had not been initially diagnosed did not receive the weekly visits from a developmental therapist. Each of these

mothers was interviewed individually soon after the diagnosis of her child's handicap and again two years later.

Burden (1991) reported that a large percentage of all three groups of mothers experienced some kind of initial shock, denial or confusion when informed that their child was handicapped. Most of the mothers who had had such feelings had worked through them by the time of the second interview, with slightly more of first group and second groups than the third group mothers resolving this crisis positively. A considerable large percentage of mothers having a child with disability experienced the emotional responses of anger and guilt and also questioned as to why they had such a child.

Burden (1991) further reported that a high percentage of the first group with a smaller percentage of the second group of mothers who had successfully worked through such feelings by the time of the second interview, but not for the majority of third group of mothers. A high percentage of over 70% of all the mothers indicated their feelings of incompetence and difficulties in adjusting to the particular role requirements of being the parent of a handicapped child, such as handling and disciplining of child. In analysis of mothers' experience under 'family and social role crisis', striking differences between the three groups were reported, with first group of mothers appeared to encounter less problems in relation to relationships with professionals, social relationships and strain on their marriages, in contrast to the other two groups of mothers.

### *Burden (1991)'s psychosocial transition model*

Burden (1991) highlighted on the significance of drawing on the *psychosocial transition model* as a framework to make sense of the emotional reactions experienced by mothers of handicapped children during the early years of their children's lives.

As shown in the above discussion, the conceptual framework of psychosocial transition model as highlighted in Burden (1991) might provide a useful theoretical lense to understand, or even to anticipate the transitional stage with which mothers having a child with DS may go through.

### **2.2.3 Some positive parental experience**

Dyson (2010) who conducted two focus group interviews with 13 parents of children with DS and other disabilities in Canada reported some variations in parental experiences. While a few of the parents experienced 'self-blame' for child's disability and the challenge of reduced amount of attention for their non-disabled children, several other families indicated otherwise. There were reports of strengths and motivation, a sense of growth in closeness in the families, increased sensitivity to others, more selflessness, learnt from their child who was loving and accepting of anyone irrespective of people, and became less materialistic (Dyson, 2010).

In another study (Kearney & Griffin, 2001), interpretive phenomenology approach which was used to explore the experiences of six Australian parents of children aged between four to six years old with significant developmental disability due to varying causes, the

experiences of hope, love, strength and joy were reported although they also experienced much anguish and sorrow.

Focus group discussion involving 15 Canadian parents of 12 mothers and two fathers of children with autism spectrum conditions and DS revealed that although parents may grapple with lost dreams, over time positive adaptations occurred in the form of changed world views concerning life and disability, and an appreciation of the positive contributions made by children to family members and society as a whole (King, Zwaigenbaum, Baxter, Rosenbaum & Bates, 2006).

#### **2.2.4 Parental concerns of child's future**

Besides the parents' practical challenges and emotional responses related to having child with DS, some other themes were also identified from the previous disability-related studies. These include parents' various concerns about their child's functioning and their future care provision.

Lam & Mackenzie (2002) reported about parents' worries about the future and child's independence, and parents who indicated their hope for their child to die before them.

Resch, et al. (2010) in the USA who conducted focus group discussions with 36 mothers and 4 fathers of children with different disabilities reported similarly findings. They were worried about their child's future care giving and expressed fear and pessimism whether their child would be independent and to be part of the community in the future.



A recently conducted cross-cultural, collaborative research study between Malaysia and UK using semi-structured interviews with seven parents of child with disabilities in the UK revealed some of parents' concerns and dilemma (Chan, 2010a; Chan, 2010b). These included their decisions about placement of their child either in the main-stream education or special school; their concerns and consideration whether to wean their child off from their home at early age by arranging for child to live away from them while still keeping in frequent contact. They perceived it would, otherwise, be too much for the child to cope if they (parents) had to leave their child altogether in future.

As can be seen from the various qualitative findings, themes of parents' child-related concerns, pessimism about the future and worries were revealed through qualitative interviews. In contrast, these might not have been identified from quantitative studies. However, as the various findings are from participants recruited from another socio-cultural context, these might not be applicable to the local parents, though these provide for some contrast and areas for thoughts in relation to care provisions in local context.

In relation to the variation of parental experience having a child with disability, what are the factors which may make a difference in the experience of these parents?

### **2.2.5 Significance of supports and parental experiences**

Some of the cited studies which explored the experiences of parents of child with disabilities reported about significance of various sources of supports as part of their parenting experience (Lindblad, Rasmussen & Sandman, 2007; Rogers, 2007).

The UK study by Rogers (2007) which used in-depth interviews indicated that with some level of practical and emotional support, and short respite care given, most parents were able to cope with the additional practical and emotional demands, and to resume their parenting-related task. Spousal support was reported as the most important sources of emotional and social support to mothers or fathers in coping with being parents of child having a disability, being related to their morale and sense of competence.

In the study in Sweden using in-depth interviews with eight mothers and five fathers of child having disability, Lindblad, et al. (2007) reported about significant supports of grandparents of children with disabilities in the provision of a broad range of practical helps such as child minding and emotional supports. Maternal grandparents were reported to provide more support than paternal grandparents, with grandmothers reportedly provided more support than grandfathers.

Financial resource straining of parents of child with disability was reported by Lloyd & Rosman (2005) in their case study among a few singled, unsupported mothers of child with disability in the USA. Financial straining was exacerbated due to reduced earnings, as one of the parents (mostly mothers) might have to stop working to care for a disabled child, as a result of difficulties in finding appropriate child care. Further financial burden was related to the need to access needed service of various therapies for child, for transportation and for babysitting of other siblings while attending treatments for the child.

Qualitative interview with seven participants include the fathers, mothers or guardians of children with various developmental delays were conducted in the

USA by Worcester, Raffaele & Keller (2008). Findings indicated participants' experience with challenges in obtaining useful and accurate information; obtaining service and supports; financial stress; stress among members of family and community isolation.

Focus-group discussion with 40 parents in the USA (Resch, et al., 2010) informed that parents who felt unsupported, those who were singled-parents, having child with learning disabilities and also behavioral difficulties experienced the most extreme emotional responses. Resch, et al. (2010) also reported that many of parents' challenges related to care giving of a child with disability were due to the mismatch of care giving needs or demands and the access to various necessary environmental supports, such as informational resources, various service provisions or financial support, besides family social support.

### **2.2.6 Summary**

Various studies used methods such as in-depth interviews, case study, phenomenological study, web-based survey using open-ended questions or focus group discussion to obtain rich qualitative data. Prior study findings showed that parents of child having disability experienced various practical and emotional challenges much greater than others who had non-disabled child (Rogers, 2007). They experienced distress and denial related to loss of a dream child (Resch, et al., 2010). Difficult emotions of grief, depression, guilt and self blame were identified (Myers, et al., 2009). Parental function was affected due to depression or sorrow in relation to child's diagnosis, with some who experienced stress and pessimism about the future (Lam & Mackenzie, 2002).

On the other hand, parents' sense of strengthened family cohesiveness, appreciative of life and opportunity for growth and achievement; experiences of hope, love, strength and joy were reported in studies among parents of child with disability (Dyson, 2010; Kearney & Griffin, 2001) although they also experienced much anguish and sorrow. Findings of parents' experiences and well-being were found to be influenced by their child-related concerns and level of socio-environmental supports.

Various studies which use qualitative methods though have their own limitations have the strength to generate rich data. However, most of the studies were conducted in the western countries where the culture, service provisions and facilities availability could be different from the Asian population.

### **2.3 Studies using quantitative approach**

Besides qualitative approach, one of the main methodological research approaches which had been identified to provide some understanding related to aspects of parental experiences is the quantitative approach. Besides the QOL measure as one of the quantitative outcome measures to assess an individual's well-being, various quantitative outcome measures were used to assess parents' stress levels, anxiety and depression. These include outcome measures such as the Parenting Stress Index (Abidin, 1990 cited in Shin, Nhan, Crittenden, Hong, Flory & Ladinsky, 2006) or resources and stress index using the 31-items Questionnaire on resources and stress (Friedrich et al., 1983 cited in McConkey, et al., 2008).

### **2.3.1 Socio-environmental supports, parental background variables and parental well being**

The effects of social support and perceived stigma, child and family variables on parental stress among the 106 mothers and 93 fathers in Vietnam whose children (age between 3 to 6 years) having cognitive delays, including DS were examined by Shin, et al. (2006). This is one of the few cited studies conducted in the Asia region where participants were recruited through 20 kindergarten programs in one of the cities in Vietnam. Parents' struggle with accepting a child with unexpected diagnosis and feeling of shame was reported. Various interviewer-assisted questionnaires were used. The Social Support Scale for parents with children with developmental delays was used to assess the availability of social support for families of child with intellectual disabilities. Participants rated the availability of informal and professional support, with a higher score indicating more social support. The 18 items-Social Life Scale assessed the degree to which social life experience of the families are limited due to the stigma of having child with developmental disabilities. Higher parental stress score was associated with the greater experience of stigma.

Mothers who were from the lower income group were reported to experience more stigma than the others (Shin, et al., 2006). The 24 items from the Parenting Stress Index (Abidin, 1990 cited in Shin, et al., 2006) assess restriction of role, sense of competence, and social isolation among parents. Findings indicated that family socioeconomic status was negatively related to parenting stress, with mothers experienced more stress than fathers (Shin, et al., 2006). Mothers with children with lower intellectual functioning and with inappropriate behaviors (inappropriate to their age group) were more stressed than the other mothers and also more stressed than the fathers, probably as they assumed greater responsibility for child care. Social supports were reported to play a mediating role between

child's functioning and perceived stress, with those who received less support experienced more stress than the others (Shin, et al., 2006). Further qualitative interviews would probably provide more explanations to the quantitative findings of higher maternal stress level and perceived stigma by those who were poor economically.

Various correlation tests in White & Hastings (2004) indicated that parental perception of helpfulness of informal sources of support had the most consistent association with the level of their wellbeing besides child's behavioral difficulties. White & Hastings (2004)'s study among 33 parents of adolescent children (13 to 19 years old) with moderate-profound intellectual disabilities in the UK used various measures; these include the Vineland Adaptive Behavior scale to estimate child's developmental level; the 14 four-point items Hospital Anxiety and Depression scale (with seven assessing depression and seven assessing anxiety) to measure parental well-being measures. The 20-items parent and family problem subscale of the Questionnaire on Resources and Stress Freidrich short form was used to score parental stress. The 30-items Carer's Assessment of Satisfaction Index was used to measure parents' level of positive well-being. The 18-item Family Support Scale was used to measure parents' availability and helpfulness of different sources of informal social supports, while support functions available to the parents were measured using the 12 four-point items short form of the Support Functions Scale.

### **Children's behavior problems and parental stress**

Beck, Hastings, Daley & Stevenson (2004) in their study in the UK explored whether children's behavior problems and pro-social behavior are predictor of maternal stress among 74 mothers of children with intellectual disabilities related to autism, DS and other

unspecific diagnosis (age range of three to 19 years old). Various quantitative child measures were used. These included the Vineland Adaptive Behavior Scale-Survey Edition (Sparrow, et al., 1984 cited in Beck, et al., 2004), a checklist which was used to assess child's adaptive behavior; the 25-item Strength and Difficulties Questionnaire to measure child's problem and pro-social behavior; the 14 four-point items Hospital Anxiety and Depression scale which measured mothers' mental health; and the 36-items Parenting Stress Index (Abidin, 1990 cited in Beck, et al., 2004) which measured the mothers' parenting stress as the main dependent variable. Findings showed that mothers of children with intellectual disabilities who were most at risk of stress were those whose children showed high levels of behavior problems and also were lack of pro-social behavior (Beck, et al., 2004)

In another study conducted in Australia, Plant & Sanders (2007) recruited 105 mothers and 34 fathers of pre-school age children with intellectual disabilities (including DS, autism and other chromosomal disorders) to investigate the extent to which the variables of difficulty of care-giving tasks, time involved in care-giving tasks, difficult child behavior during care giving and level of child disability predicted level of the Australian parents' stress in families of child having developmental disability (Plant & Sanders (2007)). Some of the quantitative measures which were used included the Vineland Adaptive Behaviour Scale-Survey Edition (Sparrow, et al., 1984 cited in Plant & Sanders, 2007), a checklist to assess child's adaptive behavior; the Most Stressful Care Giving Task checklist outlining 22 different tasks undertaken by parents in a typical day; parents selected the five most stressful task and ranked order each from five (most stressful of all) to one (less stressful)

and the Parental Stress Index (Abidin, 1990 cited Plant & Sanders, 2007). Difficult child behavior during care giving tasks contributed to parental stress.

Azar & Badr (2010)'s study among the 101 Middle-Eastern Lebanese mothers and 46 fathers of children with disabilities assessed their coping using the Coping Health inventory and Parenting Stress Index. Social acceptance and supports to parents of child with disability was reported to be more directly associated to their stress regardless of severity of child's disability; higher parenting stress index was related to lower level of informal social support. Those fathers who were recruited in the study were not the main care givers of the child, but they reported similar level of stress. However, because of the quantitative study approach utilized in this study, further probing for an understanding of contributing factor to these fathers' stress was not done. In the same study (Azar & Badr, 2010), formal support through home visits activities by nurses as the health professionals were reported to strengthen, complement the informal family support system and acted as a buffer to the stress and isolation experienced by some of the parents of children with intellectual disabilities.

Another study conducted in the UK, Hatton & Emerson (2009) examined the moderating effect of socioeconomic position on parental health among the 123 South Asian (mostly of Pakistani) mothers (who were materially disadvantaged and having a child with intellectual disabilities). The assessment of parental mental health was measured by 24-item Malaise Inventory; the anxiety and depression scores using the Clinical Interview Schedule. Parental physical health was measured by the one-item scored on a 5-point scale measure of self-assessed health. Findings indicated that the lack of economic or material resources had



strong association with families' perceived dissatisfaction with life, higher levels of psychological stress, and decreased level of well-being (Hatton & Emerson, 2009).

Besides these various cited studies which were in majority from the western countries, a few Malaysian disability-related studies were cited. Ong, et al. (1998) compared the parenting stress among 87 mothers of children with disability with a control group, using the Parenting Stress Index questionnaire. It was reported that mothers of children with disability scored significantly higher than control subjects on all sub scales of parenting stress,  $p < 0.01$  (Ong, et al., 1998). The increased care giving demands, low education level and ethnicity (Chinese) of parents were reported to be the mediating factors. Findings indicated that these mothers might not experience much higher role restriction if they have the financial resource availability, and thereby the available supports and assistance of home helpers, babysitters or close relatives (Ong, et al., 1998).

A study by Ong, et al. (1999) among 75 Malaysian mothers of child with mental retardation utilized the Parental Stress Index which yielded the child and parent-domain stress scores. Findings showed a higher parental stress of these mothers than those of the control group. In the same study, stress predictors of the mothers of child with disabilities due to DS, perinatal insult (prematurity, perinatal asphyxia, and intra-uterine infection) and brain injury at childhood were reported. Mothers's employment status, Chinese ethnicity, intelligence quotient of child and number of siblings were significant predictors.

The above two studies (Ong, et al., 1998 and Ong, et al., 1999) reported about stress of parents of child with disabilities due to CP and other causes. However, experiences of parents having a child with disability due to CP or others causes could be different from the

experiences of parents of child having DS due to the DS diagnosis which is known soon after birth, and some variation in child characteristic (Baum, et al., 2008).

### **Acceptance, religious and optimist coping styles**

Another recent cross-sectional Malaysian study by Norisan & Shamsuddin (2010) was conducted among 147 mothers of children with DS age 2-12 years, who, majority (93.9%) were the Malays, in the Malaysian State of Kedah. Study used self administered questionnaires to find out about use of coping styles and parental stress, using the parental stress scale (PSS), and their psychological well-being (depression, anxiety and stress) using the DASS21 scale. Mean score of parenting stress was reported to be higher by mothers who reported having children with behavioural problems. Parenting stress was found to be significantly correlated with frequent use of coping styles, including acceptance, religious and optimist coping styles (Norisan & Shamsuddin, 2010).

The next section discusses the use of QOL as an outcome measure to assess individuals' well-being.

## **2.3.2 QOL as a quantitative measure**

### **2.3.2.1 Definitions and uses**

There are various definitions of QOL. It was put forwarded much earlier by Campbell, et al. (1976 cited in Felce & Perry, 1995) and Felce & Perry (1995) that individuals judge their objective situation in various life domains according to standards of comparison, based on their aspirations, expectations, feelings of what would be just, personal needs, and values. Their resulting evaluation is their satisfaction with that domain.

QOL was described as the extent to which hopes and ambitions are matched and fulfilled by experience of an individual; a poor QOL occurs when the hopes do not meet with the experience or reality (Calman, 1984). It was also defined as an individual's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her measured by the QOL index (Ferrans, 1984). However, the World Health Organization has conceptualized QOL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns". It reflects the view that QOL is a "subjective evaluation which is embedded in a social, cultural and environmental context", and is "multi-dimensional", incorporating the individuals' perceived physical health, psychological state, social relationship with others, and their relationship to salient features of the environment (Figure 2.1) (The WHOQOL Group, 1996, p.5).

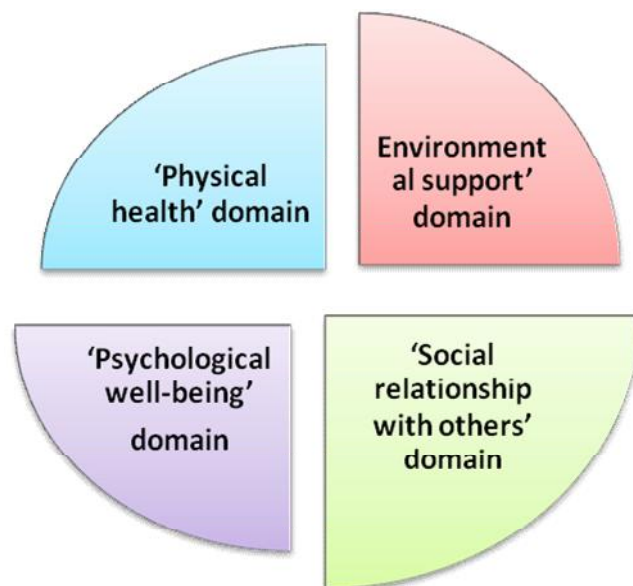


Figure 2.1 The WHO's four dimensions of quality of life

QOL measure has been historically and primarily used as a sensitizing notion that gives one the sense of reference and guidance as to what is valued and desired from the individual's perspective. It was first applied in medical practice to determine if cancer treatment could improve the sense of well being (Spitzer, 1981 in Hasanah, 2003, p. 60).

The use of QOL measure has been expanded to be included as a conceptual framework for assessing quality outcome; as a social construct that guides quality enhancement strategies and as a criterion to assess effectiveness of those strategies (Schalock, 2005). It is also used as an outcome measure in clinical research and follow-up clinical assessment on patients (Hasanah, 2003). QOL as a measure of an individual's well-being that includes multiple domains of functioning is being increasingly recognized as an important construct to be used in the study related to developmental disabilities (Schalock, 2005; Verdugo, Schalock, Keith & Stancliffe, 2005).

Previous studies have highlighted the need to examine the multi-dimensional, holistic concept of QOL to determine the well-being and needs of mothers of child with disability (Danielle, 2003; Schalock, 2005). Insights and understanding in relation to quality of the multi-dimensions of life of mothers is potentially important to influence policy makers with informed decision making, in developing care priorities, strategies, service provisions that help to meet the needs of families, specifically the mothers. It enables the necessary, supports and assistance to be put in place to enhance QOL (Lee, Harrington, Louie & Newschaffer, 2008).

### **2.3.2.2 Choices of QOL measures**

There are various existing, established QOL measures or instruments. These include measures such as the 12-item questionnaire Short Form Health Survey used in the survey of general and specific populations (Ware, Kosinski & Keller, 1996); the Quality of Life Index, copyrighted (USA) (Ferrans & Powers, 1984) to measure QOL of individuals. Another questionnaire that has been widely considered and used in assessing QOL is the 36-item short-form (SF-36) questionnaire (Ware & Sherbourne, 1992). It was constructed to survey health status in the medical outcome study. There is a criticism that it does not consider individuals' opinion on their satisfaction with the various aspects of their life (Hasanah & Razali, 1999). As these instruments were developed primarily not for the local target population, translation into the local language such as the Bahasa Malaysia to be used in the local culture 'carry the danger of distortion' and may not be valid in the 'target language setting' (Hasanah & Razali, 1999, p. 21). Furthermore, in using some of the QOL assessment instruments, there may be aspects of life which were not included in the particular instrument (The WHOQOL Group, 1995).

### **WHOQOL-BREF**

Concerning the WHOQOL-BREF instrument, its multi-domains characteristics is based on the WHO's definition of QOL (The WHOQOL Group, 1996, p. 5) as stated in Chapter One and Section 2.3.2.1 before this. Dividing the assessment of QOL into physical, psychological, social and environmental domains provides further structure for understanding the effects of life events or circumstances on QOL (Hasanah, 2003). Contrary to some other QOL instruments such as the 12-item Short Form Health Survey

(Ware, et al., 1996) that produce composite indices, this multi-domain QOL instrument offers better precision and clarity (Hasanah, 2003).

Besides its precision and clarity, the WHOQOL-BREF is a well-established QOL instrument that has its strength over the other QOL measures. It was developed with multi-centered (15 centers) and cross-cultural involvement from the beginning of its conception before it was used as an internationally and cross-culturally sensitive QOL instrument (The WHOQOL Group, 1996; Skevington, Sartorius, Amir & The WHOQOL-Group, 2004). Furthermore, the 26-item-WHOQOL-BREF takes into practical consideration the concern of ‘respondent burden’; it was deemed to be of reasonable length, either by self administration or by assisted administration (Hasanah, 2003, p. 62).

Having examined the use of QOL as a quantitative measure, the section below discusses several studies which assess QOL of mothers of child having disabilities.

### **2.3.3 QOL related studies**

A number of the studies related to assessment of perceived QOL of parents/mothers or main care givers of child having disabilities or developmental disorder in different cultural settings have been cited (Buzatto & Beresin, 2008; Chou, et al., 2009; Lee, et al., 2008; Mugno, et al., 2007; Yuen & Li-Tsang, 2003). These studies which were cited utilized the World Health Organization’s WHOQOL-BREF instrument which was discussed in the earlier section. In contrast with those of children with other disabilities, study related to QOL of parents of children with autism and their families in the USA have suggested a diminished QOL, a higher level of family stress and problems than families of children with other cognitive disability such as DS (Lee, et al., 2008).

In Brazil, a study conducted by Buzatto & Beresin (2008) using the WHOQOL-BREF instrument among the 30 parents of child having DS who were literate reported that 10% of participants perceived their QOL as 'very good' while the majority perceived it as 'good'. With higher score denotes better QOL in the particular life domain, social domain had the highest score, while psychological domain had the lowest score. However, there is a limitation in the generalization of findings of this study in view of the small sample size and child's age range which was unclear.

Chou, et al. (2009) in Taiwan studied the perceived QOL of mostly mothers (of age 55 years and older), as family carers of grown up children with intellectual disability, and those with mental illness who faced a life time of care giving responsibility. Perceived QOL of 350 family carers supporting their grown up children with intellectual disability and 66 carers supporting their children with mental illness were studied using the Taiwanese version of the WHOQOL-BREF. Their level of QOL was found to be related to the level of social support and their health (Chou, et al., 2009), with those carers of children with intellectual disability having lower QOL.

In another cited study conducted in Italy, Mugno, et al. (2007) evaluated the QOL of 115 mothers and 97 fathers of children with any developmental disorders as compared with 77 parents as control group. Parents of children with developmental disorders displayed a significant impairment of QOL in relation to physical health, psychological well-being and social relationship with others, as compared to the control group. This is one of the few studies concerning parents of child with disabilities in which a significant number of fathers were recruited. However, findings of the significant impairment of parents' perceived QOL

is not conclusive, as parents' experience might vary if only those with children having DS were recruited into the study.

In Hong Kong, Yuen & Li-Tsang (2003) used the WHOQOL-BREF (Hong Kong) questionnaire to explore the perceived QOL of 71 parents of children with developmental disabilities of various causes which showed that they scored lower in overall QOL and in all their four domains of life than their controls (n=76). Some mothers who experienced less social life and indicated a lower rating of QOL in the social domain of their lives was thought to be related to child's therapies, assessments and their concerns of societal reaction towards their child's disabilities (Yuen & Li-Tsang, 2003). The lower QOL of the psychological well-being domain was thought to be due to mothers' higher stress level and worries about child's future when they become too old to manage their child.

A cross-sectional study was conducted by Hsieh, Huang, Lin, Wu & Lee (2009) in Taiwan among the Chinese main caregivers of 48 male and 22 female children with developmental delays. Their health-related quality of life (HRQOL) was assessed using the WHOQOL-BREF and other quantitative measures. The HRQOL of Chinese main caregivers (mostly mothers) with developmental delays was not affected by the gender and age of children, parental age, employment status, family structure or the children's developmental stage. Participants from the nuclear family had higher QOL score than those staying with the extended family. However, the small sample size and the unclear conditions related to child's developmental delays make it difficult to generalize the findings. Regarding employment and parental well being, Kagan & Lewis (1993 in Kagan, Lewis & Heaton, 1997) reported that being able to cope with care giving of child and to continue with



employment helped to lighten their financial burden and provided an opportunity for a break from their caring role. This would potentially lead to a positive impact on family well being.

Hedov, et al. (2000) in their study used the Swedish version of the SF-36 instrument to survey among 165 Swedish parents of 86 children with DS and a control group of parents of children without DS regarding the domains of physical functioning, role physical, bodily pain, general health, vitality, social functioning, role-emotional, emotional and mental health. It was found that those having child with DS had lower QOL score than the control group in vitality and mental health domains ( $p < 0.001$ ). However, as commented in Hasannah (2003), individuals' opinions in relation to their levels of satisfaction with the various aspects of their life were not considered with the use of this particular QOL measure.

#### **2.3.4 Summary**

Various studies used quantitative measures to derive numerical, summative scores to denote various predictors which might be related to outcome measures such as the parental stress levels, mental health levels, anxiety and depression levels experienced by parents or care givers (Shin, et al., 2006; Kenny & McGilloyay, 2007; Beck, et al., 2004; Plant & Sanders, 2007; White & Hastings, 2004; Azar & Badr, 2010; Hatton & Emerson, 2009). A number of the cited studies used the 26-item WHOQOL-BREF measure to obtain the domain-specific QOL scores from the multi-dimensional QOL measure. It offers the clarity and precision over some other outcome measures with their composite scores. Apparently, the use of 26-item WHOQOL-BREF measure to assess domain-specific QOL scores is less

burdensome to participants than the use of multiple outcome measures or scales in a study, as noticed in a number of the quantitative studies (Beck, et al., 2004; Plant & Sanders, 2007; White & Hasting, 2004).

The various studies which adopted the quantitative approach in understanding parental experiences using QOL measure and various other measures had the strength of studying a larger sample, of correlating between variables and making statistical inference. Though ‘quantitative data gives us pattern’ relating to the social world’, however, quantitative study approach has the limitations in providing the insights and depth in understanding of the ‘process’ involved in parental experiences (Rogers, 2007, p. 137). A mixed design study incorporating qualitative interviews would provide more explanations about the quantitative findings such as paternal stress level, or their experiences such as perceived stigma as reported in one of the studies discussed above (Shin, et al., 2006)

In the following section of the literature reviews, the focus is on several studies which adopted methodological pluralism of quantitative and qualitative research approaches in providing some understandings related to mothering experience.

## **2.4 Studies using mixed methods**

Various types of mixed method study designs research were cited. These include complementing an open-ended question to be administered together with the questionnaire, or conducting interviews session after the questionnaire studies, in an attempt to provide both types of data related to mothering experience. The cited mixed method studies provide some understandings in relation to socio-environmental supports and parental well-being, child care-related stress and parental responses.

### **2.4.1 Socio-environmental supports and parental well-being**

A study conducted by Green (2007) is one of the few cited studies using mixed method research approach. Participants were 81 mothers of child with disability due to DS, CP, spina-bifida and head trauma, from three private practice pediatric clinics that provide physical, occupational and speech therapy services to children in three county areas in the USA. Quantitative measures such as the Perceived Stigma, Perceived Caregiver Burden and Perceived Benefits scales were used to assess their perceived objective and subjective stigma, perceived burden and benefits of parenting child with disability. It was reported that social constraint in relation to perceived stigma (being devalued and discriminated), and structural or environmental constraints in relation to finance, work, challenges in accessing various services and treatment were associated with the levels of parental well being in the process of their care giving for child with disabilities. Using explanatory, sequential mixed method research design, follow-up interviews with seven of the mothers examined aspects of experience of mothering child with disabilities. Most of the mothers moved beyond the initial grief to move on to love and care for their child. They perceived the ‘burden of care’ was a matter of socio-structural constraints rather than their emotional distress.

### ***Perceptions of parental and family adaptation and the resilience model***

Van Riper (2007) examined the maternal perceptions of parental and family adaptation in raising a child with DS in a study which was guided by the *resilience model of family stress, coping and adaptation* (McCubbin & McCubbin, 1993 in Van Riper, 2007). Seventy six mothers of child with disabilities completed various mailed questionnaires. Questions related to overall physical and psychological well-being, family function using 5-point Likert's scale were asked. The 71-item self-administered Family Inventory of Life Event scale (McCubbin, Patterson, et al., 1996 in Van Riper, 2007) was used to assess family demands. The Family Inventory of Resources for Management (McCubbin, Comeau, et al., 1996 in Van Riper, 2007) assessed family resources on a 4-point Likert-type scale. The 10-item self-administered Family Problem-Solving communication index and the 30-item self-administered Family-Crisis-Oriented Personal Evaluation Scale assessed family problem-solving communication and family coping respectively.

Van Riper (2007) reported that the majority of participants rated their family's overall functioning as good or excellent, and reported a stronger sense of peace during times of uncertainty. These findings further showed that family resources were related to family coping and adaptation. Those with greater resources rated their family adaption higher. There was a significant negative association between family demands and family adaptation. The various study findings were in concurrence with the 'adaptation' process as conceptualized in the *resilience model* (McCubbin & McCubbin, 1991 in Van Riper, 2007), where family adaptation is believed to be related to the availability and accessibility of family resources as the 'protective factor'.

Correlation revealed that none of the child and family variables (age of child with DS, maternal age, income, education, number of children) was significantly associated with family adaptation (Van Riper, 2007). Findings also indicated that families of children with DS had higher levels of stress. In this predominantly quantitative study, participants' response to one open-ended question regarding how their family was doing indicated they were doing well or very well, though some indicated otherwise. Those who indicated otherwise in this open-ended question, however, were not further explored because of the nature of the mailed questionnaire.

As indicated in Van Riper (1991), framework of *resilience model* (McCubbin & McCubbin, 1991 in Van Riper, 2007) which was used to guide the study might be appropriate in providing understanding and meaning to the present study among mothers of child with DS.

#### **2.4.2 Parental well-being and related family variables**

In a cross-cultural, mixed method study, McConkey, et al. (2008) recruited 209 mothers of child having intellectual disabilities, inclusive of the Irish (30%; n=62), Taiwanese (47%; n=98) and Jordanian (23%; n=49) who participated in the survey related to the inter-relationships among family functioning, mental health and child-related stress, and the variables that impacted on their lives and their coping. In relation to maternal wellbeing, three quantitative rating scales were used. The 12-item Family functioning scale (Epstein, et al., 1983 in McConkey, et al., 2008) which asked about healthy and unhealthy functioning of the family yielded a score which ranged between 12 to 48 (a high score indicated poor family functioning). The 31-items Questionnaire on resources and stress (Friedrich et al., 1983 cited in McConkey, et al., 2008) measured the impact of child on the

family, with a higher score indicative of greater stress. The 28-items General Health Questionnaire (Goldsberg & Williams, 1991 in McConkey, et al., 2008) asked questions related to stresses they experienced, relationship within family and any health problems they had, with a higher score indicative of poorer mental health.

Findings from the study McConkey, et al. (2008) showed commonality in mothers' reports concerning their well-being from the three different countries. In all three countries, irrespective of cultures, mothers had poor mental health. Maternal mental health was poorer in single mothers, and those who experienced greater child-related stress. Findings showed poorer family functioning whose children have higher levels of problem behaviours, hence an increased level of child-related stress. However, child-related stress mean scores indicated slight variation among the three countries, with the Taiwan sample group having lower mean score in stress level than the other two countries' groups, though the two groups were not significantly different. This was thought to be culturally determined, with the Chinese mothers who may be reluctant to admit personal difficulty, hence lower score of child-related stress. This indicated that the use of one particular outcome measure across three different cultural groups may not be very sensitive in assessing certain aspect of participants' life.

McConkey, et al. (2008) and Chang & McConkey (2008) reported about the responses from the mothers in relation to the interviews questions which were asked together with the questionnaire. Some of the Taiwanese Chinese mothers experienced feelings of hopelessness, depression, child as a source of sorrow, grief and withdrawal. However, there were also reports of strengthened family cohesiveness, appreciative of life and

opportunity for growth and achievement though some indicated stress and pessimism about the future. Physical fatigue and burden related to care giving for their child related to child's behavioral difficulties were reported to be a major contributing factor to maternal higher stress level.

As the participants (mothers) in the study (McConkey, et al., 2008) were self-selected, findings might be different from those mothers who declined to participate; and some others who were not known to services. Hence, sample of participants could not be assumed to be representative of the mothers of the various cultures.

In another mixed method study, the 32 Irish parents of children (<16 years old) with learning disabilities completed the Caregiver Strain Questionnaire, and an adapted version of the Carers Questionnaire. Parents showed high levels of objective and subjective caregiver strain and most were receiving inadequate support. However, parents employed a range of strategies to help them cope more effectively. The qualitative data highlighted the difficulties and rewards of care-giving and the inadequacies of current service provision (Kate & Sinéad, 2007).

A cross-cultural study which recruited 45 parents from the USA and 60 parents from Pakistan by Masood, Turner & Baxter (2007) examined parents' causal attribution for their child's disabilities using the Causal Attribution Rating Scale (Mickelson et al., 1999 in Masood et al., 2007). More Pakistani parents than the USA parents reported self-blame such as 'something I did or did not do' or as sins' punishment, besides being their fate or the will of God. Masood, et al. (2007) also reported that the parents from the USA, as

compared to the Pakistani parents were different in term of demographics such as education levels, available medical information at birth, existing resources and services, income and cultures. They attributed child's disabilities to causes such as inheritance, medical problems during pregnancy and birth, and God's will. In both group of the parents, God's will was reported as one of the attributing causes of child's disability. However, for both groups of the participants in this study (Masood, et al., 2007), information regarding their ethnicities and religious backgrounds particularly, were not known, thus some of parents' causal attribution of God's will were unable to be commented on. Findings of some of the parents' experience with self-blame could be related to a lack of information and understanding about developmental disabilities, and seems to be related to higher rate of parental depression (Masood, et al., 2007).

### **Comparison of related western and non-western studies**

From the various western and non western studies, themes of parents' child-related concerns, shock, disappointment, emotional pain, pessimism about the future, negative mental health impact and worries were revealed. Literature sources from the western and non-western contexts also indicated that socio-cultural contextual difference may influence findings of parental experience. As discussed earlier, in relation to causal attribution of child's diagnosis, more Pakistani parents than the USA parents reported self-blame such as 'something I did wrongly or did not do' or as sins' punishment, besides being their fate or the will of God (Masood, et al., 2007). Cultural difference and its influence on findings of parents' experience is also discussed in McConkey, et al. (2008) where the Taiwanese mothers who may be reluctant to personal difficulty, indicated lower child-related stress level than those Jordanian or Irish parents. Use of coping styles, including acceptance,



religious and optimist coping style was noted among the non-western mothers. Besides various concerns and worries, experiences of hope, love, strength and joy and changed world views concerning life and disability were also evident, in particular, among the western studies. In relation to findings related to mothers or parents' QOL, various studies indicate that those having a child with disability had lower QOL score. A lower rating of QOL in the social domain of their lives which was thought to be related to their concerns of societal reaction towards their child's disabilities was apparently reported in the non-western study.

## **2.5 Summary**

The chapter presented a critical review of relevant literature related to experience of parents of child having disabilities, in particular those with DS. Prior understanding and knowledge regarding experiences of mothers or parents of child having a disability, which include their parenting experiences and responses related to care giving, their well-being which was related to socio-environmental supports and parental concerns, were obtained from previous studies across different social, cultural and economic settings.

Parents' experience of having a child with DS may be different from those parents of child with other disabilities such as CP, autism, etc as reported in some of the cited studies (Beck, et al., 2004; Chang & McConkey, 2008; Green 2007; Kenny & McGilloway, 2007; McConkey, et al., 2008; Ong, et al., 1998; Plant & Sanders, 2007; Shin, et al., 2006), though there are some similarities. These differences could be related to the DS diagnosis which is normally known immediately after birth, and the developmental progress which is characteristic of this condition (Baum, et al., 2008). In a study which aims to explore

mothers' experiences of having a child with disability, the recruitment of mothers of child with one particular disability within one study would be more representative of their experience.

Many of these studies which were cited recruited participants from the western countries such as the UK, USA, Australia and Ireland. Fewer studies were from the Middle-eastern or Asian countries (such as Hong Kong and Taiwan), with even much less from the South East Asia countries. There is scarcity in research works in the similar topic area in the local setting. Many of the participants were of higher socioeconomic status, of the white, two-parents, reasonably well-educated, and of the middle to upper class. They were from a socio-economic and cultural background which was relatively different from the local context.

Much of the existing knowledge generated from a different socio-cultural context as mentioned above may not be generalizable to the local setting which is culturally, economically diverse; multi-religious and geographically different. Differences related to parents' educational levels attained, accessibility to various information resources and services may influence their experience of parenting a child with DS. It cannot be assumed that experience of parents from the local context would be similar to those found in the existing literature.

There is an indication of an existing gap in research, and a need for a study among mothers having a child with disability, in particular DS, from the local setting, which is

socioeconomically and culturally diverse within the State of Sarawak, inclusive of those who are attendants to various service provision and those who are not.

Prior studies related to perceived QOL of different life domains of parents of child with DS indicate that findings of QOL precisely related to the different domains of life can potentially contribute towards informed policy change, and influence the service provisions (Hasanah & Razali, 1999). Furthermore, with the use of the internationally established, cross-culturally sensitive WHOQOL-BREF measure, a sensible discussion of findings with those from other settings would be possible.

Many of the studies adopted a quantitative approach, using questionnaire measurements alone in the data collection to yield various composite or summative scores of parental stress index, care giver burden score or maternal mental health level. There are limitations in using merely a mono methodological approach of quantitative structured measures to assess QOL or other aspects of parents' lives. Though the quantitative approach is an efficient approach to generate findings covering a bigger sample group, by this approach of assessment alone, the complex parental experience of care giving of child with a disability may be measured relatively superficially and might not be comprehended adequately without further exploration. It is a limited way to gain an in-depth understanding and insights into the experiences of parenting a child with DS. Assumptions were often made in the discussion about the possible causes attributing to the quantitative findings.

Regarding use of quantitative measures, the use of six or more quantitative scales of 30 to 71 items in each scale within one study as in Van Riper (2007), and other studies as in

Beck, et al. (2004), Plant & Sanders (2007), White & Hasting (2004) apparently could give rise to respondent-burden. Furthermore, certain measure which was used appeared to be not sensitive in assessing certain aspect of participants' life across three different cultural contexts, as in the cross-cultural study by McConkey, et al. (2008).

Compared to the number of quantitative studies, fewer studies utilized qualitative approach in their data collection through the use of in-depth interviews, phenomenological or focus-group discussions to provide the depth and richness of data in illuminating parental experiences from their point of views. The richness and depths of qualitative data would not have been identified from inquiry using the quantitative approach. However, there is a limitation with some of the qualitative methods used such as focus group discussion (Dyson, 2010; Resch, et al., 2010), as only part of the actual parent experience might be elicited or captured, as discussion in a group may not represent individual parent's view. A few of the cited studies used mixed method study approach. In one of these mixed method study, Green (2007) conducted seven follow-up interviews after the administration of the questionnaires. The conduct of a whole session of in-depth interview allowed the flexibility of probing and further questioning for clarity and more details, complementing the quantitative data collected. However, the use of only one complementary, open-ended question as in few of the studies which used mainly quantitative measures is a limited way to gain more in-depth understanding of the parents' experience, though it was able to illicit some qualitative data.

Review of the previous studies related to parents' experiences of having children with disabilities according to quantitative, qualitative and mixed method studies lends support

for the use of parallel mixed study design of the MMR approach using qualitative interviews and a quantitative measure which is structured, precise, internationally and culturally sensitive, and not too burdensome to participants who are mothers of child with disability, particularly DS. Thus, parallel mixed study design using qualitative interviews and a structured quantitative measure which was adopted in this study was beneficial in providing answers to two different, but closely related research questions which were formulated:

1. *What are the experiences of mothers having a child with DS?*
2. *What is the overall QOL of mothers having a child with DS?*

Qualitative research approach as adopted was relevant to generate a rich data with its depth in response to the research question asking about mothers' experience while the quantitative research approach was used to examine their perceived QOL. The conduct of the research, the methodological design and methods used would be discussed in the next chapter.

## **CHAPTER THREE**

### **RESEARCH DESIGN AND METHODS**

#### **3.0 Introduction**

This chapter comprises of nine sections. Section 3.1 presents discussion related to development of mixed method research, the paradigmatic debate and the pragmatic philosophical assumptions and the related strength and limitations. Section 3.2 presents the study design using the parallel mixed design of the mixed method research (MMR), method and instruments used in this study. Section 3.3 to 3.8 present details related to research method and instrument used, including the various procedural activities related to ethics, research sites, research participants, sampling criteria. Subsequently the process of data collection, data management and analysis of both qualitative and quantitative study components, and the various procedures involved to ensure data quality are described. Section 3.9 presents the related learning from the pilot study which was conducted before the chapter concludes.

#### **3.1 Development of mixed method research**

Mixed method research (MMR) is defined generally as “research in which investigator collects and analyzes data, integrates findings, and draws inferences using both quantitative and qualitative approaches or methods in a single study or program of inquiry” (Tashakkori & Creswell, 2007 cited in Teddlie & Tashakkori, 2009, p. 7). As elaborated in Johnson & Onwuegbuzie (2004 in Teddlie & Tashakkori, 2009), it employs research strategies that involve collecting data using one of the typologies of MMR designs, such as

the parallel mixed design, sequential mixed design for exploratory or explanatory purpose. As further clarified in Creswell (2003), one method could be nested within another method to provide insight into different levels or units of analysis.

In relation to MMR, the data collection could involve the gathering of both numeric data (e.g. by using measurement instruments) as well as textual data (e.g. by interview) so that the final database represents both quantitative and qualitative data (Tashakkori & Teddlie 1998 cited in Creswell, 2003). It involves a researcher or team of researchers combining elements of qualitative and quantitative research approaches (e.g. use of qualitative and quantitative view-points, data collection, analysis and inference techniques) (Teddlie & Tashakkori, 2009). In a study using MMR approach, ‘the two components are planned and implemented to answer two related questions’ (Teddlie & Tashakkori, 2009, p. 151).

There is an increase in interest and trend for MMR study which has been motivated by pragmatic issues such as cost efficiency of research which contributes towards evidence-based decision making (Brannen, 2009). Increase in the use of the MMR study approach is also motivated by research funders who sought to commission research that meets policy and practitioner needs (Brannen, 2009). Research approach such as MMR which contributes to more comprehensive understanding of phenomena is said to be particularly useful in healthcare research (Östlund, Kidd, Wengström & Rowa-Dewar, 2010; Parahoo, 1997). However, concerning the use of MMR as a research approach which has emerged as an alternative to the two dominant quantitative and qualitative traditions (Teddlie & Tashakkori, 2009), there has been an ongoing paradigmatic debate.

### **3.1.1 Paradigmatic debate**

Traditionally the two dominant and relatively unquestioned methodological orientations in the social and behavioral sciences are the quantitative and qualitative approaches (Teddlie & Tashakkori, 2009). Researchers who adopt the quantitative approach primarily work within the postpositivist/positivist paradigm, with the interest in numerical data and analysis. They hold the view that social research should adopt the scientific method, and that research was to be conducted objectively, and that their values would not affect how they conduct their research or interpret findings. Quantitative methods are defined as the techniques associated with the gathering data from a big group of sample, the analysis, interpretation and presentation of numerical information. Quantitative data analysis is the analysis of numerical data, using techniques that include describing the phenomenon of interest or looking for significant differences between groups or among variables (Teddlie & Tashakkori, 2009).

On the other hand, researchers who adopt the qualitative approach primarily work within the constructivist paradigm and principally interested in narrative data and analysis. The goal of the qualitative research approach is to document, analyze and interpret as fully as possible the totality of whatever is being studied in the particular natural contexts from the participants' viewpoint (Leininger (1985). Leininger (1985) further argued that qualitative approach involves the 'identification and analysis of subjective and objective data in order to know and understand the internal and external worlds about people. Data which include participants' 'views, meanings, feelings, interpretations of their experiences or explanations and relevant contexts (cultural, physical, social and historical aspects) provide rich and meaningful qualitative data sources' (Leininger, 1985, p. 5). Qualitative (thematic) data



analysis is the analysis of narrative data using technique such as the categorizing strategy or thematic analysis (Teddlie & Tashakkori, 2009).

As for the MMR approach, the philosophical assumptions about what knowledge is (ontology) and how we know it (epistemologies) is on the basis of pragmatism (Crotty, 1998 cited in Creswell, 2003; Teddlie & Tashakkori, 2009)

### **3.1.2 Pragmatism**

A researcher uses MMR study approach bases knowledge claims or philosophical assumptions of pragmatism which are outcome or consequence-oriented, problem-centered and involves the use of pluralistic approach.

Pragmatic knowledge claims is concerned with application of a workable solution – ‘what works’ (outcome or consequence-orientated), the ‘how’, the ‘choosing of methods, techniques’ of finding out the solution related to the research questions (Patton, 1990 cited in Creswell, 2003, p. 11).

In pragmatic approach to research, methodological considerations are of secondary importance to the research question itself (Tashakkori & Teddlie (1998 cited in Teddlie & Tashakkori, 2009). Research question (i.e. the purpose or needs-based) was stated as the ‘most fundamental, most important’ (i.e. problem-centred) (Rossman & Wilson, 1985 in Creswell, 2003, p.11). A need-based or contingency approach to research method is advocated (Johnson & Onwuebuze, 2004, p.17). As argued by Johnson & Onwuebuze (2004), research approaches are ‘mixed in ways that offer the best opportunities for

answering important research questions' (p. 16) and to study 'different aspects of the same phenomena' (Parahoo, 1997, p. 65).

Pragmatism perspective 'rejects the either-or in paradigm selection between positivism and constructivism, which were depicted as incompatible with each other, with regards to methods, logic and epistemology. It embraces features associated with both points of view' (Teddlie & Tashakkori, 2009, p, 87), and recommends a 'pluralistic approach' to derive knowledge about the problem' (Creswell, 2003, p. 12). Both quantitative and qualitative research approaches are important and useful. In some situations the qualitative approach will be more appropriate; while in other situations the quantitative approach is preferred. In many situations, researchers can put together insights and procedures from both approaches to produce a superior product or outcome (Creswell, 2003, p. 12).

### **3.1.3 Strengths and limitation of MMR**

The fundamental principle of mixed research is for researcher to collect multiple types of data using different strategies, approaches, and methods in such a way that the resulting mixture or combination is likely to result in 'complementary strengths and non-overlapping weakness' (Johnson & Onwuebuzie, 2004, p. 18). The strengths of an additional method could be used to overcome the weaknesses in another method by using both in a research study (Green & Thorogood, 2009; Miles & Huberman, 1994; Tully & Cantrill, 2000). As an example, qualitative approach explores the meaning and experience of a phenomenon (Parahoo, 1997, p. 65), provides explanation that would not have arisen from using survey data alone (Green & Thorogood, 2009).

By using MMR approach, researcher can answer a broader and more complete range of research questions as researcher is not confined to a single method or approach. It could be used to expand the breadth and scope within one study. Analysis and integration of the two different types of data from within the same study could provide a broader perspective and insights, extending one's understanding, and for a more complete picture of the phenomenon' (Green & Thorogood, 2009).

Though MMR approach has its strength such as expansion of the breadth and scope of a study, it has its limitation with the amount of resources involved. It would be more expensive in term of resources and more time consuming in acquiring and managing both sorts of data (Johnson & Onwuegbuzie, 2004 & Miles & Huberman, 1994). It could be difficult for a single researcher to carry out both qualitative and quantitative study components, thus, a team effort may be required in the implementation of the project. Researcher has to learn multiple methods and approaches, and understand how to mix them appropriately (Johnson & Onwuegbuzie, 2004).

#### **3.1.4 Methodological considerations**

In consideration of the methodological approach to be adopted, whether research study should be using quantitative, qualitative or MMR approach, Miles & Huberman (1994) suggested for researcher to “consider the research questions and purposes and audience for the research report, whether it should be complemented with another kind of data. Creswell (2003) further emphasized that appropriate research approaches are required to provide the data to answer the research questions and to meet the intended purpose of study; neither

approach is more superior to the other, as both are valid approaches and have a place in research (Silverman, 2005).

By drawing on the strength and fundamental principles of the MMR, researcher is not confined to a single method or approach (Johnson & Onwuegbuzie, 2004). However, MMR researchers need to establish a purpose for the mixing, and a rationale for why quantitative and qualitative data need to be mixed within a single study (Leininger, 1985).

This study utilized the parallel mixed design, one of the designs in the MMR approach, based on the knowledge claim of pragmatism, which is consequence-based (or the outcome) and problem-oriented (the research questions). The next section elaborates on the research design utilized.

### **3.2 Research design of the study**

In this section, the MMR design adopted, including the priority and time order of implementation of the two study components and the integration of findings are presented. Also included is the description of methods and instruments used for the qualitative interview and the questionnaire study.

Specifically, I have adopted the parallel mixed design of the MMR approach which has ‘two parallel and relatively independent components: the qualitative and the quantitative components, with the data collection and analysis techniques, ‘planned and implemented to answer two related research questions’ (Teddlie & Tashakkori, 2009, p. 151).

In this study, the main research question aimed to explore the experiences of mothers of child with DS and the other complementary question examined mothers' perceived QOL. Qualitative interviewing was used to explore the many-sidedness of experiences of mothers of child with DS, in order to gain a holistic perspective and understanding of their experiences. Quantitative study using the QOL instrument was conducted to assess mothers' perceived QOL. The use of the parallel mixed design in this MMR study aims to achieve an extension of the breadth and scope of study within one single study. Figure 3.1 below illustrates the research design framework which is adapted from Creswell (2003), Johnson & Onwuegbuzie (2004) and Teddlie & Tashakkori (2009).

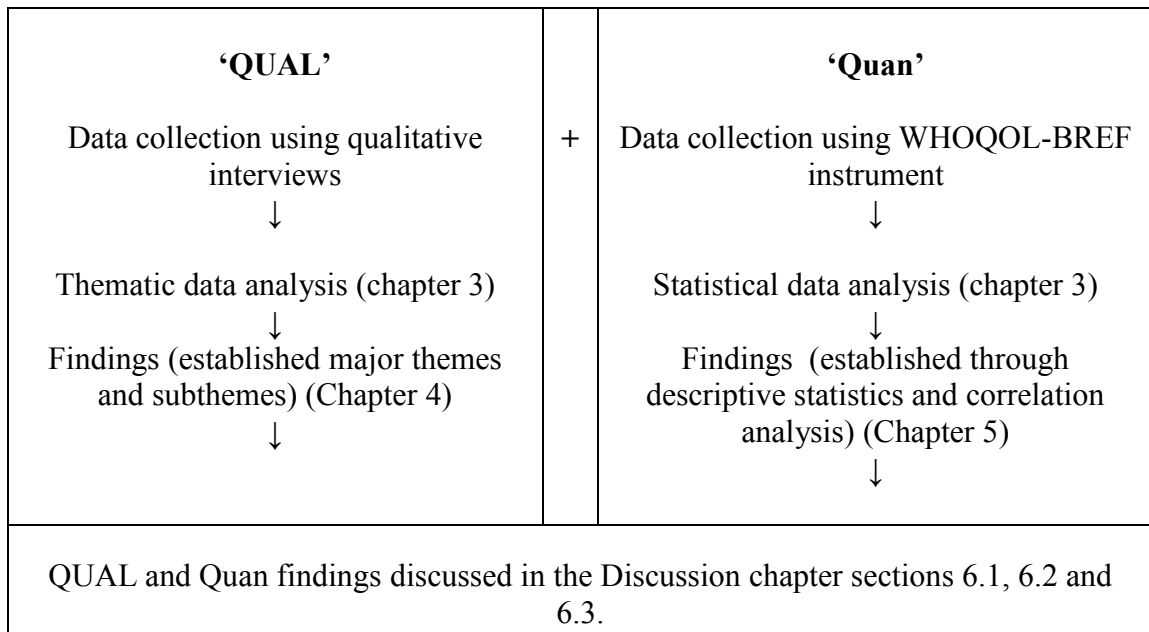


Figure 3.1 Research design framework

In this parallel mixed design as outlined in Figure 3.1, the qualitative component of the study which is assigned a higher priority or dominance is denoted by the capital letters ‘QUAL’. ‘Quan’ with the lower case letters denotes lower priority or dominance for the quantitative component (Johnson & Onwuegbuzie, 2004; Creswell, 2003; Teddlie &

Tashakkori, 2009). The main research question which aimed to explore the experiences of mothers of child with DS was answered by using qualitative interview, while the other complementary question which aimed to examine their perceived QOL was answered by using questionnaire.

The use of the sign “+” in the parallel mixed design framework as in Figure 3.1 shows that both data collection processes (‘QUAL’ and ‘quan’) occurred in a parallel manner in term of time order in the implementation process. However, as stated by Teddlie & Tashakkori (2009), in this parallel mixed design, there is no necessity for a specific time order of implementation, as one method of data collection (interviews) does not depend on the other (questionnaire study) or vice versa, unlike the sequential mixed design (Teddlie & Tashakkori, 2009). Hence, the two different data collection processes could occur ‘with some time lapse, or at different times due to practical considerations’ (Teddlie & Tashakkori, 2009, p. 144).

Data sets for the two study components were analyzed independently according to the standards of quality for each method (Teddlie & Tashakkori, 2009). Findings which were drawn from both the qualitative and quantitative study components were compared and contrasted at the relevant section of the discussion chapter. During the process, the types of data that interpretations were based on were explicitly indicated in order to maintain clarity and transparency (Ostlund, et al., 2010).

The methods and instruments which were used for the ‘QUAL’ and the ‘Quan’ study components are presented in the section that follows.

### **3.3 Methods and instruments**

#### **3.3.1 Qualitative interviews**

In-depth interviews are repeated encounters between researcher and the interviewee directed toward understanding their perspectives on their lives, experiences or situations as expressed in their own words (Minichiello, Aroni, Timewell & Alexander, 1990). We interview people to find out from them those things we cannot directly observe such as feelings, thoughts, and intentions, or those behaviors that took place at some previous point in time, or how people have organized the world and the meanings they attach to what goes on in the world (Patton in Merriam, 2001). It could sometimes, be the ‘*only way*’ of getting data (Merriam, 2009, p. 88). There are at least three significant assumptions that are inherent in this conception. Firstly, an adequate length of time is required for rapport enhancement and increased social interaction. Subsequently, the focus of the interaction is to sought and value interviewee’s perspectives or the experience of social reality through their constructed interpretations or definition of it. Finally, researcher seeks to gain an understanding of the interviewee’s perspective in a language that is natural to them (Minichiello, et al., 1990).

As discussed by Minichiello, et al. (1990), there might be concerns or views about research relying on verbal accounts from the interviewee, and concerns about the truthfulness and the accuracy of his or her definition of the situation. The argument is that ‘interviewee or participants’ definition is paramount’ (Minichiello, et al., 1990, p. 98), whether research is relying on verbal accounts or by participant observation. The stance for the researcher is not to impose own assumptions of the interviewee’s world.

### **3.3.1.1 Advantages**

Interview is said to be a powerful data collection strategy because of the one-to-one interaction between researchers and interviewees, which provide opportunities for interviewers to ask for explanations of vague answers or to provide clarifications if a question is not clear (Teddlie & Tashakkori, 2009). Interview could be conducted to obtain a significant and rich descriptive data, or the first-hand accounts (Grant & Ramcharan, 2001), interpretations and constructions of meanings of participants.

Interview is preferred to other methods such as video recording or participant observation. Video recording could be intrusive and it may result in participants' objections; participant observation would not be a useful alternative to answer the research question as it would have been too time-consuming, and some of the activities would not be accessible to or observable directly by the researchers (Minichiello, e al., 1990).

### **3.3.1.2 Use of interview guide**

Interview was guided by an interview guide prepared in outline form after review of literature of previous studies (Instrumentation A: interview guide). It consists of open-ended questions which were used as a guide during the interviews to explore participants' experiences of having a child with DS retrospectively and currently. Key questions which were prepared in advance in outline form were asked with flexibility in term of the sequence, following the clue from the participants during the interview interaction (Miles & Huberman, 1994; Minichiello, et al., 1990). Interview question such as 'tell me about how you feel having a child with DS', 'how is it like for you taking care of your child in a normal day?' were asked to explore mothers' care giving experience. Interviews with



participants were concluded with one open-ended question which was asked in all interviews, i.e. ‘what other thing that is important to you but which we have not discussed yet?’

Interview guide questions were evaluated by two senior research supervisors in term of its relevancy and appropriateness. These were translated into Bahasa Malaysia, the national language of Malaysia which could be understood by the majority of the local ethnic groups in Sarawak. Interview guide questions were also being translated to mandarin in order to cater for those participants who did not communicate in either English or Bahasa Malaysia (Instrumentation A). A bilingual language expert was asked to verify the translation from English to Bahasa Malaysia and Bahasa mandarin respectively for its accuracy and appropriateness of the words used in the translated version (Appendix E). Participants’ background and child’s developmental related information were also asked using the Part I and II of questionnaire (Instrumentation B: Questionnaires-Part I and II).

### **3.3.2 Use of questionnaire**

The questionnaires (Instrumentation B: Questionnaires) which were used for the data collection contain three parts:

Part I consists of questions from number 1 to 10 which refer to mothers’ background socio-demographics.

Part II consists of questions from number 11 to 16 which refer to child care and child development-related background information.

Part I and II's question items were scrutinized by the two research supervisors who verified thereafter to check the appropriateness and clarity of items, including the item sequence, the skip pattern, the exhaustiveness of alternatives and its readability. It was then further translated into the other two languages namely Bahasa Malaysia and Mandarin to cater to the needs of participants who did not read English. These were verified and checked by two bilingual language experts to check accuracy of translation meaning and appropriateness of words used (Appendix F).

Part III is the World Health Organization Quality of Life-100's shortened version (WHOQOL-BREF) instrument which was used to assess participants' perceived QOL. It is a summated rating scale which consists of 26-items of five-point Likert's type items to illicit participants' responses in relation to four main domains of life.

These are the 7-item Domain (DOM) 1 *physical health*; the 6-item DOM 2 *psychological well-being*; the 3-item DOM 3 *social relationships* and the 8-item DOM 4 *environmental supports* (Figure 3.2). Also included in the instrument are two single-item questions: item no. (1) 'How would you rate your quality of life?' and (2) 'How satisfied are you with your health?'

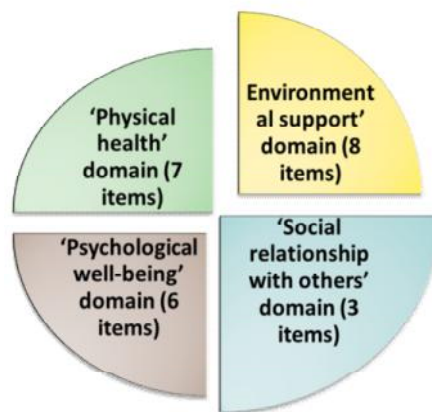


Figure 3.2 The four domains of the WHOQOL-BREF

The 7-item DOM 1 *physical health* consists of items no. 3 on pain; no. 4 on dependence on medicinal aids; no. 10 on energy and fatigue; no. 15 on mobility; no. 16 on sleep; no. 17 on daily activities and no. 18 on functional capacity.

The 6-item DOM 2 *psychological well-being* consists of items no. 5 on enjoying life; no. 6 on meaningfulness of life, no. 7 on concentration; no. 11 on self bodily-image; no. 19 on satisfied with self; and no. 26 on negative feeling.

The 3-item DOM 3 *social relationship* consists of items no. 20 on personal relationship; no. 21 on satisfied with sex life and no. 22 on support from friends.

The 8-item DOM 4 *environmental supports* consists of items no. 8 on physical safety; no. 9 on health of physical environment; no. 12 on financial resources; no. 13 on available information; no. 14 on opportunity for leisure activities; no. 23 on condition of living place; no. 24 on access to health services and no. 25 on transportation.

Various items inquire about participants' responses objectively about 'how much' (intensity), 'how completely' (capacity) and 'how often' (frequency); and subjectively about 'how good' or 'how satisfied' about their experiences, in relation to the different items during the last four weeks (Skevington, et al., 2004). Each item (except for items no. 3, 4 and 26 which are negatively scored) is scored in a positive direction with higher score denotes a higher perceived QOL.

### **3.3.2.1 Validity and reliability of WHOQOL-BREF**

The development of the WHOQOL-100 instrument from which the 26 item-WHOQOL-BREF was abbreviated, involved the incorporation of data from one of the WHOQOL group's collaborative centers in the Malaysia (Kelantan state, specifically Universiti Sains Malaysia) (Hasanah & Razali, 1999). Its trans-cultural approach as well as its collaboration with centers in Malaysia and other Asian countries make it appropriate to be adopted to be used within the Malaysia (Sarawak) setting (Hasanah, 2003). This instrument which is readily available in 19 different languages (including English, Malay and Mandarin versions) had been translated following the guidelines and process of translation and adaptation of instruments (WHO, 2010). Prior written permission was sought and obtained from the WHOQOL group before the usage of the copyrighted WHOQOL-BREF instrument (WHO, 2009) (Appendix G).

Reports from various studies indicate a good to excellent psychometric property of reliability and validity of the instrument for assessment of the perceived QOL of different life domains. Various reports indicate that the instrument has satisfactory level of item-domain correlations in the range of 0.53 to 0.78; and 0.51 to 0.64 for inter-domain correlations (Amir, Marcelo, Herrman, Lomachenkov, Lucas & Patrick, 2000; Skevington, Lotfy, et al., 2004; Yao, Chung, Yu & Wang, 2002; Jang, Hsieh, Wang & Wu, 2004). Similarly, a recent study by Webster, Nicholas, Velacott, Cridland & Fawcett (2010) reported a moderate to high level of item-domain correlations.

Evaluation by the 'Longitudinal Investigation of Depression Outcomes' research group shows that the instrument has satisfactory discriminating validity to discriminate between

groups with different levels of depression and back pain respectively (Amir, et al., 2000). A recent study among the Australian postnatal mothers (N=221) reports that the instrument has the ability to significantly discriminate between known groups (of depressed and non-depressed groups) ( $p < 0.000$ ), and it has convergent validity with the Australian Unity Wellbeing Index ( $r = > 0.45$ ), besides achieving a satisfactory internal consistency of scale items (Webster, et al., 2010).

Within the Malaysian context, the discriminating validity of the WHOQOL (the Malay version) which was pilot tested previously among the Malaysian population of 50 healthy controls and 250 individuals with various medical conditions (Hasanah & Razali, 1999). The healthy group scored a higher QOL score as compared to the other groups with various medical conditions in relation to the different domains of life. Test re-test reliability showed acceptable reliability of correlation coefficient ranging from 0.60 to 0.90 (Hasanah & Razali, 1999).

The sub sections 3.1 to 3.3 above presented on the research design of the study. Details about the MMR design, methods and instruments used for the qualitative interview and the questionnaire study were elaborated.

### **3.4 Ethical considerations**

Before commencing pilot study and fieldwork, approval from relevant bodies was obtained to ensure that research study which would be conducted was ethical, with prior informed consent from participants (Polit & Hungler, 1999).

### **3.4.1 Institutional ethics approval**

For this study, ethics approval were sought from the various gatekeepers and institutions to access the various sites, i. e. schools, health clinics and community-based rehabilitation (CBR) centers in order to recruit participants for the study. These gatekeepers' included the Sarawak State Education Department, Malaysia Ministry of Education, Sarawak Social Welfare Department, Sarawak Health Department and Sarawak State Planning Unit. The research proposal of the study was submitted together with the information sheets (Appendix H) and consent forms (Appendix I: consent forms), and the instruments (Instrument A: interview guides and Instrument B: WHOQOL-BREF questionnaires) to these relevant institutions. Ethics approval from these various institutions as 'gatekeepers' was obtained after they were convinced that the study was ethical (without harming the participants), and were convinced of the benefits (principle of beneficence) of the study. The ethics approval (Appendix J) was granted with an expectation that a copy of study reported would be submitted to them upon completion of the study.

After obtaining ethics approval from the 'gatekeepers' of various institutions, pertinent details such as list of primary and secondary government schools with the integrated special education program, list of existing CBR centers, list of health clinics with clinic-based rehabilitation (interventional) programs were obtained. Various schools' principals, nursing manager-in-charge of health clinics, and CBR supervisors concerned were thereafter contacted for further details and arrangement.

### **3.4.2 Information to participants and informed consent**

Information to participants prepared in English, Bahasa Malaysia, Chinese languages stating the nature of study, objectives and method of data collection were given to them to read before the interview sessions. For those who were illiterate, verbal explanations in the language they understood were given to them. Informed consent was obtained from the potential participants for the interviews and questionnaire study before commencing data collection. Entering the individual's world to grasp intimate, personalized and firsthand information (primary data) during qualitative interview is essential to discover and value the humanistic qualitative expressions, as argued Leininger (1985). Such an experience should be valued as a privilege and opportunity to know someone which carries ethical considerations (Leininger, 1985). Participants were informed that their choice to participate was voluntary. They were also informed they were free to end the interviewing session if they desired.

### **3.4.3 Confidentiality and anonymity**

Participants for the qualitative and quantitative studies were reassured of their anonymity regarding their identity and confidentiality with regards to the data collected. Pseudonyms were used in the study report, with no clear identification of location except for mention of study being focused in the two Divisions of Kuching and Samarahan in Sarawak. The returned questionnaire forms were kept in a locked filing cabinet with its key which is accessible only to me.

#### **3.4.4 ‘Do no harm’**

I was aware of the risk of psychological discomfort to mothers in re-visiting their experiences of bringing up disabled children in the process of in-depth interviewing. As a precaution to minimize this possible discomfort, clear explanation about the study topic and the aim of interview were explained as in the information sheet. Just in case some might require some professional counseling, I had kept ready some information of contact details of local counseling services and parent support group which would be offered to participants if necessary. None of the participants had shown any sign of psychological distress during the course of the interview. The next section reports on details of the pilot study which was conducted before the actual data collection.

### **3.5 Pilot study**

#### **3.5.1 Aims and conduct of pilot study**

A pilot study was conducted after prior ethics approval was obtained from various institutions concerned. It was conducted prior to the actual data collection with a few aims. Firstly, it was to find out the feasibility of carrying out the proposed study in term of accessing the research sites, availability and accessibility of potential participants who would be willing to participate in the present study, level of support and keenness of person-in-charge of the various institutions in facilitating the study. Secondly, it was to determine the appropriateness and relevance of the two data collection methods. For the qualitative interviews, it was in relation to the use of an interview guide which consisted of questions to explore the experiences of participants in Sarawak in relation to having child with DS. For the questionnaire study, it was in relation to the use of the WHOQOL-BREF



to assess participants' rating of QOL. Finally, it aimed to evaluate the reliability (internal consistency) of the instrument to be used among the local population.

Qualitative interview using an interview guide were conducted in their homes of three mothers of child with DS of different ethnicities (Chinese, Malay and Iban). They were contacted through the health clinic, school and the CBR centers. Interviews were conducted using the language that both the participants and I were comfortable with.

The WHOQOL-BREF instrument in the language version as appropriate was piloted among mothers of child with DS who were recruited from a few sites, namely one rural school, one rural CBR center from the rural Samarahan Division; one governmental school and one non-governmental special school from the capital city of the Kuching Division. In total, the instrument was piloted with 30 mothers, a number which was deemed sufficient in view of the relatively small number of mothers recruited in the study.

### **3.5.2 Lessons learnt from the pilot study**

The few lessons as learnt from the pilot study included the following:

#### *Supports and feasibility in recruitment of mothers as participants*

Staffs from the various institutions were cooperative and supportive in assisting and facilitating the access and recruitment of participants. Pilot study indicated that mothers were more accessible than fathers to be recruited as participants for the study. Although out of the three mothers contacted for the interviews, two of them had the fathers who were present, it was only for part of the session due to their work commitment. It was also found

out that mothers instead of fathers were seen to send their child to attend the interventional programs in the schools and CBR centres. Thus, decision was made to recruit only mothers as participant for this study.

*Importance of establishing rapport while observing cultural practice*

As a local cultural practice of showing friendliness and kind gesture when coming to someone's home, a 'buah tangan' (a gift brought along during a friendly visit) such as a small toy set, perceived as age-appropriate for any normally developing child, was brought along to the home during the first visit. The 'buah tangan' served as an ice breaker and facilitated in establishment of rapport with the mothers and their child. It helped to get the child, and also the other siblings around house at the time of visit to be settled, and the mothers more at ease during the interview.

Interviews were carried out in the naturalistic environment of the participants' homes. As these few mothers took care of their child full time, they could not be separated from the child while participating in the interview. Some amount of time was allocated to allow for the initial building of rapport with the mother and the child, and 'interruption' time for her to settle and attend to her child who cried or got restless in between for either milk, or to seek their attention. For each interview session, it lasted about one and a half to two hours, which include time for initial rapport.

During one interview session with an Iban mother contacted through health clinic, the child's grandmother who was present in the sitting room throughout the session participated also on and off. I respected her presence and gave her the time to talk as it was

culturally appropriate, though I cautiously diverted the mother's attention back to the interview guide question.

While trying not to be overly reactive to their expressions, I maintained an attitude of being concerned and listened attentively to participants' sharing of their experiences during the interviewing. Through rewording, rephrasing what was said by the mothers, and further probing facilitated clarification and elaboration of mothers' experience.

#### *Appropriateness and relevance of the semi-structured in-depth interviews*

From the analysis of textual data from the interview transcripts side by side with field notes, a number of themes could be identified. This indicated the relevance of using semi-structured in-depth interview which was guided by questions from the interview guide in generating rich data.

#### *Audio recording*

Permission was obtained from participants to have the interview being audio recorded, since it was not possible to take note of the whole interview for analysis. Furthermore, note taking during interview could distract the interviewer from the focus of the interview. The use of the conventional cassette recorder during the first two interviews was found to be rather problematic. Recordings were found to have sound interference from sources such as the ceiling fans which switched on, and thus were straining to the ears to hear the conversation during transcribing. Furthermore, as the audio recording cassettes could only hold up to 45 minutes of recording on each side, I had to turn the tape to another side to continue the recording after this period of time. It interrupted the flow of conversation with

the participant and my thought process. At times there was a delay in turning the tape over for the recording as I was engrossed in the interviewing process (Fernandez & Griffiths, 2007).

It was later that I came to know about the availability of the more reliable and versatile MP3 digital voice recorder for audio recording which I decided to use for the subsequent interviews. There were few advantages over the conventional cassette recorder associated with its use, such as doing away with the need to change sides of the cassette tape, being less conspicuous for use while interviewing due to its smaller device size and better sound quality. There was no necessity of changing batteries with this portable device as it could be easily plugged to a USB port of any computer to be recharged. Furthermore, after each recording of the interview, it was easy to upload the audio recording as a file into a computer by connecting the MP3 voice recorder device to a USB port. It was also convenient to make a backup copy of the audio recording file in another external hard disk. The more superior clarity of the recording as well as the variable playback speeds of the recording using the computer's window media player program enabled me to spend less time with transcribing (Fernandez & Griffiths, 2007).

#### *Limitation with self-administration of questionnaire*

Pilot study showed that some of the mothers had problems with self-administration of questionnaires when the forms were returned, probably due to their language difficulty. In the actual study, those mothers who had language difficulty were identified and given assistance in the administration of the questionnaire in order to avoid missing data.

### *Reliability of the WHOQOL-BREF instrument*

Reliability analysis of the 26 item-WHOQOL-BREF which was conducted using data from the pilot study showed that the items have good internal consistency with Cronbach's alpha coefficient of 0.914. Similarly, Cronbach's alpha coefficient for the four different domains indicated a good internal consistency, ranging from 0.687 to 0.802 (Table 3.1). Finding of internal consistency reliability of the WHOQOL-BREF indicated that adopted instrument was appropriate for use in the local population. Therefore, no modification was made to the instrument.

Table 3.1 Internal consistency reliability of WHOQOL-BREF

Scale domains	No. of items	Cronbach's alpha coefficient
WHOQOL-BREF (overall)	26	0.914
DOM 1 physical health	7	0.687
DOM 2 psychological wellbeing	6	0.746
DOM 3 social relationship	3	0.778
DOM 4 environmental support	8	0.802

### **3.5.3 Summary of pilot study**

Findings of pilot study indicated the support and assistance of staff from the various institutions in the recruitment of participants for the qualitative and quantitative study. It was found that mothers of child with DS were more accessible than fathers to be recruited as participants for the qualitative study. MP3 digital voice recorder was a versatile device during interview preferable to the conventional audio cassette recorder. During in-depth interviews process in the natural setting, it was important to maintain good rapport and observe cultural practice. Regarding the quantitative study, the selected WHOQOL-BREF for assessment of QOL indicated acceptable reliability of internal consistency to be used in

the local population. It was also found that many of the participants needed some assistance in the completion of questionnaires due to language difficulty. Prior pilot study influenced part of my decision making in the conduct of the actual study.

The subsequent section provides details related to ethical considerations, the research sites, sampling criteria, recruitment. Procedural activities related to gaining access to participants, data collection, data management and analysis, and the procedures to ensure data quality will also be discussed and elaborated.

### **3.6 Research sites**

For both the qualitative interviews and the questionnaire study, the participants were accessed from the child health clinics<sup>2</sup>, CBR centers<sup>3</sup> and governmental and non-governmental schools with interventional/educational programs for children with disabilities. These are located within the two Divisions of Kuching and Samarahan which are adjacent to each other within the Borneo State of Sarawak. These two Divisions were identified as the research sites for the logistics and for reason that within these two regions are located the most number of the child health clinics, CBR centres and schools with interventional programs for children with disabilities in Sarawak (Safii, 2007). In total, nine CBR centers, eight child health clinics and 20 governmental schools (16 primary & four secondary schools) with integrated special education programs, and one non-governmental special school were accessed. Three other child health clinics which also

---

<sup>2</sup>There are 39 child health clinics in Sarawak that provide interventional or rehabilitative programs, with the majority (13) located in these two regions of study.

<sup>3</sup>There are 13 CBR centres in these two regions, out of the total number of 26 CBR centres in the State (Sarawak, Welfare Department, 2012).

provided the intervention programs were not accessed as those children with DS who attended these clinics were also attending the CBR centers' programs.

Besides recruitment via the various institutions, two other villages within the Samarahan Division were accessed through snow-ball method to recruit four participants for the qualitative interviews. It is acknowledged that research sites to recruit participants did not include the hospitals as it is less appropriate or feasible to recruit mothers as participants as compared to CBR centers, schools or clinics due to logistic reasons such as time constraint and readiness of mothers to be interviewed.

### **3.7 Research participants**

#### **3.7.1 Sampling criteria**

Biological mothers of child diagnosed as having DS at or below 18 years of age and consented to participate were recruited in the study. The criteria of the age of child with DS at 18 years old or below was decided following the definition of 'a child' as stated in Part I, Article 1 of the Convention on the Rights of the Child (United Nations General Assembly, 1989, p. 3). No other criteria such as child's level of cognitive functioning (e.g. IQ) was set in recruiting participants, though this might correlate with child's developmental outcome and thus their experience, as the related information about the child was not available.

Biological mothers were recruited as they had the firsthand experience of giving care to their child having DS and were most appropriate people to provide data in answering the research questions, to provide insights into how they made sense of their lives (Polit and Hungler, 1999). Mothers having a child with DS assume a greater responsibility and spend

significantly more time in direct daily caring for their child with DS than do the fathers (Sloper, et al., 1991). As part of findings from the pilot study, two of the fathers were present during the interviews but only for part of the session due to their work commitment. It is deemed less feasible to access fathers as compared to mothers. Mothers recruited for the research should be able to communicate either in English, Bahasa Malaysia, Mandarin, Iban language (either in written or oral form) or 'Hokkien' dialect which I was able to comprehend in order to establish validity of the data collected. Those who refused to participate were not recruited.

### **3.7.2 Sampling technique and sample size**

#### **3.7.2.1 Qualitative study sampling technique and sample size**

Upon ethical approval, the various CBR centers, clinics or schools within the two Divisions of Kuching and Samarahan were accessed. Registers of names of children attending the various institutions were screened through as a way to access and to recruit their mothers as participants. A non-probability, maximum variation, purposive sampling method was used to recruit participants who met the sampling criteria, who were of different ethnicities with diverse socioeconomic background to enable a wide variation of perspectives to be represented. Four other participants whose child was not attending any of these institutions were also recruited from informal sources through snow-ball method.

Regarding the number of participants recruited for the qualitative interviews, no sample size calculation was done. To ensure that a maximum variation in term of participants' perspectives of care experiences was obtained, participants who were recruited were of various ethnicities and from both the rural and urban localities. It was emphasized by



Sandelowski (1995 in Parahoo, 1997) that sample size should be adequate to allow in-depth analysis to provide a new and more in-depth understanding of the topic. “Trade-off” in emphasis should take into consideration constraints of time, resources and logistics (Teddlie & Tashakkori, 2009, p. 184). Having considered the depth and richness of the data which I managed to obtain, hence the decision was made for a recruitment of 26 participants in total for the qualitative interviews. A smaller number of participants (n=18) were reported in one of the previous qualitative studies which explored mothers’ experiences (Lam & Mackenzie, 2002). Furthermore, the aim of qualitative study is not to obtain a statistically representative sample size in order to generalize the findings (Tully & Cantrill, 2000).

#### **3.7.2.2 Quantitative study sampling technique and sample size**

The various institutions where mothers were recruited earlier for the qualitative interviews were accessed to recruit bigger number of mothers for the quantitative study.

As the official statistics and related details related specifically to children with DS within the two regions were not available from the State Social Welfare Department which registers children with disabilities<sup>4</sup>. An estimation of the number of children with DS available from each of these main sources were obtained by screening through the registers of students with DS at various schools (available from the Education Department) and several enquiries made from the staff-in-charge of the various CBR centers and child health clinics concerned of children who were currently attending programs actively. Through manual calculation, the number of the children with DS who attended schools and CBR centres were 115 and 94 respectively. Apparently, however, it was quite tricky problematic

---

<sup>4</sup>The existing statistics of children with DS were subsumed in the broad category ‘learning disability’ which includes autism, dyslexia, global developmental delay and mental retardation.

to ascertain the number of children with DS from the child health clinics registration as some of them were also registered at and attended the CBR centers or schools. Thus, for these clinics, only 21 of those who actively attended the clinic intervention programs during the period of data collection were considered. In total, the number of mothers who were targeted and distributed the questionnaires was 230.

At the end of the period of data collection which was started from the beginning of September 2009 till end of January 2010, a total of 180 forms were collected.

Questionnaire forms which were unreturned were due to non-attendance of these children after the forms were given. Various reasons as given included 'parents not free to send child to school', 'child was hospitalized' or 'problems with transportation'. There might be some elements of non-response bias related to those mothers who were not recruited in the study (Polit & Hungler, 1999). Apparently these were the mothers who were likely to experience more challenges with less availability of resources and supports.

After checking and screening through the forms collected back, seven of the forms were considered ineligible for analysis because of missing data. One form was excluded to avoid a biased analysis, as participant appeared to be responding in a rote manner (repetition without regards to meaning) by answering every item on the WHOQOL-BREF with the same highest possible rating. It is perceived as unlikely that any participant would have perfect satisfaction of every aspect of their QOL, as stated by Wang, Summers, Little, Turnbull, Poston & Mannan (2006). Another 11 of the collected forms were not included in the data analysis as they did not meet the sampling criteria. A total of 161 questionnaire forms were eventually analyzed in this study. Slightly more than half of the group (n=89)

were accessed through schools, while the rest of were accessed from the CBR centers and the child health clinics (Table 3.1). Of these, 49.1% (n=79) were from the rural Samarahan Division, and slightly more than half of them (n=82) were from the urban Kuching Division.

Table 3.1 Sites accessed and number of participants (N=161)

Sites accessed	N (%)
Schools	89 (55.3)
CBR centers	51(31.7)
Child health clinics	21 (13.0)
Total	161 (100)

### **3.8 Data collection procedure**

#### **3.8.1 Qualitative interviews**

The period of data collection using interviews which were all conducted by myself stretched from end of May 2008 till early July 2009. Interview sessions in the mothers' homes lasted between one and a half to two and half hours, inclusive of the time to establish rapport with them before the 'actual' interview. Most of them were interviewed twice except for a few who refused because of family commitment and for reason not specified.

##### **3.8.1.1 Establishing rapport and making initial contacts**

Having obtained the ethics approval officially from the various gatekeepers of the various institutions concerned did not guarantee an open door to access participants successfully. The skills of the researcher, as an information-gathering instrument, had an influence on the validity and reliability of data. Miles & Huberman (1994) highlighted the significance for

qualitative researcher-as-instrument to gain familiarity with the phenomenon and the setting under study. As part of the efforts to establish rapport and to be familiarized with the settings to facilitate the data collection process, I made a number of visits to the various institutions. I participated in some of the activities organized for the children with DS, including the combined camping co-organized by the State's Welfare Department and the health clinics for children with DS from the various CBR centers from around Kuching and Samarahan Division.

The proposed study on exploring experience of mothers having a child with DS living around Kuching & Samarahan Divisions was communicated to the medical specialist in charge of the Sarawak Family Health Development Unit, Ministry of Health Malaysia. Being convinced that study would be able to generate useful findings, the specialist was very supportive by giving me relevant background information related to clinic-based rehabilitation (intervention programs). The Health matron from the Health Department was also supportive as she was informed of my plans to meet the nurses and mothers from the different child health clinics.

#### *CBR centres and health clinics*

Some of the mothers sent their child to the CBR centres and health clinics for the interventional programs and stayed back with their child till the end of the sessions. My visits during the sessions and rapport which was established with the staff and these mothers there facilitated their confidence and trust in me as I made my initial contact with them to recruit them as participants for interviews. Instead of regarding me as a total stranger, there was some form of 'research partnership' which was established. Besides

familiarity with the settings, as stated by Unger, Tressell, Jones & Park (2004), this established rapport helped to improve the validity and utility of the research.

### *Schools*

Many other mothers came to the schools to send and to pick their children without staying back much longer time than was required, unlike in the CBR center or clinics. Through the supports and assistance of the school heads and teachers concerned I was able to have access to the contact details of those who were the potential participants for the qualitative interviews. To begin with, principals of schools and the class teachers were briefed regarding the objectives and method of the study. Information sheet (Appendix H) and a response slip (Appendix K) which were prepared and distributed to potential participants in one Special school through the teachers in the various classes concerned. The response slips with the phone contact and home address details which were returned by those who consented to be contacted for interviews were given back to me. Thereafter, I was able to contact them through phone and subsequently to request for an appointment for interview sessions with them in their homes at a time convenient to them.

#### **3.8.1.2 Accessing participants for interviews**

After making the initial contacts and explaining the objectives of study to those potential participants from the CBR centres, health clinics and schools, I requested for an interview appointment with them at a time and place most convenient for them to grant the interviews. I tried to minimize any disruption to their normal activities by fitting in with their choice of time and place. Interviews were conducted in the natural setting of their own homes or any other place of their choice, including in the premise of the shop of one of

the parents where they stayed and also where they did the home business. They would probably be more comfortable and relaxed in their own homes compared to the clinic or CBR centre setting, considering the participants' role as main care givers of their child with DS. Furthermore, it granted me the opportunity to observe and gain understanding of the participants' care giving activities within the natural setting of their homes.

For those mothers who were on paid employment outside of home, interviews were granted either in the evening after the dinner in their home, or on the weekend when they were not working. For mothers who were not working outside of home, time for interview was granted normally in the afternoon when they were more settled with household chores.

Participants who were recruited lived in different parts of Kuching and Samarahan Divisions of Sarawak. Besides making arrangement to meet participants at certain meeting point, the process of searching for the way to their homes were facilitated by the road map accessed from the internet at [www.google.maps.com](http://www.google.maps.com)' (Figure 3.2).

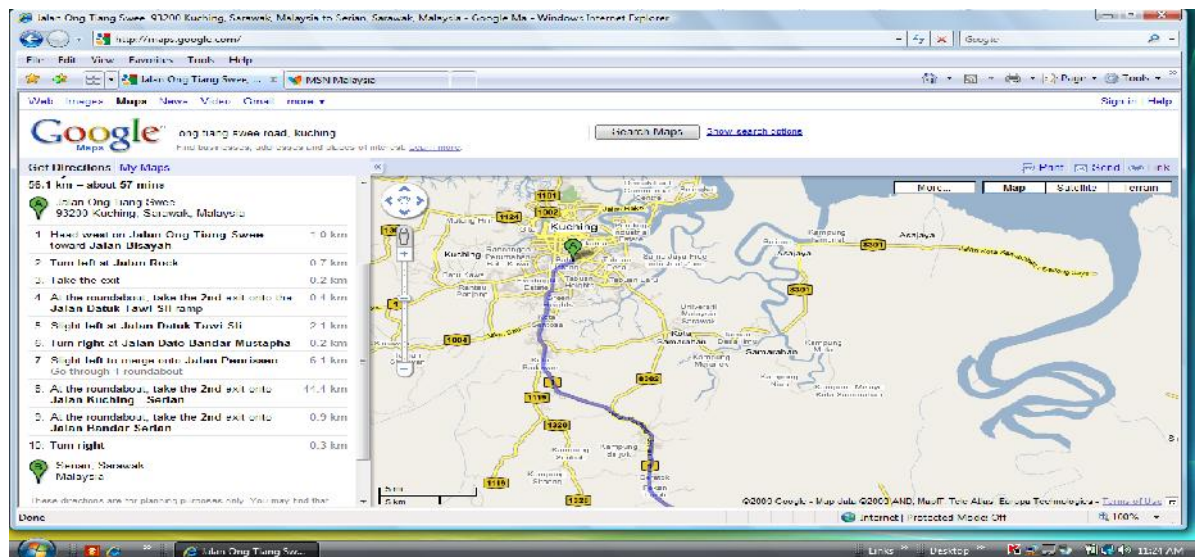


Figure 3.3 Road map

Other means to learn the routes to the homes of participants were by consulting the van driver who sent the children from the school back to their homes. Besides these, I made prior appointments to meet some of the mothers at the CBR centers and thereafter I drove my car behind theirs on their way back to their homes.

### **3.8.1.3 Before the actual interview**

A small gift such as children toy set or picture cards appropriate to the child's age was brought to the participants' homes during my first visit to the homes as a culturally appropriate gesture of friendliness (Ling, 2000), and it had been found to serve its purpose as ice-breaker, facilitating the interview process as their child was also present.

Prior to the actual interview, the list task as preparations was observed (Appendix L) to ensure various details were followed. These included observing mundane social cultural practice people engaged with one another in the local context, such as waited to be invited before taking a seat either on the floor or on the sofa, or taking a drink and food together with them. I ensured that adequate length of time was allocated for informal conversation and interaction in order to build rapport for a greater empathic understanding. As part of the process of establishing rapport with the participants before engaging in the social interaction of interviewing, I gave a brief introduction of myself to the participants. I introduced myself as a nursing lecturer from the local university and informed them about the prior ethics approval from the different Ministries and Department concerned (i.e. Ministry of Education and Health, and the Social Welfare Department which act as the 'gatekeepers' of the various institutions where their child had received one form of service or another.

I bore in mind that ‘using too direct, confronting type of communication styles in the local context could be fraught with difficulties’ (Ling, 2007, p. 133). Also emphasized by Minichiello, et al. (1990), a highly interactive and collaborative approach with the interviewee in the research process is a way of increasing credibility of data and procedural rigor.

During the process of data collection using interviews which were carried out in the natural setting of the participants’ homes, ongoing ethical consideration was observed to make sure no harm would be done to the participants. Participants were assured about maintaining anonymity and confidentiality of information given by them. Informed consent would be signed by participants prior to the interviewing.

A pre-interview questionnaire related to background information and child development-related information was completed with help given as necessary. Prior permission was also obtained from the mothers to have the interviewing being audio recorded using the MP3 digital voice recorder, except for one of them who indicated her discomfort for their interview to be audio-recorded. However, for this interview, permission was given for me to take notes of important points which were said during the session. For all the interviews, field notes regarding any thoughts, things observed or heard which could form part of the data for analysis were taken as soon as possible after the sessions.



#### **3.8.1.4 During the interviews**

Interviews with the participants were guided by interview guide (Instrumentation A: interview guide). Key questions which were prepared in advance in outline form were asked with flexibility in sequence and wording of questions.

At times when participants ‘open other doors’ (talking about another aspect of their experience beyond the key questions in the interview guide, I would ‘go with the flow’ with them and follow their lead, and would come back later to the question guide. This was to allow opportunities and the flexibilities to draw out more understanding of their experiences, and to avoid premature closure to what participants had to express further (Miles & Huberman, 1994).

During the interview process with a number of the Iban participants, on and off they would express in their Iban language though key questions were asked in Bahasa Malaysia. The interpreter who came along with me during the interview would on and off help me with clarification of participants’ meaning whenever necessary, to ensure accuracy in understanding of the data collected.

#### ***Cultural sensitivity, flexibility and ‘interruption’***

On few occasions, different members of the family came in and out of the house when I was with the participants for the interviews. These included the child’s auntie or grandma who lived few houses away, who also came in after they knew of my visit to their home. On other occasions, the child’s uncle or auntie came in after they came back after their work. As they ‘joined’ in and started some social conversation, interview sessions were

interrupted. It is being culturally appropriate to accommodate other members of the family in the conversation during research interview sessions in the local setting (Ling, 2000).

Flexibility of interviewing in the home setting with participants also meant allowing interruption time period for some participants to attend to their child who were restless or crying. For some participants, I had to follow their flow and cue as they decided to attend to some other household related matter during visit; there was a time I had to wait in the house for some time with the participant's children, though appointment time for interview was made earlier. On another interview session in the home of a mother, there was thunderstorm and it was raining heavily outside the home. Interview was interrupted due to the loudness of thunder and the heavy rainfall on the roof.

For one of the mothers interviewed, the sundry shop where she ran her family business was the choice of venue for the interview. As customers were her priority, interview was interrupted on and off. In this situation, while it was quite 'distracting' to the interview session, the process itself provided me with the contextual data which helped in gaining further understanding of the daily life and coping in the natural setting of the home<sup>5</sup>.

Qualitative research data collection process is a flexible and social process directly influenced by the interaction between researcher and participants that took place (Green & Thorogood, 2009). On a few occasions, as part of the interaction and interview process

---

<sup>5</sup> As an example, during the interview session, a customer came in a motorbike to buy ice, asking '*beli satu ringgit... ice batu*' (in Bahasa Malaysia for 'buy one ringgit (RM) ... ice cubes'). Another one customer asked to buy sugar. At the same time, the child with DS was seen to lie down on the floor by herself oblivious of the surrounding. Her mother was later noticed to lift her up from the floor and put her inside the '*uyut kain sarong*' (Bahasa Malaysia word for 'linen hammock') (the family set it up at the door post for child to take her nap in the afternoon). After the mother had settled her child inside the hammock and attended to her customers then we continued with the interview.

with the participants during my visit to their homes, I was invited to take meal with them. This is a local cultural practice and gesture of the host's hospitality. By accepting their invitation, sitting down crossed-legged on the floor, and sharing meal together with them was a gesture of my appreciation on my part (Ling, 2007). After meal was over then I continued with the core business of interview with them.

### ***Visual and written materials as additional data source***

During the interviewing process within the participants' home settings, visual materials that I had accessed provided further data source. These helped to provide further insights and at times help to validate what participants verbalized about their experience (Minichiello, et al., 1990). These visual materials included the 'OKU' card (registration card for 'person with disability' in Bahasa Malaysia), child health records, hospital discharge certificates or the family photo albums. A Chinese mother shared with me her experiences from her journal she wrote since the time of her child's birth. Correspondence through an email (Appendix M) with one of the participants provided an additional data source.

### ***Field notes and journaling***

Besides using interview for data collection, field notes were taken after each session in the participants' home (Appendix N). These notes related to settings within the homes, child's behaviour, mother's response towards child, interaction with child, gesture etc, added further as data source. When analyzed together with textual data of the interview transcripts, field notes often helped to validate (though it may not always be) what the mother had verbalized about her experience. This could be illustrated by the transcripts<sup>6</sup>

---

<sup>6</sup>Feeling stressed, she is so active, once you open the door, she would run, go everywhere... went to the clinic, she pulled the fans, made other children cried, made other children scared, then the staff in the CBR, put her in another room...everything she wants to throw; she

and the field notes<sup>7</sup> which demonstrated challenges faced by a mother. I observed firsthand what the mother told me, concerning care giving demands and tiredness related to child's inappropriate behavior.

### **3.8.1.5 Subsequent interviews**

An appointment for a subsequent interview was requested from each of the participants at a time convenient to them, within one week after the initial interview. A gap of about one week from the initial interview allowed enough preparation time for the subsequent visit. Audio recording of the first interview was listened to ensure its clarity and notes were taken for any point(s) which need further clarification and verification related to the data collected from the participants. Subsequent interview was also conducted for further interviewing on any questions which were not yet being covered in the first session. This is especially for participants who might be restricted in their sharing of experience due to concern of privacy during the first interview session due to presence of grandma or their spouse. It was stated that increasing the number of interview sessions to more than one time over extended time would help to increase the representativeness of the data obtained (Fraenkel & Wallen, 1993).

For three of the Iban mothers, I was granted the appointments for the subsequent visit and interview in their villages which coincided with the Iban Gawai festival<sup>8</sup>, a time of celebration for the people after the padi (rice) harvest. I was welcomed warmly as their

---

*is too active, ai yo, she pulled your spectacles just now... I have to see child whole 24 hours, non-stop active, only when she slept then ok(Mirah, Malay, mother of girl, age 4).*

<sup>7</sup> During the visit to the home, this child was very active, pulled off my pair of spectacles till one side went out of shape. Child was seen trying to climb up the wooden shelf to reach the TV set. Later, she was seen throwing toys out of the opened window. Mother was apologetic child disturbed my spectacles.

<sup>8</sup> Gawai is a festival celebrated by the Iban (natives of Sarawak) to mark the end of harvesting season.

‘guest’ to their homes before I went about the core business of seeking further clarification and responses from them.

### **3.8.2 Questionnaire administration**

Biological mothers of child with DS aged 18 years and below were recruited via the various CBR centres, schools and the child health clinics, including a number of these institutions which were accessed earlier on to recruit the participants for the qualitative interview.

Questionnaire data collection took place over a period of time starting from the beginning of September 2009 till end of January 2010.

As discussed earlier in Section 3.2 (Research Design), in this parallel mixed study design which is utilized in this study, there is no necessity for a specific time order of implementation, as one method of data collection (qualitative interviews) did not depend on the other (QOL questionnaire study), or vice versa, unlike the sequential mixed design (Teddlie & Tashakkori, 2009). Thus, the two data collection processes (qualitative interviews and questionnaires administration) ‘occur at different times due to practical consideration’ Teddlie & Tashakkori, 2009, p. 144).

Appointments were made to meet with the heads of various institutions or persons-in-charge of the various special education program classes in schools, CBR centres and health clinics within the capital city of Kuching and more rural Samarahan Divisions of Sarawak. Objectives of questionnaire study and the procedure for its administration were explained accordingly. Permissions were obtained from them to approach the mothers of child with DS. Only those mothers who consented to participate were given the questionnaire forms

of the appropriate language that they could understand, either in English, Bahasa Malaysia or Mandarin (Instrumentation B: Questionnaires). They were each given a copy of the informal letter titled ‘Information to mothers’ specifying the study objectives. Informed consent was obtained from them before their completion of the questionnaires.

Questionnaires were self-administered if they had sufficient literacy ability as this had the advantages in term of saving time and cost (The WHOQOL Group, 1996; Fraenkel & Wallen, 1993). For those who had problems with self-administration of the questionnaires due to language difficulty, assistance was provided to them.

Due to logistics and variation in the programs in the various institutions (*schools, CBR centers and clinics*), there were slight variations in the procedures for the administration of questionnaire to the mothers.

As for the *CBR centers*, arrangement was made to meet the mothers of child having DS who stayed back at the CBR centers while their child attended the interventional program. Questionnaires were administered by me and collected back immediately after they finished answering them, with assistance provided as needed. Arrangement was also made to meet few other mothers for the administration of the questionnaires when they came to receive the Social Welfare Department’s monthly financial allocation from the CBR center supervisors.

Due to logistic reasons, questionnaires (with the attached copy of ‘information to mother’ and the informed consent form) were distributed to mothers when they came to the schools to send or pick their child, assisted by the class teachers who were given prior explanation

regarding the study. For those who took the questionnaires back home, they were requested to complete and return them within one week. Class teachers were requested to remind the mothers to return the questionnaire forms. Helps from the teachers were sought to urge mothers to return the questionnaires and also to help to screen through the forms for completeness upon their returns. For those mothers who were found to have difficulties with completion of the questionnaires, the teachers were requested to provide them the assistance in completing the questionnaire forms in order to reduce missing data. After one week, a follow-up phone call was made to the teachers for any progress or any practical problem regarding the questionnaires. Visits to the schools concerned were made to collect back the returned questionnaires two weeks later.

Questionnaires were also distributed to those mothers who sent their child with DS to the clinics for the clinic-based interventional programs appointment. Nurses-in-charge in the health clinics who had been given clear, prior explanation about the questionnaires and study objectives were also requested to assist in administering the questionnaires to few other mothers who came with their child with DS to attend the monthly clinic appointment, or when they went to their homes for the home visits.

### **3.9 Data management and data analysis**

#### **3.9.1 Qualitative data management and data analysis**

Thematic analysis guided by Creswell's *six generic steps of data analysis* (Creswell, 2003) was done to identify common and recurring themes (Figure 3.3). The process of data management and analysis was assisted and facilitated by using the computer assisted

qualitative data analysis software (CAQDAS) NVivo 7.0 (Jones, 2007; QSR International, 2009).

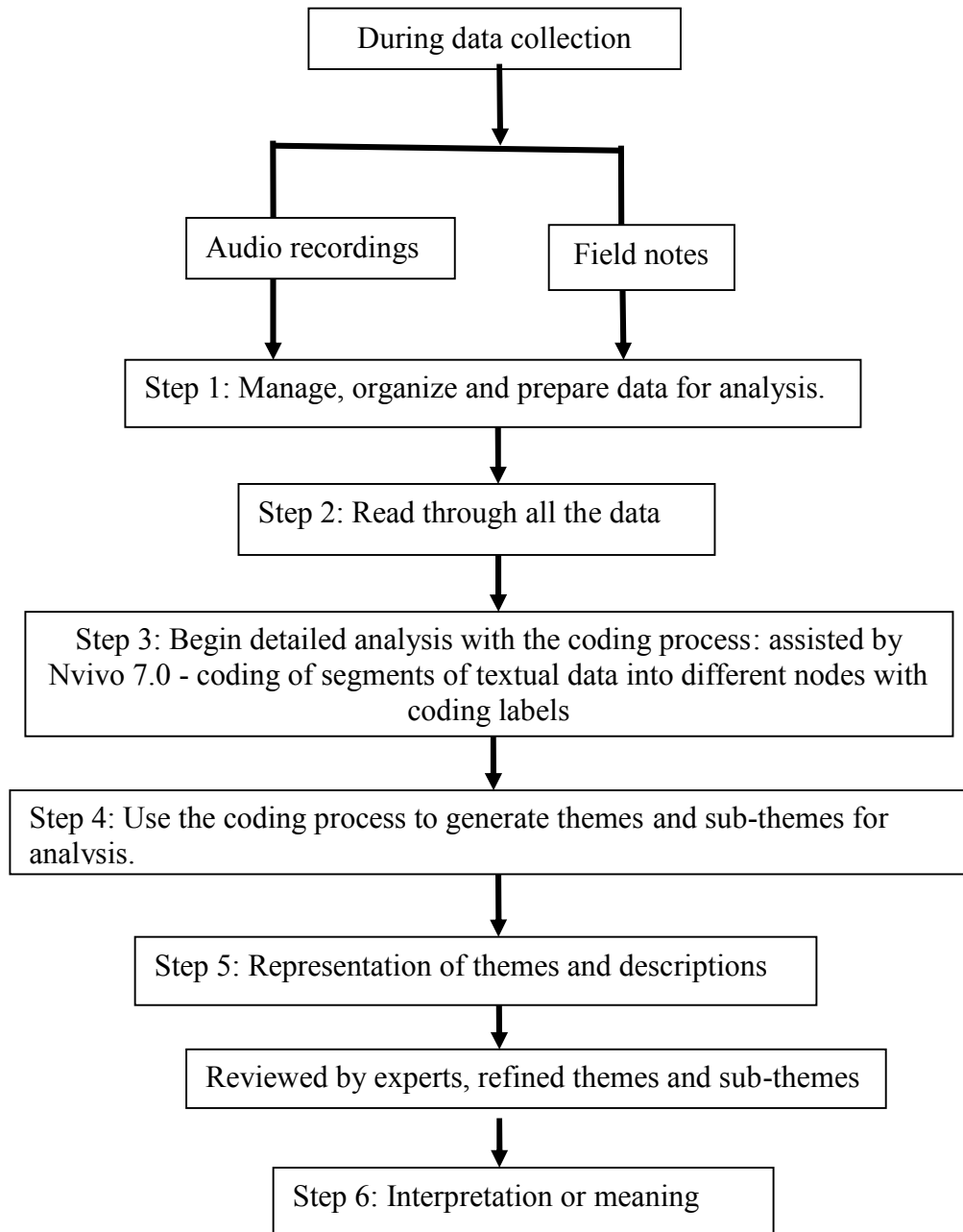


Figure 3.4 Outline of the generic steps of data analysis (modified from Creswell, 2003)



### **Step 1: Manage, organize and prepare data for analysis.**

After each interview, audio recording files which were done with the MP3 player was uploaded into a computer and stored in a folder by connecting the device to a USB port. Another backup copy of the recording file would be saved in another pen drive or external hard drive. Audio recordings from the in-depth interviewing were transcribed verbatim into textual data after repeated listening to the recordings. As soon as possible after one interview session, field notes (some of these were scribbled while in the field) related to settings within the homes, child's behaviour, mother's response and interaction with child, gesture etc were written to avoid loss of details due to forgetfulness, before commencing the next interview. Textual data of the interview transcripts and the written field notes which was included as part of the data for analysis were saved as the 'Microsoft' 'rich text file' and files were being imported into the NVivo 7.0 (Instrumentation C: NVivo 7.0) as the data source to be managed and analyzed.

### **Step 2: Read through all the data**

Data was read through in order to obtain a general, preliminary sense of the information, and to reflect its overall meaning about what participants were saying, and to get a general impression of the overall depth and credibility of the information.

### **Step 3: Begin detailed analysis with the coding process.**

After initial reading to acquire a general, preliminary sense of the content of the textual data, thorough reading of all parts of the data source was started with one of the documents (i.e. the interview transcripts). Textual data was read, sentence by sentence and in detail, as part of comprehensive data treatment, as described by Silverman (2005), in order to be

more familiar with the data content. While reading through the data source between the lines, I was mindful to ask related questions about the data such as ‘what is this parent trying to tell? Which experience is represented here?’, ‘What is this segment of data about? What are the issues raised? How is this like, and not like, other data segments?’(Boeije, 2010).

I tried to be alert to participants’ statements of meaningful expression of perspectives, views and experience and tried to interpret them. During the preliminary coding process using the NVivo 7.0, data segments of various lengths which were identified as relating to a relevant theme were attributed a code name or label, using an in vivo term. As the textual data of the interview transcripts was read through, annotations were made of any thoughts arose regarding any particular data segments before proceeding to read the next part of the textual data and to do coding.

#### **Step 4: Use the coding process to generate themes for analysis.**

It is the analysis of the content of the data to identify recurrent or common themes (or unit of information with similar content from the textual data. All the unit of information (data segments) that had been coded from within a single document (interview transcripts) were inspected and compared with the others within the data sources which also had been coded at (Figure 3.5 in Appendix O). During the process, there was a repeated moving back and forth between different parts of the data source in order to explore the context of certain coding references and the various textual data of the transcripts. A particular document in the data source would be returned to for more coding, un-coding, or annotating of that source if necessary. As Glaser and Strauss (1967 cited in Silverman, 2005) stated, this is

one of the ways to aim for more trustworthy findings. During the coding process, various themes were identified and analyzed for each individual case and across different cases. Further elaboration on the process of using NVivo 7.0 during the data analysis is in the notes<sup>9</sup> below. A sample copy of coding summary report is attached in the Appendix P.

### **Step 5: Representation of themes and descriptions**

Quotes of varying length of the narratives of the participants' experience (in their own wording) relevant to the themes were selected to illustrate various themes and sub-themes which were identified. This is to enable readers to judge the interpretations of participants' multiple perspectives and their way of seeing the social world (Minichillio, et al, 1990; Tully & Cantrill, 2000). These quotes which are in the different local languages were presented in italics to reflect cultural sensitivity (Creswell, 2003).

---

#### **<sup>9</sup> Notes on doing data analysis facilitated by NVivo 7.0**

Using NVivo 7.0, data analysis involved the process of coding from within one document, referring back to the source of the coding reference (data segments), merging few codes (nodes) into a selected node or uncoding when necessary. Memo was also written concerning any thought or idea arised concerning the node, and linked to any of the nodes during the data analysis process. Please refer to Appendix O for illustrations of related coding process (Figure 3.5 to Figure 3.11), and the 'coding summary report' of coding of data segments from different documents (interview transcripts) related to a particular code (or node as in NVivo 7.0). The process is elaborated in the section below:

##### *(i) Coding from within one document*

As data collection using interview was less structured, segments of textual data related to a theme could be scattered about in one transcript document. Segments of the textual data from within one interview transcript and from across the whole the data set (from other interview transcripts) were identified and coded together, and retrieved together at a later stage. Common themes or recurring themes that emerge and segments of text were selected (Figure 3.5 in Appendix O).

##### *(ii) Referring back to the source of the coding reference*

The source of coding reference could be referred to, to review the context of the segments of coded texts (see Figure 3.6 in Appendix O). In the illustrations, list of tree nodes and the retrieved data segments of the node using Nvivo 7.0 software, labeled 'social support' with the source document of 'Mok' located, while that of 'Kay', 'Julian' and 'Farah' also located but 'hidden' but can be viewed by a click on these named documents.

Sub-codes (free nodes) were assigned to the main code (tree node) using 'cut' and 'paste' feature. The illustration in Figure 3.7 showed the sub-nodes 'sibling support', 'spouse support', 'family support' and 'parent support group' while 'support' is the main node.

##### *(iii) Merging nodes into a selected node, and uncoding*

Two or more preliminary codes (nodes) could be 'merged' into another code (node). After coding of the data fragments into different nodes were done, these nodes were retrieved and checked whether each fragment (segment) was coded appropriately. These segments could be uncoded if it contained the unrelated fragments (Figure 3.7 - Figure 3.9 in Appendix O).

##### *(iv) Writing memo during the data analysis process*

Memos such as analytical memos provide a way to store and efficiently retrieve ideas, insights, interpretations that came to mind in the process of analysis (Boeije, 2010) and growing understanding within the data. Memo which was written could be linked to a particular source or node, indicating that the ideas, insights, reflections and information in its content are linked to that item (Figure 3.10 –Figure 3.11 in Appendix O).

## **Step 6: Interpretation and meaning making**

This is the final step of the data analysis. ‘What were the lessons learned?’ was the question which were asked. It could be the researcher’s personal interpretation, couched in the individual understanding that was brought to the study from her own culture or experiences (Crewell, 2003). Learning from the analysis of data obtained from mothers contributes to understanding of mothers’ experience in their perspectives within the local setting. Interpretation of meanings of their experience was also compared and contrasted with prior knowledge from the general literature in the topic.

### **3.9.1.1 Data quality**

Data quality concerns with ‘how we can increase our readers’ confidence in what we have found’ (Miles & Huberman, 1994, p, 263). It concerns with whether there is a correspondence between the way the participants actually perceive social constructs and the way the researcher portrays their view-points (Merten, 2005 in Teddlie & Tashakkori, 2009, p. 295). It also pertains to the controllability of the research process that led to the findings (Boeije, 2010). Various procedures were taken to enhance data quality, which included maintaining procedural rigor, interpretive rigor and reflexivity (Boeije, 2010; Kitto, Chesters & Grbich, 2008). As a criteria of data quality, transferability which concerns with ‘whether the findings of study is transferable or how far or the degree they can be generalized to other context’ (Miles & Huberman, 1994, p. 279).

The section that follows will present the various data quality-related procedures in maintaining procedural rigor, interpretive rigor and reflexivity:

## **(a) Procedural rigor**

### *1. Keeping a clear, detailed account of the various research related activities*

Throughout the research process, a clear, detailed account of various research related activities including experience related to data collection in the field, thoughts and concerns that emerged was kept in the research journal (Appendix N). It serves to assess justification for researcher's choices and lines of reasoning (Boeije, 2010; Green & Thorogood, 2009).

### *2. Spending extended time in the field*

The time spent in the field or research setting started a few months before the actual data collection. This included the time spent to visit the various research settings, attended some of their activities in order to get familiar and to build rapport with the staff, and to orientate myself with the program of activities in the various institutions (special school, child health clinics, CBR centers) as described earlier. A good rapport with staff in the various settings had facilitated and assisted my access to the participants' homes for the interviews.

Through interaction with the participants, an in-depth understanding of the phenomenon under study was better developed with more details gathered and thus credibility to the narrative account (Creswell, 2003).

### *3. Ethics approval from the related 'gatekeepers'*

Ethics approval which was obtained from related 'gatekeepers' such as the Sarawak State Planning Unit, the Sarawak Welfare Department, Ministry of Education Malaysia and Sarawak State Health Director before accessing various related institutions was paramount in gaining confidence and trust of the institutions. It facilitated the support, assistance and

cooperation throughout the research process essential to enable credible, trustworthy data to be collected.

#### *4. Qualitative data management and analysis assisted by computer software*

The use of computer software NVivo 7.0 in the qualitative data management and analysis as clearly described in the earlier Section 3.9.1 which allows coding of segments of the textual data from within one interview transcript and from across the whole the data set (from other interview transcripts) together into a node, uncoding, or annotating of that source (Appendix O and Appendix P), is one of the ways to aim for more trustworthy findings (Glaser and Strauss, 1967 cited in Silverman, 2005)

#### **(b) Interpretive rigor**

Interpretative rigor, or the degree to which credible interpretations have been made on the basis of the obtained results, is another aspect of data quality (Teddlie & Tashakkori, 2009) which includes the following:

##### *1. Peer examination*

This is considered an important mechanism for assessing credibility of findings by assessing the interpretive agreement between peers (Teddlie & Tashakkori, 2009, p. 304). The two lecturers as supervisors experienced in qualitative research reviewed, scrutinized and verified the study findings as represented in the categories of themes which were supported by selections of participants' own quotes. The peer examination process helped to provide new perspectives on aspects which were overlooked. This was to ensure that findings and interpretation resonate with others besides my own.

## *2. Check the accuracy of the data with participants through repeated interviews.*

During the subsequent session with participants, I seek verification and clarification from them regarding main issues discussed in the previous session and asked for their feedback (Creswell, 2003; Finlay, 2006; Polit and Hungler, 1999; Streubert & Carpenter, 1995).

## *3. Use of multiple data sources*

Besides interview transcripts and field notes as the textual data, some other data sources which were available from some of the participants were also included as part of the data source which helped to provide more insights into their experiences of parenting a child having DS. These included printed materials of child's hospital discharge certificates, child health records, emails correspondence (from one of the participants), participant's journal records (by one of them), family photo albums of some of the participants and their child's disability registration cards.

## *4. Multi-lingual use and translation of interviews*

Audio recording of interviews with participants in English, Bahasa Malaysia and Bahasa Iban were being transcribed verbatim. Selected quotes of varying length of the narratives relevant to the various themes were translated into English for readers' understanding.

These were verified by a bi-lingual expert for accuracy of translation (Appendix Q).

A bi-lingual expert<sup>10</sup> assisted with and verified translation of the Bahasa Malaysia and Iban transcripts into English, by conveying the contextual meanings, instead of literally translating them using word by word, which would not make much sense.

---

<sup>10</sup> The bi-lingual expert was a local native speaker of the Bahasa Iban language, and also fluent in Bahasa Malaysia. He is also an English language graduate with a master degree of education in Teaching of English language as a Second Language (MED in TESL).

The same bi-lingual expert who assisted in translation of transcripts into different languages were also engaged in discussing and debating on meanings of certain participants' utterances in the cultural context of the particular set of translated textual data. As stated by Green & Thorogood (2009), "interpreter could have an influence on the data being produced; involved the person who assisted in the interpretation and translation also in the data analysis and discussion could improve on the validity of the data concerned" (p.100).

As an illustration:

*Nadai enggau orang bepinta ke nya... Nya meh kitai amai diau di Kuching, sebuta sebengal, nadai nemu kuing utai. Kadang orang udah minta kitai agi dibelakang, orang udah nyau. Ni orang madah ka kitai, utai bakanya lubah orang madah ke kitai.* (in Bahasa Iban)

*We did not join people to ask. That's why, we stay in Kuching, just like the deaf and blind, don't know anything; sometimes others already got what they want, we are left behind, people already went ahead. Things like this people won't tell you.* (in English)

This segment of transcript was interpreted in the cultural context as 'with any good things, people were slow to let them know about it and they are often left behind'.

During my interviews with a few of the Iban mothers using Bahasa Malaysia which is the commonly used language in the local context, they preferred to express in Bahasa Iban. As a non-native speaker, I was assisted by an interpreter who helped to interpret and further clarified some of the words spoken, though I was able to communicate quite fluently with them. As for the few interviews which were conducted using Mandarin language and Chinese 'hokkien' dialect as participants were more comfortable with their use, the audio recordings were listened to a number of times to get their meanings. As I also used Mandarin and 'hokkien' dialect, I have no problem to translate the contextual meaning into



the English language, instead of literally translating them word by word, which, otherwise, would not make much sense.

##### *5. Rich, thick, detailed description*

Selection of quotes of participants in their own words were used to report findings of major themes and sub themes, ‘instead of being collapsed together or reported as summary of their data’ (Green & Thorogood, 2009, p. 219) to provide an adequately rich, thick, detailed description, including the context to allow readers to judge the data interpretation. It has been stated that “detailed data presentations which make minimal inferences are always preferable to researchers’ presentation of their own summaries of their data” (Silverman, 2005, p. 221). Selections of participants’ quotes add further to transparency and trustworthiness to their findings and interpretations of the data (Tong, Sainsbury & Craig, 2007). It is also in line with the qualitative research’s belief regarding ‘importance of describing the experience of people from their own point of view’ (Parahoo, 1997, p. 357).

As an example, one of the participants’ quotes for the sub-theme ‘stigmatization’ is as follows:

*Once I brought my child to the clinic, she had fever. An elderly lady told her daughter (who was pregnant) ‘Don’t look at the person over there, otherwise your child also become like that’ she said. I am aware of this, I didn’t even look at those people over there, I would not dare to greet them even, especially those who are pregnant. I brought my child straight inside (clinic). If there’s anyone pregnant in their house, I will not dare to visit them. Felt lonely and humiliated.*

### **(c) Reflexivity/ reflection on researcher's role**

Reflexivity, the consideration of whether researcher's view and value having any possible impact upon the data is accounted, is one of the criteria for assessing qualitative research rigor (Kitto, et al., 2008). It is stated that 'self reflexivity' is one of the ways of taking subjectivity seriously. It is the 'recognition of the role of the presence of the researcher herself in generating and analyzing their data and an attempt by the researcher to account explicitly: who and where I am, my social status relative to those interviewed, my institutional base which could inevitably shape the data collected, my past experience, socio-cultural belief and value which could shape the meaning of the data analyzed' (Green & Thorogood, 2009, p. 222).

Similarly, the possible impacts or bias due to research's roles on data collection and analysis due to the various personal experience and personal value was also supported by Fraenkel & Wallen (1993). As emphasized by Boeije (2010), it is important for researchers to be aware of their own personal characteristics, experiences, background, opinions, feelings, etc, and to be able to overcome any possible bias that may be caused by them (p. 175). As researcher attempted to account for causes of possible bias explicitly, the reader makes the judgment about the findings presented.

#### *Researcher, professional role and institutional allegiance*

The process of introducing myself as coming from the university, doing research with approval from the various Ministries and Department as mentioned earlier in Section 3.4.1 might have an impact on the participants' willingness to participate in interviews, and the way they presented themselves. As Green & Thorogood (2009) cautioned, those who are

interviewed might ‘place’ the interviewer in terms of their institutional allegiances and their presumptions about what they want to find out. Their placing of the interviewer might influence their potential ‘interviewee’ role and could inevitably shape the data collected. Clear information regarding study’s objectives and method of data collection, how study findings would be used were conveyed to participants to reduce possible ‘researcher effects’ on interviewee.

### **3.9.1.2 Presenting qualitative findings**

Rich narratives of the mothers’ experience were selected and presented for their relevance to the themes and so that the reader would judge the interpretations of the researcher (Tully & Cantrill, 2000). As far as possible, presentation of analysis is accompanied by their verbatim quotes. For audit trail purpose, selections of verbatim quotes are identified by brief descriptions of the coding, i.e. nodes’ label/name of document (interview transcripts or fieldnotes & serial no.)/reference no. of selected quote (Appendix P for illustrations of ‘coding summary report’).

In order to provide some contextual understanding of selected verbatim quote of participants, the selected coding details were followed by brief descriptions related to ethnicity, age, followed by ‘mo of’ (mother of), child’s gender (using symbol of either ♂ for male or ♀ for female), and child’s age (in years). As an example:

*Nodes/ initial responses/shock & disbelief/14 Julia/ref 1/Chinese, 37 yrs, mo of ♂ age 8)*

In the interest of readability, I have deleted phrases or words of the transcripts without altering the content of what was said. Verbatim quotes in Bahasa Malaysia or Iban are

presented in italics as they were spoken and followed by translation in English. Quotes of different languages are included to reflect ‘cultural sensitivity’ (Creswell, 2003, p. 197).

Having presented the qualitative data management and analysis with its procedural and interpretive details and discussion related to reflexivity in regards to data quality, the subsequent section will present quantitative data management and analysis details involved.

### **3.9.2 Quantitative data management and analysis**

After the questionnaire forms were returned, they were each given an identity number.

Data entry was done, further processed and analyzed using the Statistic Package for Social Sciences (SPSS) version 19.0. Descriptive statistics are used to summarize numerical data, in frequency counts, percentage (of nominal or ordinal level measures such as marital status, education levels); means, standard deviations, maximum & minimum values (for interval level measures such as child’s or maternal age, or domain scores). Non-parametric analysis using Spearman’s rank-order correlation was used. Significance level  $p < .05$  was regarded as significant statistically.

#### *Data checking and cleaning*

These were guided by SPSS syntax (Appendix R). The 3 negatively phrased items (no. 3, 4 and 26) were re-coded individually using the ‘transform’ and ‘recode into same variable’ functions (1=5, 2=4, 3=3, 4=2 and 5=1).

#### *Missing data*

Where an item is missing from an assessment, the means of other items in the domain is substituted. This is done using SPSS (version 19.0) using ‘transform’, ‘recode into same

variables', then select variable to recode, click 'old and new value' command; in the 'old value' box, select 'system or user-missing'; in the 'new value' box, type in the means of the variable as obtained earlier using 'analyze' and 'descriptive statistics'. Any missing data for the variable concerned will be replaced with the mean of the variable (Coakes & Steed, 2003, p. 8). When more than two items are missing from the domain of an assessment, it would be discarded (with the exception of 'social' domain, where the domain would only be calculated if less than one item is missing)' (The WHOQOL Group, 1996, p. 10).

#### *Computing overall and domain mean scores*

The mean scores of all the 26 items and means of item within each domain were used to calculate the overall QOL and the four domains' QOL scores respectively, using the 'transform' and 'compute variables' functions. It is to be noted that the overall and domain mean scores were multiplied by a factor of 4 (in order to obtain possible scores that range between 4 and 20), to be 'comparable with the scores used in the WHOQOL-100' (WHOQOL Group, 1996, p.10) (Appendix R: SPSS syntax). A higher mean score denotes a better perceived QOL.

#### *Re-categorization of selected background variables*

To facilitate further data analysis, few of the background variables were re-categorized using 'transform' and 'recode' into different variables' function. These included the 'education levels' which was re-categorized as 'less than primary school', 'more than secondary school'; 'household income' which was also re-categorized into three categories. Nominal variables for ethnicity and religion were re-categorized into two categorical as Malays and non-Malay groups, Muslim and non-Muslims respectively.

*Examine correlation between selected background variables and QOL means*

Descriptive exploratory data analysis (Appendix S) of the outcome measures of the overall QOL and domain-specific QOL mean scores show kurtosis and skewness within the range of  $\pm 1$ , indicating mean scores could be regarded as close to normality. Test of normality using Kolmogorov-Smirnov indicated data of QOL of DOM 1 physical health, DOM 2 psychological well being, and DOM 3 social relationship with  $p < 0.05$ , except for the DOM 4 environmental support and the overall QOL. Therefore, assumption of normal distribution for use of Parametric Pearson's moment-product correlation is violated. Hence, as another appropriate option, the non-parametric Spearman's rank order correlation was used to quantify the extent of correlation between selected background variables (locality, education, income, maternal age, marital status, religion, ethnicity and employment status) and the outcome measures (overall QOL and domain-specific QOL mean scores). To facilitate the correlation analysis with the outcome measures (of continuous variables in mean scores), the dichotomous categorical variables (locality, marital status, religion, ethnicity, employment status) were coded as 0 and 1 (Coakes & Steed, 2007).

The Spearman's rank-order correlation coefficients ( $\rho$ ) indicate the relative strength of correlation of each of the selected background variables with the overall QOL and domain-specific QOL. Spearman  $\rho$  of 0.1 to 0.29 indicates the strength of relationship as weak, whereas  $\rho$  of 0.30 and above is considered as moderate (Cohen in Pallant, 2007, p. 132). For those selected background variables which were found to be correlated with the overall QOL mean score with statistical significance, further statistical analysis were conducted using multiple linear regression analysis to examine the correlation of the linear combination of these variables in accounting for variance in the QOL score (Table 5.18).

### **3.10 Chapter summary**

In this chapter, the knowledge claim associated with MMR which is based on pragmatism as consequence (outcome) based, problem oriented (research questions) has been highlighted. MMR as an alternative to the other two dominant research traditions of qualitative and quantitative research approaches, is pluralistic and reject the either-or dualism of these two research traditions is emphasized. The chapter discussed the use of parallel mixed research design used to answer two different but related research questions. Details related to methods and instruments use, research participants, pilot study to indicate the appropriateness of instrument used for data collections, research sites, the conduct of the interviews and questionnaire administration, various procedural activities related to qualitative and quantitative data management, analysis and data quality were elaborated. Details of data analysis including the use of CAQDAS NVivo 7.0 and SPSS (19.0) to assist in the data management and analysis were also presented.

The next chapter (Chapter Four) presents the various findings of mothers' experience from the thematic analysis of the interview transcripts and field notes. Findings are organized into five main categories of themes and their sub-themes. Selected quotes in the mothers' own words as relevant to the themes are presented as illustrations. Subsequently, quantitative findings of mothers' QOL, and the association of mothers' selected variables with their QOL are presented in Chapter Five.

## CHAPTER FOUR

### QUALITATIVE FINDINGS OF MOTHERS' EXPERIENCES

#### 4.0. Introduction

The qualitative component of this study aims to gain an understanding of the experiences of mothers of child with DS among the different ethnic groups in Sarawak. The first section of the chapter provides a brief description of the background characteristics to facilitate reader's understanding. The subsequent section presents the various findings from the thematic analysis of the interview transcripts and field notes. Findings were organized into five main categories of themes and their sub-themes. The major themes underlying their experiences which were established from the analysis are '*various emotions*', '*extra care demands*', '*variation of supports*', '*coping strategies*' and '*life impacts*'. Various sub-themes were identified under each major theme. Selected quotes in mothers' own words as relevant to the themes are presented together as illustrations.

#### 4.1 Mothers' background characteristics

The background characteristics of the mothers and their child are outlined in Table 4.1 to Table 4.5. Individual mother's background characteristics are outlined separately in Table 4.6 to provide the context which would facilitate reader's understanding of their experience.



Table 4.1 Mothers' background characteristics

<b>Characteristics (N=26)</b>	<b>n (%)</b>
Maternal age (years)	
Mean (SD)	42.4±8.3
Range	23 – 61
30 yrs and below	2 (7.7)
31-45 yrs	16 (61.5)
45 yrs and above	8 (30.8)
Maternal age (at birth of child with DS)	
Mean (SD)	34.5±5.7
Range	22 – 44
Age of child with DS	
Mean (SD)	7.4±5
Range	1 – 17
Ethnicities	
Malay	9 (34.6)
Chinese	9(34.6)
Iban	5 (23.1)
Bidayuh	3 (7.7)
Religions	
Islam	9 (34.6)
Christianity	11 (40.7)
Buddhism	6 (22.2)
Marital status	
Married	24 (92.3)
single	2 (7.7)
Highest educational level	
No education	3 (11.5)
Primary education	7 (26.9)
Secondary education	13 (50.0)
Tertiary education	3 (11.5)
Employment status	
Unemployed	15 (57.7)
Employed	11(42.3)
Household income	
RM 500 and below	4 (15.4)
RM 501-1000	8 (30.8)
RM 1001-2000	6 (23.1)
RM2000 and above	8 (30.8)
Transports	
Use own car	16 (61.5)
Own motorcycles	8 (30.8)
Public transports	2 (7.7)

The 26 participants were recruited purposively for the in-depth interviews from a diverse socioeconomic background to ensure a maximum variation of mothers' perspectives to be adequately represented. They were the biological mothers of 28 children with DS from within and nearby Kuching the capital city and rural Samarahan Divisions of Sarawak, including two of the mothers who had two children having DS in the same family. They were recruited through various contexts, namely the CBR centers, the child health clinics, the non-governmental special school and the governmental schools with special education integrated program. Besides these, four of the mothers were recruited through informal contacts by snow-ball method (Table 4.2).

Table 4.2 Sites accessed and numbers of participants (N=26)

Sites accessed:	Number
CBR centers	12
Child health clinics	4
Non-governmental schools	5
Governmental schools	1
Informal contacts	4
Total	26

#### **4.1.1 Marital status, maternal and child's age and number of children**

Majority of the mothers interviewed were married, except for two of them who were single. The number of children these mothers had ranged from a minimal of one child to a maximum of 11 children in the family. Children with DS had a mean age (in years) of  $7.42 \pm 5.0$ . The group of mothers had a mean age (in years) of  $42.44 \pm 8.35$ , with the majority of them who were in the age category of 31 to 45 years old. Among the mothers, they delivered their child with DS at a mean age (in years) of  $34.54 \pm 5.73$ . Seven of them delivered their first child who had DS, with three of them who were less than 30 years old

as first time mothers. Besides their child with DS, these mothers were also parenting other children who were in their mean age (in years) of  $4.1 \pm 2.43$ .

#### **4.1.2 Ethnicity, locality, religions**

The group of mothers comprises of different ethnic groups, namely the Malays, Chinese, Iban and Bidayuh who came from the rural and also the urban locality. There were more Chinese mothers who came from the urban than from the rural region; whereas more Malays, Ibans and Bidayuh came from the rural than from the urban region. The distribution was reflective of the population distribution in Sarawak (State Planning Unit, 2009). In term of religion, a big proportion of them were Christians (40.7%), with 34.6% of them who were Muslims, whereas the other 22.2% were Buddhists.

#### **4.1.3 Education, income, employment and transport**

These mothers who were recruited received various levels of education. Half of the group received formal education till the secondary school level (50 %) while only a few of them attained tertiary education. The rest of them received their education only till primary school or less.

Among the mothers, 15.4% (n=5) of them reported a monthly household income of RM 500 and below. They were considered as poor, with a household income which was below the poverty line income of RM 830 per household (Economic Planning Unit, n. d.).

Contrastingly, the other 30.8% (n=8) reported household income of RM 2000 or more.

Slightly more than half of them were housewives, while the rest were employed in the

government department, private sector or practicing own business, including one who worked as a staff in the CBR centre.

Slightly more than half (n=16) of them used their own cars as the main mode of transport to commute from one place to the other. One third of them (n=8) depended on motorcycles whereas a small percentage of them could not afford either a car or motorbike, but depended on solely on public transport such as buses that travelled along the main road, on fixed routes or private vans that ferry passengers to negotiated destinations.

#### **4.1.4 Background information of the children**

There was an indication of delayed development among the children with DS in relation to their walking, bladder and bowel controls and language learning (Table 4.3). Besides this, they were reported to suffer from various medical conditions which required treatment due to congenital cardiac conditions, ear, eye, breathing or rectal conditions. Among these conditions, cardiac condition was most frequently reported (Table 4.4).

Table 4.3 Child-development related information

Child development-related	Age of child (in yrs)
	Mean (SD)
Attained bladder control	3.55 ± 0.66
Attained bowel control	3.62 ± 0.58
Could walk	3.17 ± 1.13
Spoke less than five words	4.56 ± 1.13

Table 4.4 Child-health related information

Medical conditions	n (%)
Cardiac conditions	10 (38.5)
Ear condition	4 (15.4)
Eye condition	2 (7.7)
Breathing condition	6 (23.1)
Rectal condition	3 (11.5)
Other condition	1 (3.8)

Fifty percent (n=13) of the children were attending at least one of the programs, which may be the nearest CBR centers, clinics, governmental schools or the non-governmental special school. However, this is in contrast with the 15.4% (n=4) who did not attend any of the programs (Table 4.5), whose mothers were accessed and recruited by snow-ball method. The reason for the four children with DS, aged between 5 and 17 years old who did not attend any of the programs was reported to be due transport and financial constraints.

Table 4.5 Attendance to service provisions

	n (%)
Attend at least one of the programs*	13 (50.0)
Attend two or more programs	9 (34.6)
Not attending any of the programs	4 (15.4)

\* either at the CBR centres, clinics, governmental school's integrated Special education programs or non-governmental school's program

Table 4.6 Individual mother's background characteristics

Transcript serial no./ pseudonym/ ethnicity, maternal age, child's gender/ age	Background characteristics
1. Adrina, Bidayuh, 44 yrs, mo of ♂, age 6	Mother of three children; including the youngest, with DS who suffered from Leukemia complication. Had secondary school education; full time employment as government staff; lived in an urban housing area; received extended family support. She was accessed through CBR centre.
2. Rose, Iban, 50 yrs, mo of ♂, age 17.	Mother of three grown-up children, including the youngest, who was with DS; a full time housewife; husband worked as a labourer; lived in along house in an Iban rural kampong (village). Child did not attend any interventional program. She was accessed through snow-ball method.
3. Anders, Iban, 44 yrs, mo of ♂, age 5	Mother of 9 children, including the 2 <sup>nd</sup> youngest who was with DS. Child was born with congenital cardiac abnormality and duodenal atresia, and was operated soon after birth. Did not send child to any CBR or any intervention program. A full time housewife; husband worked as a labourer; lived in an urban, squatter area. She was accessed through snow-ball method.
4. Aziah, Malay, 41 yrs, mo of ♀, age 5	Mother of 8 children, including the youngest child who was with DS. Child was born with congenital cardiac abnormality; on medical follow-up. A full time housewife; husband worked as a farmer; lived in the rural village. She was accessed through CBR centre.
5. Bisroh, Malay, 40 yrs, mo of ♂, age 4	Mother of 8 children, including the youngest child who was with DS. A full time housewife, husband worked as farmer; lived in the rural village. She was accessed through child health clinic.
6. Chara, Bidayuh, 41 yrs, of ♀, age 14	Mother of 2 children, including the youngest child who was with DS. Child had delayed motor development with delayed walking till 10 years old. Worked as a factory operator on shift hour, lived separately from husband; lived in the rural village about 19 km away from Kuching. She was accessed through CBR centre.
7. Daniela, Chinese, 31 yrs, mo of ♂, age 3	Mother of 2 children, including the youngest child who was with DS. Child was operated for congenital cardiac abnormality at age of one year old. A full time housewife; husband worked as a laborer; lived in an urban housing area. She was accessed through CBR centre.

Table 4.6, continued (i)

8. Emmy, Iban, 23 yrs, mo of ♀, age 1	Mother of the only child with DS. Child had breathing problem, admitted, on medical follow-up. A full time housewife; husband worked as a teacher; lived in the village. She was accessed through child health clinic.
9. Farah, Malay, 48 yrs, of ♀, age 16	Mother of 4 children, including the youngest child who was with DS. Worked as staff at a CBR centre; husband worked as a driver; lived in an urban housing area. She was accessed through CBR centre.
10. Gabe, Chinese, 49 yrs, mo of ♂, age 5	Mother of 5 children, including the youngest child who was with DS. Child was operated for congenital Hirshsprung's disease; also had with cardiac condition. Had secondary school education; employed in private sector while husband worked as a businessman; stayed in an urban housing area. She was accessed through CBR centre.
11. Harris, Iban, 61 yrs, mo of ♂, age 17	Mother of 3 children, including the youngest child who was with DS. Two other grown up children were married and not living with her. She was a full time housewife; husband left her. Had an old mother who was dependant on her for care provision. Dependent on Welfare's monthly subsidy. The growing up child with DS was not attending any interventional program or CBR. Lived inside one of the 'unit' of an Iban longhouse about 30 km away from Kuching. She was accessed through snow-ball method.
12. Hazlin, Iban, 54 yrs, mo of ♀, age 13	Mother of 4 children, including the youngest child who was with DS. Two other grown up children were married and not living near her. Another daughter who was married but stayed short distance away from her in an Iban longhouse in the village. Could not send child to any CBR or school due to transport problem. She worked part time in a cocoa plantation as a labourer; husband also worked as a labourer. She was accessed through snow-ball method.
13. Jen, Chinese, 39 yrs, mo of ♂, age 3	Mother of 2 children, including the child who had DS as the eldest. Had secondary school education; both she and the husband worked as private company employee. Child had congenital cardiac abnormality and was operated at one year old; still on medical follow-up. Lived in an urban housing area. She was accessed through CBR centre.
14. Julia, Chinese, 37 yrs, mo of ♂, age 8	Mother of 4 children, including the child who had DS as the 3 <sup>rd</sup> child. Had secondary school education; managed an early child care centre; husband was employed as a government staff. Child had congenital ear and nose problems; still on medical follow-up. Lived in an urban housing area. She was accessed through non-governmental school.

Table 4.6, continued (ii)

15. Jupi, Bidayuh, 35 yrs, mo of ♂, age 3	Mother of 3 children, including the child who had DS as the youngest. She was a full time housewife while husband worked as a storekeeper. Lived in the company's rented shop lot in the city. She was accessed through CBR centre.
16. Kay, Chinese, 45 yrs, mo of ♀, age 9	Mother of 2 children, including the child who had DS as the youngest. Child was treated for severe jaundice and congenital cardiac condition when she was much younger. Had secondary school education; a full time housewife while husband managed own business. Lived in an urban housing area. She was accessed through governmental school.
17. Kua, Ch, 50 yrs, mo of ♀, age 9	Mother of 4 children, including the child who had DS as the youngest. Child was treated for ear, nose and throat conditions when she was much younger. Had received tertiary education; both she and her husband were on full employment as government staff; lived in an urban housing area. She was accessed through non-governmental school.
18. Khaitijah, Malay, 43 yrs, mo of ♂, age 7	Mother of 5 children, including the child who had DS as the 2 <sup>nd</sup> youngest. Had primary school education; a full time housewife while husband was a driver. Family lived in a rural area. She was accessed through CBR centre.
19. Wang, Chinese, 33 yrs, mo of ♀, age 6	Mother of 2 children, including the child who had DS as the youngest. Had secondary school education; both she and her husband worked full time in a private company. Family lived in an urban housing area. She was accessed through non-governmental school.
20. Normirah, Malay, 43 yrs, mo of ♀, age 4	Mother of 4 children, including the child who with DS as the youngest. Child was operated for duodenal atresia soon after birth. Had secondary education; both she and her husband were on full employment in the private company; lived in an urban housing area. She was accessed through child health clinic.
21. Noraryna, Malay, 24 yrs, mo of ♀, age 3	Mother of 2 children, including the child who with DS as the eldest. Had secondary school education; a full time housewife; her husband worked as a supervisor in a factory. Family lived in the urban area. Accessed through CBR centre.
22. Mok, Chinese, 40 yrs, mo of ♀, age 8	Mother of 2 children, including the child who with DS as the eldest and the younger child being adopted. Had secondary school education; both she and her husband operated own business from home; did not have extended family support; live in the urban area. Accessed through non-governmental school.



Table 4.6, continued (iii)

23. Ann, Malay, 44 yrs, mo of ♂, age 6 and ♀, age 2	Mother of 4 children, including the 3 <sup>rd</sup> child and 4 <sup>th</sup> child both with DS. The younger child with DS suffered from congenital cardiac abnormality and was due for operation; on 2 monthly medical follow-up; received primary school education; a full time housewife; her husband worked as a labourer; had problem with extended family support; lived in the village. She was accessed through clinic.
24. Salina, Malay, 42 yrs, mo of ♀, age 3	Mother of 11 children, including the child with DS as the youngest. Child suffered from congenital cardiac abnormality and was operated at one year old; still on medical follow-up; received primary school education; a full time housewife; her husband worked as a labourer. She was accessed through the CBR centre.
25. Tan, Chinese, 48 yrs, mo of ♂, age 16	Mother of 3 children, including the child with DS as the eldest. Child suffered from frequent diarrhea when younger. Received secondary school education; a full time housewife; her husband operated own business in the city. She was accessed through non-governmental school.
26. Zuriah, Malay, 37 yrs, mo of ♂, age 5	Mother of 5 children, including the child with DS as the youngest. Received secondary school education; a full time housewife; her husband worked as a labourer. She was accessed through CBR centre.

## 4.2 Experiences of mothers having a child with DS

Using thematic analysis, textual data from the interview transcripts and field notes which were gathered were analysed. Five major themes with their sub-themes were identified. These major themes were ‘various *emotions*’, ‘*extra care demands*’, ‘*life impacts*’, ‘*variation of supports*’ and ‘*coping strategies*’. These major themes and sub-themes are outlined in Table 4.7 below.

Table 4.7 Outline of the major themes and subthemes of mothers’ experiences

<p><b>4.2.1 Various emotions</b></p> <ul style="list-style-type: none"><li>• Shock and disbelief</li><li>• Sadness</li><li>• Anger</li><li>• Difficulty in accepting child</li><li>• Shame and self-blame</li><li>• Worries</li><li>• Excited with child’s developmental progress</li><li>• Joy and pleasure of mothering</li></ul> <p><b>4.2.2 Extra care demands</b></p> <ul style="list-style-type: none"><li>• Child health-related care demands</li><li>• Developmental delay-related care demands</li><li>• Child’s behavior-related care demands</li></ul> <p><b>4.2.3 Variation of supports</b></p> <ul style="list-style-type: none"><li>• Informal supports</li><li>• Formal support</li><li>• Environmental supports</li></ul> <p><b>4.2.4 Coping strategies</b></p> <ul style="list-style-type: none"><li>• Reframing perspectives</li><li>• Maintaining hopefulness</li><li>• Religious beliefs and convictions</li></ul> <p><b>4.2.5 Life impacts</b></p> <ul style="list-style-type: none"><li>• Being stigmatized</li><li>• Family role impacts</li><li>• Personal growth and competence</li><li>• Motivated to reach out to help others</li></ul>
--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Experiences of mothers having a child with DS as represented by the various themes and sub-themes as emerged are illustrated by the mothers' verbatim quotes.

#### **4.2.1 Various emotions**

This section provides a picture of mothers' experience of '*various emotions*' within self and within the context of family related to having a child with DS. Being mothers having a child with the diagnosis of DS, many of them went through emotions such as shock, disbelief, sadness, with several who experienced anger, intertwined with feeling of shame and self-blame. A few of them recounted their experience of difficulty in accepting their child. Besides these, their feelings of excitement upon child's new progress, their experience of joy during the process of mothering their child were evident. At the same time, expression of worries concerning child's self-care ability, future care provision for their child and worry of risk of recurrence of DS were apparent

The various heartfelt emotions of these mothers could be described in the several sub-themes as:

- Shock and disbelief
- Sadness
- Anger
- Difficulty in accepting child
- Shame and self-blame
- Worries
- Excited with child's developmental progress
- Joy of mothering

#### 4.2.1.1 Shock and disbelief

Many of the mothers' experience of initial responses of shock and disbelief, bewilderment when being told of the unexpected diagnosis of child could be illustrated by the following quotes from Julia and Kay:

*Middle of the night I just walked to the nursery where my baby was, I saw one big sign board, so nice sign hung up at the side of the cot, 'Down's syndrome', I was... ah. I was extremely shocked!*

(Nodes/emotions/shock & disbelief/14 Julia/ref 1/ Chinese, 37 yrs, mo of ♂, age 8)

*What do you mean my child is not good?' I really could not take it anymore. The doctor said, 'your child got DS', I asked 'what is DS... what is it?' Really, what is it? I could not hear anything, just could not hear anything after that. Sie ah (Hokkien dialect word for I am going to die!)! Cho mi eh seh zhi eh kia ah ne kuang? An zhua ho?' (ChineseHokkien dialect word for 'how could I deliver a child like this? What do I do now?')*

(Nodes/emotions/shock & disbelief/16 Kay/ref 1/Chinese, 45 yrs, mo of ♀, age 9)

#### 4.2.1.2 Sadness

A number of mothers indicated their sadness that accompanied by uncontrollable crying, with feeling of lethargy and lack of motivation to breastfeed or care for their newborn child after disclosure of child's diagnosis.

Kay acknowledged her sadness and lack of motivation as her initial experience after her delivery while she and her child were still in the hospital:

*She (her baby) was inside the Nursery. I was in my (hospital) bed. Breast feeding, no, I had no energy to feed her, I was too weak, I slept, could not get up. I had no strength, went to sleep. If she (baby) cried, the nurse fed her. What to do...the nurse did say 'come to Nursery to feed her when it's time'. I did not want to go to there to see baby. I just could not care for her. An zjua ho! (Chinese Hokkien dialect word for 'what to do?') I just kept thinking.*

(Nodes/emotions/sadness/16 Kay/ref 1/ Chinese, 45 yrs, mo of ♀, age 9)

Kay further related her experience of sadness, after she was back to her own home:

*I still had no mood to breastfeed my baby. She did not cry, always slept. Both baby and I went to sleep. My mother-in-law had to frequently sneaked into the bedroom to have a look*

*at us, asked 'you gave milk to baby or not?' I kept crying in my bed, kept looking at the words Down syndrome on the baby card. An zjua ho! (Chinese Hokkien dialect words for 'what do I do now?').*

(Nodes/emotions /sadness/16 Kay/ref 3-6/Chinese, 45 yrs, mo of ♀, age 9)

A Chinese mother Tan, who delivered her first male child having DS felt devastated after she knew of her child's diagnosis:

*Very sad, I only knew how to cry in the hospital, I just cried, felt numb.*

(Nodes/initial responses/sadness/25 Tan/ref 1/Chinese, 48 yrs, mo of ♂, age 16)

Mothers' emotional experience during the child's early age could be overwhelming, as

illustrated by Julia and Kua's quotes below:

*For the first two years I cried a lot.... I didn't have a peaceful life. So much of pressure I had, very bad ah. I could have jumped down from the building, you know. So many things gave me pressure. The heart had a lot of bitterness.*

(Nodes/emotions/sadness/14 Julia/ref 1/Chinese, 37 yrs, mo of ♂, age 8)

*I had suicidal thoughts till she was about 2 years old. At the beginning when I had her, I thought I was going to die, could not take it; felt like crazy.*

(Nodes/emotions /sadness/17 Kua/ref 1/Chinese, 50 yrs, mo of ♀, age 9)

The emotions of sadness related to child's disability was felt even years later, though their child had grown older. This was especially so if they did not receive spousal support.

Harris, a 61-years old Iban mother described her feeling in her quote as below:

*Susah ati, memang susah. Kati kitai enda tusah, iya enda ulih kerja, gari enda ulih muat. Maya enda ringat, enda ringat, hati tu sedih bah. (in Bahasa Iban)*

(Nodes/emotions/sadness/11 Harris/ ref 1/ Iban, 61 yrs, mo of ♂, age 17)

*Feel sad, really. Why not sad, he (child with DS) cannot do any work, cannot even fold the clothes. At times only can forget, just feeling sad. (in English)*

### 4.2.1.3 Anger

Besides sadness, feeling devastated, some mothers experienced anger which was easily triggered by anyone who came by the way. Kay recounted her experience as below:

*The male nurse came to check my body temperature, asked where my baby was, 'baby is it not in the nursery? (They) kept asking (where her baby was)! One by one kept asking! I was already so sad, not that I hid the baby, why kept asking (with angry tone of voice). So angry that time, they kept asking.*

(Nodes/emotions/initial responses/anger/16 Kay/ref 1/Chinese, 45 yrs, mo of ♀, age 9)

Kay was also angry with the doctor for the way he explained the child's condition:

*He (the doctor) said 'she (child) will not be able to walk'. Having a child who cannot walk! (Note: mother raised her tone of voice at this point). He said, 'she may need to use a wheelchair' because her limbs were 'too soft'. If I meet this doctor again, I would challenge him! He dared to say she couldn't walk.*

(Nodes/emotions/anger/16 Kay/ref 2/ Chinese, 45 yrs, mo of ♀, age 9)

In fact, for Kay's daughter, she was able to walk about but at 6 years of age, which was much delayed as compared to other children of her age. Kay further recounted her experience of anger with the doctor who had seen her during her pregnancy:

*I called the doctor (after delivery of baby), "why when I did check-up in your clinic ... you always said 'baby is ok, ok, no problem', why I delivered a baby like this one?" ... "if I need to do the test (amniocentesis), let me know, then I go and do the test"(with angry tone of voice) ... he said he did not expect it. How can, he did not expect it! Why he didn't realize my age and asked me to do the 'test'. Why the doctor did not check properly ... Really, if the doctor had detected it (DS diagnosis) I would have aborted it.*

(Nodes/emotions/blame self & others/16 Kay/ref 1/Chinese, 45 yrs, mo of ♀, age 9)

#### 4.2.1.4 Difficulty in accepting child

Part of mothers' emotional responses in relation to parenting a child with DS was their initial struggle with acceptance of their child. Noraryna who had her first child having DS described her initial difficulty in accepting child:

*Mula mula memang rasa tak dapat terima.* (in Bahasa Malaysia)  
(Nodes/emotions/difficulty in accepting/21 Noraryna /ref 1/Malay, 24 yrs, mo of ♀, age 3)

*At the beginning I just felt could not accept.* (in English)

Their struggle with accepting the reality of child with DS could last for a variable period of time. There is an evidence of contemplation to abandon the child, as recounted by Kay with her second child having DS in her quote below:

*I wanted to give her away to my sister-in-law. It was hard to accept this child, for 6 years, she could not do anything, tongue protruding out.*  
(Nodes/emotions /difficulty in accepting/16 Kay/ref 1/Chinese, 45 yrs, mo of ♀, age 9)

#### 4.2.1.5 Shame and self blame

For few of the mothers, the initial period after disclosure of diagnosis was a time of struggling with feelings of shame as child was not like others'. Noraryna expressed her feeling of shame as below:

*Ada perasaan malu. Malu lah, sebab lain orang dapat anak normal, yang kita dapat macam ini ... malu bergaul dengan orang lain, nanti orang cakap macam macam* (in Bahasa Malaysia).

(Nodes/ mixed emotions/shame/21 Noraryna/ref 1/Malay, 24 yrs, mo of ♀, age 3)

*Have feeling of shame... shame, because other people have normal child, but what I have one like this... feel shameful to mix with other people, other people may say this and that* (in English).

Due to their feeling of shame, there were mothers who chose not to reveal child's diagnosis to others or hid the child from the others' view.

*I kept it secretive (child's diagnosis), did not tell anyone. I did not want to carry her. Others want to see my baby, I felt shameful... during Chinese New Year festive season, when people come to visit, I would move the baby (in the baby walker) further away, nearer to TV, so that the baby would not face the people; I did not want people to look at her.*  
(Nodes/emotions/shame/16 Kay/ref 2/Chinese, 45 yrs, mo of ♀, age 9)

Among the mothers, there were those who attributed the delivery of a child with DS to various causes which were indirectly related to themselves. As example, Chara, a Bidayuh mother, recounted that she took a lot of green tea during her pregnancy, questioning whether it might have caused the abnormality of DS in her pregnancy. There were mothers who apparently linked their child's DS condition with untreated infection; own blood group or some wrong deeds committed during the pregnancy. The following quotes from Jen and Juliaas below are illustrative:

*My sister also got one DS child, why I am so careless not to do any testing (to detect DS). Beginning I felt maybe our blood has this type of chromosome. Maybe be I was too careless.*  
(Nodes/emotions/blame self & others/13 Jen/ref 1/Chinese, 39 yrs, mo of ♂ age 3)

Julia apparently blamed on some untreated infection she had for her child's condition as she described in her statements below:

*When I was three months to five months pregnant, I had a lot of vaginal discharge, my discharge was very bad, the doctor wanted to give me injection but I didn't want, that is why.*  
(Nodes/emotions/blame self & others/14 Julia/ref 1/Chinese, 37 yrs, mo of ♂, age 8)

As part of the emotions experienced by mothers having a child with DS, several of them went through a time of struggling with feeling of shame. Besides this, there were several



mothers who apparently associating child's DS condition with self as the indirect cause, including the type of food or drinks taken, own blood group, or body's infection.

Apart from those experiences of various emotions as mentioned above, their feeling being worried was obvious among the mothers.

#### **4.2.1.6 Worries**

- Worries about child's self-care ability
- Worries about child's future care provision
- Worries about risk of recurrence of DS

##### ***Worries about child's self-care ability***

One of the worries and concerns of mothers was whether their child had the ability to take care of themselves and to protect self from bully or harm.

One of Gabe's concerns was about whether her son's self care ability, including matter such as handling of money:

*I hope to see that he's like any other normal child- able to read, able to write, able to look after himself, able to feed himself, to clothe himself, to bath himself, but whether that is possible or not is another thing... Hope that when he has money, he is not being cheated.* (Nodes/emotions/worries about care self ability/10 Gabe/ref 1/Chinese, 49 yrs, mo of ♂, age 5)

Several mothers expressed their worries about child's self care ability and the vulnerability of their growing-up child when outside the home. The following quotes of Farah and Chara are illustrative of their worries:

Farah, a mother expressed her concern as illustrated in her quote below:

*People like to bully the children like this! Ask them to do smoking, dancing... because they want to make friends, but they don't know how! People bully him, "ah, you want to be my friend? Do you want to smoke?"... that's why I like him (the son) to stay at home! So far, he never go out anywhere (alone). But sometimes on Saturday or Sunday, I bring them out.* (Nodes/worries about self care ability /9 Farah/ref 8/Malay, 48 yrs, of ♀, age 16 and ♂, age 28)

As expressed by Chara, though she was concerned that her growing up daughter did not have friends and felt shy, however, she would not let her go out without following her. She was concerned of her ability for self-care:

*Jikalau (dia) mahu suruh dia pergi jalan, tak sampai hati, mesti ada orang ikut dia, sebab tak sampai hati dia berjalan macam itu, sebab nanti kena orang buli nanti pun tak tahu* (Bahasa Malaysia). (Nodes/concern of self care ability/6 Chara/ref 2/Bidayuh, 41 yrs, of ♀, age 14)

*If she wants to go out, must have someone follows her; I don't have the heart to let her goes out by herself, otherwise, bullied by other people she also doesn't know* (English).

Though mothers hope that their children are able take care of themselves, independent, a few of them hesitated to allow child to do things due to their concern of harm upon themselves. Rose, an Iban mother's words illustrate this:

*Enggai aku ngajar ia masak masak, enggai aku ngajar ia..takut api...dulu ia agi.. baru 13-14 tahun, nemu ia, nyumai beras nya, tangar ia periuk (measure the pot), beri ia air, tangar ia. Nya meh aku takut amai aku meda ia, 'badu agi, badu' Enti bisi orang ngajar ia nadai ngawa, enti kitai bisi jaga ia* (Bahasa Iban). (Nodes/ mixed emotions/worries about child's self care ability/2 Rose/ref 1-2/Iban, 50 yrs, mo of ♂, age 17)

*I would not want to teach him cooking (using stove). (I'm) scared he gets hurt by the fire. Last time he could, about 13-14 years old, he knew how to cook rice, measure the rice, put inside pot, put water. Now, I'm really scared... I see him like this. No, no. If got someone to teach him then ok, if we are around to supervise him* (English).

### ***Worries and uncertainty about child's future care provision***

Many of the mothers irrespective of their ethnicity, were worried about the future care provisions for their children with DS, knowing that they would grow old one day and would not be able to continue to care for them any further. They placed their hope on someone who was closest to the child in the family, the child's siblings, to continue the care in the future. However, they expressed their uncertainty as to the extent of sibling's dependability, knowing well that one day they too would have their own family to take care. Their sense of worries and uncertainty were vividly illuminated in quotes of the few mothers below:

Emmy, an Iban, first time mother of one-year old child with DS, was worried about child's future care provision, illustrated by her words below:

*Saraan tu, itu saya bingung juga saya, susah bah macam mana dia besar nanti, menjaga diri lagi, mau sara diri lagi...susah juga,* (in Bahasa Malaysia).

(Nodes/emotions/worries about future care provision/8 Emmy/ref 1-2/Iban, 23 yrs, mo of ♀, age 1)

*About support for her living, that's the thing that I'm worried about. It's hard, when she grows up later, she has to take care of herself, provide for herself, it's difficult* (in English).

*Bingung-bingunglah ati meda ia baka tu. Enti masa kitai udah tuai, enggai ka bala menyadi ia ila enda manah enggau ia; semina tu aja meh nanggul-nanggul. Enggai ka udah mati ila, takut enggai ka bala menyadi ia nadai tentu nyaga ia* (in Bahasa Iban).

(Nodes/emotions/worries about future care provision/2 Rose/ref 1-2/Iban, 50 yrs, mo of ♂, age 17)

*I'm really worried to see him in this condition. Later, when we are already old, I'm worried that his other siblings don't treat him well, that's the only thing that bothers me. I'm worried that when I die next time, his siblings don't really take good care of him* (in English).

Chara, a Bidayuh mother who lived separately from her husband, apparently did not have any other option but to expect the child's sibling to continue with the future care provision:

*Saya harap kakak dia sayang dia macam saya sayang dia, kalau dia kahwin pun nanti, kalau dia sudah ada anak pun, saya akan suruh dia tinggal dengan kakak dia... dia (child with DS) akan tolong jaga anak kakak dia, bantu kakak dia, supaya kakak jaga dia sampai tua. Itulah penting, saya selalu cakap dengan kakak dia. Belum tau, Kadang kadang kita fikir, kita sudah tua... kita belum tahu lagi keadaan dia (in Bahasa Malaysia).*

(Nodes/emotions/worries about future care provision/6 Chara/ref 1-2/Bidayuh, 41 yrs, of ♀, age 14)

*I hope the sister will love her like I love her; if she (the sister) gets married later, if she has her children, I will ask her to stay with her sister, she can help to take care of the sister's children, help the sister, so that the sister will take care of her till old. That is important, I always tell the sister. Don't know yet, sometimes I think by the time when I am old, don't know how her condition will be like (in English).*

The same mother also having the hope was that if her daughter were to get married one day and able to have her own child, this child of her own would then grow up and later on help to provide care to her in return.

Wang, a Chinese mother, related her plans to secure her child's future care provision through the child's sibling:

*I gave birth to (child's) the younger brother, next time he can help to look after her. Our future plan is to give her our house which will be named under her name, give everything to her.*

(Nodes/ emotions/worries about future care provision/19 Wang/ref 1-2/Chinese, 33 yrs, mo of ♀, age 6)

Besides the concerns of child's self-care ability and future care provision which constituted their load of worries, many of the mothers' were worried about the risk of recurrence of DS in the subsequent pregnancies.

### ***Worry about risk of recurrence of DS***

Having had the prior experience of mothering a child with DS, mothers' hope for a 'normal' child or sibling who might be able to help to take care of child with DS was mixed

with the worry of the risk of recurrence DS. Worry and fear related to the risk of recurrence DS was daunting to several of the mothers; their worry and concern influenced their decision-making concerning their pregnancy.

Tan, a Chinese mother who had the first child born with DS related her experiences with subsequent pregnancy:

*During the second pregnancy, every month I checked 3 to 4 times; people checked once, I was very afraid, from the beginning of pregnancy till I delivered the baby; when I went to hospital for delivery, so worried, the nurse had not brought the baby to me, worried how the baby was, whether baby was like this (DS) or not.*

(Nodes/emotions/worries about recurrence DS/25 Tan/ref 1-3/Chinese, 48 yrs, mo of ♂, age 16)

Kay, a Chinese mother recounted her decision with termination of her subsequent pregnancy in her words as quoted below:

*I was pregnant, 3 months already... now no more, I aborted it already. Doctor said the percentage (for another child with DS) is high, I got the history (child with DS), better don't keep (pregnancy), cannot look for trouble, deliver one like this (again) will be hard life for me.*

(Nodes/emotions/worries about recurrence DS/16 Kay/ref 1-2/Chinese, 45 yrs, mo of ♀, age 9)

Worried about the risk of recurrence DS, but desiring for another child, one of the mothers,

Mok, a 40-year-old Chinese mother adopted another boy child.

However, there were those who were hopeful for a 'better', 'more normal' child in the subsequent pregnancy, though they had some amount of fear, as Daniela described below:

*With this one (present pregnancy) I am scared... but they asked me to try again, maybe this one is a better one, more normal, not possible it is still like this (having DS).*

(Nodes/emotions/worries about recurrence DS/7 Daniela/ref 1/Chinese, 31 yrs, mo of ♂, age 3)

Irrespective of the socio-cultural and economic background variation among mothers, they recounted their various heartfelt emotions such as the initial shock, sadness, shame, anger or difficulty in accepting child and worries as mentioned above. Besides these, mothers emotional such as their excitement and joy as part of their mothering process were evident.

#### **4.2.1.7 Excitement with child's developmental progress**

Some of the mothers' excitement with their child's each new progress which could be something that others may take granted for was evident.

The few quotes from two of the mothers, Kay and Chara below illustrated their excitement:

*She can help herself to put on her sandals; can also dress up herself; arrange her shoes neatly, she can be well behaved, independent now I can bring her to go anywhere, know how to feed herself. What we have done is worth it. At least she can absorb what we taught her. When she spoke any words it is clear.*

(Nodes/emotions/excitement with new progress/16 Kay/Chinese, 45 yrs, mo of ♀ age 9)

Chara, a Bidayuh mother's excitement of her child's development was obvious:

*Kalau saya pulang kerja, saya tengok ada air dia sedia atas meja, tuala mandi pun dia standby untuk saya sebelum dia pergi tidur. Tu lah saya senang hati tengok macam perkembangan dia semakin boleh, semakin pandai (in Bahasa Malaysia).*

(Nodes/emotions/excitement with new progress/ 6 Chara/ Bidayuh, 41 yrs, of ♀, age 14)

*If I came back from my work, I saw the drink she prepared on the table, even bath towel also she prepared for me before she went to sleep... that is why I am happy... see her improved, getting better and better (in English).*

During the session of interview in her home Chara proudly showed me her child's room neatly kept with some of her toys lined up all along the side of the room.

Excitement of Hazlin, an Iban mother who lived in the village was expressed as she showed me the two small fresh water fish inside the aquarium caught by her daughter:

*Pancing ikan pun dia boleh. Ka ia bermain enggau budak bukai.... hobby ia pancing...Bisi bulih ikan. Nginti di parit, enggau orang. Dia tidak takut cacing, dapat ikan simpan dalam akuarium (in Bahasa Iban).*

(Nodes/emotions/excitement with new progress/12 Hazlin/ref 1/Iban, 54 yrs, mo of ♀13)

*She could even do fishing, is her hobby, she caught this fish from the drain. She is not scared to handle earthworm (as a bet for fishing) (in English).*

Jupi, a mother was excited about what her child could do:

*Dia ambil CD pasang sendiri, pandai pasang. Tekan (remote control), kalau dia tidak suka dengar lagu itu, ah dia (press) 'next' lah. Atau pun 'reverse'; kalau bateri remote sudah habis, saya ketawa tengok dia, ini macam 'kok kok' (mother imitated child's action of hitting the remote control on his palm). Dia ikut orang, tak payah disuruh. Dia tahu, dia pandai (in Bahasa Malaysia).*

(Nodes/mixed emotions/excitement with new progress/15 Jupi/ ref 1-4/Bidayuh, 35 yrs, mo of ♂, age 3)

*He took the CD and turned on it himself, he knew how to turn on. Press the remote control, if he didn't like the song, he pressed the 'next' button, or 'reverse'. If the remote battery level was low, I laughed look at him, 'kok kok' (mother imitated child's action of hitting the remote control on his palm). He imitated people, no need to be told. He knew, he could. (English).*

Not only was mothers who felt the excitement with child's each new progress but the other members of the family such as the child's siblings or grandparents were as excited, as Julia described below:

*When he could do some new thing, it's really a joy, not only I, but the whole family will really feel very glad. Everyone is very happy, like the younger brother said, "mummy, mummy, you see Jo can do this, Jo can do that".*

(Nodes/emotions/excitement with new progress/14 Julia/ref 3/ Chinese, 37 yrs, mo of ♂, age 8)

Julia's excitement with child's progress was further expressed in two of her entries inside the journaling she used to keep about her child, 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'.*

*'Jo walked another 1-2 more steps today...what an excitement...Jo could master new skills of using scooter, dribbling a ball and had the first dip in swimming pool'.*

(Nodes/emotions/excitement with new progress/fieldnotes/Julia/ref 1-3/Chinese, 37 yrs, mother of ♂, age 8)

#### **4.2.1.8 The joy of mothering**

The experience of joy during their mothering process was obvious among several mothers who described their child as a blessing, and fun to be with, as 'lovable' to them.

Apparently their joy increased further especially as their child was able to be responsive and able to reciprocate. The quotes by a few of the mothers below are illustrative:

Chara, a Bidayuh mother expressed her increasing love for her child. She recounted her experience of her child who comforted her when she mentioned to the child she was unwell:

*Saya cakap dengan dia, 'saya susah hati lah, sakit lah', dia pergi sayang saya; dia tanya 'apa hal?' kalau saya cakap 'saya sakit badan', 'cuti lah...tak payah turun kerja', dia pandai cakap macam tu. Hati kita rasa bertambah lebih lagi sayang dengan dia (in Bahasa Malaysia).*

(Nodes/emotions/joy & delight in mothering/6 Chara/ Bidayuh, 41 yrs, of ♀, age 14)

*I said to her, 'I feel sad, not feel well' and she came near to hug me; she asked 'what happen?', if I said 'I'm not well', she knew how to say, 'take day off, don't go to work'. She knew how to say like thing that. My heart just felt so much love for her. (English)*



Kua expressed her delight about her child as compassionate and as a blessing to her:

*She is very compassionate, full of love and caring. She is a blessing and motivation to us. ...my husband also...certain time got frustrated with work and other children; he felt she is a comfort, and enjoy being with her.*

(Nodes/emotions/finding joy & delight in mothering/17 Kua/ref 1/Chinese, 50 yrs, mo of ♀, age 9)

As described by Kay, her child was loving and fun to be with:

*She is very funny, she went to the clinic, they gave medication, pushed it through her anal, and she pointed at the nurse, she did not know how to talk, just keep pointing with the finger; so funny, we laughed non-stop.*

(Nodes/emotions/joy & delight in mothering/16 Kay/ref 1/Chinese, 45 yrs, mo of ♀, age 9)

For Daniela and Normirah, their joy and sense of closeness with their child were illustrated in their quotes below:

*When he sleeps, is very lovable, sometimes he knows how to play with me, he will playfully hit me, 'aik' and make me laugh, he is funny.*

(Nodes/emotions/joy & delight in mothering/7 Daniela/ref 1/Chinese, 31 yrs, mo of ♂, age 3)

*I enjoyed her, sometimes, as we sat down, she came near to kiss me, hug me, she could hug me, you know.*

(Nodes/emotions/joy & delight in mothering/20 Normirah/ref 1/Malay, 43 yrs, mo of ♀, age 4)

The few quotes above are illustrative of the joy, excitement of mothers who had seen the developmental progress of their child, and had experienced the reciprocal responsiveness from their child.

However, even for child who were not able to reciprocate or not responsive, such as

Adrina's child, she found the love and contentment of just providing the care to her child,

as she described below:

*This child is totally different from those who are normal, your love is different, he can't do things on his own, we are very close to him, your love is there for him... the mother's love... the first thing you reach home (from work), you want to go and see him for a while then do my house work...I just hope for his wellness.*

(Nodes/emotions/joy & delight in mothering/1 Adrina/ref 1/Bidayuh, 44 yrs, mo of ♂, age 6)

#### **4.2.2 Extra care demands**

'*Extra care demands*' is one of the major themes which was established in representing experiences of mothers of child having DS. The experiences of various extra care demands contributed much to mothers' physical stress and fatigue. These are related to

- health-related extra care demands
- developmental delay-related extra care demands
- child behavior-related extra care demands

##### ***4.2.2.1 Health-related extra care demands***

For many of the mothers, care demands during the child's early life were related to the medical conditions of their child who often suffered from one of the forms of congenital abnormalities (refer Table 4.4). The acuteness of the congenital rectal abnormalities, such as duodenal atresia and Hirshsprung's disease accounted for the urgent, immediate surgeries after birth, followed by days of intensive incubator care in the hospital's nursery as recounted by several of the mothers. Commonly occurring, the congenital cardiac conditions necessitated intensive care, which may include continual medication, frequent hospitalizations and surgery when their child attained the optimal weight. Besides these, other conditions which were reported by the mothers include blood related disease (leukemia), ear, nose, throat, eyes, and lung related conditions.

Child-health related care demands which was recounted by many of the mothers affected family's routine of work and family life. As an example, Adrina who had a full time employment had to work during the day and night time had to take care of child having DS when he was hospitalized for leukemia and lung infection.

Kua, a Chinese mother struggled to cope with a full time work and to meet with the care demands related to child's medical conditions. Her description as below is illustrative:

*I needed to hold her up then she would sleep the whole night; it was so tough, my sleep was affected, the next day I still have to go back to work.*

(Nodes/care giving demand/child-health related/17 Kua/ref 2-3/Chinese, 50 yrs, mo of ♀, age 9)

Salina described her care giving experience as a mother of a child who frequently had breathlessness and intolerance in sucking milk due to the decompensated cardiac condition. Her sleep was frequently affected as she needed to take turn to be awake to attend to the child to ease her breathing:

*Even sleeping at night was difficult, sometimes I slept first and my husband slept later, because if we didn't carry her, she would cry, ar, we were scared that she might faint... Sometimes I cried seeing that she kept crying and could not keep quiet, I didn't know what to do. At last we had to send her to hospital, sometimes at 1am or 2am.*

(Nodes/care giving demand/child-health related/24 Salina/ref 2-3/Malay, 42 yrs, mo of ♀, age 3)

#### ***4.2.2.2 Developmental delay-related extra care demands***

For many of the mothers, the extra care efforts and time demands were related to seeking various interventional therapies, assisting with child's activities of daily living during meal time, toileting and communicating with their child, in helping their child to learn, and in watching over safety of their child who is delayed in various developmental aspects.

## **Seek therapies and treatment**

Being concerned of the developmental delay, and with the intention to help the child, many of the mothers seek various therapies and treatment for their children, including physiotherapy or speech therapy.

Kay and Daniela, both were Chinese mothers, related their experience of being busy because of seeking various therapies and treatment from various places for their child:

*Was two years old already, but she still moved on her buttock, could not walk; four or five years old that time, still could not talk. We brought her for physiotherapy every Tuesday, CBR once a month, brought her for speech therapy, heard the church also provided the early intervention program, we also sent her there, we rushed to go here and there.*  
(Nodes/care giving demand/delayed development related/ref 1-2/16 Kay, Chinese, 45 yrs, mo of ♀, age 9)

Daniela, a Chinese mother talked about her experience in seeking treatment for her child:

*People told me to find the temple medium, I went; also brought him to places like Saratok and Sarikei (small town in Sarawak), to look for the Iban (local native) man who could apply traditional medicine; also looked for the Chinese 'sin seh' (traditional massage therapist) who could do massage.*  
(Nodes/care giving demand/delayed development related/ref 1/7 Daniela, Chinese, 31 yrs, mo of ♂, age 3)

## **During meal time**

For some of the mothers, during the meal time while their child was at a younger age could be a very trying time as child was less than being cooperative.

Daniela, a Chinese mother's quote is illustrative of her experience with the child at meal time:

*During eating time, he liked to play with the rice, asked him not to throw the rice, asked him to stop, he refused to listen, very stubborn.*  
(Nodes/care giving demands/delayed development related/ref 2/17 Daniela, Chinese, 31 yrs, mo of ♂, age 3).

## Toileting needs

The description of Aziah whose child with DS had delayed bowel control depicted the level of care demands incurred due to care giving of the child:

*Purit dia cuci pun saya, pakai ai... tahi dia tinggal pun saya basuh, saya mau nangis, saya tengok dia; tak cakap mahu berak; anak ini saya setengah mati jaga dia. Berak si pandai madah...saya tengah makankah, tengah tidurkah, baru dudukkan, tengah buat kerja pun saya semua tinggal. Kadang-kadang pandai dia cakap, kadang-kadang sudah keluar baru cakap, mahu gugur air mata, saya tengok dia berak merata (In Bahasa Malaysia).*

(Nodes/care giving demand/delayed development related/4 Aziah/ref 3-4/Malay, 41 yrs, mo of ♀, age 5)

*Her buttock also I had to wash her buttock, I have to wash off the shit she dropped, I felt like crying when I saw her like this; she couldn't tell when she shit. 'Half dead' (really tough) I take care of this child. Wanted to shit, she couldn't tell. Half way eating or sleeping, just about to sit down, half way doing my work, I have to leave everything aside first (to attend to child). Sometimes she could tell, sometimes the shit came out then she indicated, feel like to cry, I saw her shit all over the place (in English).*

## Communicating with child

In their daily care giving, difficulty in communicating with and understanding their child's needs brought much challenges to the mothers, as illustrated by several of the mothers' descriptions below:

*You actually didn't know what he wanted, he could cry whole night, didn't know what he wanted! Cried and cried like that, very demanding and stubborn. He could not communicate, ah, he didn't know how to communicate, very frustrating.*

(Nodes/care giving demands/delayed development related//14 Julia/ref 1/Chinese, 37 yrs, mo of ♂, age 8)

Daniela lamented about her child's way of communicating through crying:

*When he wanted something, he could not tell, he screamed loudly, it is just very hard.*

(Nodes/care giving demands/delayed development related/7 Daniela/ref 1/Chinese, 31 yrs, mo of ♂, age 3)

## Difficulty in learning

Jen described her untiring effort in teaching child to learn as child was slow in learning:

*I tried to teach him a bit of alphabet...I have to keep on teaching him and reminding him, because if you missed a week, he would forget...have to keep on reminding.*

(Nodes/care giving demand/ delayed development related/13 Jen/ ref 1-6/ Ch, 39 yrs, mo of ♂ age 3)

This mother's efforts in trying to help child to remember and learn was evident during my visit an interview session with her in her house as she arranged the picture cards on the floor, asking child questions and teaching child.

Also described by Daniela,

*Sometimes I tried to give a pencil to him to try to write... he scribbled every where, after a while....he did not want anymore. Those things for playing one, after a while...it would not be long ... that is why sometimes it is very tiring... Sometimes I taught him to say 1, 2, 3, he did not even bother about you, just 'er' ... 'er', I taught him till very tired (sigh)*

(Nodes/care giving demand/ delayed development related/7 Daniela, Chinese, 31 yrs, mo of ♂, age 3)

## Starting the normal monthly menstrual period

Among the mothers, especially for those with daughters who reached puberty, one of their care demands of concerns was when their daughters started their menstruation. Hazlin told about her concern:

*Yang paling mencabar ... masa dia sudah datang haid...sebab dia perempuan, nadai nemu ngena pampers, ia jalai kiput kiput...jalai ke kin din...tanjut ia merah... bisi darah... bisi pan orang meda nya. (in Bahasa Iban)*

(Nodes/delayed development related/when daughters menstruate/12 Hazlin/ ref 1/Iban, 54 yrs, mo of ♀, age 13)

*The most challenging...is when she got her period... as she is a girl, not know how to use sanitary pad yet...walking here and there...can see red on the pant... blood stained...could be seen by other people. (English)*

As voiced out by a mother who had similar concern about her daughter when she had her monthly menstrual period, she had to help her daughter as her other daughters who had

grown up were not around to help her anymore. Another mother had the difficulty to persuade her daughter to finally agree on using sanitary pad.

### **Constant need for supervision**

For many of the mothers of child having DS across different age range, their experience of care giving included the needs to supervise and protect their child due to concerns of child's safety.

Kay recounted an incident when she almost lost her child who wandered away:

*Once, she was almost lost in 'P' supermarket. We were inside the lift. Someone maybe pressed the lift, it opened, she just slipped out of the lift by herself, but we were still inside the lift. I rushed down out to look for her. I saw her later, was squatting there at the shop. (Nodes/ care giving demand/need for supervision/16 Kay/ref 2/Chinese, 45 yrs, mo of ♀, age 9)*

Kay further related another incident which she indicated child's needs for supervision.

One day she went out of the house to buy vegetables with her husband, leaving her child who was still asleep in the house with the child's elder sibling. She was shock to find her child waiting outside (the house) at the roadside when she came back.

Farah, a Malay mother of her teenage child, talked about the need to constantly keeping her child under her watchful eyes in her quotes below:

*This child 'ah, sekelip mata' ('at the blink of an eye' in Bahasa Malaysia), dia boleh jalan (she can just walk away). Once, while walking outside the house with her, suddenly I didn't know where she walked to, I searched the whole housing area of housing area. I even had to ask for help from my neighbor. Later I found her in the police station, finally. That is why now I like her to stay at home, cannot let her go out by herself. Only on Saturday or Sunday, I bring her out (in mixed English and Bahasa Malaysia). (Nodes/ care giving demand/need for supervision/9 Farah/ref 3-4/Malay, 48 yrs, of ♀, age 16)*

A Malay mother Aziah had to constantly keep watch and supervise her child as she was concerned that her child liked to follow anyone, even stranger. The mother's concern for child's safety and constantly keeping watch over child was due to her child characteristics of no social-inhibition or having no fear of strangers. This was evidenced during my visit to the home as the mother tried to get the child to take her nap after her lunch. She came close to me, brought her own pillow and went to sleep on the settee, next to where I sat. She placed her two legs on my lap while I was sitting down at the settee. Being aware of her child's characteristics, Aziah had to lock her house's front main door all the time for fear that she might go outside of the house which was located near the roadside unnoticed. She quoted:

*'That's what I'm scared of. She may just sit right there at the road side and wave at people passing by. This is the main road (lots of danger due to traffic).*

(Nodes/care giving demand/need for supervision/4 Aziah/ref 7/Malay, 41 yrs, mo of ♀, age 5)

Further to this, for this mother Aziah, not only she was concerned about her child's safety, she was also concerned about being criticized by other people in the neighborhood for not taking care of their child well enough.

#### **4.2.2.3 Child behavior-related extra care demands**

Many of the mothers' experiences of care demands were related to child's personal-social behavior such as tantrum, behaviors that were socially or age-inappropriate or behaviors that were disruptive. In relation to child's behavior, apparently several of the mothers felt inadequate or incompetents to set any limit on child's behavior; or to impose any discipline.



Kay related an incident when she brought her child to the supermarket:

*Really tough, not so easy to tell her, she was very stubborn. I brought her to the supermarket, she refused to leave, squat there on the floor. I did not know what to do, have to follow her way. She put her two hands in the pockets, jumped like a frog, step by step down the staircase, blocking other people who walked up and down the staircase, so embarrassed. 'I pity her' I can't insist that she (child) listens to us. I see this type of child, I pity her, what I think is, honestly, I follow her way, I regard her as a 'special' child, I do not have the heart to hurt her, felt guilty to raise my voice.*

*( Kay/Chinese, 45 yrs, mo of girl, age 9)*

(Nodes/care giving demand/child-behavior related/16 Kay/ref 4/Chinese, 45 yrs, mo of ♀, age 9)

For several of the mothers, caring for their child who had a heightened level of

activeness was physically exhausting, as described by Normirah in her quotes that follow:

*Feeling so stressed, she is so active, once the door is opened, she would run out, go everywhere. One time when in the clinic, she pulled the fans, made other children cried. Everything she threw (sigh). I have to see this child 24 hours, only when she slept then ok.*

*(Nodes/care giving demand/child-behavior related/20 Normirah/ref 1-2/Malay, 43 yrs, mo of ♀, age 4)*

During the interview with this mother in her house, her four-year-old daughter came near me and abruptly pulled away the spectacles which I was wearing, and thus caused one of sides to go out of shape. Normirah was apologetic about it. Child was later seen trying to climb up the wooden shelf to reach the TV set but was stopped by the father who was also around. Later, she was seen throwing toys out of the opened window. Later, the child tried to pull the MP3 recorder away from my hands but was stopped by the mother.

#### **4.2.3 Variation of supports**

As one of the major themes, '*variation of supports*' represents the supports as experienced by mothers in their mothering process. '*Informal supports*' as supports accessible to mothers from their spouse, child's siblings, extended family members and other sources of

supports, while *'formal supports'* were supports accessed by mothers from the various professionals, service provisions and paid workers. *'Environmental support'* was in relation to supports sources of financial resources, accessibility to transports, public facilities and informational sources.

#### **4.2.3.1 Informal supports**

Many of the mothers indicated their access to informal supports from family support network of spouse, extended family members or child's own siblings for both practical helps and emotional support. Some other mothers received social supports of friends, colleagues, religious groups and other parents of child with DS who provided them with much needed helps. However, as will be shown later, there were other mothers who face difficulty due to the lack of access to the informal support sources.

- ***Spousal support***

According to many of the mothers, their spouse helped them to cope with the extra care giving demands of child by providing them with practical helps. The extent of their spouses' involvement with practical helps in care giving was subject to flexibility with their working hours. Those with more flexibility with working hours such as doing own family business, or on shift duty work were shown to be more able to provide the practical care giving of child. Otherwise, most of care giving of child was carried out by mothers themselves, assisted by the child's siblings, grandparents, or in-house paid workers.

#### *Spousal support of emotional support*

Spouse provided important emotional supports especially during the period after child's delivery. In the word of a Chinese mother Kay, during the initial stage of child's life when

she refused to carry her child due to her feeling of shame, her husband provided her the emotional support. He was the one who carried the child for her.

Emmy who had the first male child with DS recounted her husband's supportiveness. She considered herself as 'lucky' to have her supportive husband.

*Nasiblah suami saya ni dapat apa tu terima [laugh] ...Dia bagi sokongan...dari belah lelaki tu...Kalau saya dapat family saya terima kalau bapa dia tidak dapat terima susah juga*(Bahasa Malaysia).

(Nodes/informal supports/spousal support/8 Emmy/ref 1-4/ Iban, 23 yrs, mo of ♀, age 1)

*Luckily my husband is able to accept...he gives me the support, from the in-law also. If my own family is supportive, but the child's father is not able to accept, it will be hard also* (in English).

#### *Spousal support of practical helps*

For those mothers who were on full time employment and having a child with DS, availability of spousal support and assistance helped to maintain a balance between meeting the demands of employment, the extra care giving demands related to child, needs of other children and family as a whole. It fostered and maintained a sense of security and stability with minimal family life disruption. As Adrina explained, while she worked during the day time, besides her own sister, her husband who worked in the afternoon shift would help to take care of child and send the two other children to school in the morning.

Gabe, a Chinese mother highlighted the contribution of her spouse towards care provision which enabled her to continue with her employment:

*I have to work and I also have to do this for him (carried out daily manual rectal cleaning procedure) once in the morning. We (with the husband) just made it together.*

(Nodes/informal supports/spousal support/10 Gabe/ref 1-2/Ch, 49 yrs, mo of ♂ age 5)

Julia, a Chinese mother talked about her spouse's participation in handling child's inappropriate behavior. She recalled an incident her husband turned off the house lighting and closes the house door as a way to discipline her child who refused to come out from the car after coming back from a care ride.

Many mothers encountered extra care demands related to having a child with DS besides the demands of other typically developing children. Spouses who were supportive helped the mothers to maintain a balance in meeting these demands.

#### *Problem with spousal support*

While many of the mothers had accessibility to spousal supports, several others experienced problem with access to spousal supports. Harris, an Iban mother who lived in one of the 'bilik' (room) in one of the 'Iban longhouses'<sup>11</sup> located in the rural area, in close proximity with other families in the neighboring 'bilik' (rooms)' described herself as a victim, shouldering the care provision for a child having DS and yet not having her spouse to share with the responsibility, as illustrated by quotes as below:

*Iya enda ibuh, iya nadai begulai enggau aku ditu ...aku tu nyadi mangsa, jadi mangsa lah ko aku...dia nadai begulai enggau aku. Kadang datai, sekali sekala ngagai aku. Iya diau rumah din. Iya enggai enggau kami di Kampung ditu. Nadai kami duai bercerai (in Bahasa Iban).*

(Nodes/informal supports/lack of support/11 Harris/ref 1/Iban, 61 yrs, mo of ♂, age 17)

*No need to mention about him (her spouse), he was not with me here. I am the victim, I say is victim. He did not stay here with me. Sometimes only he came to see me. He stayed there (another longhouse). He refused to stay with us here in the village here, though we were not divorced (in English).*

---

<sup>11</sup> The 'Iban longhouse' is a typical dwelling place for the Sarawak Iban people. It has many rooms called 'bilik' which are adjacent to each other, with a shared corridor outside of their rooms (or 'bilik') for socialization purpose.

A Chinese mother, Kua recounted her experience with lack of spousal support during the early stage of child's life. Apparently, the impact of the lack of spousal support and yet having to cope with extra care demands added on to mother's psychological demands which was immense as she illustrated in her words:

*I had suicidal thoughts when she was about 2 years old; at the beginning when I had her, I thought I was going to die; could not take it.*

(Node/emotions/sadness/17 Kua/ref 2-3/Chinese, 50 yrs, mo of ♀ age 9)

Jen who had another younger child besides the first one with DS, apparently handled the majority of the day to day care demand without much of spousal support, as she described below:

*My husband most of the time is outside of home with his own hobby, like playing cars. So I said he is still like a single...he is seldom at home... at night, it is me and the two children only. He does his own thing, I do mine.*

(Nodes/informal supports/challenge of lack of support/13 Jen/ref 1-6/Chinese, 39 yrs, mo of ♂, age 3)

- ***Support from child's siblings***

Child's siblings played important roles and contributed to care provision of child with DS.

They could play their roles as advocate, playmate and as role model for the child with DS.

Julia described about the helps of her child siblings in the quotes below:

*When we brought him around, people looked at him... he (elder brother) will go to them and say, "he is very friendly, you know", he didn't like others 'kua suey ee' (Hokkien word for look down on child)...his younger brother was a great help to me all through... they grew up and learnt together.*

(Nodes/informal supports/supports of siblings/14 Julia/ref 1-2/Chinese, 37 yrs, mo of ♂, age 8)

Siblings played important supporting role in providing practical help in the family as evidenced by Kay's words:

*Her sister helped a lot, she would listen to her... if we go to supermarket, she will put her in the trolley basket and walked around together, I will go to the supermarket upstairs to look at the clothes by myself.*

(Nodes/informal supports/supports of child's sibling/16 Kay/Chinese, 45 yrs, mo of ♀, age 9)

Another mother talked about siblings' help and support:

*The older children know how to do cooking, they know. They (other siblings) are ok. They have learnt to see the situation and help up; they are more mature now.*

(Nodes/informal supports/supports of child's sibling/1 Adrina/Bidayuh, 44 yrs, mo of ♂, age 6)

Child's sibling support was evidenced during my interview visit to the home of Khaitijah, mother of a 7-year-old son from the rural region. The older sister was seen to help to bathe him after he woke up from his sleep. Half way through the interview, Khaitijah gave RM 2 for him to buy ice cream from the neighbourhood with child's younger sister. Later, the 7-year-old boy was seen to follow the other siblings to the nearby 'community library'.

- ***Supports of extended family***

Besides own spouse, quite a number of the mothers indicated their access to the practical help and emotional supports of extended family of either child's grandparents or aunties. Informal support from the extended families enabled these mothers to maintain a balance between meeting the extra care demands related to child with DS and that of the family, to minimize family daily life disruption, including continuation of their out-of-home employment. The significance of supports of extended families was evidenced in the quotes of Wang, Adrina and Kay below:

Wang informed that she was supported and helped by child's grandma and auntie in the day to day care provision. Their supports enabled her continuation of out of home employment

and to maintain the normality of day-to-day life. These included the transporting child to special school and back to their house, toilet training child in the use of pottie and preparation of child's three meals. Besides these, the grandma also helped in the behavioural aspect of her child like when she threw tantrum knocking her own head on the floor to show her anger. Quotes of Wang's words below are illustrative:

*When it is time to come back (from work), we come back; in the morning, when it's time to go out to work, we'll send her (to grandparents) then say bye-bye to her, and I go for my work. My sister fetched her back to the house (in the evening). Then we go and change our clothes and go upstairs to sleep, sometimes let her watch movie, or talk to her. She'll sit near me and look at me when I'm folding the clothes. Everyday is like this. In the morning, bathe her, give her food to eat and get her ready.*

(Nodes/informal supports/extended family support/19 Wang/Chinese, 33 yrs, mo of ♀, age 6)

With the help of the child's auntie and own husband who took turn in providing care, Adrina, a Bidayuh mother of a 6-year-old child, was able to maintain her daily routine of going out to work, and providing for the needs of her child with DS, and that of the other children. While she went out to work, the auntie helped to feed the child. The husband took over the care when the auntie was out for her work. When she herself came back from work, she did other household chores.

Kay recounted her sister-in-law as an important source of support after she was discharged from the hospital and back to own home:

*Her auntie (child's) was very good, always came to see us, she really loved her (baby). Without her, I would have collapsed. She said 'you quickly do something to help her, treat the legs, are you going to let her sit in the wheelchair, carry her for the whole life?' My child was floppy then; felt so good got someone to concern for me.*

(Nodes/informal supports/extended family support/16 Kay/Chinese, 45 yrs, mo of ♀, age 9)

### ***Problem with support of extended family***

For several other mothers, instead of getting the practical helps and emotional support their parents-in-law who stayed nearby them, they were confronted with the question of ‘why’ and blame for delivering a child having DS; these added on to their psychological demands. In particular, these were predominantly the Chinese mothers. Quotes from a few of the Chinese mothers Kay, Tan and Julia as below are illustrative.

Kay described her experience of being blamed by the extended family:

*I ever went to XX Road there to have a walk when I was pregnant. The grandma (child’s) blamed me till ‘half dead’, asked ‘why pregnant that time you wanted to go to this type of place, of all the places!’*

(Nodes/informal supports/challenge of lack of support/16 Kay/ref 1/Chinese, 45 yrs, mo of ♀, age 9)

After Tan had the delivery of her first male child with DS, the lack of acceptance and supports from the child’s extended families was apparent from their questioning as in her quote below:

*The grandparents (child’s), one of them asked ‘is it because when you were pregnant you did not eat proper tonic food?’ another one asked, ‘how can you delivered this type of child? Is it because during pregnancy you were disturbed by something?’ The aunties who came to the house also asked, ‘why delivered this type child?’*

(Nodes/informal supports/challenge of lack of support/25 Tan/ref 1-3/Chinese, 48 yrs, mo of ♂, age 16)

The lack of supports from extended family added on to mothers’ psychological demands as described by Tan below:

*I did not know how to answer. I cried; did not know what to do, could not explain to the child’s grandparent; they could not accept you, asked why delivered this type of child. I felt numbed.*



Julia illustrates further her problem of lack of access to support of the extended family:

*When I gave birth to this son, his grandpa wasn't very supportive, the grandma also. At the very beginning, very frustrated, they did not even touch him... they (parents-in-law) said they have pain here, pain there, (they) gave all the reasons (excuses of unable to help in care giving).*

(Nodes/informal supports/challenge of lack of support/14 Julia/ref 1-2/Chinese, 37 yrs, mo of ♂, age 8)

The following case description about one Malay mother, Ann illustrates the challenges of a mother who did not receive adequate supports to cope with the extra demands related to care giving of child with disability:

### **Challenges of lacking of informal supports**

*Ann, a Malay mother had a 6-year-old boy and 2-year-old girl, both of them having DS. She had to take care of the 2-year-old child who was often breathless due to congenital cardiac problem. The child's grandparents who stayed in another town only came to visit the family once in a while during to geographical distance. Her husband had to leave the house early to earn a living for her family. She had to always make sure she closed the house's gate to prevent the boy from going out, as she said about her child, 'dia selalu suka pergi ke sungai sana main...sebab itu saya selalu kunci pintu' (he liked to go the river bank to play, that's why I have to always close the gate'. She was concerned about the safety of her 6-year-old who also had difficulty in language communication. A few months later, as told by a staff worker in the CBR center, the 6-year-old boy got drowned after he fell into a river nearby the house. This incident serves to highlight a mother's experience of immense challenges of care demands and the lack of adequate informal support sources.*

- ***Informal support from other sources***

Other sources of informal support where many of the mothers obtained practical helps, emotional support include from friends, colleagues, church and other parents also having child with DS. Informal supports such as from the church helped to provide the emotional and spiritual support to the parents, especially during the initial stage of child's life.

As for Julia who did not have the access to extended family's support, the supports from the church as accessed by her constituted an important source of helps for her to cope with additional care demands.

*My husband called the church friends (after delivery of child with DS), thank God, I have the pastor and many members who came to visit; the whole church was very, very supportive; whenever we attended any church meeting, we brought all our children.*  
(Nodes/informal support/other social supports/14 Julia/Chinese, 37 yrs, mo of ♂, age 8)

Chara, a Bidayuh mother talked about her experience of informal social support through in work place. She received emotional support through sharing feelings and experience with colleague and friends.

- ***Informal supports from other parents***

Other mothers of child having the similar condition in places like the child health clinics or the CBR centers contribute as important source of informal support for several of the mothers. They seeked and obtained emotional and practical supports from one another.

Noraryna described her experience with supports of other mothers:

*Kita sama sama lah, saya ada anak macam ini, ada lagi ibu bapa yang anak mereka lebih teruk dari macam tu, kita susah ada orang lain yang lebih susah; selepas selalu tengok anak orang lain di CBR, bergaul dengan orang lain (parents), rasa ok sekarang* (in Bahasa Malaysia).

(Nodes/informal support/other social supports/21 Noraryna/Malay, 24 yrs, mo of ♀, age 3 yrs)

*We are all the same, having a child like this (having DS). There are parents whose child's condition is worse off; we have hardship, others' are even worse; after seeing others' children, and mixing with other parents at the CBR, we feel better now (in English).*

According to several of the mothers, meeting with other mothers of child also having DS at the clinic or the CBR centres gave them the opportunities to talk to one another and to share their feelings. Support and socialization of mothers one with the others was evident from my observation during my visits to the CBR centers. Among them who were housewives who came with their child to the CBR centers, while waiting to pick their child back after their intervention program, they spent their time to chat and to do things together. These included activities as observed in one center where they did handicraft making rug from small pieces of fabrics which they planned to put up for sale for their fund raising purpose during their CBR center open day.

The informal support group thus formed, besides emotional support, it also helped in provision of practical help to one another, such as transports to the CBR center and to go home to those who needed the helps.

#### **4.2.3.2. Formal support**

Formal support which was accessed by mothers includes supports from the various professionals, supports of the service provisions, including financial assistance, and support of paid workers. While several mothers were appreciative of care professionals' helpfulness and enthusiasm, there were those who were concerned about the service provisions as inadequate and ineffective. Several mothers' concerns related to Welfare Department's procedure for managing financial assistance was raised.

- ***Professionals' support***

Several of the mothers were appreciative of professionals' helpfulness in facilitating various therapies for their child in the clinics and the CBR centers.

*When I went to the clinic or to the CBR center, I felt good, got people who helped her, taught her; we feel happy they received her in that way, we did not give up (felt encouraged).*

(Nodes/formal supports/professional service/6 Chara/ref 1-2/Bidayuh, 41 yrs, mo of ♀, age 14)

Kay recounted her pleasant experience with health professionals:

*At the 'X' clinic, the nurse was very good, she would phone me to inform if physiotherapist is coming, said 'you must come, don't miss the date'. She (nurse) knew my child, helped to process the application to education department. They will call me if got any meeting (with other parents and staff at clinic). She learnt a lot from there (speech therapist), learnt 'ar, er'. After she (child) went for the therapy (physiotherapy), she could walk.*

(Nodes/formal supports/professional service/16 Kay/ref 1/Chinese, 45 yrs, mo of ♀, age 9)

The approach of health professionals, including nurses who handled child with DS just like any other 'normal' child, was perceived by mothers as supportive to them emotionally. As described by Salina, a 42 years-old Malay mother of a 3-years-old girl, when she took her to the clinic, the nurses would take her, passed her from one to the other. According to the mother, she felt good that her child was treated just like any other 'normal' child. Few other mothers who had come across nurses' visit to their home to see their child were appreciative of them who showed concern about their child.

- ***Service provisions***

There were some concerns about the existing professional service provisions of various pertinent therapies and interventional programs for child with DS which were perceived as ineffective and inadequate. The quotes of Gabe are illustrative:

*Speech therapy is an issue: my son was seen by one at the clinic for 3 times only, after that the speech therapist was bogged down with work and the next appointment never materialized. We truly need more of such therapists. If this is not enough locally, we*

*should look for international volunteer, which can be arranged through many organizations. Clinic-based rehabilitation (interventional) programs at clinics, not sufficient, only once a month though I do understand the constraint of physiotherapists...care givers at the CBR centre are also not sufficiently trained.*  
(Nodes/formal supports/professional service/10 Gabe/ref 1/Chinese, 49 yrs, mo of ♂, age 5)

Furthermore, as expressed by several mothers, they were concerned about the ‘what next’ after the child reached teenage, and later adulthood, as they perceived that the existing training facilities and service for their child were limited.

- ***Welfare’s financial assistance***

For many of the mothers, especially those from the lower income group, the monthly financial assistance of RM 150 from the Social Welfare Department which was received by them via CBR centre was a significant help to them. Issue for concern related to procedure for management of financial assistance to mothers of child with disability was voiced out by several of them.

One of the mothers, Azuriah, a 41-years-old Malay mother of 2-years-old girl, related an incident when she was unable to bring their child to the CBR center as child was sick. She was disappointed with the deduction of the allocated financial assistance for the month due to child’s absence for any one of the sessions. She perceived that the expectation for her to give prior notice to the CBR center staff for not child’s absence to the scheduled session at the same time when she had to bring her child for treatment as unreasonable.

The Welfare Department’s implementation procedure of financial assistance with the expected minimal number of sessions of child’s attendance to CBR centre before allotted

amount is fully given to mothers who sent their child to attend the various programs is an issue which deserves further attention and dialogue with relevant stakeholders.

- ***Source of supports from paid workers***

As another source of practical support, a number of mothers engaged the service of paid stay-in domestic workers or helpers. These paid domestic helpers could be the locals, distant relatives of the family or the foreigners who were engaged through the relevant agencies. The accessibility of these paid workers or helpers in the homes of several of the mothers enabled them to continue with their employment. They contributed significantly to maintaining family life continuity, in meeting the care demand of child, the other family members' needs as a whole, in the absence of the extended family's support. The domestic paid workers or helpers also provided practical helps such as bathing or feeding of the child complementarily to those who had their extended family's support. As related by Chara, a Bidayuh mother, who employed someone who stayed in to help her to provide care to her children enabled her go out to work when her child was much younger. This, however, is financially costly, thus not affordable for many families in the local context.

#### **4.2.3.3 Environmental supports**

Financial resources, accessibility to transports, public facilities and informational supports are important sources of environmental supports which impacted on mothers' care giving experience. Many of the mothers experienced constraints and limitation in relation to these aspects of environmental supports.

***(a) Financial constraints***

Mothers who were from the low socioeconomic group and having a child born with DS experienced the ‘double jeopardy’ of financial extra burden due to increased need for expenses and further limited household income associated with the need to meet child-related additional care giving demands.

*Increased expenses*

The extra financial burden experienced by mothers was attributed by the increased expenses incurred in the process of care giving of child with DS. According to Ann, a 44 year-old Malay mother of 6-year-old boy and 2-year-old girl, both with DS, for each trip she travelled to attend the monthly specialist follow-up appointment using a van, she needed to spend RM 6 or RM 7 one way. Even for her and the two children to travel back from the CBR centre after the twice a week session, she also had to pay a few ringgit (RM). Besides the need to spend on the transport expenses, she further lamented that she needed to spend for the bigger child whom she informed, *‘insisted to buy drinks or tit bits from outside, instead of the water that she brought from home’*. Financially she was further strained having another child (now two years old) also having DS still on pampers as she was not toilet-trained yet.

*Limited financial income*

Financial resource of several of the mothers was affected due to extra care demands of child with DS. Due to distance from their homes and concern of fuel cost, some of the fathers who helped to send their child and mother for the CBR center programs would stay back to pick them back after the CBR session ended. As described by Bisroh, 40-years-old

Malay mother of 4-years-old girl, her husband who was self-employed, doing small scale farming and other odd jobs, would lose his income for the day for sending them to the CBR center. As quoted by her, *'financial resource is, a challenge, at times it's difficult to meet end need'*.

Salina elaborated on her financial resource constraints related to the need to meet the extra care demands of her child and time commitment in her quotes below:

*Dulu saya dapat buat kuih, buat bagi saya belanja, sekarang tidak dapat, macam mana saya mau buat, jaga dia. Dulu saya memang jual nasi lemak. Bawa depan, Lama saya jaga dia, tidak pernah buat lagi. Tidak ada masa, tidak ada orang jaga dia. Anak- anak lain mau sekolah* (in Bahasa Malaysia).

(Nodes/environmental supports/financial constraints/24 Salina/ref 5/Malay, 42 yrs, mo of ♀, age 3)

*Last time I could make different kinds of cake, to earn something for us to spend, now I can't, just not possible, have to take care of her. Last time I also sold glutinous rice in front (of the house), I have never sold again. Just don't have the time, no one will take care of her. Other children have to go to school (cannot help)* (in English).

Most of the mothers from the low socioeconomic group had financial resource constraint and were compounded by having a child with DS. Their child was not able to contribute financially to the household. The challenges encountered by those mothers who were single, in their advance age, was more than a 'double jeopardy'.

Harris, a 61-years-old mother of her 17-years-old child with DS, from an Iban longhouse in the village, was left by her spouse with no other family social support. The child's other siblings had left home for work and had own families. Furthermore, Harris' mother who was 81 years old was also dependent on her for care provision, including her medical expenses. They depended on the Welfare financial aid to maintain the daily living



expenses. In the rural village setting where there is availability of land, a common practice for local people is to produce farm products such as rice padi for own household's consumption. However, this would not be possible for Harris who had a child with DS who was 'less abled' and her dependent 81-years-old mother. The financial constraint experienced by her could be illustrated by the following quotes:

*Peda nuan nya agi begulai enggau anembiak. Nadai paki aum. Beri orang tu tadi beri orang belanja enda cukup. Inik kita nya, beli aku ubat tu tadi. Semua dia magang-magang, api ai semua magang. Semua bala gena duit nya, enda cukup; tanah bisi tang nadai orang ngereja, nadai orang nebas, nebang kayu; beli beras (in Bahasa Iban).*  
(Nodes/environmental supports/financial constraints/11 Harris/ref 4/Iban, 61 yrs, mo of ♂, age 17)

*Look at him (the child with DS), still mix around with small kids; just cannot count on him to do anything. People (Welfare department) gave some financial aid but that was not enough. Have to buy his grandma's medicine, pay water and electricity bill, and all that. Everything depends on that money, just not enough; I have the land, but nobody to work, nobody to cut the grass, clear the bush. Have to buy rice instead (in English).*

The lack of financial resource added on to mother's psychological demands and stress, as Harris further described below:

*Bisi asai lantang ga ati ga kadang-kadang tusah ga baru, kati enda tusah nadai duit (in Bahasa Iban).*  
(Nodes/environmental supports/financial constraints/sadness/11 Harris/ref 1/Iban, 61 yrs, mo of ♂, age 17)

*At times I feel fine; at time I start to just feel sad again, why not feel sad, don't have money (in English).*

### **(b) Limitation related to transports**

For many of the mothers, especially those from the low socioeconomic background, who could not afford an appropriate mean of transport but only having a motorcycle, faced various challenges in relation to access to various service provisions for child.

The case descriptions of mothers Ann below are illustrative of the lack of environmental supports in term of transports:

*Ann, a Malay mother whose husband could afford only a motorcycle, experienced further challenges as she had more than one child having DS. Ann described how she and her two children, travelled together in one motorbike with her husband to go to the CBR center early in the morning to attend the bi-weekly sessions on his way to work, during those days when there were no rain. Her 6-years-old boy would sit at the front of his father, while her two-years-old girl would be positioned between where her father and she on one motorbike. But this would not be possible every time it rained, otherwise they would all get wet. Ann with her two children had to find their way back home at the village after the CBR session. The only option for them was to follow one of the mothers from the CBR center who owned a car till the junction somewhere in the village, to wait for another private van that would take them back to their house with payment of a fare.*

Evidence of limitation of transport which hindered care provision is illustrated in the family of Anders, an Iban mother of a 5-years-old child with DS who lived in poverty in the squatter area in the city. Her husband worked hard as a labourer to cope with pressing demands of the basic daily needs of eight other children, and did not have the mean to own a car or motorbike.

*Laban nadai utai kena aku nganjung (clinic), kami empu mai ia. Aku ka nganjung ni aku ulih, nadai utai utai kena... Motor pedis, kadang ngena motor orang...kadang orang enggai nyali.* (in Bahasa Iban)

(Nodes/environmental supports/constraints in transport/3 Anders/ref 4-7/Iban, 44 yrs, mo of ♂, age 5 yrs)

*I do not have anything to use to send child (with DS) to clinic. We ourselves do the exercise for him (child with DS); transport is a problem; sometimes follow other people's car, sometimes people not willing* (in English).

Further information from the child health card of Anders' 5-year-old child with DS showed that her child did attend clinic-based intervention program when he was much younger, but had defaulted follow-up appointment. He was left at home and not attending any program. The family had migrated to the city from the village. Anders, the mother often went out to look for 'miding' (a local wild vegetable) or fishing at a stream some distance away from their house to supplement the food for the family. The other elder daughter stayed at home to look after the child with DS and his three other siblings (including two of them who were school-going age but not attending school).

***(c) Inadequacy of basic public facilities***

While not having their own transport posed a challenge for many of the mothers, the issue of inadequacy of basic public facilities such as parking space for their vehicle in a health care setting added to several of the mothers' care giving demand of time and energy.

Adrina described the related experience as below:

*It was tiring, when I went to clinic, I have to carry him, hard to find any parking lot, sometimes when we finished with the clinic appointment and he (child's father) still could not find a parking space.*

(Nodes/limitation in basic public facilities/1 Adrina/ref 1/Bidayuh, 44 yrs, mo of ♂ age 6)

***(d) Informational support needs and challenges***

The need of supports for various essential informations such as aspects of child-care related information or parents support group soon after child with DS was born was apparent from the quotes of the few mothers below:

*We werereally feeling helpless, so desperate, after baby one month, looking around for help, nobody seemed to be bothered about us.*

(Nodes/information support needs/16 Kay//ref 1/ Chinese, 45 yrs, mo of ♀, age 9)

Information support needs about available service provisions is indicated as quoted by

Normirah:

*Where is the place (intervention program)? For those who sends child to join in the program, do they receive financial assistance? Is it every day? Do I need this card (OKU) (registration card for people with disability) also?*

(Nodes/information support needs/20 Normirah/ref 1/ Malay, 43 yrs, mo of ♀, age 4)

Jupi recounted that clinic staff during each clinic session would assess child's development, about what he could do, whether he could speak or not, however without much sharing of knowledge or teaching. Information support needs related to communication and speech-learning is evidenced in Jupi's quotes below:

*If we talked (to child), we just use everyday talk like that. If purposely teach him like 'this is fish', or all that, I don't. His father is worse than I; when he asked the child to eat, he followed his style of talking, 'ah, ah, ah' like that.*

(Nodes/information support needs/15 Jupi/ref 4/Bidayuh, 35 yrs, mo of ♂ age 3)

Daniela's frustration with teaching child to speak further illustrates the needs for support with speech-learning related information:

*I don't know what to talk to him, sometimes I want to teach him to say 1, 2, 3, a, b, c, eye, ear, nose, he won't listen, he does not even bother to look at me. If at night I lie down on the bed together, teach him 1..2..3, he just utters ar...ar...ar say also not accurate..*

(Nodes/information support needs/7 Daniela/ref 3/Chinese, 31 yrs, mo of ♂, age 3)

### *Challenges in accessing information source*

Apparently, accessing of relevant information sources is a challenge to several of the mothers due to various reasons, such as their language difficulty, limited skill in accessing internet and constraints of time.

Daniela described her difficulty in communicating with professionals due to language barrier:

*I do not know how to read or speak Bahasa Malaysia... can understand a bit only. I asked the Chinese doctor, I asked the nurse also...once I had meeting with the nurses in the clinic, they spoke in Bahasa Malaysia, I didn't understand what they said.*

(Nodes/challenges to access information sources/7 Daniela/ref 1-2/Chinese, 31 yrs, mo of ♂, age 3)

Wang related her problem of time constraint in accessing information sources as below:

*We look after her, try to understand her and learn from there because we really don't have the time to go and read up.*

(Nodes/challenges to access information sources/19 Wang/ref 1/Chinese, 33 yrs, mo of ♀, age 6)

The gap in term of preparedness among mothers who were disadvantaged in their access to information resources and several other urban mothers in this study who had better access to various informational resources was obvious. They were noted to be more knowledgeable, more confident in relation to child care giving, and had a more positive parenting attitude. It is also evident in this study that these mothers who were better prepared with information on child's language learning were more responsive and interactive with their child.

#### **4.2.4 Coping strategies**

'*Coping strategies*' is another major theme which includes the subthemes of '*reframing of perspectives*', '*maintaining of hopefulness*', and their '*religious beliefs and convictions*'.

#### 4.2.4.1 Reframing perspectives

Reframing or conceiving another way round their perspectives of mothering a child with DS positively and realistically are evidenced from the quotes of several of the mothers below:

Wang, a mother of 6-years-old girl perceived positively and realistically the extent that her child could achieve academically:

*We don't have a very high expectation for her to be very good academically... We just want her to be well and healthy and know how to take care of herself. This kind of child needs to be taught slowly, let her learns naturally. Why want to get so stressed?*

(Nodes/coping strategies/reframing parenting/19 Wang/ref 3/Chinese, 33 yrs, mo of ♀, age 6)

Kua, a mother regarded her 9-years-old child as *a blessing* to her family. She attributed her child as a blessing and a unifying force in bringing the family closer together, in their sharing of love and caring for one another. Her child with DS was regarded as the motivation factor for her, including her spouse to involve herself in volunteerism, to spend her time and effort for the parent support group, and to reach out and to help others, besides her own child.

A few of the mothers' sense of reassurance was attributed to their perception of child with a disability as a divine gift given in accordance to their ability to handle, as Julia described below:

*God had given this gift to me according to each one's uniqueness and ability. God knows that I'm able to take good care of this child'.*

(Nodes/coping strategies/reframing parenting/14 Julia/ref 1/Chinese, 37 yrs, mo of ♂, age 8)

#### 4.2.4.2 Maintaining hopefulness

For many of the mothers, they maintained their hopefulness that their child would be able to perform like other ‘normally developing’ children, though they were concerned and battled with uncertainty. Many of them counted their blessings that their child was not as disabled as others’.

As Julia described below, her hope was for her child to get an education:

*Of course education for him is one of my aims... if he can even go to university, why not...or let him learn some skill, not necessary all have to be lawyer, or doctor, or whatever.*

(Nodes/coping strategies/maintaining hopefulness/4 Julia/ref 1/Chinese, 37 yrs, mo of ♂, age 8)

Chara had the hope that her daughter would get married, and may be have her own children:

*Saya fikir, tidak masuk akal, kalau boleh kahwin saya pun senang hati. Jikalau dia kahwin pun, macam takut juga bah. Samada nanti lelaki bagus sama dia kah tidak. Takut laki buli.Saya tak sampai hati, tidak senang hati tengok.Kalau kita panjang umur lah, kalau dia kahwin kita boleh jaga anak dia, macam anak dia sudah besar, anak dia boleh jaga dia lagi (in Bahasa Malaysia).*

(Nodes/coping strategies/maintain hopefulness/6 Chara/ref 1/Bidayuh, 41 yrs, mo of ♀ age 14)

*I thought it's ridiculous, if she can get married I would be happy. If she is married, not sure whether the husband will treat her well or not, scared he will bully her. I don't have the heart to see that happen. If I live a long life, if she gets married, we can take care of her kids, and when her kids have grown up they can in return take care of her (in English).*

Farah talked about her hope for her daughter to get a job:

*One day, I may open a nursery, I'll take in special children like them; can ask her to take care; because she is very caring with the small kid; maybe she can work at the KFC down the road.*

(Nodes/coping strategies/maintaining hopefulness/9 Farah/ref 3/Malay, 48 yrs, mo of ♀, age 16)

#### **4.2.4.3 Religious beliefs and convictions**

Among the mothers interviewed in this study, their religious inclinations and convictions related to having a child with disability were found to be helpful. These include their convictions that mothering a child with a disability as one of the testing from God; they could lay hold of the divine care provision; child as God's gift and destined with a purpose.

##### ***God's testing***

Though experienced sadness having a child with DS as a mother, Farah had the conviction that mothering the child was God's testing.

*Sedih memang sedih ('of course I felt sad' in Bahasa Malaysia), I got this child with DS; sometimes I pray, maybe this is a test from God for us to face.*

(Nodes/coping strategies/religious beliefs/9 Farah/ref 1/Malay, 48 yrs, mo of ♀ age 16)

##### ***Trusting the divine care provision***

Though there was still uncertainty regarding child's future provision, apparently their confession of their trust and faith in divine care provision instilled in them a sense of confidence:

*If God is able to give me this type of child, and taught me so much, I'm sure God will also take care of him, at the end of the day, I do not lack anything; I can see that God is giving him for me for a purpose, I mean, I trust God.*

(Nodes/coping strategies/religious beliefs/14 Julia/ref 1/Chinese, 37 yrs, mo of ♂ age 8)

##### ***Child as God's gift and predestined***

Among the Muslim mothers, there was the conviction that child with disability they had was predestined and was given to them as a gift. The quote below is illustrative:

*Terima saja. Anak juga, Tuhan bagi kita (laugh) Kami anggap ia anak kamik macam dianugerahkan Tuhan. Ini macam sudah ditetapkan; terimalah hakikat. Yang satu tentang*



*perkara ini, ada sesuatu Allah tentukan, yang jadi budak ini memang sejak lahir kurnia dunia ini* (in Bahasa Malaysia).

(Nodes/coping strategies/religious beliefs/5 Bisroh/ref 1/Malay, 40 yrs, mo of ♂, age 4)

*Just accept. Is our child also (though has a disability) God gave to us; we regard our child like a gift from God. It's already decided (by God). We accepted the reality; it's something that is decided by God, who created this child into this world* (in English).

#### **4.2.5 Life impacts**

As one of the major themes, 'life impacts' pictures part of the mothers' experiences in mothering a child with DS which is represented in several sub-themes as below:

- Being stigmatized
- Family role impacts
- Personal growth and competence
- Motivated to reachout and help others

##### **4.2.5.1 Being stigmatized**

The experience of being stigmatized because of their child with DS was shared across several of the Chinese and also the Malay mothers.

As described by Aziah, a Malay mother who had a five years-old daughter with DS, she would not dare to greet any woman who was pregnant whenever she was with her child, due to her concern that she might be blamed for causing the pregnant person to have an abnormal child. The following quotes illustrated Aziah's experience in the clinic while she was with her child:

*Seorang tua cakap dengan anak perempuan yang bunting, 'jangan tengok itu orang', 'nanti anak kamu dalam perut ikut'; saya tahu saja, tidak saya tengok orang sana, mana saya mau tegur (greet) orang, orang itu bunting. Saya masuk terus ke dalam klinik, bawa*

*saya punya anak. Kalau orang bunting di rumah, saya tak berani jalan, rasa kesunyian, rasa hati tersinggung. Saya jadi diam saja* (in Bahasa Malaysia).

(Nodes/life impact/stigma/4 Aziah/ref 1-6/Malay, 41 yrs, mo of ♀, age 5)

*An elderly lady told her daughter who was pregnant, 'don't look at the person over there, otherwise, your child also become like that', she said. I wouldn't want to greet her, people is pregnant. I brought my child straight into the clinic. If there's anyone pregnant in the house, I wouldn't dare to go there. I felt lonely and alienated. I just kept quiet* (in English).

Another incident as described by Kua illustrates societal reaction and attitude towards her child which was hurting:

*There was once a performance in the shopping complex before the Chinese New Year, there was no public clapping of hands or applause after the children from Centre had performed. One parent from the crowd came to ask me, 'this type of children "cacat" ('handicapped' in Bahasa Malaysia), can they perform?' I felt like my heart was 'bleeding'.*

(Nodes/ life impacts/stigma/17 Kua/ref 1/Chinese, 50 yrs, mo of ♀, age 9)

Kay recounted her experience of being really upset due to others' attitude towards her child when she was with her child in the supermarket:

*Got this mother (in supermarket), when she saw my child, she asked her child to go to the side, to avoid my daughter, I heard she said, 'avoid her, avoid her'. I heard, just at my side; I got really angry, straight away I gave my daughter one ringgit and asked her to go to the counter to make paymen<sup>12</sup>. This mother didn't say anything after that.*

(Nodes/life impacts/stigma/16 Kay/ref 1/Chinese, 45 yrs, mo of ♀, age 9)

Experiences of mothers due to prevalent 'belief' related to disability, societal reaction and attitude towards their child with DS were stigmatizing and isolating mothers and has implications on the social life and supports for mothers.

---

<sup>12</sup> Apparently this was done by the mother to show that the child can do normal activity.

#### 4.2.5.2 Family role impacts

##### *(a) Family tension*

As a result of having a child with DS in the family, mothers were subject to pressure and tension within the family. Child's behavior-related felt tension was described by Kay as below:

*The father was waiting inside the car (to send children to school). He would scold me, keep scolding me; said a lot of things. The child was the one who had tantrum, not me; I often told my mother-in-law about this. Because of this child, it is becoming an issue in the family; almost every morning like that.*

(Nodes/life impact/family tension/16 Kay/ref 1-2/Chinese, 45 yrs, mo of ♀, age 9)

When mothers also had other children in their schooling age besides child with DS, the pressure on the mothers due to the need for care provision for both the other family members and the child with DS were heightened.

*In the morning, I wanted to help her to put on her uniform, she didn't want, later she looked for her stocking, insisted to wear a different one and she cried; by 6.40 am, we must all leave the house: once, I got so angry with her, before putting uniform on her, I made her go inside the car, otherwise, by 7.05 am the school teacher will mark her (the other eldest daughter's) name for being late.*

(Nodes/ life impact/family tension/16 Kay/ref 1/Chinese, 45 yrs, mo of ♀, age 9)

Though family tension was the experiences of a few of the mothers, several others described how their families had grown closer, more supportive and appreciative of one another as a result of the needs to pull the family efforts together to help and support their child with DS.

##### *(b) Family cohesiveness*

Several mothers describe how their families had grown closer, more supportive and appreciative of one another as a result of the needs to pull family resources and efforts

together to help their child and each other. The quotes of Julia, Kua and Adrina below are illustrative:

*I see that everybody is working very hard towards helping him, our family is actually very well knitted together, everybody (including the other children) is putting our effort to help him, my husband is also very supportive, we all really work together.*  
(Nodes/life impacts/family cohesiveness/14 Julia/ref 1/ Chinese, 37 yrs, mo of ♂ age 8)

Inclusiveness of the child into the family and the cohesiveness for one another in her family was evidenced from the few family photo albums which Julia showed to me concerning family events with child since the child's birth.

Kua expressed about the sibling's supportiveness in her quote:

*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.*  
(Nodes/ life impacts/family cohesiveness/17 Kua/ref 2/Chinese, 50 yrs, mo of ♀, age 9)

Family's cohesiveness and supports among spouse, siblings and extended family to pull their family resources together to meet the additional care demands for the child was apparent as Adrina described below:

*Usually if my husband works in the afternoon shift, he will take care of child in the morning. My sister will be back at 12noon and she took care. My husband will then send the two children to school. When I come back (from work) in the afternoon, I take over. When sometimes he comes back from night duty... he has to take care till my sister comes back then he goes to sleep. The children are ok, the older one knows how to cook, they know.*  
(Nodes/ life impacts/family cohesiveness/1Adrina/ref 1/ Bidayuh, 44 yrs, mo of ♂, age 6)

#### **4.2.5.3 Personal growth and competence**

At the personal level, many of the mothers demonstrated growth and competence during the process of care giving of their child with DS, such as in advocating for their child in various

situations, in handling their child's behavior and in their effort in helping child to be more independent.

*(a) In advocating for child*

Salina demonstrated her confidence as she advocated for her child and insisted that the doctor provided her child the appropriate treatment at hospital emergency department. She recalled the incident when her child had severe breathing difficulty, and she brought her to the hospital in the middle of the night for treatment. However, she was only given salt solution and was asked to take the child home. The quotes below are illustrative Salina's confidence in speaking up for her child's sake:

*Saya tanya doctor, 'kitak pandai tak jadi doctor?' Anak saya bukanlah cirit birit. Kalau tahu saya, ubat garam untuk cirit birit'. Saya cakap, 'anak saya bekas bedah jantung, doktor cakap, 'kalau susah nafas susah tidur, pergi bawa balik hospital' ... Dia cepat cepat pergi check jantung, kakinya (in Bahasa Malaysia).*  
(Nodes/life impacts/personal growth & competence/24 Salina/ref 1/Malay, 42 yrs, mo of ♀ age 3)

*I asked the doctor, 'do you know how to be a doctor?' My child is not having diarrhea. If I am not wrong, the salt solution is for diarrhea. I said, 'my child just had heart operation and the specialist had said earlier on, 'if child has breathing difficulty or cannot sleep, bring her back to hospital'. Then only he quickly checked the (child's) heart and legs (in English).*

As a result of Salina who spoke up, her child was urgently admitted to the ward due to breathing difficulty and her poor oxygenation level.

*(b) In handling child behavior*

Despite the care demand related to child's behavior, the competence of a few other mothers in their approach to handling child's behavior is obvious. Julia perceived that her child should not be given any special treatment but should be disciplined firmly, if she

misbehaved. Her strength and competence in relation to approach of handling child or setting limit on child's behavior is evidenced in her descriptions below:

*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 all the house lighting, closed the door and let her 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 consistently.*

Julia further elaborated on her firmness in setting limit / disciplining her child:

*I also smacked him if he did something wrong ... use a wooden spoon, just hit the leg... follow the same way I did to the other children. I don't think that I need to give him special treatment... 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.*  
(Node/ life impacts/personal growth & competence/14 Julia/ref 1-2/Chinese, 37 yrs, mo of ♂, age 8)

During the interview session with Julia, her child was playing around with another child.

Her competence and confidence in handling child's behavior was demonstrated. Her child was noticed to take away a chair from the other child Joyce while she stood up and that action caused her to fall. At that moment, she asked the son,

*What happened if Joyce knocked the head and bleed? You cannot do that! Please say sorry to Joyce'.*  
(Node/ life impacts/personal growth & competence/field notes/14 Julia/ref 1/Chinese, 37 yrs, mo of ♂, age 8)

Julia was seen to take his hand to hold Joyce's hand while asking him to apologize.

Wang, a Chinese mother described her experience about handling her child's misbehavior: her emphasis was about being consistent in disciplining child.

*It's hard if you don't use a rotan, have to be strict ... when she didn't listen then only we'll scold her and hit her buttock, not that we keep hitting her very hard, we don't abuse her, sometimes we just hit the table and she listened.*

(Node/ life impacts/personal growth & competence/19 Wang/ref 2-3/Chinese, 33 yrs, mo of ♀, age 6)

*(c) In helping child to be more independent*

Strength and competence of some of the mothers in their provision of care to child is illustrated in the quotes of Zuriah:

*It is challenging...we regards him like any other child... only that we need to be patient in whatever, we must not give up...continue to teach...he's a bit slow, unlike other children, push myself to continue to teach, like teaching other children... if we pity him, dress-up also help him, in this way, will cause him to be stunted in his development, as he is always waiting for us to help him only... Until when are we going to continue to help him? When he is already an adult, how? ... Yes, we are forced to teach him the same way (like for other children)... we have to, with the excuse we want to teach him ... we love him, we should have less pity for him (the child)'*

(Node/ life impacts/personal growth & competence/26 Zuriah/ref 2-4/ Malay, 37 yrs, mo of ♂ age 5)

#### **4.2.5.4 Motivated to reach out and help others**

In the process of mothering a child with disability, especially when their child developed and demonstrated further progress, among the mothers, a few of them developed strong sense of motivation to help others who were struggling with various challenges. Though still faced with challenges and care demands, they assumed new roles as peer counselor, encourager, motivator, parent-group leader in non-governmental organization (NGO) and other social network. The various roles involved sacrifice of mothers' time and efforts, however they were committed and determined to help.

As was described by Julia who headed the parent support group in a clinic, she helped as a volunteer in helping other mothers who were accessed through the clinic, those who were feeling lost and needy of help. The quotes from her below are illustrative:

*I feel very pleased, when I can help people more. The other day my friend called me and said her friend who just gave birth was very stressed, because her child was also like that, I was always willing, at least (to) counsel them. The end of last year, this new mother, the child has Down syndrome, autistic, and I did counseling.*

Julia's motivation to help others was in stark contrast with the initial emotion which was overwhelming her during the child's early age:

*The first two years I cried a lot, I didn't have a peaceful life. So much of pressure I had; I could have jumped down from the building; so many things gave me pressure at the same time. Had a lot of bitterness in my heart, When he was young that time, he was very demanding.*

(Node/initial responses/motivated to help others/14 Julia/ref 2-3/Chinese, 37 yrs, mo of ♂ age 8)

Kua who was very committed and motivated in helping as volunteer in a parent support group center spent much of her effort and after duty hour for the group. Her commitment to serve was clear as she motivated the other parents in 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.*

(Node/initial responses/motivated to help others/17 Kua/ref 2/Chinese, 50 yrs, mo of ♀ age 9)

Kua's level of motivation and commitment in helping other parents was in great contrast to the earlier her heart-felt emotion as mentioned in the earlier section:

*I had suicidal thoughts till she was about 2 years old. At the beginning when I had her, I thought I was going to die, could not take it; felt like crazy.*

(Node/initial responses/sadness/17 Kua/ref 2-3/Chinese, 50 yrs, mo of ♀ age 9)



### 4.3. Chapter summary

This chapter highlights the findings as elicited from the interviews with the 26 biological mothers of child having DS. Experiences of mothers having a child with DS were represented through the five major themes as established, namely their *extra care demands*, *various emotions*, *variation of supports*, *coping strategies* and *life impacts*, and their related sub-themes.

Many of them experienced **various emotions** such as shock, sadness and anger, feeling of shame and self blame, difficulty in accepting child. Integral to all these experiences were mothers' worries related to child's self care ability, future care provision and the risk of recurrence of DS in their subsequent pregnancy. As part of the mothers' experiences, there were sense of excitement related to child's developmental progress and the joy of mothering their child during the mothering process. Among mothers, many experienced child-related **extra care demands** related to child's health conditions especially during child's younger age; delayed developments or behavioral characteristics. Mothers experienced a **variation of supports** from various sources. The reality of several of the mothers who did not have the accessibility to adequate informal supports was also elicited. Constraints and limitations in relation to various environmental supports, including financial resources, transports and informational resource in meeting the care demands related to having a child with DS were illuminated in the mothers' verbal quotes. Mothers' **reframing of perspectives** of mothering a child with disability, the **maintaining of hopefulness** regarding their child's potential, and their **religious beliefs and convictions** were helpful to them as they encountered with various care demands and challenges in their mothering process. Though several of the mothers experienced being stigmatized and

family tension, as part of **life impacts** having a child with DS, many others indicated increased family cohesiveness, personal growth and competence and the motivation to reach out to help others.

Chapter Five presents findings from the quantitative component of the parallel mixed design study concerning QOL among 161 mothers.

Subsequently, Chapter Six would further analyze and discuss findings of major themes and subthemes of mothers' experiences and their perceived QOL. In trying to further make sense of mothers' experience and QOL findings, several concepts from Burden (1991)'s model of psychosocial transitions, social model of disability (Shakespeare, 2006) and the resiliency model of family stress, adjustment and adaptation framework (McCubbin & McCubbin, 1991 in Riper, 2007) will be drawn upon in the discussion.

## CHAPTER FIVE

### QUALITY OF LIFE-RELATED FINDINGS

#### 5.0 Introduction

The chapter presents the findings from the cross-sectional questionnaire study as an expansion of the scope of the main study which utilized the parallel mixed study design. Study participants were recruited from within the same study settings as the qualitative interviews study, i.e. the various CBR centers, health clinics and schools within Kuching and Samarahan Divisions, two of the regions in the Malaysian State of Sarawak. The main aims of the study were to answer the research questions concerning '*what is the QOL of mothers having a child with DS*'.

Data were collected following the procedures as described in Chapter Three Methodology. Besides perceived QOL, participants' background characteristics and child care related information were collected. Findings of descriptive data analysis using Statistical Package for Social Sciences (version 19.0) were presented in percentage, means, median and standard deviation (SD). Also included are findings of non-parametric data analysis which was conducted to examine correlation of selected variables and their perceived QOL.

#### 5.1 Participants' background characteristics

Participants' background characteristics in relation to demographics (age, ethnicity), socioeconomic status in term of educational levels, employment, household income, marital status, religions, access to own transport and related information on maternal and child's age are summarized and tabulated in Table 5.1.

Table 5.1 Summary of mothers' background characteristics

Characteristics (N=161)	n (%)
Maternal age (years)	
Mean (SD)	43.6±8.4
Range	22 - 65
Median	44
30 yrs and below	13 (8.1)
31-45 yrs	80 (49.7)
45 yrs and above	68 (42.2)
Mothers' age (in years) @ birth of child with DS	
Mean (SD)	34.5±5.7
Range	17 - 48
Child's age with DS (in years)	
Mean (SD)	9.3±4.2
Range	1 - 18
10 years and below	97(60.2)
11 yrs and above	64(39.8)
No. of children	
≤ 4	99 (61.5)
≥ 5	62 (38.5)
Median	4
Range	1-12
Ethnicity	
Malay	76 (47.2)
Chinese	33 (20.5)
Iban	18 (11.2)
Bidayuh	29 (18)
Others	5(3.1)
Religions	
Islam	84 (52.2)
Christianity	55 (34.2)
Buddhism	17 (10.6)
No religion	5 (3.1)
Marital status	
Married	151(93.8)
Unmarried	1 (0.6)
Divorced	4 (2.5)
Widowed	5 (3.1)
Highest education	
None at all	20 (12.4)
Primary school	46 (28.6)
Secondary school	90 (55.9)
University	5 (3.1)

Table 5.1, continued

Employment	
Housewife	116 (72)
Own business	11 (6.8)
Government staff	13 (8.1)
Private employee	21(13.0)
Household income	
≤ RM 500	65(40.4)
RM 501-1000	47(29.2)
≥ RM 1001	49(30.4)
Transports	
Own car	81(59.6)
Own motorcycle	55(34.2)
None	25(15.5)

### 5.1.1 Ethnicity, mothers and child's age

The mean age (in years) of the mothers was  $43.67 \pm 8.5$  (within the range 22 years old to 65 years old). Almost half of them (42.4%, n= 68) were 46 years and older. They delivered their child with DS at a mean age of  $34.11 \pm 7.5$  (with the youngest at the age of 17 years old). Each of them had one child with DS except for one of them who had two children with DS in the family. Among their child (children) with DS, their mean age in years was  $9.39 \pm 4.3$  (range from one to 18 years of age). Majority of them (60.2%; n=97) were at the younger age group of  $\leq 10$  years old. Besides being mothers of child having DS, they were also mothers to a varying number of children (range from one to 12 children) (Table 5.1).

Almost half of the group of mothers were Malays (47.2 %; n=76), followed by Chinese (20.5%; n=33), Bidayuhs (18.0%, n=29); Ibans (11.2%, n=18), and the 'others' (3.1%; n=5) (of one Kenyah, one Melanau and three Indonesian Jawanese who resided in Sarawak).

Almost half of the group (n=79) lived in the rural community. Apparently there is some differences in the locality where mothers of different ethnic groups lived. The Malay and

Iban mothers lived in both the rural and the urban regions. More of the Chinese mothers lived in the urban region whereas more of the Bidayuh were from the rural (Table 5.2).

Generally, the State has its predominant ethnic group the Ibans, which accounted for 30.1% of the State's population, followed by the Chinese (26.7%) and Malays (23.0%)(Sarawak Government Official Portal, 2010). However, the prominently Malay ethnic majority of the group of mothers in this study (47.2%) was not exactly reflective of the population ratio of the State of Sarawak. This could be related to the mainly Malay ethnic group who historically settled down in these two particular regions of Sarawak where the mothers were recruited.

### **5.1.2 Education, employment, income, transport and locality-related difference**

Among those mothers who attained their education only till primary school level or no formal education (41%; n=66), a big proportion of them (n=46) were from the rural locality. Regarding employment, among those who were unemployed (72%; n=116), 70 of them came from the rural locality (Table 5.2). In relation to household income, nearly half of the group (40.4%; n=65) self-reported an income of less than RM 500, with the majority of them (n=49) lived in the rural locality (Table 5.2). A household income of this amount as reported is considered as below the poverty line income of RM 830 per household income (Economic Planning Unit, n. d.).

Different modes of transports were used by the mothers, with only slightly more than half of group (59.6%, n=81) who had their own car or van for family use. The rest of them depended on either motorcycles (34.2%; n=55) or public transport (15.5%; n=25). Among

those who depended on motorcycles or public transport, most of them came from the rural region.

Table 5.2 Selected mothers' background characteristics by localities

	n (%)	<b>Rural</b>	<b>Urban</b>
		n	n
Maternal age: mean (SD)		42.87(9.7)	44.44(7.06)
Ethnicities			
Malay	76(47.2)	37	39
Chinese	33(20.5)	7	26
Iban	18(11.2)	9	9
Bidayuh	29(18.0)	24	5
Others	5(3.1)	2	3
Education			
≤ primary schools	66(41.0)	46	20
≥ secondary schools	95(59.0)	33	62
Employment			
Unemployed	116(72.)	70	46
Employed	45(28.0)	9	36
Household income			
≤ RM 500	65(40.4)	49	16
RM 501-1000	47(29.2)	20	27
≥ RM 1001	49(30.4)	10	39
Transport			
Public transport	25(15.5)	18	7
Motorcycles	55(34.2)	36	19
Cars/vans	81(59.6)	25	56
<b>Total</b>	<b>161 (100)</b>	<b>79</b>	<b>82</b>

### 5.1.3 Religions and marital status

The majority of the mothers embraced one of the three main religions (Islam, Christianity and Buddhism). With slightly more than half of them embraced Islam (52.2%; n= 84), this was almost in line with the Malay ethnic component of 47.2 % (n=76). Christianity was embraced by slightly more than one third of the mothers (34.2%; n=55) who were Chinese, Ibans and Bidayuhs. Predominantly, Buddhism was embraced by the Chinese mothers (10.6%; n=17). It is also shown in this group of mothers that the majority of them (93.8%; n=151) were married and stayed with their spouses (Table 5.1).

### 5.1.4 Child care-related information

The sections that follow present information related to child-care, in particular their communication with child, family supports in care giving, service provisions, early child health conditions and care related information sources which are tabulated in Table 5.3 to Table 5.8.

#### 5.1.4.1 Communication with child

Table 5.3 Communication with child

Mothers' communication with child	n (%)
Using sign language	23 (14.3)
Using spoken words	159 (98.8)
Using picture cards	5 (3.1)
Total	161 (100)

There were few participants (n=23, 14.3%) who reported using sign language to communicate with child having DS, while most of them communicate using spoken words with their child (Table 5.3).



#### 5.1.4.2 Supports in care giving

Among the mothers from the different ethnicity, more than one third of them (39.8%; n = 64) indicated not getting any other family support; their own spouse provided them the main supports in care giving of their child. A significant number of them received family supports from child's siblings (n=40), aunties (n=33) or grandparents (n=24) in helping with the daily care giving of child. Among those who were singles (n=10), 5 of them (50%) did not have access to other family support (Table 5.4 and 5.5).

Table 5.4 Family supports by ethnicity

		Family supports in care giving				
		No other family supports	Siblings	Grandparents	Aunties	Total
		n(%)	n(%)	n(%)	n(%)	
Ethnicity	Malay	28(36.8)	21(27.6)	11(14.5)	16(21.1)	76(47.2)
	Chinese	18(54.5)	4(12.1)	6(18.2)	5(15.2)	33(20.5)
	Iban	8(44.4)	1(5.6)	3(16.7)	6(33.3)	18(11.2)
	Bidayuh	9(31.0)	13(44.8)	3(10.3)	4(13.8)	29(18.0)
	Others	1(20.0)	1(20.0)	1(20.0)	2(40.0)	5(3.1)
Total		64(39.8)	40(24.8)	24(14.9)	33(20.5)	161(100)

Table 5.5 Family supports by marital status

		Family supports		
		No other family supports	Have other family supports	Total
		n (%)	n (%)	n (%)
Single mothers		5 (50)	5 (50)	10 (100)
Married & stayed with spouse		59 (39.1)	92 (60.9)	151 (100)
Total		64 (39.8)	97 (60.2)	161 (100)

### **5.1.4.3 Service provisions for child with DS**

All of them sent their child to attend at least one of the various service provisions, either the school-based special education integrated programs, CBR centres or the clinic-based intervention programs.

Under the Sarawak education department, several selected schools implement the integrated special education programs. Children from the age of four years and above who meet the minimal criteria of self care ability (such as for toilet needs) would be placed in the pre-school special education classes. They would later be enrolled for the primary school class, and thereafter secondary school class (Manisah, Ramlee & Zalizan, 2006). A lower percentage of 11.2% (n=18) attended the clinic-based intervention programs which were catered more for the younger age group children. The other children attended either the school-based integrated special education programs or the CBR centres' programs.

About a third of them (28.6%; n= 46) sent their child to attend two or more of the programs service provisions, including both the clinic-based program and the CBR center program (Table 5.6). This could be related to the clinic appointment which was given for the clinic-based program for their child was less frequent, thus these mothers also enrolled their child to the CBR center program while waiting for their turn for the clinic-based program.

Besides the reason of infrequency of appointment, the other possibilities for some of their children who were enrolled to attend both clinic-based and CBR center programs, or, school-based and also CBR center programs could be attributed to the added benefits of attending CBR centres. During the period of the data collection in year 2008, the Welfare

Department allocated financial assistance to those children registered as disabled and attended the CBR center programs which were run by the Welfare Department.

Table 5.6 Attendance to service provisions

Programs attended	n (%)
School-based special education integrated program	53 (32.9)
CBR center programs	44 (27.3)
Clinic-based programs	18 (11.2)
Two or more of the above programs	46 (28.6)

#### 5.1.4.4 Child development and health-related background information

Participants' children with DS had delayed developments. They attained their various developmental abilities such as walking, bladder and bowel controls at a much later age than the other 'normally developing' children (Table 5.7). Among their children, many of them were reported to have problem with language communication, with 92 of them (57.1%) who were reported to speak only five words or less at mean age (in years) of  $8.35 \pm 4.6$ .

Table 5.7 Child development related information

	Mean age in years
Attained bladder control	$5.64 \pm 1.64$
Attained bowel control	$5.99 \pm 1.68$
Able to walk	$2.94 \pm 0.99$
Able to speak less than five words	$8.35 \pm 4.6$
Able to speak more than five words	$10.78 \pm 3.2$

A significant number of the child with DS suffered from various congenital health conditions which required treatment soon after birth, including congenital heart conditions, or conditions of the ear, eye, breathing or rectum. The most frequently reported condition is congenital heart condition (45.3%; n=73) (Table 5.8).

Table 5.8 Child-health related information

Medical conditions	n (%)
Heart conditions	73 (45.3)
Ear condition	43 (26.7)
Eye condition	45 (28.0)
Breathing condition	36 (22.4)
Rectal condition	26 (16.1)

### 5.1.5 Child care related information sources

Among the information sources accessed by the mothers, health professionals were the most highly sought after (89.4%; n=144) to obtain information related to care giving of child with DS, either in the rural or the urban areas. Apparently, health professionals such as doctors or nurses play an important role as information source for mothers in the aspect of care giving related information in Sarawak. There were relatively less mothers who indicated reading from books or newspapers as their information source, especially in the rural locality. This could be attributed, partly to their relatively lower education level and hence limitation in acquiring information through reading. It could also be related to the culture for some of them where reading was not a part of their life style. Fewer mothers (n=16; 9.9%) accessed the internet as an information source, probably due to inaccessibility of the facility, especially in the rural area (Table 5.9).

Table 5.9 Information sources accessed by locality

Information sources	Locality		n (%)
	Rural	Urban	
1. Health professionals	<b>73 (45.3)</b>	<b>71 (44.1)</b>	<b>144 (89.4)</b>
2. Internet	<b>1 (0.6)</b>	<b>15 (9.3)</b>	<b>16 (9.9)</b>
3. Newspaper	<b>14 (8.7)</b>	<b>18 (11.2)</b>	<b>32 (19.9)</b>
4. Books	9 (5.6)	17 (10.6)	26 (16.1)
5. Friends & relatives	37(23.0)	33 (20.5)	70 (43.5)

Note: the above are items with multi-responses, participants were allowed to select more than one response.

## 5.2 QOL-related findings

### 5.2.1 Overall and domain-specific QOL

The overall and four domain-specific QOL mean scores provide answers to the research objective to *determine the overall QOL and QOL of their physical health, psychological well-being, social relationship and environmental support domains.*

Table 5.10 Overall QOL and domain-specific QOL‡

	Mean $\pm$ SD*
†Overall QOL (26-items)	14.0 $\pm$ 1.84
DOM 1 physical health	14.5 $\pm$ 2.26
DOM 2 psychological well-being	14.2 $\pm$ 2.03
DOM 3 social relationship	<b>14.9 <math>\pm</math> 2.11</b>
DOM 4 environmental support	<b>13.3 <math>\pm</math> 2.11</b>

Note: \* mean score (multiplied by 4); potential scores range between 4 and 20; a higher mean score denotes a better perceived QOL;

† obtained by calculating the mean of all 26 items' mean scores

‡ obtained by calculating the mean of domain-items' mean scores

A composite mean score of 14.0 $\pm$ 1.8 (possible scores range between 4 and 20) which was obtained (from the 26 items) indicated mothers' *overall QOL* (Table 5.10).

There are some variations in relation to the mothers' QOL of the four different life domains.

The highest and lowest mean domain scores were found for *DOM 3 (social relationship, mean =14.9 $\pm$ 2.1) and DOM 4 (environmental supports, mean=13.3 $\pm$ 2.1)* respectively

(Table 5.10). The higher domain mean which was obtained for *DOM 3 (social relationship)* indicated mothers' level of satisfaction in this domain. Lower domain mean

of the *DOM 4 (environmental support)* denoted mothers' relative dissatisfaction. In

particular, 'having enough money to use' and 'opportunity for leisure activities' for

Question (Q.) 12 and Q.14) respectively, were identified as the two items with the lowest means (Table 5.11).

Regarding *DOM 1 (physical health)*, a mean of  $14.5 \pm 2.3$  was obtained (Table 5.10). Item on ‘satisfaction with sleep’ (Q. 16) was noted to have a relatively lower mean score (Table 5.11). As for the *DOM 2 (psychological well-being)*, mean =  $14.2 \pm 2.03$ , in particular, questions related to the extent that mothers ‘enjoy life’ (Q.5) and ‘feeling life to be meaningful’ (Q.6), and frequency of ‘negative feelings such as blue mood, despair, anxiety, depression’ (Q.26), a relatively lower mean scores were obtained (Table 5.11).

Table 5.11 Distribution of domain (DOM) and item means

	Item mean (SD)	DOM Mean (SD)	DOM mean (SD)*
<i>DOM 1 (physical health)</i>			
3. To what extent do you feel that physical pain prevents you from doing what you need to do?	3.6±0.9	3.6±0.6	14.5±2.3
4. How much do you need any medical treatment to function in your daily life?	3.6±0.9		
10. Do you have enough energy for everyday life?	3.7±0.8		
15. How well are you able to get around?	3.6±0.9		
<b>16. How satisfied are you with your sleep?</b>	<b>3.5±0.9</b>		
17. How satisfied are you with your ability to perform your daily living activities?	3.6±0.7		
18. How satisfied are you with your capacity for work?	3.7±0.8		
<i>DOM 2 (psychological well-being)</i>		3.6±0.5	14.2±2
<b>5. How much do you enjoy life?</b>	<b>3.3±0.8</b>		
<b>6. To what extent do you feel your life to be meaningful?</b>	<b>3.5±0.8</b>		
7. How well are you able to concentrate?	3.5±0.8		
11. Are you able to accept your bodily appearance?	3.9±0.9		
19. How satisfied are you with yourself?	3.8±0.7		
<b>26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?</b>	<b>3.4±0.9</b>		

Table 5.11, continued

<i>DOM 3 (social relationship)</i>		3.7±0.5	14.9±2.1
20.	How satisfied are you with your personal relationships?	3.8±0.7	
21.	How satisfied are you with your sex life?	3.7±0.7	
22.	How satisfied are you with the support you get from your friends?	3.7±0.7	
<i>DOM 4 (environmental support)</i>		3.4±0.5	13.3±2.1
8.	How safe do you feel in your daily life?	3.5±0.8	
9.	How healthy is your physical environment?	3.4±0.7	
<b>12.</b>	<b>Have you enough money to meet your needs?</b>	<b>2.9±0.9</b>	
13.	How available to you is the information that you need in your day-to-day life	3.2±0.9	
<b>14.</b>	<b>To what extent do you have the opportunity for leisure activities</b>	<b>2.6±1.0</b>	
23.	How satisfied are you with the conditions of your living place?	3.7±0.9	
24.	How satisfied are you with your access to health services?	3.7±0.7	
25.	How satisfied are you with your transport?	3.6±0.9	

Note: \* mean score (multiplied by factor 4); potential scores range between 4 and 20; a higher mean score denotes a better perceived QOL

### 5.2.3 Single-items (Q. 1 and Q. 2)

Pertaining to the single-item Q. 1 which elicited mothers' response concerning their QOL, nearly half of the group of mothers (45.3%; n=73) indicated their QOL as 'neither poor nor good'; with only a few of them (n=10) who perceived it as 'very good' (Table 5.12). The mean of the Q. 1 (13.9±2.9) is almost identical to that of the overall QOL (14.0 ± 1.84).

Concerning their satisfaction with own health (single-item Q. 2), less than half of the group (42.2%; n=68) indicated being 'satisfied' (Table 5.12). Mean of 14.5 ± 3.24 for this single-item 'satisfaction with own health' (Q. 2) (14.5±3.2) is found to be almost the same as the mean of DOM 1 (physical health, mean = 14.5 ± 2.3).

Table 5.12 Single-item (Q. 1 and Q. 2)

	n (%)	Mean $\pm$ SD
<i>Single-item 'quality of life' (Q. 1)</i>		13.9 $\pm$ 2.88
Very poor	0	
Poor	11 (6.8)	
<b>Neither poor nor good</b>	<b>73 (45.3)</b>	
Good	67 (41.6)	
<b>Very Good</b>	<b>10 (6.2)</b>	
<i>Single-item 'satisfaction with own health' (Q. 2)</i>		14.5 $\pm$ 3.24
Dissatisfied	15 (9.3)	
Neither satisfied nor dissatisfied	61 (37.9)	
<b>Satisfied</b>	<b>68 (42.2)</b>	
Very satisfied	17 (10.6)	
Total	161 (100.0)	

The subsequent sections present details related to correlation analysis between selected background variables and mothers' overall and domain-specific QOL. Correlation analysis provides answer to the specific research objective (no.4), i. e. *to examine the relationship between selected background variables (i. e. locality, education, income, maternal age, marital status, religion, ethnicity and employment) and mothers' overall QOL*. Besides correlation with the overall QOL, each of these selected variables was also correlated with the domain-specific QOL for a more precise understanding.

### 5.3. Relationship between selected background variables and QOL

Preliminary exploratory data analysis was carried out to examine data distribution of the few outcome variables of QOL before correlation analysis using SPSS (version 19.0) was run.



### 5.3.1 Exploratory data analysis

Data summary of outcome measures, including the QOL mean scores, standard deviation, median values and the reported minimal and maximum scores were obtained using descriptive statistics (Appendix S: descriptive exploratory data analysis). Exploratory data analysis shows that the skewness and kurtosis values were in the acceptable range ( $\pm 1.0$ ) for it to be regarded as close to normality. Test of normality was also run to further examine normality of data distribution (Table 5.13).

Table 5.13 Tests of normality of overall and domain-specific QOL

	Kolmogorov-Smirnov <sup>a</sup>			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
DOM 1 physical health	.080	161	0.013	.987	161	.126
DOM 2 psychological well-being	.099	161	0.001	.979	161	.013
DOM 3 social relationship	.183	161	0.000	.948	161	.000
DOM 4 environmental supports	.067	161	0.077	.988	161	.187
Overall QOL	.062	161	0.200*	.991	161	.447

a. Lilliefors Significance Correction

The Shapiro-Wilk and Kolmogorov-Smirnov tests of normality with a significance level  $p > 0.05$  for the overall QOL and QOL of DOM 4 environmental support indicate that normality of data distribution was assumed. However, as for QOL of DOM 1 physical health, DOM 2 psychological well being and DOM 3 social relationship, a significance level of  $p < 0.05$  indicates that normality of data distribution was not assumed (Table 5.13).

Due to normality of data distribution was not assumed for the QOL mean scores of three of the domains as stated above, and limitation of non-probability sampling, the use of parametric correlation analysis was violated. Non-parametric analysis using Spearman's

rank-order correlation was run to examine the relationship between mothers' selected background variables and the overall QOL. Subsequently these were also correlated with the outcome measures of domain-specific QOL means (Table 5.14).

### 5.3.2 Correlations between selected background variables, overall and domain-specific QOL

Table 5.14 Spearman's rho correlations between selected background variables and QOL

		Overall QOL	DOM1 phy hlth	DOM2 psycho	DOM3 social	DOM4 Environ
rho	Rural-urban locality	<b>0.24**</b>	<b>0.19**</b>	0.11	0.14	<b>0.29**</b>
	Education	<b>0.28**</b>	<b>0.23**</b>	<b>0.16*</b>	0.13	<b>0.30**</b>
	Income	<b>0.23**</b>	<b>0.16*</b>	0.15	0.04	<b>0.31**</b>
	Maternal age	<b>-0.17*</b>	<b>-0.24**</b>	-0.11	-0.13	-0.06
	Marital status	<b>0.22**</b>	<b>0.18*</b>	<b>0.21**</b>	<b>0.19*</b>	0.15
	Religion	0.12	0.09	<b>0.16*</b>	0.11	0.09
	Ethnicity	0.10	0.08	0.12	0.13	0.06
	Employment	0.10	0.10	-0.03	-0.03	<b>0.17*</b>

#### 5.3.2.1 Rural-urban locality, education and income

Correlation analysis indicates significant positive correlations of locality, education and income with the overall QOL, with correlation coefficients of between 0.23 and 0.28 with  $p < 0.01$  (Table 5.13).

Mothers from the rural locality are more likely to score lower in overall QOL, with rho (161) = 0.24 ( $p < 0.01$ ). Locality is also significantly correlated with QOL of physical health and environmental support domains with rho (161) = 0.19 ( $p < 0.01$ ) and 0.29 ( $p < 0.01$ ) respectively.

Mothers with lower education level are more likely to score lower in their overall QOL, rho (161) = 0.28;  $p < 0.01$ ). Education level is also significantly correlated with QOL of their physical health, rho (161) = 0.23 ( $p < 0.01$ ); psychological well-being, rho = 0.16;  $p < 0.05$ ) and environmental support domains, rho (161) = 0.30;  $p < 0.01$ ).

Those mothers who were poorer in household income are more likely to score lower in their overall QOL, with rho (161) = 0.23 ( $p < 0.01$ ). Income level is also significantly correlated with QOL of physical health, rho (161) = 0.16 ( $p < 0.05$ ) and environmental support domains, rho (161) = 0.31 ( $p < 0.01$ ).

### **5.3.2.2 Maternal age**

A statistically significant negative correlation was found between maternal age and overall QOL (Table 5.14). Mothers who are older in age are more likely to score lower in overall QOL, rho (161) = - 0.17 ( $p < 0.05$ ). It is also negatively correlated with QOL of physical health domain, with rho (161) = - 0.24 ( $p < 0.01$ ).

The scatter-plot linear regression (Figure 5.1) below displays the negative correlation between maternal age and QOL of physical health. The straight line tracks the apparently negative relation between the two variables as suggested by the fewer points in the upper right and lower left of the plot area.

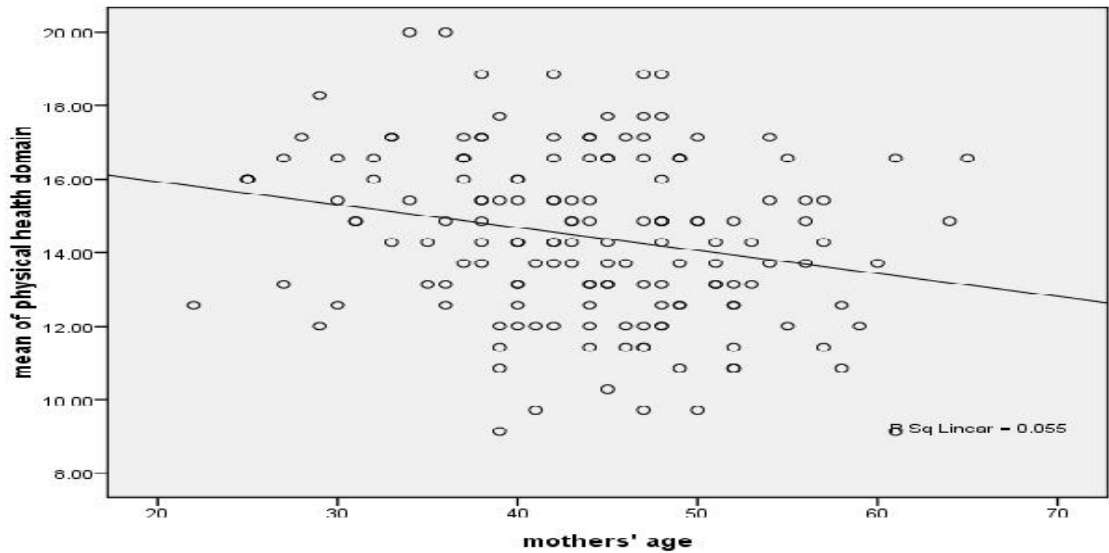


Figure 5.1 Correlation between maternal age and DOM 1 (physical health)

### 5.3.2.3 Marital status

Significant, positive relationships between *marital status*, overall and domain-specific QOL were demonstrated with  $\rho(161) = 0.22$  ( $p < 0.01$ ). Mothers who were singles are more likely to perceive poorer overall QOL as compared to married mothers. A significant positive, but weak correlation between marital status and QOL of DOM 1 physical health,  $\rho(161) = 0.18$  ( $p < 0.05$ ), DOM 2 psychological well-being,  $\rho(161) = 0.21$ ;  $p < 0.01$ ), and DOM 3 social relationship,  $\rho(161) = 0.19$ ,  $p < 0.05$ ) (Table 5.14).

### 5.3.2.4 Linear regression analysis

Further linear regression analysis shows that the linear combination of the few significant variables together accounted for 14.5% of the QOL variability in the sample ( $R^2 = 0.145$ ;  $F = 5.24$ ,  $p < 0.001$ ). These findings merit attention and consideration by policy makers and service providers (Table 5.15 in Appendix T).

### 5.3.2.5 Religion, ethnicity, employment

Mothers' *religious difference*, whether Muslims or non-Muslims (Christians or Buddhists) and their *ethnicity difference*, whether they were Malays, Chinese, Ibans, Bidayuh or others did not show significant correlation with their overall QOL ( $p > 0.05$ ). However, there is an indication of a positive but weak correlation of religious difference and mothers' QOL of DOM 2 psychological well-being, with  $\rho(161) = 0.16$  ( $p < 0.05$ ).

Among the group of mothers, though a majority of them (72%,  $n=116$ ) were unemployed, their *employment status* itself did not correlate with their overall QOL ( $p > 0.05$ ). However, a positive, but weak correlation with QOL of DOM 4 environmental support was indicated with statistical significance (Table 5.14).

### 5.3.2.6 Child and family-related variables

Variables such as child's age and family-related variable, such as the number of children in the family were found to be statistically insignificant in relation to mothers' perceived QOL ( $p > 0.05$ ).

## 5.4 Chapter summary

With potential scores range between 4 and 20, an overall QOL mean of  $14 \pm 1.8$  (26-items) was obtained. The highest and lowest domain-specific QOL means were found for DOM 3 (social relationship, mean= $14.9 \pm 2.1$ ) and DOM 4 (environmental support, mean= $13.3 \pm 2.1$ ) respectively. Nearly half of the group of mothers (45.3%;  $n=73$ ) *perceived QOL generally (Q.1) as neither good nor bad*, with only a few of them ( $n=10$ ) *perceived it as 'very good'*. Less than half of them were 'satisfied' (42.2%;  $n=68$ ) with own health. Hence, one's

attention should be drawn to the needs of mothers, in particular to their environmental support domain. Background variables of mothers' *rural-urban locality, education, income, and marital status* were found to be significantly correlated with their overall QOL, with  $\rho(161) = 0.23$  to  $0.28$  ( $p < 0.01$ ). *Maternal age* was found to be inversely correlated with their overall QOL and their DOM 1 (physical health). Linear combination of rural-urban locality, education, income, maternal age and marital status together accounted for 14.5% of the QOL variability in the sample ( $R^2 = 0.145$ ;  $F = 5.24$ ,  $p = 0.001$ ). *Religions, ethnicity and employment status* of mothers were found to have positive, but weak correlation with their QOL without any statistical significance.

## CHAPTER SIX

### DISCUSSION

#### 6.0 Introduction

The first section of the chapter discusses the experiences of 26 mothers of child having DS. Their experiences as represented in term of the five major themes, i. e. *various emotions, extra care demands, variation of supports, coping strategies* and *life impacts* with their sub-themes are further analyzed and discussed. The second section 6.2 discusses the QOL findings and correlations of selected variables obtained from among 161 mothers. In the subsequent section 6.3, the themes of mothers' experiences and QOL would be discussed to examine their complementarities. Interrelatedness between major themes and the QOL findings are further discussed in section 6.4 to provide a broadened perspective, a more in-depth and holistic understanding and knowing of life of mothers having a child with DS. The chapter concludes with a summary of the main findings from the study.

As would be seen in the discussion related to mothers' experience, there are universal themes in keeping with what is known from the literature related to experience of mothers from the other cultural contexts. There are, however, certain aspects of their experiences which differ from existing studies, due to the socio-cultural, economic, physical structural and service provision differences within the Sarawak context.

## 6.1 Discussion of mothers' experience

### 6.1.1 Making sense of mothers' various emotions

In my attempt to explain and to make sense of the various emotions as experienced by mothers of having children with DS, conceptual basis of *psycho-social transitions* (Burden, 1991) and *grief cycle* (Kubler-Ross, 1969 in Antara & Mertz, 2006) would be drawn upon in the discussion.

The transition periods as highlighted by Burden (1991) include four critical transition periods. Firstly, the *initial shock crisis period* was postulated to involve five possible sub-stages of emotional reactions of *shock, disbelief, denial, rejection and confusion*. This is further postulated to be followed by *realignment of personal values period*, a natural transition period which may manifest itself in one form or another for the initial two years of the child's life (Burden, 1991). Sadness and anger could be anticipated, and could be overlapping. Moreover, emotion reaction of anger could be 'displaced in all directions and projected onto the environment at times almost at random' (Kubler-Ross, 1969 in Kearney & Hyle, 2006, p. 114). The two other transition periods that parents (or mothers) are likely to pass through are periods of *readjustment of parental role expectation*<sup>13</sup> and *pressures on family and social roles*<sup>14</sup> (Burden (1991).

---

<sup>13</sup> During the *period of readjustment of parental role expectation* (Burden, 1991), positive adjustment to their new roles will lead to increased feelings of competence, realistic appraisal of the child's strengths and weaknesses, involvement in helping the child's development, with no excessive anxiety or depression, besides a balanced outlook about what is possible. There is a possibility for other children in the family who may receive less adequate parenting; difficulties in setting limits and providing discipline; overprotection, or underestimation of the child's potential, unrealistic goals being set and general insecurity about childbearing.

<sup>14</sup> During the period of *pressures on family and social roles* (Burden, 1991), there is a need for an adjustment in family and social roles. There may be an increase in tension and an inability to share the burden with one's spouse or with others and difficulties in communication. With positive adjustment, tensions of natural day to day living will be seen as distinct from problems caused by the child, and there will be open communication with others within the context of a natural social life.



According to the *grief cycle* in Kubler-Ross (1969 in Antara & Mertz, 2006), depression or overt sadness signals the replacement of initial sense of anger and shocks with a sense of great loss. Overt sadness may be acknowledged and honestly expressed only to trusted friends or to no one at all.

#### **6.1.1.1 Feelings of shock, difficulty in accepting, anger, sadness and shame**

The various emotions after the delivery of their child with diagnosis of DS such as shock or disbelief were viewed as part of the *initial shock crisis* stage; feelings of anger, difficulty in accepting, sadness, shame, self-blame and worries were viewed as part of the *psychosocial transitional period* before *realignment of personal values* (Burden, 1991). As indicated in this study, these emotions among mothers did not appear to occur in a linear, logical manner or progressively one after the other. These were experienced in a varied level of intensity, for a variable period of time.

A significant number of mothers experienced feeling of sadness and depressive symptoms to some extent, as indicated in the qualitative and quantitative data in the study. This includes mothers who reported having suicidal thoughts and negative feelings of despair, blue moods, etc). The feeling of sadness which lingers on even when their child has grown older years later, as experienced by the 61 years-old Iban mother, Harris in the study is a concern. According to the *grief cycle* in Kubler-Ross (1969 in Antara & Mertz, 2006), depression or overt sadness signals the replacement of initial sense of anger and shock with a sense of great loss. Overt sadness may be acknowledged and honestly expressed only to trusted friends or to no one at all. There is an indication that mothers' energy level and readiness to care for their newborn child was affected to some extent. Apparently there was

also some difficulty with absorption of information from the health professionals about their child's disability. Furthermore, their expression of *anger* after the disclosure of diagnosis as in section 4.2.2.3 might have been interpreted as unreasonable or irrational, including by those health professionals who attended to them. Provision of appropriate reassurance and support to mothers are thus required; repetition of information and guidance from professionals is called for.

Several mothers' *struggle with acceptance* of child which lasted for a variable period of time was evident irrespective of ethnic differences, not only among the Chinese, but also the Malay and Iban mothers. Apparently, their struggles of accepting child are related to initial shock, child's slow developmental progress and their perceived 'different look' of their child. This struggle with accepting child, especially at their early stage of child's life is a universal theme experienced by mothers across different cultures and nationalities, as reported in Chang & McConkey (2008) and Lam & Mackenzie (2002) among the Hong Kong and Taiwanese Chinese mothers respectively; in Bloom (2005), Cable (n.d.) and Gatford (2001) among the UK mothers. This initial emotion of struggle to accept child could be overwhelming to mothers. There could be a potential of contemplation to relinquish their child, as disclosed by one of mothers in Section 4.2.2.4. Care professionals' attention and sensitivities to mothers' initial emotions such as this is warranted. Decision of any mothers such as to give away their child which was made at a point of life when they are still experiencing the '*initial shock crisis*' or '*realignment of personal values*' (Burden, 1991) might leave mothers to be 'scarred by guilt' and also regret (Cable, n.d.).

- ***Feeling of shame and self blame***

The feeling of shame (Section 4.2.2.5) discouraged mothers involved/concerned from socializing with or revealing to the others about their child and may give rise to a sense of isolation and stress. The feeling of shame and self-blame which was described as part of the *psycho-social transition period of 'realignment of personal values'* by mothers (Burden, 1991) brought about a sense of stress and isolation which could be 'damaging emotions in the human soul' (Greening, 2001, p. 110).

Several other mothers experienced '*self-blame*', attributing child's disability to own negligence during pregnancy. This was, apparently a common experience, not only from mothers of any one particular ethnicity, but from among the Chinese, Malay and also the Bidayuh mothers (Section 4.2.2.5). This might be influenced by various cultural disability-related beliefs as highlighted in Chang & McConkey (2008), Lam (2006), Ling (2007), Moyle, et al (2006) and Meyer-Rochow (2009). However, existing literature appears to point to some cross-cultural variation in term of mothers' attribution of child's disability. Though reported among the Asian mothers as in Lam & Mackenzie (2002) and the Middle-Eastern Pakistan mothers (Masood, et al., 2007), apparently, this is less reported among the mothers from the western context. Masood, et al. (2007) reported more of the USA mothers attributed child's disability to scientific reason rather than self-blaming.

An awareness of mothers' understanding about the causes of child's disabilities, and thoughtful exchange of information with mothers at the appropriate moment regarding developmental disabilities could clear any of their misunderstanding or misconception, thus prevent from any self-blame which leads to feeling of guilt.

It augurs well for care professionals to be anticipative and sensitive to the possible emotions of mothers such as their *feeling of shame* and *self-blame*. Timely supports and assistance should rightly be given to them, such as words of comfort, reassurance and hope that they need at the critical point of their life.

#### **6.1.1.2 Worries**

Apparently the feeling of worries, as experienced by mothers locally, is not unlike those from other cultural contexts, such as those of the Irish mothers (Kenny & McGilloway, 2007), the Hong Kong mothers (Lam & Mackenzie, 2002), or mothers in the USA (Resch, et al., 2010) who reported about fear and uncertainty about child's independence.

However, the extent of mothers' worries apparently varied and subjected to their accessibility to various sources of supports and resources, including their family financial resources and informal supports.

It is noteworthy to find out from among them that there was a sense of dilemma of expectation and hope for their child to attain self-care ability and their own fear on the other hand, that their child might be exposed to harm or danger if allowed to do anything unsupervised. There is a place for supportive activities such as regular camping or independent-living' program for children with disability with the aim of maximizing the children's potential for self-care ability (Malaysia, Social Welfare Department, 2009).

Due to concerns and worries of child's future welfare and care provision, several mothers, in particular those with the financial resources, had in their plans to secure a life insurance

policy for their child, to save up a sum of money in the bank account, or to have a piece of property under the child's name. However, those who were socio-economically disadvantaged and living from hand to mouth, without any financial resources, these options were beyond their reach. The hope of one mother that if her child (daughter) were to get married and had her own child in the future, this child of hers would grow up later and in turn would be able to provide care to her, is heartening (Section 4.2.2.6).

### ***Expectation on siblings to continue with care provision***

Many of the mothers' hope and expectation was for the child's siblings to continue to provide care to their child with DS in the future, apparently not having the luxury of better options. Their expectation on the siblings in the local context could be due to the apparent lack of formal service provision within the local social welfare and health care systems such as the provisions for residential, assisted, independent living, or financial assistance to pay for personal assistants.

This is in contrast with those in the more advanced western countries such as Sweden or Norway which practice the welfare state model (Askheim, 2008) or the UK (Chan, 2010a; Chan, 2010b). In a recent cross-cultural UK-Malaysian collaborative study, the UK parents had the option of arranging for their child for an early residential supported independent living. This option involved having their child to leave home early and to live independently of them, instead of living with them for the whole life (Chan, 2010a; Chan, 2010b). They perceived that supported independent living arrangement would ensure their child's future continued care provision and part of a gradual transition process, while they could still continue to visit their child. Thus, their child might not have to deal with the

multiple cultural shock of transitioning to new environment with new people, language, and a totally alien way of life later, as stated in Ling (2007).

Expectation and hope among mothers in the local context which are apparently different from those in the developed countries, as those in the UK (Chan, 2010a; 2010b) were related to variations in term of social policies and social service provision for individuals with disability. The social policies and the disability rights movement in Britain have resulted in the development of provisions such as support for independent living, and provision of direct payments for the service of personal assistants for individuals with disability (Shakespeare, 2006).

Besides the apparent lack in term of formal service provision as discussed above, many of the mothers' expectation for the child's other siblings in the same family to continue with the future care provision of the child with DS could be related to their family tradition of children in the family to stay together until such time they are married and start their own family (Ling, 2007).

However, as indicated in this study, they were uncertain as to the extent siblings could be depended on for the demand of a life-long continuum of care (Findings section 4.2.2.6). They were concerned that family care and support would not continue on if siblings are not willing or unable to take on the caring role. This could be due to lack of emphasis or obligation related to care provision among siblings. As highlighted by Thompson (1989 in Lazzarini, 2009, p. 59), though family members 'would normally strive to meet each other's need, prevent harm and take positive action to protect and promote each other's

welfare, this does not imply that one member in the family would always be self-sacrificing in order to meet the needs of the other family member'. Nevertheless, there is an expectation or 'filial piety' obligation for 'abled' adult children to care and provide for parents in their later years (Baldassar, Baldock & Wilding, 2007; Chang & McConkey, 2008).

Regarding mothers' expectation on the siblings to undertake the future care provision of child with DS, this could imply care demands and impacts on the siblings which could be enormous and should be a related issue which is worthy of note. In a recent informal communication I had with the older brother of one Bidayuh boy with a disability, he commented that he might not want to get married in the future because of his younger brother whom he has to take care when his parents are too old to continue the care provision. He further indicated his uncertainty and dilemma by saying that no girl would want to marry him if she knows that he has a disabled sibling that he has to provide care for.

On another note, mothers' expectation for their child to live with them or their siblings to ensure continual care in the future may, ironically, hinder any effort or attempt to develop and encourage child's independence and potential for growth as an individual. Lai (2011) reported about the outcome of a Malaysian one-year pilot project of 'supported living project' for the growing-up children with disability, a number of the mothers did not prefer for their child to participate in the assisted independent living project. This indicates an area which might need to be explored in the future.

Besides their worries about child's ability for self-care and their future care provision, for several other mothers their worries were related to the risk of recurrence of DS in the subsequent pregnancies.

### ***Worries related to risk of recurrent DS***

For several other mothers, their hope for a 'normal' child in the subsequent pregnancy was mixed with worries about the risk of recurrence of DS (Findings Section 4.2.2.6). This is especially so for those who did not receive the much needed support at the early stage after delivery of their child. The impact of worries concerning the risk of recurrence on them is immense. It accounted for the more frequent antenatal check-ups or specialist consultation by mothers such as Tan, a 48-year-old Chinese; or invasive prenatal diagnostic procedures by Jen, 39-year-old Chinese mother. There was also evidence of mothers who underwent termination of pregnancy (TOP), which, within the local context, is still illegal except under specific contexts (Dalvie, Barua, Choong, Chin & Ramasami, n. d.). Thus, any mother's choice for TOP may not be discussed openly to care professionals, though the procedure itself may lead to guilt impact and family conflict (Barr & Millar, 2003; Korenromp, Page-Christians, van den Bout, Mulder & Visser, 2007; Lalor, Begley & Galavan, 2009). It augurs well for care professionals, though they may have their own personal value and belief system, to be non-judgmental as they encounter mothers in similar situation expressing their concern of recurrence of DS. Findings point to the possibilities of care professionals who may encounter situations which involve medical-legal and ethical dilemma.



### ***6.1.1.3 Feelings of excitement, joy and acceptance***

Though having a child with the unexpected diagnosis was overwhelming for many mothers with their various emotional responses, including their worries and concerns, however, for many of them, the *sense of excitement* with child's new development and the feeling of joy of mothering their child constitute as part of their experience (Section 4.2.2.7 and Section 4.2.2.8). Apparently, these could be related to mothers' accessibility to adequate supports (Section 4.2.3), as will be further elaborated and discussed in the later section in relation to '*life impacts*' in the subsequent sections.

### ***6.1.1.4 Summary***

As shown in the above discussion, many of the mothers experienced various emotions of shock, disbelief, difficulty in accepting, sadness, anger, self-blame and shame, and also their worries related to concerns over various issues, interwoven with their feelings of excitement, joy and pleasure of mothering. Many had worries and various child-related concerns including their self-care ability, future care provision and their own concern about recurrent DS in subsequent pregnancy. Emotions such as shock, disbelief, difficulty to accept child, anger and sadness can have impacts on mothers in their readiness to absorb information and to provide for the care of their new born, especially at the early stage of the care giving process. Understandings and insights into mothers' experience in relation to their 'various emotions' suggest for care professionals to provide care with empathy to mothers' individual needs, and to allow them the time and space to express their feelings and emotions. Further implication of findings for practice will be elaborated in the final chapter of this thesis.

### **6.1.2 Extra care demands**

When even mothering a child who is ‘normally’ developing, motherhood has been described as ‘not an easy task’ (Liamputtong, et al., 2004), motherhood experience having a child with disability is clearly more challenging and demanding due to the child’s health condition, various developmental delays and personal-social behavioral characteristics.

The various care demands constitute the sacrifice of motherhood as discussed in Liamputtong, et al. (2004) and Lupton (2001). Experience of mothers having a child with DS as presented in this study provides insights into the challenges and obviously, the extra care-demands which require extra efforts and time commitments from the mothers.

Apparently mothers’ experiences of care demands varied at different stages of child’s life. Care demands experience of many of the mothers soon after their child’s birth was related to child’s health. Without doubt, their extra care demands were also due to their child’s delayed development (Findings section 4.2.2.2) in relation to the day to day task of assisting child with his or her basic needs such as feeding, toileting and communicating with the child. These could be due to the child’s lack of understanding or limitations in his or her ability to communicate, as highlighted in Coleman (2006). Mothers’ concerns about child’s vulnerability to harm and risk of encountering dangers due to the characteristics of having less social-inhibition or fear of strangers accounted for many of the mothers who constantly took precautionary measures to watch over their child.

Furthermore, for those mothers with daughters who reached their puberty with their physiological development, the starting of their normal monthly menstrual cycle, the need

to help their child with their self care posed as a challenge, as also reported in Mason & Cunningham (2008).

At a later stage of child's life, about pre-school age onwards, child's behavioral characteristics which were deemed socially or age-inappropriate attributed to their care demands (Findings section 4.2.2.3). Several of the mothers' difficulties in setting limit or imposing discipline in relation to child's social behavioral characteristics could be due to their underestimation of child's potential. In relation to this, specific advice on how best to manage the extra care demands, emotional support and reinforcement of parental competence might be needed (Cunningham, 2002).

It is obvious from the present study and the previous studies that *extra care demands* related to having a child with DS is a universal theme experienced by mothers from across different cultural contexts. A significant number of the studies among mothers including those from the more advanced western countries reported their various child-related extra care demands which impacted their well being (Beck, et al., 2004; Green, 2007; Kenny & McGilloway, 2007; Lloyd & Hasting, 2009; Myers, et al., 2009; Plant & Sanders, 2007; Van Riper, 2007; White & Hastings, 2004). Care giving experience was also reported in Chang & McConkey (2008) and Lam & Mackenzie (2002) among the Asian mothers in Hong Kong and Taiwan respectively, including also a recent Malaysian study (Norisan & Shamsuddin, 2010). Similar experience was also highlighted in Azar & Badr (2010) among the Middle-Eastern parents.

### *Time, efforts and psychological demands*

Besides extra time and efforts involved (Dyson, 2010) care demands in particular, related to personal-social behavioral characteristics were psychologically demanding to several mothers, when they had to be concerned about how they might be criticized by others in the neighborhood for not taking care of their child well enough. Apparently, there is a sense of helplessness and stress pertaining to this issue. Care giving could involve the 'social and psychological costs' and could cause much 'emotional pain' as highlighted in Couper (1989, p. 15), when being questioned about their parenting abilities (Rogers, 2007).

In relation to care demands related to child's behaviors, a few of them struggled with feeling of guilt to 'discipline' their child, apparently due to perception that it would not have any impact, as child was unresponsive, or perceived their child with DS as special and felt pity for the child. Thus they would not discipline child as they would do to other children. Gibbs & Carswel (1991) emphasize that unacceptable behavior can recur due to unhelpful beliefs of the caregivers, such as child is disabled and thus, are not doing anything proactively. Apparently, Coleman (2006) highlighted the needs for parents to be empowered with positive parenting skills', to exercise 'assertive discipline and have realistic expectations' (p. 305).

The significance for parental preparedness in this aspect of care giving is resounded by a call from the president of National Early Childhood Intervention Council (NECIC) (Malaysia) for society 'to offer concrete action to help the children' (The Borneo Post, 2011, p. 11). In this regards, there is a need for formal support to mothers to enhance their preparedness towards assisting the child's development. National organization such as the

NECIC offered relevant programs related to various aspects of child care through conferences such as the 4th NECIC Conference (Malaysia, NECIC, 2012). However, considering mothers out there in the community who are not accessed as their child with DS are not attending any of the service provisions, or those who have difficulty with language, they are clearly disadvantaged.

Nurses in the community settings, as health care providers, the frontline primary health care members in the multi-disciplinary team closest to the children with disabilities and their families, provide, facilitate and reinforce the interventional programs through the clinics or through home visits (Family Health Development Division, Ministry of Health Malaysia, 2006). There is an implication for a needs-sensitive and humane care provision by facilitating mothers' accessibility to various sources of supports and to empower them in their care giving process. Furthermore, it augurs well for them to facilitate a platform for sharing of experiences and exchanging of practical knowledge on various aspects of care giving of child among mothers and other health professionals.

Besides to the nurses, insights into mothers' experiences of extra care demands should be enlightening to the other relevant members of the multi disciplinary team in relation to the care of persons with disabilities, including the doctors, therapists, social workers or educators towards implementing their action plan and strategies

### **6.1.3 Variation of supports**

#### ***6.1.3.1 Variation with access to informal supports***

Mothers' accessibility to informal supports from different sources (Section 4.2.4.1) was found to be significantly helpful to many of them in maintaining a balance between meeting the extra care demands related to child having DS and the needs of the family as a whole. Thus, these helped to minimize any daily family life disruption, including their continuation with their out-of-home employment and their social relationship with the others. Furthermore, the various informal supports sources provided the mothers with emotional supports and encouragement. The undeniable significant impact of informal supports on mothers in term of their psychological well-being, adjustment and coping in the care giving process have been highlighted in previous studies across different cultural contexts (Gatford, 2001; Greening, 2001; Lindblad, et al., 2007; Mbekenga, et al., 2011; Resch, et al., 2010), some of which have been discussed earlier in Chapter Two.

#### ***6.1.3.2 Problems with access to informal supports***

Though many of the mothers had the access to informal supports from the various sources, findings indicate that several others did not have adequate access to informal supports of their own spouse or their extended family (Section 4.2.3.1). This was, to a great extent, deemed to be a source of stress to them. Further to this, due to an expectation from the elderly parents-in-law to contribute to the family, as evidenced by one of the mothers in this study, it is likened to a 'doubled' care demands.

In the local context which is multi-ethnic, predominantly more of the Chinese mothers than mothers of other ethnicities experienced problem with getting support from their parents-in-

law. The experience of the local Chinese mothers could be attributed to the traditional expectation for the boy in the family to carry the 'family name' on to the next generation. When a child with DS, especially a boy is born to the family, this expectation from the grandparents for their grandson to carry the family name might be thwarted. This might provide some insight as to the Chinese mothers' initial problem with getting support from their parent-in-law.

The problem with getting support from extended family could also be reflective of the existing local traditional beliefs about the etiology related to disabilities such as bad 'Feng Shui', family curse, spirits or punishment for wrong acts of parents (Moyle, et al. (2006). These beliefs could have indirectly influenced the perceptions and acceptance of a child with disabilities and their mothers by the society, including own extended family involved.

The experience of problem with accessibility to informal support and acceptance at the early stage of the mothering experience as discussed earlier is apparently less reported in the western context, except for the Asian context. A few Asian studies are cited which reported similar problem with support and acceptance. These include studies among the Hong Kong Chinese mothers (Lam & Mackenzie, 2002), the Taiwanese mothers (Chang & McConkey, 2008) and the Vietnamese mothers (Shin, et al., 2006).

Informal social context that is unsupportive, judgmental and critical of child's disability, detached from the child with disabilities or the mothers, are related to mothers' experience of recurring sadness and disappointment, as evident among several of the mothers. This could be associated with poorer well-being of mothers. As cautioned by Dyson (2010),

Rogers (2007) and Van Riper (2007), without the right level of support and acceptance, the whole family experienced higher level of stress. This is further substantiated by Plant & Sanders (2007)'s study among the Australian parents of child with developmental disabilities which revealed significant inverse relationships between partner/family support and level of parent stress.

These findings of variations in accessibility to informal supports among the different ethnic groups, including those who had difficulty in gaining access to assistance due to the locality of place where mothers lived, geographical distance and limited access to public transports, indicate to care providers the need to be sensitive to the variation in the mothers' various background differences, and to be needs-sensitive in their care provisions within the local context.

### ***6.1.3.3 Issues with professional service provisions***

Under the existing provision within the Malaysian legislation with the 'Person with Disabilities Act 2008' (Malaysia, Ministry of Women, Family & Community Development, 2008), various strategies and action plans have been in place within the period of the year 2008 to 2010 by various agencies. These include the medical services and the rehabilitation (interventional) programs by the Family Health Development Division of the Public Health Department, under the MOH since the year 2000 (Malaysia, MOH, 2006). Care professionals such as doctors, nurses and therapists provide care to mothers and their children with DS in the hospitals and the community health setting. Service provisions are available through their maternal and child-health clinic activities during home visits, clinic-based rehabilitation (early intervention) for children below 18 years of age. Early



stimulation activities for the children concerned were provided to foster their optimal psychomotor and cognitive development and to reduce complication (Sarawak, Health Department, 2007b).

Professionals such as nurses were perceived as supportive among mothers through the way they approached their child either in the clinic or during their home visits, as evident in Section 4.2.3.2. Professionals' supportiveness significantly contributes to strengthening the informal family support system and to buffering the stress and social isolation which might be experienced by some parents of children with disabilities (Azar & Badr, 2010). Their priorities in establishing therapeutic relationship with mothers would encourage them to discuss issues and facilitate their preparedness in various aspects of care giving of child (Unger, et al., 2004). Among local mothers, there were concerns related to professional health service provision of various therapies for their child with DS as provided through clinic or community-based interventional program as these were deemed inadequate and ineffective.

As emphasized by Kiger (2004), it is one of the health professionals' roles to advocate for clients (mother and child) that they access 'adequate professionally-provided service' (p.139). Professional service provisions of pertinent therapies for the child and information resources are important as these would help to promote child's growth potential from the early age of child's life (Unger, et al., 2004) and prevent or offset potential future negative outcomes (Fidler, 2005). Pertinent therapy such as the speech & language learning intervention process for the child as guided by the speech-language pathologist, with the

family as part of the intervention process would reinforce child's language learning in the home environment (Kumin, 1998).

In relation to professional service provision, there is a role for care provision in the area of genetic counseling, or psychological support by counselors for mothers or families of child with DS within the local context. The importance and significance of relevant service provisions and information to empower and enable mothers of child with DS in their care giving is further supported by the provision of the Convention on the Right of People with Disabilities. It states that "countries will make sure that health and health-related rehabilitation services are available, making sure that people with disabilities can get services they need related to their disability and to protect them from further disability (Article 25 on Health)" (Weiss, 2009). Some of the mothers' concerns related to professional service provisions were echoed by a call from the president of the NECIC (Malaysia) to the government, 'we urgently need effective, integrated and convenient (accessible) services provided by well-trained, highly skilled and intensely motivated professionals' (Borneo Post, 2011, p.11).

### ***Financial aids***

As a matter of fact, the local State Government Social Welfare Department has been providing the monetary assistance as a support to mothers who have a child registered as having disability to send their child for interventional programs at the CBR centers. This is provided on condition of child's fulfillment of at least 75% of the attendance at the CBR centers (Malaysia, Social Welfare Department 2009). In the face of the various child-related extra expenses, the monthly financial aids of RM 150 as provided by the local

Government (Social Welfare Department 2009) to mothers having a child with DS was a small amount which is barely sufficient. However, this financial contribution is undeniably significant to the family. Several mothers' unhappiness related to 'deduction' of the monthly financial assistance due to child's absence to some of the sessions at the CBR centers, apparently is an issue which warrants further attention and concern. There is a need to bring together family (parents), professionals and policy makers to discuss these issues and concerns.

Apparently, from a previous report, there is a criticism of abuse related to some parents who regarded the child's attendance to CBR centre as a means of getting the financial assistance instead of the intended objectives of its rehabilitative activities (Chataika, 2009). Nevertheless, policies and practices related to assistance for mothers with the confounding challenges of living in poverty and having a child with additional care giving demands need to be continually improved, as to how these could best serve to help, and not to 'hurt' families (Lloyd & Rosman, 2005). Provision of material resources for disadvantaged families with financial constraint is an important factor in reducing parents' stress (Phelps, Jennifer, Hodgson, Mccammon & Lamson, 2009). This provision motivates and enables those families who lived in poverty to send their child to receive the related care provisions. It helps to buffer against the effects of extra care demands related to care giving of child, by paying for the child-minding, thus relieving parents of certain care and household tasks (Resch, et al., 2010).

#### ***6.1.3.4 Issues with environmental supports***

Many of the mothers, especially those from the low socioeconomic background and in particular, those who lived in the rural locations, encountered various forms of constraints and limitations which directly and indirectly jeopardized their care provision process, and thus the potential developmental outcome of their child with DS.

Due to financial constraints, these mothers had to struggle to meet their daily basic needs of food and shelter for the family; often they did not have the option to pay attention to the needs of their child with a disability, including participation in their child's interventional programs. Furthermore, their difficulties with financial constraints were compounded by rural disadvantage of geographical distance from the available service provisions and a relatively inefficient public transport service in the region.

As evidenced by four of the mothers in this study who were accessed and recruited as participants through informal sources using snow-ball method, including one from the urban area, did not send their respective children with DS to any CBR centre or school, but left their children at home. These children missed out on the opportunity to benefit from the existing rehabilitation program (Section 4.2.3.3), thus, their potential developmental outcome were jeopardized.

The problem of disparity in the accessibility to service provisions between urban and rural areas was highlighted in the WHO Rethinking Care Initiative and Conference (Barnes, 2001). This is also in concurrence with Parnes (2008) who stated that poverty of the people hinder their access to care provisions and service. The constraints and barriers could

potentially lead to a 'decrease in parental care and support to the disabled child and possibly well-being of the child' (Glasscock, 1997 cited in Yuen, et al., 2003, p. 20).

Findings point to an implication for practice and policy makers which should prioritize care provision and environmental supports to mothers. This includes policy which facilitates mothers' accessibility to transport and provision of financial resources. In relation to easing the environmental constraints, the call for the government to seriously consider investing in key sectors such as public transport is most timely (Lim, 2012).

#### ***6.1.3.5 Barriers in accessing informational resources***

The initial emotional responses could pose a barrier to mothers' receptiveness to any given information soon after disclosure of child's diagnosis. This leads to an implication for practice to take into consideration the initial emotional responses as one of the possible barriers to receptiveness of pertinent information and thus, the need for informational support. Information such as existing parent support groups or early interventional programs for child is pertinent information which contributes to parents' acceptance of child with the unexpected diagnosis and improved parental well-being, as supported by various reports (Burden, 1991; Phelps, et al., 2009; Rogers, 2007; Stone, 1989).

Many of the mothers especially those from the low socio-economic background encountered barriers in accessing pertinent child-care related information due to limitation in language use, inaccessibility to internet facility or limited information assessing skills. These limitations and barriers to information resources disadvantaged mothers, in term of preparedness and confidence in their mothering process. As observed in this study,

mothers who had better access to information resources were more responsive and interactive with their child. Mothers' responsiveness and interaction with child especially during the critical learning age of child is thought to be one of the modifiable factors which influenced the child's language learning and development of communicative ability (Buckley, 2000; Kumin, 1998).

It is especially important for care professionals to provide informational supports, to disseminate various pertinent child care related information to mothers to those who experience limitations and barriers in accessing information resources. Pertinent information could be related to the link to available resources (such as early intervention programs, special school or provision of welfare assistance). Without given the informational support and assistance to those who are disadvantaged due to socioeconomic background could imply possibility of their child to be left to grow by himself/herself without given any intervention.

#### ***6.1.3.6 Mismatch between care demands and supports, the 'double jeopardy'***

Mothers of child with disability are themselves 'disabled' and not only their child, due to their disadvantaged socio-environmental and economic background, as indicated in this study. These mothers were disabled due to constraints in the 'material factors- the environment and poverty significantly' (Shakespeare, 2006, p. 22), likened to a situation of 'double jeopardy' (Driedger, 1991, p. 3). As further highlighted in Goodley (2011), disability could be '... a phenomenon of cultural, political and socio-economic condition' (p. 9). Constraints and limitation in various family resources in term of various sources of supports as experienced by the mothers in this study are persistent problems which extend

beyond child's early years, especially for those from the lower socioeconomic background, as highlighted in previous studies (Beresford, 1994; Dyson, 2010; Grant, 2005; Kagan, et al., 1997; Unger, et al., 2004; Van Riper, 2007).

The persistent constraints and limitation experienced by mothers is a vicious cycle which warrants urgent need for attention and support in order to achieve better family functioning (Olsson & Hwang, 2008). There is a need for an understanding from the mothers' perspectives, and for practice which address the issue of mismatch between child-related care demands, economic implications and the social-environmental supports.

A review of the current social system is called for in order to move away from the charitable welfare model (Borneo Post, 2011, p. 11) but to provide genuine, rightful supports to child with disability and the family. There is a need for provision of rightful services and support 'no matter where they live', emphasized as one of the objectives to be achieved in the 'Every Disabled Child Matters Campaign' (2007).

#### **6.1.3.7 Summary**

Accessibility to informal and formal sources of supports enabled many of the mothers in meeting with the child-related extra care demands. Those who encountered problems with getting adequate informal supports from their spouse or extended family experienced further psychological demands. Informal social context that is unsupportive, judgmental and critical of child's disability, detached from the child with disabilities or the mothers, are related to mothers' experience of recurring sadness and disappointment and poorer well-being.

Constraints and limitations with formal and environmental supports disadvantaged mothers and affected them in their care giving preparedness. These include limitations of formal supports of professionals care and therapies. Professional service provisions of pertinent therapies for the child and information resources are important as these helped to promote child's growth potential from the early age of child's life (Lim, 2007; Unger, et al., 2004). Constraints in various supports could potentially lead to a 'decrease in parental care and support to the disabled child and possibly well-being of the child' Glasscock (1997 cited in Yuen, et al., 2003, p. 20).

Many of the mothers from the low socio-economic background experienced constraints related to various environmental supports. These include issues of financial constraints, inaccessibility of transports for them to access service provision, coupled with geographical distance and inadequate public facilities. There is a need for an understanding from the mothers' perspectives, for practice which address the issue of mismatch between the needs related to care giving of child and the social-environmental supports with the various constraints, and to provide the needed supports.

#### **6.1.4 Coping strategies**

##### *6.1.4.1 Reframing perspectives*

Reframing another way around the perspectives of parenting a child with DS positively and realistically (Section 4.2.4) and being realistic of the child's condition, parenting process was thus not perceived as a burden too difficult to handle for many of the mothers.

By reframing the identity of their child positively as a divine gift, a blessing and motivation factor for their family to reach out to the others, and reframing their given role as a carer for



a child with disability as God's recognition of their special ability, reckoned themselves to have an edge over the others in parenting a child with disability, many of the mothers find new meaningfulness and purposes of life.

Across different cultural context, positive reframing of perspectives of parenting of child with DS was regarded as one of the protective factors which influenced the well-being of mothers (Grant, et al., 2007; Hastings, Kellyanne, et al., 2002; Olsson & Hwang, 2008).

#### *6.1.4.2 Maintaining hopefulness*

While many of the mothers were aware of their child's limitation, they compared their child to the others with more severe disabilities and counted their blessings that their child was not as disabled. Their optimism and hopefulness about their child, though still being concerned and uncertain about child's capabilities for independence, was apparently helpful to them. It is paramount that care professionals are supportive and maintain similar hopefulness, and not being judgmental towards mothers who demonstrate their hopefulness of their child's potential for development and ability.

Maintenance of hopefulness and optimism is perceived as the management of the internal tension of opposing forces, between hopefulness for the child's future while being given negative information and battling with own fears (Larson, 1998). It was related to mothers' subjective well-being and was shown to function in a compensatory fashion with decreased psychological distress (Kearney & Griffin, 2001; Larson, 1998). The attitude has 'clear benefits in the present, even if that better future could be an illusion' and further help to 'keep the parents' mind at ease, lower their stress and improves their physical health'

(Sharot, 2011, p. 36). The hopefulness within the mothers could become a driving force which energizes them in their effort to find programs and search for ways which aim at bettering their child's progress. A positive view of future possibilities is fostered in parents who view themselves as capable of affecting this change and believe that things would improve (Larson, 1998) and has been conceptualized as a personal coping resource (Lloyd & Hasting, 2009). It is important that care professionals are not judgmental but instead being supportive in the way that mothers demonstrate their hopefulness.

#### *6.1.4.3 Religious beliefs and convictions*

Within the local context which is multi-ethnic and multi-religious where the majority of the people are considered as having a religion (Sarawak Government Official Portal, 2010), several disability-related, religious beliefs and convictions were indicated to be reassuring and helpful, especially among mothers of the Christian and Muslim faith. Their beliefs and convictions that having a child with disability was '*God's testing*' and '*God who gave the child*' were reassuring and affirming to the mothers. Furthermore, beliefs and convictions that the child whom they had was given to them was God's gift, *predestined with a divine purpose* helped mothers in accepting her child. Apparently, many of the mothers gained a sense of confidence and hope as they entrusted the mothering of child to the divine care provision and purpose.

Religious beliefs and convictions just discussed were in contrast to some cultural disability-related beliefs and taboos, which apparently would leave some negative impacts on mothers of child with disability. This includes such belief about the birth of a child with disability

by mothers to be a punishment for their misconduct in their former life (Lam, 2006; Superstitions of Malaysian Chinese, n.d.; Yahya, n.d.)

Helpful and reassuring disability-related religious beliefs and convictions are reported in Tess & DeLuca (1996). In another study among 119 mothers in the USA, their positive beliefs and convictions were reported to be associated with higher self esteem, life satisfaction and psychological well-being (Ekas, Whitman & Shivers, 2009). These positive religious convictions as discussed here are in contrast with the alternative, negative religious coping of blaming God (Tarakeshwar & Pargament, 2001).

Significantly, within the multi ethnic, multi religious local context, *positive religious beliefs and convictions* related to disability such as child as God's gift and assurance of God's care and provision are helpful family resources to many of the mothers. It augurs well for care professionals to be supportive of the mothers as they draw their strength and assurance in their disability-related religious beliefs in the mothering process.

#### **6.1.4.4 Summary**

The various coping strategies are believed to have a positive influence on mothers in maintaining their well being and family role function. *Reframing of perspective* of having a child with DS positively and realistically, in perceiving the child as a blessing and motivation in their lives brought new meaning of life to them. Maintaining their *hopefulness and optimism* that their child would be able to perform or function motivates mothers to continue in their efforts to help child to develop. Positive disability-related *religious beliefs and convictions* held among them were reassuring and helpful to them as

they entrusted their child to divine care provision. It augurs well for care professionals to be non-judgmental and supportive to mothers in reframing their perspectives of mothering, in maintaining their hopefulness and continue with their religious convictions in relation to having a child with DS.

### **6.1.5 Life impacts**

#### ***6.1.5.1 Being stigmatized***

Societal reactions related to child with disability as reported in Section 4.2.5.1 stigmatizes some of the mothers. To avoid being further stigmatized, one of their responses was to try to avoid socializing with the others. This gave rise to a sense of isolation and discrimination, thus directly or indirectly subjected mothers to social disadvantage in term of social support network. Being the main care givers, mothers experienced as much stigmatization as the child with disability due to their ‘close association to their child’ (McHatton & Correa, 2005, p. 137). On the other hand, fathers could be less affected since more often they are not the main care givers to their child. The experience of being stigmatized could be associated with the traditional beliefs related to disability among certain ethnicity locally which warrant further exploration.

Experience of being stigmatized and the sense of social isolation within their social context that was seemingly negative were reported by Chataika (2009) in her recent field report of the disability-related research as part of the UK-Malaysia cross-cultural collaborative study. Similar mothers’ experience of stigmatization is reported in a few other Asian studies, including those studies among the Hong Kong Chinese (Lam & Mackenzie, 2002), the Taiwanese (Chang & McConkey, 2008) and the Vietnamese (Shin, et al., 2006). This is

something that is unique, an Asian belief system which may be incomprehensible in the western culture context.

Societal reaction towards their child with DS as 'less-abled' in this study is equally stigmatizing and hurting to mothers. This phenomenon related to misconceptions and stereotypes involves the 'identification of differences and labeling', the 'categorization and placement of stigmatized individuals into distinct groups' separated from the dominant culture and the subsequent 'loss of status and discrimination' (Link & Phelan, 2006, p. 528).

The '*social model of disability*', as one of the social-contextual approaches to understanding disability locates disability outside the individual and places it in an oppressive and disabling environment (Sheldon, et al., 2007). 'Disability' which denotes the collective economic, political, cultural and social disadvantage or barriers encountered by people with impairments (Barnes, 2001) could be the 'society's negative attitude and assumption' towards disabled people and their families (Dowling & Dolan, 2001 in Grant, 2005, p. 227). The social model of understanding disability is as relevant in making sense of the experience of mothers who were stigmatized 'as is for the disabled people' (Oliver, 1990 in Grant, 2005, p. 227).

There is a concern that stigmatization and the associated social isolation as experienced by mothers within a social context that is negative and critical could hinder mothers' readjustment of their parental role (Burden, 1991; Shin, et al., 2006). Contrarily, social context of acceptance and understanding which are shown to families are helpful in the

adjustment and coping in the parenting process (Gupta, 2007). Insights into mothers' experience of being stigmatized point to practice implications which will be further highlighted in the final chapter.

#### ***6.1.5.2 Not all negative experiences***

Motherhood experience has been described as challenging even when mothering a child who is 'normally developing' (Liamputtong, et al., 2004). Conflicts and tension either with own spouse or extended family could occur in the family; more so when mothering a child with additional needs, as evident among several of the mothers who experienced *tension* in their day to day family life (Section 4.2.5.2) due to the need to meet the needs of family and also child-related extra care demands.

Apparently contradictory to *stigma* and *family tension*, *increased family cohesiveness* with supports of spouse, extended family and child's other siblings within their families was evident among several mothers, due to their needs to pull their family resources together to help and support their child. *Personal growth and competence* (Section 4.2.5.3) in aspects of care giving of child, and *motivation in reaching out* and helping others (Section 4.2.5.4) were evident. These, according to Burden (1991), are indicators of positive outcome of *readjustment of mothers' parental role expectation*.

To reiterate, mothers' experience of *positive life impacts*, and their *joy and excitement* with child's development constitute as a part of their mothering experiences, though there were worries that many mothers had to deal with, and various child-related *extra care demands* that they had to cope. Obviously, the outcome of mothering a child with DS is not

completely negative among mothers. This is further substantiated in various other studies across different cultural contexts which highlighted mothers' experience of *strength, competence, and resilience* in their journey of care giving of child with a disability. To name a few, these include the studies among the Canadian parents (Dyson, 1991; King, et al., 2006); among the Taiwanese parents (Chang & McConkey, 2008), among the UK parents (Hastings, Thomas, et al., 2002), the Australian parents (Kearney & Griffin (2001); among the American mothers (Myers, et al., 2009; Van Riper, 2007) and also with the Irish parents (Kenny & McGilloway, 2007).

In view of the findings of strength and confidence among mothers just discussed, there need not be any stereotyped, discriminating perceptions of persistent sorrow, grief and burden related to mothering a child with disability. As argued by Sheldon, et al. (2007), the assumption of invalidity and tragedy which equated disability needs to be challenged. Mothers' resilience and positive experiences as were also highlighted in Grant, Ramcharan & Flynn (2007) and Margalit & Ankonina (1991) should be highlighted and valued. There are criticisms that the positive outcomes of mothering a child with disability has been overlooked; furthermore, their role as activist mothers, working to effect change on behalf of their child with a disability and for other disabled people was largely undervalued (Runswick-Cole, 2008). As emphasized in Cuskelly, Hauser-Cram & Van Riper (2008), in highlighting parents or mothers' positive experience and strength, a more balanced perspective about family having a child with DS can be provided to families. Furthermore, it is also important that the broader society be aware of these experiences in order that they may contribute to attitude change and thus, increase in their inclusiveness in our society.

These various positive life impacts of *growth and competence* and the *excitement and the joy of mothering* child, apparently were related to the level of *accessibility to various* sources of *supports* and their *coping strategies* during the process of care giving of child. Besides these, their experiences were apparently associated with their background characteristics of higher education level, better access to financial resource, urban locality and good marital support. This could be seen in the examples of mothers such as Julia (participant no. 14) and Kua (participant no. 17) (Table 4.6).

### **6.1.5.3 Summary**

Despite experience of *stigma* and *family tension* as indicated by several of the mothers, apparently contrasting experience demonstrating mothers' personal *growth and competence* in aspects of care giving of a disabled child, and their *motivation in reaching out* to help others were evident. There is a wealth of practical knowledge and wisdom which could be learnt from and emulated by those mothers with child having extra needs and also by care professionals. There is a need for support and empathic approach from care professionals during the period of time when mothers go through pressure and tension related to family roles.

Findings of QOL of mothers and the associations of selected background variables with their QOL as were presented earlier in Chapter 5 provide a broadened, and more comprehensive understanding in relation to mothers' experience having a child with DS. These are further elaborated and discussed in the subsequent QOL-related discussion sections.



## 6.2 QOL of mothers

Data analysis which was carried out to examine the QOL of mothers' four domains of life provides better clarity and precision in understanding. There are variations in relation to mothers' perceived QOL of their different life domains.

In particular, QOL of *environmental supports domain* was perceived as relatively lower than the other life domains, i. e. physical health, psychological well-being and social relationship. A significantly lower QOL of *environmental supports domain* with a mean of  $13.3 \pm 2.1$  was obtained, despite 'tendency of higher rating of QOL by participants, no matter what environment and life conditions they maybe in' as cited in Schalock (1977 in Wang, et al., 2006, p. 985), and the tendency of 'skewed responses of respondents' (Wang, et al., 2006, p. 985). Participants indicated a relatively low mean score of  $2.6 \pm 1.0$  in response to one particular item on '*opportunity for leisure activities*'. Apparently, the participants indicated a need for respite care. It could also possibly be related to the relative lack of facility for leisure activities for mothers within the local environmental context.

QOL of *social relationship domain* with a mean of  $14.9 \pm 2.1$  which was noted to be higher than the other life domains indicated mothers' level of satisfaction in relation to this dimension of life. This could be explained by the close-knit socio-cultural context among the Malay, Chinese, Iban and Bidayuh groups in the local community, both in the urban and the rural in this region of Sarawak (Ling, 2007). However, it is to be acknowledged that the non-inclusion of those mothers whose children were absent from the CBR centers or schools for various reasons during the period of data collection, and those mothers whose

child with DS did not access any of the formal service provisions at all might have influenced the QOL finding as obtained.

The finding of nearly half of the participants who indicated their QOL as ‘neither poor nor good’ (45.3%; n=73) could be related to their comprehension of the question being asked. However, in this parallel mixed design study, quantitative study was conducted after completion of interviews, thus there was a difficulty for further exploration of the finding qualitatively. Only a few (n=10; 6.2%) of the participants perceived their QOL as ‘very good’. One previous QOL study using WHOQOL which was conducted among healthy adults and those with medical conditions in the Malaysian State of Kelantan (Hasanah & Razali, 1999) indicated a QOL mean score of 15.0 among the healthy adults which is higher than the present study findings of overall QOL mean score of 14.0. However, any study using the WHOQOL-BREF to determine the QOL of mothers of normally developing children in the local context, in particularly Sarawak, has yet to be cited, thus, no comparison was made between the QOL mean scores of mothers of child having DS as obtained and that of mothers of normally developing children.

Previous past studies from across different other study contexts which reported lower QOL of parents of child with disability. Studies among the Brazilian parents (Buzatto & Beresin, 2008) and the Italian parents (Mugno, et al., 2007) which also used the WHOQOL measure reported lower QOL of mothers of child having DS than those of non-disabled children. They were reported to be economically disadvantaged. Similarly, Hedov, et al. (2000); Hsieh, Huang, Lin, Wu & Lee (2009); McConkey, et al. (2008) and Yuen, et al. (2003) reported lower QOL of mothers having child with DS.

The general perceived QOL and variation of QOL of different life domains of mothers in this study could be attributed to various influencing factors, besides their child-related extra care demands, worries and concerns. Apparently, the background characteristics of the mothers which show that a significant proportion of them who had relatively lower education levels and household income of  $\leq$  RM 500 (Table 5.1), especially those from the rural locality is noteworthy. Their background characteristic differences apparently are implicated in relation to their QOL of different life domains, as shown in the section below.

### ***6.2.1 Correlation of mothers' background variables and their QOL***

It is shown that variation in background characteristics (in term of *rural-urban locality, education levels, household income, marital status and maternal age*) (Table 5.14) are significantly correlated with QOL of mothers. Regression analysis indicates that linear combination of the few selected variables together accounted for 14.5 % of the QOL variability ( $R^2 = 0.145$ ;  $F = 5.24$ ,  $p < 0.001$ ). Mothers having a lower education and income levels, living in the rural locality, being single and more advanced in age are more likely to perceive a poorer overall QOL.

#### *Rural-urban locality differences*

Though locality difference as a background variable is found to be statistically significant in relation to mothers' QOL ( $p < 0.01$ ), this could be related to the various confounding factors. Mothers' background characteristics as presented in Table 5.2 would provide the context for the understanding in relation to these confounding factors in relation to *locality difference* and mothers' perceived QOL.

The levels of education are somewhat lower among the rural mothers, with a bigger proportion of them having only a primary education and below (46 mothers in the rural compared with 20 in the urban), and a smaller proportion having a secondary education (33 mothers in the rural compared with 62 in the urban).

In regards to income, a higher proportion of rural mothers (n=49) reported a lower household income of <RM 500 compared with the urban mothers. Fewer rural mothers were employed compared with the urban mothers (n=36). Furthermore, they could be further disadvantaged due to the sparsely populated rural context, where there is less employment opportunity, with a relatively less efficient public transport in accessing health services and care provision. This is in line with a recent European report concerning the significant differences of urban-rural locality on QOL of people, which are more marked particularly in the less developed or affluent countries (Karppinen & Buschark, 2006).

Within the local context, it is noteworthy that the access to some of the basic infrastructures are reported to lag behind the other Peninsular states though these are within the same country, with obvious rural-urban inequalities, with more of the poor concentrated in the rural (Japan Bank for International Cooperation, 2001). Clearly, findings lend support for policy makers to prioritize service provisions or financial assistance for mothers of child with DS in this state of Sarawak, with particular attention to the related rural disadvantage. There is a need for flexibility in policy that take into consideration the rural-urban regional difference and difference in between the Sarawak state and several other richer states in term of poverty (Japan Bank for International Cooperation, 2001). This could include policy

in relation to provision of financial assistance and distribution to families of child with DS, a related issue of concern which was raised by several mothers in this study.

#### *Maternal education and income difference*

Several studies reported significant, positive correlation of background variables of mothers such as *education and financial* resources with their QOL (Hatton & Emerson, 2009; Olsson & Hwang, 2008; Shin, et al., 2006; Sloper, et al., 1991). In particular, lower level of *maternal education* has been reported to be significantly associated with various disadvantages, such as job opportunities and financial resources. It was reportedly to be correlated with maternal stress, due to decreased level of accessibility to practical supports and assistance in alleviating strain of care demand (Ong, et al., 1999). It was also associated with their role restriction and decreased competence (Gupta, 2007) related to difficulty in language use. Among the mothers in this study, those Chinese mothers might encounter difficulty in accessing service provisions which used the national language due to their language difficulty. However, inconsistency in findings was found between this study and another study which reported non-significant correlation between the family variables of maternal age, income, education, number of children and family adaptation of mothers in the USA (Van Riper (2007).

#### *Marital status differences*

QOL which was found to be poorer among those who were *single mothers* could be attributed to the various worries and child-related care demands which add on to the other concerns as single mothers. There are reports of poorer mental health in single motherhood (Hsieh, 2009; McConkey, et al., 2008) and higher parenting stress among those who were

divorced or widowed (Norisan & Shamsuddin, 2010; Resch, et al., 2010). On the other hand, spousal support or satisfaction with the marital life has been reported to be associated with lower levels of parental stress in relation to parenting of children with disabilities (Slopper, et al., 1991, White & Hastings, 2004).

### *Significance of maternal age*

Though one may postulate that with advancement of *age*, mothers could be more experienced and competent in their care giving and hence influence their level of well-being, present study found that *maternal age* was inversely correlated with their overall QOL and QOL of physical health domain. This could be related to their needs to meet the various child-related extra care demands which were straining physically, especially as they grew more advanced in age. Furthermore, care demand apparently was not decreased as their child gradually grew and progressed to their puberty; thus had different physiological and social related needs as an individual (Baum, et al., 2008; Glidden & Schoolcraft, 2003).

In addition to reasons just mentioned, decrease in family support and assistance available to mothers may also account for the inverse correlation of maternal age and their QOL. These include supports such as from their parents-in-law; or child's siblings who might have grown up and have own families to provide care for. This finding apparently contradicts the insignificant finding of maternal age and level of stress of older-age mothers of child with DS as reported in a few cited studies (Janet, 2005; Van Riper, 2007; Hsieh, 2009). This difference could be related to the level of participants' accessibility to the important informal and formal supports in their study contexts.

### *Ethnicity, employment status and religious difference*

*Ethnicity* as another background variable was found to be insignificantly related to mothers' QOL. This is contrary to findings of the two previous Malaysian studies which reported that parents of Chinese ethnicity were associated with a higher risk of stress than their Malay or Indian counterparts (Ong, et al., 1998 and Ong, et al., 1999). The difference as found in these two studies could be related to their recruitment of participants which were mainly from the urban Peninsular Malaysian state, where the ethnic compositions are different from the local context of the Borneo state of Sarawak, though both states are within the same country

Present study which recruited mothers from both the rural (49.1%; n=79) and urban regions (50.9%; n=82) indicates insignificant correlation of *employment status* and their QOL ( $p>0.05$ ). Majority of the mothers, especially those from the rural region attained lower education level and hence indicated relatively lower household income; even for those who were employed. Thus, employment status is not a significant variable in correlation with their QOL ( $p>0.05$ ). However, this is in contrast to the significant findings of the previous studies which recruited participants mainly from the urban community in Ong, et al. (1998) and Ong, et al. (1999) and in Kagan & Lewis (1993 in Kagan, Lewis & Heaton, 1997).

Besides the two variables mentioned above, within the local setting where the majority of the mothers embraced one of the three main religions in the country, difference in their *religions*, as Muslims, Christians or Buddhists was also insignificantly correlated with their overall QOL. However, religious beliefs' positive correlation with parental coping was reported earlier in Ong, et al. (1998) and Ong, et al. (1999).

Findings of significant correlation of the selected variables with QOL from this study point to implications for policy makers and care providers. Those mothers from a background of rural locality, with lower educational and income levels, as single mothers, and are more advanced in age warrant priorities for service provisions, supports and attention, irrespective of their *ethnicity or religious difference* which were found to have insignificant influence to perceived QOL. Various service provisions and supports that contribute towards meeting the needs and thus improving the QOL of mothers would indirectly enhance and promote the optimal growth and development of their child with DS (Hasanah & Razali, 1999).

### **6.2.2 Summary**

Nearly half of the group of mothers perceived generally their QOL as ‘neither poor nor good’ (45.3%; n=73) with only a few (n=10) who perceived it as ‘very good’. Further assessment of the multi-dimensional QOL indicates that *QOL of environmental support domain* (13.3±2.1) was perceived the poorest among the different life domains. Findings provide insights into the extent of mothers’ experience of constraints and existing gap in their accessibility to various aspects of environmental supports in this region of Sarawak.

Variation in background characteristics in term of *rural-urban locality, education, household income* and *marital status* are found to be positively correlated with their overall QOL with statistical significance. On the other hand, *maternal age* was inversely correlated with their overall and physical health domain QOL. Regression analysis shows that the linear combination of *locality, education, income, maternal age and marital status* together accounted for 14.5% of the QOL variability in the sample ( $R^2 = 0.145$ ;  $F = 5.24$ ,  $p = 0.001$ ).



*Ethnicity* difference, either Malay, Chinese, Iban or Bidayuh, *religions* difference and *employment status* were insignificant as background variables to influence mothers' QOL.

### **6.3 Discussing themes of mothers' experience and QOL**

This section of discussion involves comparing and contrasting findings from the two components of study which were discussed earlier:

The qualitative finding of a significant number of mothers who experienced feeling of sadness concurs with the quantitative findings of a relatively lower QOL mean score related to item on 'negative feelings' of despair, blue moods, etc).

As detailed in the earlier section, the *extra care* demands involved for their child with DS could be straining physically to mothers, especially as they get more advanced in age. Furthermore, they had various worries related to child's self-care ability, the future care provision and the uncertainty of 'what next' as their child transits from the special school's program. These qualitative details illuminate and further make sense of the significant, *inverse correlation of maternal age and their overall QOL, and QOL of their physical health domain* ( $p < 0.01$ ).

Experiences of *positive life impacts* of growth and competence and the experience of *excitement, joy of mothering* child, were seen apparently among mothers with background characteristics of higher education level, better access to financial resource, living in the urban locality with good marital support. These findings lend support to the positive,

significant correlations of mothers' few selected background variables (*locality, education, income and marital status*) and their overall QOL ( $p<0.01$ ).

Many of the mothers, in particular, those who lived in the rural locality, encountered various forms of constraints and limitations such as financial resources, transports or access to information source in their care provision process. Qualitative details as obtained from the interviews with mothers concurred with the relatively lower mean ( $13.28\pm 2.1$ ) of QOL of *environmental support domain*. Obviously, this is an indication of the extent of existing gap in term of environmental supports accessible to the mothers.

The above discussion which contrasted and compared between several of the themes and the QOL findings illustrate generally, their *complementarity* to yield a broader and more comprehensive understanding concerning mothers' experience having a child with DS. On the other hand, the limitation, methodologically, of using numerical QOL mean score alone in providing a broadened understanding of mothers' experience is evident in the following discussion:

As shown earlier, among the mothers, predominantly the Chinese mothers, there were several mothers who had difficulties with access to informal supports from their own spouse and also their extended families for emotional supports and practical helps. The earlier QOL findings as reported in Chapter 5 indicate a relatively higher mean score of  $14.9\pm 2.1$  for QOL of *social relationship domain*, and the insignificant correlation findings of *ethnicity* in relation to QOL. Apparently, these QOL findings are quite contrary to several of the mothers' experiences just mentioned. These could be due to reasons such as

the relatively fewer items of the *social relationship domain* of the WHOQOL-BREF which may not be representative, though the instrument was used previously among the Malaysian (Kelantan) population and the non-randomized sampling and sample size which was used for the quantitative study.

#### 6.4 Interrelatedness among the themes and QOL

As highlighted earlier in Chapter Two, family *resiliency* is the ability of a family to respond positively to an adverse event and emerge strengthened, more resourceful and confident (McCubbin & McCubbin 1993). Successful *family adaptation* in a challenging situation such as in a family with a child with disability is believed to have occurred when the family is able to achieve a balance between the family demands,<sup>15</sup> the needs of the child, and the needs of the family as a whole. High levels of parental well-being and overall family functioning suggest successful adaptation. This resilience or adaptation is fostered by ***protective factors*** (availability of family resources<sup>16</sup>) and inhibited by ***risk factors*** (lack of family resources) according to the resiliency model *of family stress, adjustment, adaption* (McCubbin & McCubbin 1993).

Protective factors modify or transform responses to adverse events so that families avoid possible negative outcomes. Conversely, *risk factors* are circumstances that increase the

---

<sup>15</sup>**Family demands** include the demands on or in the family system created by a family member who has a chronic condition and family life cycle changes (McCubbin, Patterson, & Wilson, 1996).

<sup>16</sup>**Family resources are regarded as protective factors** which modify or transform responses to adverse events so that families avoid possible negative outcomes and thus foster family resilience in the process of families' coping and adaptation to stressful life changing situation for family adaptation. These family coping resources include **physical resources** of health, energy, stamina; **utilitarian family resources** (e.g., housing, finances, and employment & other material resources); **social resources** of social networks and support systems (marital bonding, family harmony or cohesion, and family support). **Family psychological resources** include belief systems, spirituality (Benzies & Mychasiuk, 2009). **Coping strategies** as cognitions and behaviors used by the individuals in evaluating stressors and in initiating activities with the aim of decreasing their impact (Margalit, Raviv & Ankonina in Bailey & Smith, 2000) are other factors which influence adaptation.

probability of poor outcomes. Protective and risk factors are not static entities but dynamic as they change in relation to context (Walsh, 2003 in Benzie & Mychasiuk, 2009).

For many of the mothers, they have to meet the *extra care demands* of their child with DS which involved more time and efforts, besides the needs of the family as a whole. They experienced various emotions, in particular, their worries about child's self-care ability and future care provision. The level of care demands experienced by mothers could have given rise to mothers' emotions such as worries and uncertainty related to future child care provision (Figure 6.1). However, despite all these, *positive life impacts* of *increased family cohesiveness, personal growth, competence and motivation to reach out* to help others were evident among them. Many of them expressed their *excitement related to* child's developmental progress, the *joy of mothering* like any mothers would, though, however, the feeling of being *stigmatized* formed a part of few other mothers' experience. The various life impacts could have shaped their perceived QOL (Figure 6.1).

The variation among mothers' experience, especially the positive *life impacts* of strength and confidence (Figure 6.1), both at the personal and family levels, could be explained by the *availability and their accessibility to family resources* of various *supports and coping strategies* which are regarded as the '*protective factors*', according to the resiliency model (McCubbin & McCubbin, 1993). These family resources help the mothers to achieve a balance between the family demands,<sup>17</sup> the needs of the child, and the needs of the family as a whole.

---

<sup>17</sup>**Family demands** include the demands on or in the family system created by a family member who has a chronic condition and family life cycle changes (McCubbin, Patterson, & Wilson, 1996).

However, there were those who had difficulties to access the needed informal supports for their emotional supports and practical helps. Moreover, many of them experienced constraints in environmental supports (as external factors) in relation to financial resources, informational resources and accessibility to public transports within the local context which is vast in land area and geographically spread out. The extent of the constraint is evident in the findings of *poorer QOL* of their *environmental support domain*. The constraints or lacks of the important family resources of *informal supports and environmental supports* (or external factors) pose as ***risk factor*** (Figure 6.1) which can potentially hinder the well-being and adaptation, and hence overall QOL of these mothers (McCubbin & McCubbin, 1993; Olsson & Hwang, 2008). Interrelatedness of mothers' experience among themes and with QOL is illustrated in the framework in Figure 6.1.

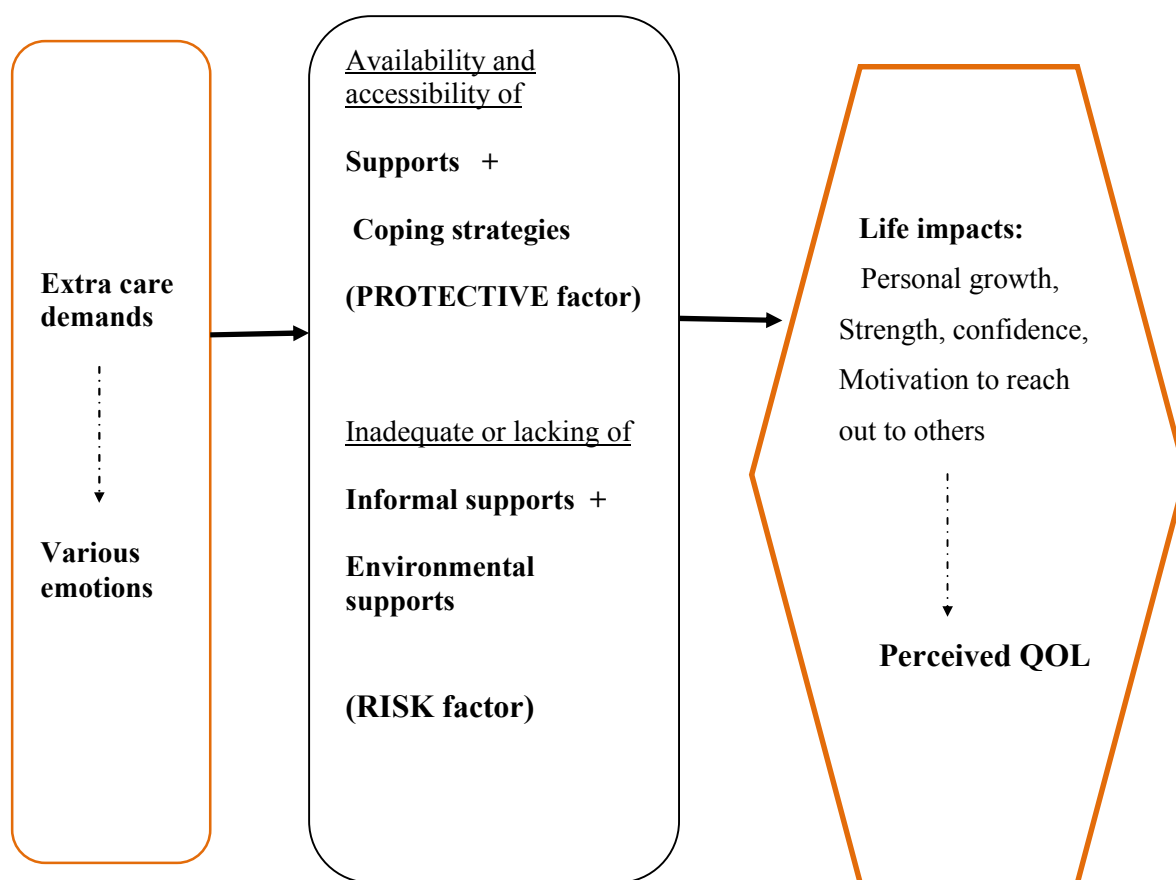


Figure 6.1 Framework of discussion of inter-relatedness among themes and with QOL

### 6.5 Summary of major findings of mothers' experiences and QOL

This section provides a summary of the findings which are drawn from the parallel mixed design study with the various issues of concerns being highlighted.

Mothers of child having DS experienced *extra care demands* which were attributed to child's health condition during child's early age, child's developmental delays and behavior which could be physically straining. This is in tandem with findings of the inverse correlation of maternal age and their overall QOL, and QOL of physical health domain.

Irrespective of their socio-economic, religions, ethnic or age differences, many of the mothers experienced *various emotions* such as shock, disbelief, the difficulty in accepting child, anger, sadness and feelings of shame and self-blame which lasted for a variable period of time after delivery of their child with DS. Besides these, worries in relation to child's future care provision, self care ability and risk of recurrence of DS were indicated. Apparently not having better options, many expected the child's siblings to continue with future care provision of child with DS, but with uncertainty.

Variation of *informal supports* was accessed by mothers for their emotional supports and practical helps is evident in this study. Those who experienced problem with support from their parents-in-law were predominantly the Chinese mothers. Among mothers, especially those from the rural locality, their experience of limitation of access to the informal supports of extended families was partly attributed to the rural disadvantage of geographical distance and limited access to public transports.

Mothers' perceived inadequacy of *formal supports* of service provisions warrants one's attention. Many encountered various constraints and limitation in relation to *environmental supports* in particular, their access to informational source, financial resource and transports. Constraints and limitation in the various environmental supports disadvantaged them in their preparedness in care giving of child with DS. *QOL of environmental support domain* with a relatively low domain mean ( $13.3 \pm 2.1$ ) provides insights into the extent of constraints and gap in term of the mothers' accessibility to various environmental supports. The lack of adequate informal supports and environmental

supports pose as risk factor which potentially influence mothers' well-being, adaptation and maintaining of balance between meeting the needs for the child and the needs of the family.

**Coping strategies** such as *reframing perspectives* of mothering a child with DS realistically and positively was helpful to mothers. A few others maintained their *hopefulness* and optimism concerning child's potential, though still battling with their uncertainty.

Disability-related *religious beliefs* and conviction were helpful in providing reassurance and confidence among mothers.

**Life impact** of *stigma* was part of the experience of a few mothers, apparently associated with societal disability-related belief. At the family level, *increase in family cohesiveness* due to the need to pull the family resources to help and support their child was evident. At the personal level, there was personal *growth and competence* in aspects of care giving of child and the *motivation to reach out* to help others besides the experience of *excitement and the joy of mothering* their child. The various positive life impacts of growth and competence and the experience of *excitement, joy of mothering* child were apparently related to the level of accessibility to **various supports** and their **coping strategies** during the process of care giving of child.

Besides the supports and environmental (or external) factors, it is also apparent from the findings of significant correlation analysis that **selected background variables** of mothers do have some influence or impacts on the mothers having a child with DS. These include the *rural-urban locality, education levels, household income and marital status* which were significantly correlated with their overall QOL ( $p < 0.01$ ), except for *maternal age* which



was negatively correlated. Those mothers from the rural locality, with a lower education level and income, being single and older in age are more likely to perceive a poorer QOL.

In the Conclusion Chapter, implications of findings are elaborated with several recommendations made in relation to practice, policies, education and future research included. Study limitations are acknowledged and its strengths are highlighted. Some closing reflections that arise from the thesis writing are also included.

## CHAPTER SEVEN

### CONCLUSION

#### 7.0 Introduction

This study has set out to explore and provide answers to two related research questions.

The first research question explores ‘*what are the experiences of mothers having a child with DS?*’ using qualitative interviews with mothers of child having DS with the purpose to understand how mothers ‘interpret their experience’ having a child with DS, and the meaning they attribute to their experiences (Merriam, 2009, p. 5). The other complementary question which asks about ‘*what is the QOL of mothers having a child with DS?*’ is answered using questionnaire survey.

Having gained some understanding and insights into the experiences of mothers of child having DS and the perceived QOL of mothers in the two regions of Sarawak (Kuching and Samarahan Divisions) from the parallel mixed design study, several areas of concerns which warrant attention have been discussed and highlighted earlier. Study findings point towards implications for practice, policy and education which would be addressed foremost in the first section of this chapter. Side by side with the implications are study limitations to be acknowledged and its strengths which give weights to its credibility and significance. Subsequently, related recommendations are put forward for practice, policy and education considerations, together with some suggestions for future research. Some notes of reflection are also included before concluding the chapter.

## **7.1 Implications of study findings for practice, policy and education**

Commonly, care professionals such as doctors, pediatric nurses and therapists in the course of their care provisions in the hospital setting provide care to children diagnosed with DS and their parents, in particular, mothers soon after the delivery. These could either be in the postnatal or pediatric wards. As in the community health care setting, opportunities and venue for care provision could be through the maternal and child-health clinics.

Findings point out to implications for various care professionals towards provision of care which is empathic and sensitive to the needs of mothers, and contribution towards a family environment which promotes optimal growth and development of their child with DS.

Insights as gained have implications for health care and social work's basic education curriculum, including aspects to be focused and expanded in preparation of their professional care provision. Furthermore, there is a need for policy-makers to be sensitized towards the needs and challenges faced by mothers of child having DS.

Insights and understanding related to the correlation of the selected background variables of the mothers and their perceived QOL point to implications for national policy-making to give priorities and due consideration to mothers' socio-economic background characteristics and differences. These include those who are of *lower education and household income levels, from the rural locality, without adequate accessibility to transports, those who are of older age group and are single*, irrespective of their *ethnicities and religions*.

There are study limitations to be acknowledged and strengths which would be highlighted in the subsequent subsection before recommendations are made for practice, policy and education in relation to the study findings.

## **7.2 Limitations and strengths**

### **7.2.1 Limitations**

There might be some elements of non-response bias (Polit & Hungler, 1999) related to non-attendance of several of the children with DS to the schools with their mothers due to various reasons, and thus were not recruited. Reasons as given include ‘problem of transports for child to go to school as father went on travelling duty’; ‘nobody to send child to school as mother was sick’, or ‘mother had just given birth to another younger sibling’ during the period of data collection. Furthermore, as recruitment of mothers for the QOL questionnaire study was done through the various institutions where service provisions were provided, there may be mothers, not insignificantly in number, whose child with DS did not have access to any of the formal service provisions, thus were excluded in the study. These mothers as a group are those who probably need the most help.

It is to be acknowledged that study which reports about care experiences of mothers (or parents) bringing up children who are ‘normally developing’ or children with no Down’s syndrome in the local Sarawak context has yet to be cited. There may be unique characteristics in experiences in relation to bringing up even normal children in Sarawak - a land with vast geographical distances, as compared to experiences from a different socioeconomic or cultural background.

In analyzing mothers' care experiences of having a child with DS, no distinction was made in relation to the level of severity of the child's medical or surgical complication, though the experiences of mothers of child with more severe complication may differ.

Data was collected only from the two regions of Sarawak State (the urban capital city of Kuching and the adjacent rural Samarahan Divisions), thus limiting the generalization of findings to other broader region of the State of Sarawak. Other variables such as the level of child's severity of disability or child's developmental stage which were not taken into account in the analysis of data may have influenced mothers' experiences or perceived QOL. It would be useful to extend this study to a wider, more representative sample.

The slight variations in approach in the administration of questionnaires among schools, clinics and CBR centers as a result of differences in the programs and activities in these institutions and logistics reason may have contributed in an unknown way to the differences in the QOL scores.

Items on participants' background information (Instrumentation B: Section I Background information) were reviewed and verified by two bi-lingual language experts for clarity and accuracy of translation from the English to Bahasa Malaysia and Mandarin version. Future study would undertake to carry out a back translation of the translated version into the original English version (WHO, 2010).

Apart from religious beliefs related to pre-destination which were illicit among the mothers who were Muslim and Christians, the study did not explore further the religious differences in their beliefs, attitude and coping with a child with DS.

### **7.2.2 Strengths**

The few points as discussed in this section give further credibility and significance to the findings which were derived from the study, namely the *use of the parallel mixed design* study approach, the *characteristics of participants* as recruited and the *multi-lingual use of the researcher* in relation to conduct of the study within the multi-ethnic, multi-cultural background of the local context.

#### ***Use of parallel mixed design study***

This study which used the parallel mixed design approach takes recent Malaysian (Sarawak) disability-related study a step further towards understanding the experience of mothers having a child with a disability due to DS. Qualitative interviews allowed exploring and probing to provide an enriched, in-depth understanding and insight into the experiences of mothers of child having DS which is based on their perspectives within the local context. Qualitative data analysis identified five major themes representing the meanings of those experiences as supported by quotes of mothers' own words which the quantitative QOL mean scores cannot convey. Quantitative component of the study which was conducted using a cross-culturally-sensitive WHOQOL-BREF instrument answers another closely related question to examine the QOL of mothers complements the qualitative findings.

It is concluded from the comparisons and contrasts of qualitative findings with quantitative findings that using a parallel mixed design of the MMR approach is a meaningful way to explore experiences of mothers of child having DS and to examine their QOL. It contributes towards an enriched, a more broadened perspective and comprehensive understanding and valuable insights into the lives of mothers of child having DS in the local region, more than it would be possible if it was studied using only either one of the two methodological approaches. The majority of the findings indicate that the “complementary strengths” of using mixed design study (Burke & Onwuegbuzie, 2004, p.18).

The parallel mixed design study which yields various findings as supported by the qualitative details and in majority complemented by the quantitative findings highlighted various issues of concerns. A number of recommendations for practice, policy and education are forwarded in the subsequent sub-section on the basis on these findings.

### ***Participant characteristics***

This study recruited participants from a variation of socioeconomic, cultural, ethnic and religious backgrounds which is reflective of the local population’s heterogeneity. Mothers from across different background characteristics provide for a broader and more comprehensive understanding pertaining to experiences having a child with DS. The use of qualitative interviewing on a purposive sampling of mothers from different background characteristics who were willing to share their experience, concerns and hope had yielded a deeper insight into mothering experiences in this part of Sarawak. Recruitment of mothers from a varied socioeconomic background is more reflective of the local population than

sample from a selected ethnic group or a certain socioeconomic status. However, the recruitment of participants who were of different ethnicities gave rise to the need for transcribing and translating the interview transcripts in order to convey the meaning of the mothers' experience in a way that could be comprehended by the readers, as described in the Methodology Chapter.

### ***Researcher's multi-lingual use***

As a Malaysian Chinese, born and educated in the Borneo state of Sarawak, a multi ethnic and multi-lingual state of Malaysia, I have the advantage as an 'instrument' in data collection, to personally interview the participants who were of different ethnic and multi lingual backgrounds. I have the advantage of being able to use the three main languages, i.e. English, Bahasa Malaysia and Mandarin which are the three main languages used locally, besides the Hokkien dialect. My position of being in a cross-cultural marriage to the Iban culture which uses the fourth language i.e. the Iban language had given me the advantage as a researcher, to access and to interact with several of the participants from the Iban community for the interview sessions. However, for better clarity and accuracy, I did engage the assistance of an interpreter during the interview process using the Iban language.

## **7.3 Recommendations**

### **7.3.1 Recommendations for practice in relation to findings:**

*Findings of 'various emotions' in relation to shock and disbelief, sadness, anger, difficulty in accepting child, shame and self-blame, worries about self care, future care provision and recurrence of DS:*



- There is a role for care professionals to be anticipative of and empathic towards the various emotions of mothers and to provide them a supportive environment which facilitates expression of their feelings and concerns without fear of being judged.
- Some mothers may need extra practical help with care of their new born during the early stage after child's delivery while in the hospital or in their own homes. Thus home visit by nurses at the earliest possible time would be helpful. Spousal supports to meet emotional needs and practical help may be lacking for some mothers in their individual social situational contexts.
- Clarification with mothers their beliefs about causes of child's disabilities, with thoughtful information provided may be helpful to reduce possible self-blame in relation to delivery of a child with disability.
- Due to the social and health needs of growing-up individuals with DS and mothers who may have worries related to future care provision of their child, health professionals' continual support and care is warranted. These include home visit and follow-up, and appropriate referral of child with DS and their family which might need to be extended beyond the present age limit of 18 years of age.
- It augurs well for care professionals in their practice to approach antenatal mothers (with previous history of a child with DS) with sensitivity in relation to their concerns of risk of recurrence of DS. It would be helpful for them to be given the opportunity to verbalize and express their feelings and concerns without fear of being judged.

- It augurs well for care professionals to be prepared to provide appropriate assistance by being equipped with the relevant knowledge and skill of genetic counseling, as they may encounter with the medical-legally and ethically debatable issue in relation to decision for termination of pregnancy.
- The ‘insensitive’ practice of putting a ‘Down’s syndrome’ sign by the cot side as described by one of the mothers in section 4.2.1.1 should be stopped.

*Findings of ‘extra care demands’ which are child-health related, delayed development related and behavioral-related:*

- It would be beneficial for mothers who came from the different background to exchange their experiences and views during occasions such as the parent support group gathering. A session with facilitation by the related professionals could be an opportunity for further discussion and dialogue related to different aspects of child care, including child’s behavioral management or discipline.
- It would augur well for care professionals like nurses and doctors to be anticipative and empathic of the various extra care demands due to having a child with DS, and to facilitate appropriate supports and assistance to mothers.

*Findings of ‘variation of supports’ in relation to informal supports, formal support and environmental supports; significant correlation of selected background variables (lower education and household income levels, from the rural locality, without adequate accessibility to transports, those who are of older age group and are single) and their QOL:*

- In order to provide a care that is needs-sensitive, it is pertinent for assessment by care professionals to include aspect on mothers' accessibility to socio-environmental supports, such as informal social supports from spouses or extended family such as grandparents, and other social supports of parental support group, accessibility to formal supports of relevant therapies, informational resources or financial resources. Mothers of one particular ethnicity might experience more problem than the other in getting support from their extended family.
- It augurs well for care professionals to mediate and facilitate mothers' access to and use of the various resources. This includes earliest possible referral of those from the lower socioeconomic background with limited financial resources to the appropriate agencies and departments such as Social Welfare Department for financial aids.
- Care professionals are in a position to provide individual informational support related to child's condition, the existing available resources of support groups, interventional programs, and other pertinent child care related information. Due to emotional responses which may affect their receptiveness to information giving, informational supports should be provided at an appropriate time when they are ready psychologically, together with their spouse.
- As there can be a barrier with the use of English or Bahasa Malaysia by mothers locally, the use of appropriate language that mothers can understand with appropriate translation service and other supports in relation to information giving is warranted.

- Health professionals such as nurses, in collaboration with speech therapist can facilitate, organize regular, small group sessions to be participated by mothers and other health professionals in the clinic. These clinic-based sessions could be teaching-learning opportunities to emphasize to mothers importance of parental involvement such as pre verbal stimulation activities for child and emphasize on continuing care at home as guided by the Ministry of Health manual (MOH, 2004). Sessions organized can be opportunities for mothers to share their practical knowledge and experience related to various aspects of care giving of child related to child behavior, toilet training or language learning to other parents.
- Designation of a ‘clinical specialist nurse’ trained in DS care provision would be beneficial in facilitating the various care provisions starting from the time the mother and child are still staying at hospital ward or nursery, through to home visits, and health clinic follow-up program. Through networking mothers to other families and in facilitating their access to resources at other agencies such as CBR centers, special education, various therapists and care providers, the designated nurse would be able to ensure continuity of care provision and support to mothers and their child with DS.
- In relation for professional service provision, there is a need for care provision in the area of genetic counseling and for psychological support by trained counselors or social workers for mothers or families of child with DS within the local context.

*Findings of ‘coping strategies’ in relation to reframing perspectives, maintaining hopefulness and religious beliefs and convictions:*

- It would augur well for care professionals to be non-judgmental but being supportive of mothers who verbalize and utilize various coping strategies in their mothering of child with DS. They could be encouraged to verbalize their own perspectives of mothering their child, their hope and their religious convictions related to child's disability. Activities which are tailored to include a spiritual or religious element to inculcate positive religious beliefs and hope in relation to mothering a child with a disability has its role to better support mothers of children with DS within the local setting.
- There is a role for institutions such as religious bodies to be sensitive of the needs of mothers of child having DS and to provide them with support and spiritual encouragement and assurance in their mothering process.

*Findings of 'life impacts' related to being stigmatized, family role impacts, personal growth and competence and motivated to reach out to help others:*

- Health professionals could be involved in organizing public seminar with the aims to disseminate information such as genetic causes of DS. Media resources such as video recordings of children with DS participating in daily 'normal' social activities in different settings, integrating with other non-disabled children or adults can be screened for viewing by the public in various settings. These efforts will be helpful in increasing public awareness and to put into right perspective any unhelpful disability-related cultural beliefs and myth which influence societal attitude towards child with DS.

- Sharing of mothers' experiences of motivation and personal growth, competence during get-together session or public seminar will provide encouragement, insights and valuable practical knowledge to other parents, care professionals and the public. It can help to reduce discrimination and unhelpful assumptions or stereotyping towards mothers and their child having DS.

### **7.3.2 Recommendations for policies:**

In relation to findings of significant correlation of the selected background variables (*lower education and household income levels, from the rural locality, without adequate accessibility to transports, those who are of older age group and are single*) and their *QOL*:

- It augurs well for national policy-makers to focus on decentralizing service systems and outreach service designs for rural areas.
- There is a place for flexibility in policy related to implementation process of allocated financial assistance from the Welfare Department which might thwart its intention and objectives to assist the mothers financially, especially those from the rural, low socioeconomic background.
- It would be helpful for health care facilities to consider a mechanism to allocate adequate priority parking to individuals with disability including DS, and their care givers, to lessen the care demand as they come for the various service provisions. Probably there are provisions of existing parking lots which have been specified for

this purpose but probably further enforcement would enable their care givers to better utilize the service provision.

- During the research process to search for preliminary background information and for research sites to access participants, it was found that the condition of DS in children in the existing system of registry in the State's Social Welfare Department is categorized under 'learning disability', together with other conditions such as autism, slow learners and dyslexia. It gave rise to difficulty in getting vital information which is specific to the DS condition, such as the statistics of child with DS in the State of Sarawak. A separate individual category for registering of children with each of the conditions as an alternative would provide for a database for each specific condition registered. This is useful for purpose of monitoring the trend of new cases or for research.

### **7.3.3 Recommendations for education**

- Educational preparation and training of various care professionals related to the field of disability such as nurses, doctors, therapists or social workers in their undergraduate programs would do well to include components on impairment and disability related issues, highlighting the concerns of mothers having a child with disability such as DS in the local setting. An appreciation of experience of mothers in relation to various concerns and extra care demands would better prepare them for care provision with sensitivity to the needs of child with disability and the mothers.

It would be beneficial for the university to develop and offer as a complementary course with curricular content related to developmental disability conditions including DS and disability related issues and policies to be taught to all students. This would help to inculcate awareness and the right values among students and thereafter in the society the various concerns and needs of mothers and their child with DS.

- There is a place for ‘clinical specialist’ nursing education preparation for the roles of clinical nurse specialist nurse for child with DS and the mothers to ensure a continuing care provision and support. Specialised disability-related nursing preparation hopes to prepare nurses to facilitate the various care provisions, right from the time the mother and child are still at hospital ward or nursery, through to home visits and health clinics, besides to network mothers to other families and in facilitating their access to resources at other agencies.

#### **7.3.4 Recommendations for future research**

Findings from the studies point to several suggestions concerning future research studies. Furthermore, future studies are warranted in due consideration of the limitations and various constraints of resources in the present study.

- As there are concerns among mothers about the existing service provisions of various pertinent therapies and interventional programs for their child which were deemed to be inadequate, further study to explore care professionals’ perspectives related to their care provision to children with disabilities and families might yield further insights to the issues of concerned.



- Experiences and perceived QOL of fathers, and those adoptive parents or grandparents who are the main care givers of child with DS could be explored in future study in order to extend the knowledge base and insights concerning caring for a child with this condition. Their experience might be different from those who are the biological mothers, as were identified in the present study, due to difference in their care giving roles, background characteristics and contexts.
- The statistically significant correlation of maternal age and their QOL point to the need for future research to explore more in-depth the experience of older age group mothers who still have a dependent child with DS which may indicate a different set of needs and expectations.
- The hope and expectation for the siblings to take on the care provision for their child with DS could imply a life-long continuum of care demands on siblings. Future study which explores siblings' experience and their perceived impacts is warranted to illicit further understanding which might aid in provision of relevant supportive program for families.
- Recruitment of mothers whose child with DS who are non-attendants to various institutions for interventional programs and those who were unreached in different parts of Sarawak might bring to light different sets of experience and needs. Various means of getting access to them could be through snowball method or through the local village head men who might have more information concerning the people dwelling within the village or community.

- Further to the above, as suggested by some mothers in this study, future research study which further explores the society's views towards children with DS would be a worthwhile study.
- There is a need to for a future study which examines the caregiving experiences and QOL of mothers of children who are normally developing using the same instrument WHOQOL-BREF among the Sarawak population. Findings from the future study would enable further comparison to be done between mothers of children with DS and those with children who are normally developing.

#### **7.4 Closing reflections**

In closing, as result of going through the process of conducting this study using the MMR study (parallel mixed design) to explore experience of mothers having a child with DS and to examine mothers' perceived QOL, there are few lessons that I have learnt.

##### **7.4.1 Research with mothers as participants**

Several mothers expressed their gratefulness to be given the opportunity to share their life experiences as mothers having a child with a disability through their participation in the in-depth interviews. My initial concerns that the qualitative interview process itself might interfere with their daily lives and might not be able to receive responses from the mothers are proven wrong. They indicated that participation in the research process itself provided an opportunity and a platform through which their voice could be heard. The interview process was also deemed as therapeutic and 'soothing to their hearts' as described by one of them. They further indicated that being involved in the research process gave them a sense

of being given the attention which they needed. This is illustrated by the quote such as ‘I’m thankful that someone is trying to understand how the feelings is like having a child like this’. Similarly, another mother quoted, ‘at least someone is interested in us, in finding out how we feel and how our lives are, having a child with DS’.

The interest of mothers for their voice to be listened to is further evidenced by mother of a child with CP (who was also present in one of the CBR centers where other mothers of child having DS were accessed) who asked, ‘why do you only choose to ask these mothers of child having DS, how about us (having child with other condition)?’

In fact, mothers of child with a disability want to be listened to. Stone (1989) highlighted that research process gave opportunities for parents to express various responses related to the birth, diagnosis and care-giving of their child, thus help towards their enablement and enhancement in the process of making a positive adjustment.

#### **7.4.2 Conducting research that empowers mothers**

Being through part of informal conversation among mothers having a child with a disability, it dawn on me the obligation for researchers to consider the process of research study to ensure that it is empowering to the ‘researched’. As expressed by one mother, *‘some parents were stupid to tell everything, thinking that they (researchers) were going to help’*. Another mother expressed her concern in her quote, *‘these people only come here to do the research...they come and go, never give us any feedback. We want their feedback. It (research) didn’t help us, (but) may be only to help them to achieve their goal (academic), to get their degree or something’*.

Apparently, from the words of these mothers, there is probably misunderstanding from their points of view. This implies the importance for study purpose which is to empower them, to be clearly explained to potential participants, as the 'researched'. As much as possible, feedback of study should be disseminated to them in return. Mothers as the main care givers, have so much to teach us from their real live experience. It is the researcher's role to 're-present' and disseminate as accurately as possible, their interpretation of the meaning of their experience having a child with disability from their perspectives.

#### **7.4.3 Lessons learnt using MMR study design**

The process of using the MMR study (parallel mixed design) was not without challenges. These include the amount of time required in relation to data collection, data analysis and write-up. Besides time involvement, one other challenge is concerning the uncertainty in situating the discussion of the qualitative and quantitative findings, whether it should be start with qualitative findings followed by discussion or vice versa. As shown in this study write-up, the decision for discussion of the two components of study was finally made to have the 'discussions' that follows the qualitative and quantitative findings sections.

During the discussion that involves comparing and contrasting findings from the two components of study, one particular point which is noteworthy is about the importance of constantly bearing in mind which component of the mixed design study as the dominant component and which component as complementing the other. This is to facilitate a more coherent discussion of the findings and to demonstrate the complementary strength of combining the two approaches of study. This could be illustrated from the earlier section's discussion of qualitative findings of mothers' experience related to constraints and

inadequacy of environmental supports and findings related to QOL of environmental supports domain.

### **7.5 What this study adds to the existing literature**

This indigenous study as conducted in Sarawak using parallel mixed design provides new and original knowledge about mothers' care experiences with much details and depth and also QOL of mothers which is of notesworthy. Factors correlated with QOL with statistical significance- rural-urban locality, education, income, age and marital status were identified, which in combination accounting for just over 14% of the variance in QOL. These findings suggest that environmental and familial factors provide important keys to understanding QOL. Findings also suggest the relevance of 'resilience model' in explaining and making sense of the mothers' care experiences having a child with DS in the local context.

Furthermore, findings also indicate that the pluralistic methodological approach of parallel mixed design is meaningful in providing a broadened and comprehensive understanding of mothers' experience of having a child with DS and their QOL.

### **7.6 Conclusions**

Mothers experienced various *emotions* related to having a child with DS, some of which potentially affected their energy level to care for the newborn temporarily or to absorb given information concerning their child's disability. Part of their heartfelt emotions was their worries about child's ability for self-care, uncertainty of future care provision for their child and their fear of the risk of recurrence of DS.

Their worries and concerns about child's self-care ability and future care provision, coupled with the various child-related extra care demands, illuminate and lend support to the findings of significant, negative correlation of maternal age with their overall QOL and QOL of physical health domain ( $p < 0.01$ ).

It could be concluded that irrespective of their ethnicity or economic backgrounds, many of the mothers having a child with DS experienced various *extra care demands*, since the birth of their child. These were related to child's health conditions, delayed development and child's socio-behavioural characteristics, particularly behaviors which were deemed as age or socially inappropriate. The care involvement for their child demands much of their time and were physically straining, especially as mothers get more advanced in age.

The evidence of *life impacts* such as family cohesiveness, personal growth and competence, motivation to reach out and to help others, excitement with child's new progress, the expression of joy of mothering their child, indicate the resilience of mothers. These also indicate that experiences of mothers having a child with DS were *not completely negative*. Apparently, these could be associated with the availability and their accessibility to various family resources of various *supports*, such as *informal supports* from their spouse or extended families in meeting the various child-related extra care demands, and the environmental support. Besides *reframing perspective* of mothering child positively and realistically, *maintaining hopefulness* and optimism concerning child's future as helpful *coping strategies*, *religious beliefs and convictions* are helpful in providing reassurance and confidence to many of the mothers.

The availability and accessibility to these various supports and coping strategies as family resources were regarded as the '**protective factor**' which influence the potential of mothers' adaption within the circumstances where they have to meet the various child-related extra care demands and concerns, in accordance to the resilience model (McCubbin & McCubbin, 1993 cited in Van Riper, 2007).

There were circumstances where mothers experienced difficulty with accessing informal supports of spouse or extended families. Mothers also experienced constraints with environmental support (in term of financial resources, access to information resources and transports, in particular by those who lived in the rural locations. The extent of the various environmental constraints and limitation experienced was evidenced by mothers' perceived poorer *QOL of environmental support domain* with a mean of  $13.28 \pm 2$ .

Circumstances of difficulty with accessing informal supports and the various environmental constraints constitute '**risk factor**' which may influence mothers' adaption and well being.

Mothers' background variables in term of their *rural-urban locality* of their place of living, *education levels, household income, marital status and maternal age* were found to have a *significant correlation with their overall QOL ( $p < 0.01$ )*. It augurs well for care professionals in their care provision for mothers to be sensitive to their unique background characteristics, and prioritize care provisions accordingly, irrespective of their *ethnicity or religious* background.

Mehodologically, it is concluded that using parallel mixed design research approach is a meaningful way to explore the experiences of mothers and to assess their QOL. Findings

demonstrate the “complementary strengths’ of using two different methodological approaches in the same study, and a ‘non-overlapping weakness’ of using only either one of the two approaches (Burke & Onwuegbuzie, 2004, p.18). Using qualitative approach as the dominant component and quantitative approach complementarily provide a broadened perspective, more comprehensive, in-depth understanding and insights into motherhood experience having a child with DS (Green & Thorogood, 2009; Miles & Huberman, 1994; Teddlie & Tashakkori, 2009; Tully & Cantrill, 2000).

Findings concerning mothers’ *various experiences, QOL of different life domains, correlations of selected background variables of statistical significance with their QOL* warrant the attentions of care professionals and policy makers. Implications for a more humanistic care provision and supports to mothers to ease their care demands, and improve their QOL in relation to environmental support dimension are indicated.



## **Instrumentation A**

### **(i) Interview guide (in English)**

1. Tell me about how you feel having a child with Down's syndrome.
2. How is your experience of taking care of your child in a normal day?
3. Tell me who else helps in taking care of your child.
4. Tell me your experiences with various child-related service provisions.
5. Where do you find information about how to take care of your child? (information such as therapy, intervention programs, special education)
6. What is your hope regarding the future of your child?
7. Are there things which are important to you but which we have not yet discussed?

### **(ii) Interview guide (in Bahasa Malaysia)**

1. Bagaimanakah perasaan anda mempunyai anak yang Sindrom Down?
2. Bagaimanakah pengalaman dengan menjaga anak anda pada suatu hari biasa?
3. Siapa lagi yang bantu menjaga anak anda?
4. Sila berkongsi pengalaman anda berkenaan dengan perkhidmatan yang sedia ada untuk anak.
5. Dimanakah anda mendapat maklumat berkenaan dengan penjagaan anak anda (maklumat seperti terapi, program intervensi, pendidikan khas)
6. Apakah harapan anda berkenaan dengan masa depan anak anda?
7. Adakah perkara-perkara lain yang anda anggap penting tetapi belum lagi dibincangkan?

**(iii) Interview guide (in Mandarin)**

1. 告诉我你对有一个唐氏综合征孩子的感受.
  2. 你在正常的日子照顾孩子的经历是如何?
  3. 请告诉我, 还有谁帮助你照顾你的孩子.
  4. 请告诉我一些服务提供的经验是什么?
  5. 你在哪里找到有关如何照顾你的孩子的资料?
  6. 你对你的孩子未来的希望是什么?
  7. 有哪一些对你很重要, 但我们还没有讨论过的东西吗?
-

## **Instrumentation B**

**Questionnaires (in English, Bahasa Malaysia and Mandarin)**

**(a) Questionnaire in English:**

---

**Section (I): Background information:**

Please write down your answer or tick (√) the most appropriate answer inside the box (☐):

(1) Age of mother: \_\_\_\_\_years

(2) Race:

Malay

Chinese

Iban

Bidayuh

Melanau

Others (please specify): \_\_\_\_\_

(3) Highest education attained:

UPSR

SRP / PMR

SPM /MCE

Diploma /Certificate

University Degree

Others (please specify): \_\_\_\_\_

(4) Marital status:

Married

Single

Divorced

Widowed

Living separated

(5) Religion:

Islam

Christianity

Buddhism

No religion

Others (please specify): \_\_\_\_\_

(6) Employment:

Full-time housewife

Own business

Government employee

Private company employee

Others (please specify): \_\_\_\_\_

(7) Household income:

RM 500 and below

RM501-1000

RM1001-2000

RM2001-3000

RM 3001-4000

RM4001-5000

Above RM5001

(8) Mode of transportation used by my family:

Own vehicle:

Public transport:

Car

Bus

Truck

Taxi

Van

Van

Motorbike

Others (please specify): \_\_\_\_\_

Bicycle

Others (please specify): \_\_\_\_\_

(9) Does your child receive any allowance from the following departments?

	Yes	No	Please state amount received
i. Education Department:	<input type="checkbox"/>	<input type="checkbox"/>	RM _____
ii. Social Welfare Department:	<input type="checkbox"/>	<input type="checkbox"/>	RM _____

(10) Regarding your child(ren) you have:

i. Age of my eldest child: \_\_\_\_ years

ii. Age of my youngest child: \_\_\_\_ years

iii. Age of child with Down's syndrome: \_\_\_\_ years.

iv. Total number of children I have: \_\_\_\_\_

**Section (II): Questions related to child care and child's development (tick your answer in the appropriate box)**

(11) Who else helps you to take care of your child with Down's syndrome besides your spouse? (you can tick in more than one box for your answer)

- No one else
- Child's grandparents
- Child's brothers and sisters
- Child's auntie

(12) How did you first obtain information regarding care of your child with Down's syndrome?

- |      |                             | Yes                      | No                       |
|------|-----------------------------|--------------------------|--------------------------|
| i.   | Consulting pediatrician     | <input type="checkbox"/> | <input type="checkbox"/> |
| ii.  | Consulting clinic nurse     | <input type="checkbox"/> | <input type="checkbox"/> |
| iii. | Searching from the internet | <input type="checkbox"/> | <input type="checkbox"/> |
| iv.  | Reading from newspaper      | <input type="checkbox"/> | <input type="checkbox"/> |
| v.   | Reading from books          | <input type="checkbox"/> | <input type="checkbox"/> |
| vi.  | Asking friends & relatives  | <input type="checkbox"/> | <input type="checkbox"/> |

(13) When I communicate with my child normally I usually use

- |                   | Yes                      | No                       |
|-------------------|--------------------------|--------------------------|
| i sign language   | <input type="checkbox"/> | <input type="checkbox"/> |
| ii spoken words   | <input type="checkbox"/> | <input type="checkbox"/> |
| iii picture cards | <input type="checkbox"/> | <input type="checkbox"/> |

(14) Regarding development of my child with Down's syndrome: please tick  $\surd$  in the appropriate box )

- | My child is able to                           | Yes                      | No                       | Since what age? |
|-----------------------------------------------|--------------------------|--------------------------|-----------------|
| i. Walk                                       | <input type="checkbox"/> | <input type="checkbox"/> | ___ years       |
| ii. Control over toileting needs (urination). | <input type="checkbox"/> | <input type="checkbox"/> | ___ years       |
| iii. Control over toileting needs (bowel)     | <input type="checkbox"/> | <input type="checkbox"/> | ___ years       |
| iv. Speak using less than 5 words.            | <input type="checkbox"/> | <input type="checkbox"/> | ___ years       |
| v. Speak using more than 5 words.             | <input type="checkbox"/> | <input type="checkbox"/> | ___ years       |

(15) Indicate any interventional program or school that your child is attending:

- |                                                              |                          |
|--------------------------------------------------------------|--------------------------|
| Clinic-based rehabilitation                                  | <input type="checkbox"/> |
| Centre for Community-based Rehabilitation                    | <input type="checkbox"/> |
| Early intervention program (non-government organization)     | <input type="checkbox"/> |
| School integrated special education program                  | <input type="checkbox"/> |
| School for special education (non-governmental organization) | <input type="checkbox"/> |
| None at all                                                  | <input type="checkbox"/> |

(16) After your child's birth, did he or she receive any specialist treatment and follow-up due to the following health problems?

- |                                    | <b>Yes</b>               | <b>No</b>                |
|------------------------------------|--------------------------|--------------------------|
| i. Heart problem                   | <input type="checkbox"/> | <input type="checkbox"/> |
| ii. Ear problem                    | <input type="checkbox"/> | <input type="checkbox"/> |
| iii. Eye problem                   | <input type="checkbox"/> | <input type="checkbox"/> |
| iv. Breathing problem              | <input type="checkbox"/> | <input type="checkbox"/> |
| v. Rectal problem                  | <input type="checkbox"/> | <input type="checkbox"/> |
| vi. Others (please specify): _____ |                          |                          |

### Section III

The following questions ask how you feel about your quality of life, health, or other areas of your life **in the last four weeks**.

**Please answer all questions. Please place a tick (✓) on the number to indicate your most appropriate answer to the questions below.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4.	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how **completely you experience or were able** to do certain things in the last four weeks:

		Not at all	A little	A moderate amount	Very much	Extremely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5



13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5
20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

**Do you have any comments about this assessment?**

---



---

**Thank you very much for all your time and effort.**

## (b) Questionnaire in Bahasa Malaysia

### Seksvn (I): Maklumat Latarbelakang:

*Sila tuliskan jawapan atau tandakan  $\surd$  pada kotak () yang bersesuaian dengan jawapan anda..*

(1) Umur ibu: \_\_\_\_\_ tahun

(2) Bangsa:

Melayu

Cina

Iban

Bidayuh

Melanau

Lain lain (sila nyatakan) \_\_\_\_\_

(3) Tahap persekolahan tertinggi:

UPSR

SRP / PMR

SPM /MCE

Diploma /Sijil

Sarjana muda

Lain-lain \_\_\_\_\_

(4) Taraf perkahwinan

Berkahwin

Belum kahwin

Bercerai

Balu

Tinggal berasingan

(5) Agama :

Islam

Agama Kristian

Agama Buddha

Tidak ada agama

Lain lain (sila nyatakan): \_\_\_\_\_

(6) Pekerjaan:

- Suri rumah tangga
- Perniagaan sendiri
- Pekerja kerajaan
- Pekerja syarikat swasta
- Lain lain \_\_\_\_\_

(7) Pendapatan bulanan sekeluarga:

- RM 500 dan ke bawah
- RM501-1000
- RM1001-2000
- RM2001-3000
- RM 3001-4000
- RM4001-5000
- RM5001 dan ke atas

(8) Cara pengangkutan digunakan oleh keluarga:

- |                                             |                                             |
|---------------------------------------------|---------------------------------------------|
| Kenderaan sendiri: <input type="checkbox"/> | Pengangkutan awam: <input type="checkbox"/> |
| Kereta <input type="checkbox"/>             | Bas <input type="checkbox"/>                |
| Lori <input type="checkbox"/>               | Taxi <input type="checkbox"/>               |
| Van <input type="checkbox"/>                | Van <input type="checkbox"/>                |
| Motosikal <input type="checkbox"/>          | Lain lain (sila nyatakan): _____            |
| Basikal <input type="checkbox"/>            |                                             |
| Lain lain (sila nyatakan): _____            |                                             |

(9) Adakah anak anda terima elaun daripada jabatan seperti di bawah?

- |                                  | Tidak                    | Ya , Sila nyatakan amaun diterima: |
|----------------------------------|--------------------------|------------------------------------|
| i. Jabatan Pendidikan            | <input type="checkbox"/> | <input type="checkbox"/> RM ____   |
| ii. Jabatan Kebajikan Masyarakat | <input type="checkbox"/> | <input type="checkbox"/> RM ____   |

(10) Berkaitan dengan anak anak anda :

- i. Umur anak sulung: \_\_\_\_\_ tahun
- ii. Umur anak bongsu: \_\_\_\_\_ tahun
- iii. Umur anak yang ada Down's syndrome: \_\_\_\_\_ tahun
- iv. Jumlah nombor anak anak yang anda ada: \_\_\_\_\_

**Seksyen (II): Soalan berkaitan dengan penjagaan dan perkembangan anak anda: (tandaikan (√) dalam kotak yang bersesuaian untuk jawapan anda.**

(11) Siapa lagi yang tolong anda menjaga anak yang ada Down's syndrome selain daripada suami? (Anda boleh tandakan lebih dari satu kotak)

- |                      |                          |
|----------------------|--------------------------|
| Tidak ada orang lain | <input type="checkbox"/> |
| Nenek anak           | <input type="checkbox"/> |
| Adik-beradik anak    | <input type="checkbox"/> |
| Auntie anak          | <input type="checkbox"/> |

(12) Bagaimanakah anda mendapat maklumat berkaitan dengan jagaan anak yang ada Down's syndrome.?

- |                                   | Ya                       | Tidak                    |
|-----------------------------------|--------------------------|--------------------------|
| i. Tanya doctor pakar kanak kanak | <input type="checkbox"/> | <input type="checkbox"/> |
| ii. Tanya jururawat di klinik     | <input type="checkbox"/> | <input type="checkbox"/> |
| iii. Cari dari laman web          | <input type="checkbox"/> | <input type="checkbox"/> |
| iv. Baca dari surat khabar        | <input type="checkbox"/> | <input type="checkbox"/> |
| v. Baca dari buku                 | <input type="checkbox"/> | <input type="checkbox"/> |
| vi. Tanya kawan dan saudara       | <input type="checkbox"/> | <input type="checkbox"/> |

(13) Bila saya berkommunikasi dengan anak, biasanya saya gunakan:

- |                              | Ya                       | Tidak                    |
|------------------------------|--------------------------|--------------------------|
| i Bahasa isyarat             | <input type="checkbox"/> | <input type="checkbox"/> |
| ii Bertutur dengan perkataan | <input type="checkbox"/> | <input type="checkbox"/> |
| iii Kad bergambar            | <input type="checkbox"/> | <input type="checkbox"/> |

(14) Berkaitan dengan perkembangan anak yang ada Down's syndrome: (tandaikan √ pada  yang bersesuaian:

- | Anak saya boleh                                         | Ya                       | Tidak                    | Sejak umur |
|---------------------------------------------------------|--------------------------|--------------------------|------------|
| vi. Berjalan                                            | <input type="checkbox"/> | <input type="checkbox"/> | ____ tahun |
| vii. Mengawal diri dalam pembuangan air kencing.        | <input type="checkbox"/> | <input type="checkbox"/> | ____ tahun |
| viii. Mengawal diri dalam pembuangan air besar          | <input type="checkbox"/> | <input type="checkbox"/> | ____ tahun |
| ix. bertutur dengan menggunakan kurang dari 5 perkataan | <input type="checkbox"/> | <input type="checkbox"/> | ____ tahun |
| x. bertutur dengan menggunakan lebih dari 5 perkataan.  | <input type="checkbox"/> | <input type="checkbox"/> | ____ tahun |

(15) Tandakan program intervensi atau sekolah yang dihadiri oleh anak anda:

- |                                                |                          |
|------------------------------------------------|--------------------------|
| Pusat pemulihan dalam komuniti (PDK)           | <input type="checkbox"/> |
| Pemulihan dalam klinik (CBR)                   | <input type="checkbox"/> |
| Program intervensi awal (badan bukan kerajaan) | <input type="checkbox"/> |
| Progran Integrasi pendidikan khas sekolah      | <input type="checkbox"/> |
| Sekolah pendidikan khas (badan bukan kerajaan) | <input type="checkbox"/> |
| Satu pun tidak ada                             | <input type="checkbox"/> |

(16) Selepas lahir, adakah anak anda menerima rawatan pakar dan rawatan susulan daripada doktor pakar untuk masalah kesihatan yang berikut?

- |                                      | Ya                       | Tidak                    |
|--------------------------------------|--------------------------|--------------------------|
| i. Masalah jantung                   | <input type="checkbox"/> | <input type="checkbox"/> |
| ii. Masalah telinga                  | <input type="checkbox"/> | <input type="checkbox"/> |
| iii. Masalah mata                    | <input type="checkbox"/> | <input type="checkbox"/> |
| iv. Masalah pernafasan               | <input type="checkbox"/> | <input type="checkbox"/> |
| v. Masalah bahagian usus (rektal)    | <input type="checkbox"/> | <input type="checkbox"/> |
| vi. Lain lain (sila nyatakan): _____ |                          |                          |

### **Sekysen III:**

Soalan-soalan berikut bertanyakan tentang perasaan anda terhadap kualiti kehidupan anda, kesihatan dan beberapa aspek tertentu dalam kehidupan anda **sepanjang empat minggu yang lepas**. Sila jawab semua soalan. Tandakan (✓) pada nombor yang bersesuaian dengan jawapan anda.

		Sangat tidak baik	Tidak baik	Sederhana	Baik	Sangat baik
1.	Bagaimanakah anda menilai kualiti kehidupan anda?	1	2	3	4	5

		Sangat tidak berpuas hati	Tidak Berpuas hati	Sederhana	Berpuas Hati	Sangat Berpuas hati
2.	Setakat manakah anda berpuas hati dengan kesihatan anda?	1	2	3	4	5

Soalan-soalan berikutnya bertanyakan tentang berapa banyakkah anda telah mengalami sesuatu perkara **dalam empat minggu yang lepas**:

		Tiada langsung	Sedikit sahaja	Sederhana	Sangat banyak	Teramat banyak
3.	Setakat manakah anda berasa kesakitan (fizikal) menghalang anda dari melakukan apa yang anda perlu lakukan?	1	2	3	4	5
4.	Berapa banyakkah rawatan perubatan yang anda perlu untuk berfungsi dalam kehidupan harian anda?	1	2	3	4	5
5.	Berapa banyakkah anda menikmati keseronokan dalam hidup anda?	1	2	3	4	5
6.	Setakat manakah anda rasa hidup anda bermakna?	1	2	3	4	5
		Tiada langsung	Sedikit sahaja	Sederhana	Sangat banyak	Teramat banyak
7.	Berapa baikkah anda dapat memberi tumpuan?	1	2	3	4	5
8.	Berapa selamatkah anda rasa dalam kehidupan seharian anda?	1	2	3	4	5
9.	Berapa sihatkah persekitaran fizikal anda?	1	2	3	4	5

Soalan-soalan berikutnya bertanyakan **bagaimana sempurnanya** anda mengalami atau berupaya melakukan sesuatu perkara dalam **empat minggu yang lepas**:

		Tiada langsung	Sedikit Sahaja	Sederhana	Kebanyak - kannya	Sepenuh nya
10.	Adakah anda mempunyai cukup tenaga untuk kehidupan harian anda?	1	2	3	4	5
11.	Adakah anda dapat menerima rupa dan bentuk tubuh anda?	1	2	3	4	5
12.	Adakah anda mempunyai wang yang cukup untuk memenuhi keperluan anda?	1	2	3	4	5
13.	Setakat manakah kemudahan bagi anda untuk mendapatkan maklumat yang diperlukan dalam kehidupan harian?	1	2	3	4	5
14.	Setakat manakah anda mendapat peluang untuk aktiviti riadah?	1	2	3	4	5

		Sangat Tidak Baik	Tidak Baik	Sederhana	Baik	Sangat Baik
15.	Sebaik manakah keupayaan anda bergerak dari satu tempat ke satu tempat yang lain?	1	2	3	4	5

Soalan-soalan berikut bertanyakan tentang perasaan anda terhadap beberapa aspek tertentu dalam kehidupan anda **sepanjang empat minggu yang lepas**:

		Sangat Tidak Berpuas Hati	Tidak Berpuas Hati	Sederhana	Berpuas Hati	Sangat Berpuas Hati
16.	Adakah anda berpuas hati dengan tidur anda?	1	2	3	4	5
17.	Adakah anda berpuas hati dengan keupayaan anda melaksanakan aktiviti kehidupan harian anda?	1	2	3	4	5
18.	Adakah anda berpuas hati dengan keupayaan anda bekerja?	1	2	3	4	5
19.	Adakah anda berpuas hati dengan diri anda?	1	2	3	4	5
20.	Adakah anda berpuas hati dengan perhubungan peribadi anda?	1	2	3	4	5
21.	Adakah anda berpuas hati dengan kehidupan seks anda?	1	2	3	4	5
22.	Adakah anda berpuas hati dengan sokongan yang anda dapati dari kawan-kawan anda?	1	2	3	4	5
23.	Adakah anda berpuas hati dengan keadaan tempat tinggal anda?	1	2	3	4	5
24.	Adakah anda berpuas hati dengan kemudahan mendapatkan perkhidmatan kesihatan ?	1	2	3	4	5
25.	Adakah anda berpuas hati dengan pengangkutan anda?	1	2	3	4	5

Soalan berikut merujuk kepada kekerapan anda merasa atau mengalami sesuatu emosi **sepanjang empat minggu yang lepas**:

		Tidak pernah	Jarang jarang	Kerap	Sangat kerap	Sentiasa
26.	Berapa kerapkah anda mempunyai perasaan perasaan negatif, seperti susah hati, kecewa, kegelisahan atau kemurungan?	1	2	3	4	5

**Adakah anda mempunyai sebarang maklumbalas tentang soal-jawab ini?**

---



---

**TERIMA KASIH ATAS KERJASAMA DAN PERTOLONGAN ANDA**

## (c) Questionnaires in Mandarin

### 第一节：背景资料：

请写下您的答案或剔✓在最适当答案的空格(□)里：

(1) 母亲的年        岁

(2) 种族:

马来人

华人

伊班人

比达友人

其他(请注明):                   

(3) 最高学历:

小学 UPSR

中学 PMR

中学 SPM

文凭

大学

其他(请注明):                   

(4) 婚姻状况:

已婚

单身

离婚

丧偶

分居

(5) 宗教:

回教

基督教

佛教

没有宗教

其他(请注明):



- (6) 职业
- 全职家庭主妇
- 政府公务员
- 私营公司雇员
- 自己的业务
- 其他 (请注明): \_\_\_\_\_

- (7) 家庭每月收入:
- RM 500 以下
- RM501-1000
- RM1001-2000
- RM2001-3000
- RM 3001-4000
- RM4001-5000
- RM5001 以上

(8) 家人使用的交通工具:

- |                  |                          |                 |                          |
|------------------|--------------------------|-----------------|--------------------------|
| 私家车::            | <input type="checkbox"/> | 公共交通:           | <input type="checkbox"/> |
| 汽车               | <input type="checkbox"/> | 巴士              | <input type="checkbox"/> |
| 罗里               | <input type="checkbox"/> | 的士              | <input type="checkbox"/> |
| 货车               | <input type="checkbox"/> | 载客货车            | <input type="checkbox"/> |
| 电单车              | <input type="checkbox"/> | 其他 (请注明): _____ |                          |
| 脚踏车              | <input type="checkbox"/> |                 |                          |
| 其他 (请注明):: _____ |                          |                 |                          |

(9) 您孩子是否有从以下部门领受津贴?

- |           | 没有                       | 有, 请写下领受数额: (RM)         |          |
|-----------|--------------------------|--------------------------|----------|
| i. 教育局    | <input type="checkbox"/> | <input type="checkbox"/> | RM _____ |
| ii. 社会关怀局 | <input type="checkbox"/> | <input type="checkbox"/> | RM _____ |

(10) 有关 孩子的:

- i. 长子年龄: \_\_\_\_ 岁
- ii. 幼子年龄: \_\_\_\_ 岁
- iii. 患唐氏症的孩子年龄: \_\_\_\_ 岁.
- iv. 孩子的总数: \_\_\_\_ 个

第二节：有关儿童保健和发展的问题：请写下您的答案或剔√在最适当答案的空格 里

(11) 除了你的丈夫， 还有谁帮助您照顾唐氏症孩子？

- |         |                          |
|---------|--------------------------|
| 没有其他人   | <input type="checkbox"/> |
| 孩子的祖母   | <input type="checkbox"/> |
| 孩子的兄弟姐妹 | <input type="checkbox"/> |
| 孩子的阿姨   | <input type="checkbox"/> |

(12) 您是怎样发现有关照顾唐氏症孩子的服务资料??

- |               | 有                        | 没有                       |
|---------------|--------------------------|--------------------------|
| i. 咨询儿科医生     | <input type="checkbox"/> | <input type="checkbox"/> |
| ii. 咨询诊所护士    | <input type="checkbox"/> | <input type="checkbox"/> |
| iii. 互联网网站搜索  | <input type="checkbox"/> | <input type="checkbox"/> |
| iv. 阅读报纸      | <input type="checkbox"/> | <input type="checkbox"/> |
| v. 阅读书本       | <input type="checkbox"/> | <input type="checkbox"/> |
| Vi 向朋友和亲戚索取资料 | <input type="checkbox"/> | <input type="checkbox"/> |

(13) 您与孩子的沟通模式

- |            | 有                        | 没有                       |
|------------|--------------------------|--------------------------|
| i. 使用手语    | <input type="checkbox"/> | <input type="checkbox"/> |
| ii. 使用语言对话 | <input type="checkbox"/> | <input type="checkbox"/> |
| iii. 使用图片卡 | <input type="checkbox"/> | <input type="checkbox"/> |

(14) 有关 患唐氏症的孩子的发展

- | 孩子能够                 | 不能够                      | 能够                       | 年龄是:  |
|----------------------|--------------------------|--------------------------|-------|
| i. 步行                | <input type="checkbox"/> | <input type="checkbox"/> | ___ 岁 |
| ii. 控制上厕所的需要 (排尿)    | <input type="checkbox"/> | <input type="checkbox"/> | ___ 岁 |
| iii. 控制上厕所的需要(大便)    | <input type="checkbox"/> | <input type="checkbox"/> | ___ 岁 |
| iv. 能够使用字词对话(少过五个字词) | <input type="checkbox"/> | <input type="checkbox"/> | ___ 岁 |
| v. 能够使用字词对话(多过五个字词)  | <input type="checkbox"/> | <input type="checkbox"/> | ___ 岁 |

(15) 请指出您的孩子所参加的康复（干预）计划“或”学校教育：

- 以诊所为基础的康复中心
- 以社区为基础的康复中心
- 早期干预计划（非政府组织）
- 学校综合特殊教育（政府资助）
- 非政府特殊教育学校
- 根本是没有

(16) 自出生后，您的孩子有否下列 *健康问题*，需要任何专科治疗以及后续治疗？

- |                   | 有                        | 否                        |
|-------------------|--------------------------|--------------------------|
| i. 心脏问题           | <input type="checkbox"/> | <input type="checkbox"/> |
| ii. 耳朵问题          | <input type="checkbox"/> | <input type="checkbox"/> |
| iii. 眼睛问题         | <input type="checkbox"/> | <input type="checkbox"/> |
| iv. 呼吸问题          | <input type="checkbox"/> | <input type="checkbox"/> |
| v. 直肠问题           | <input type="checkbox"/> | <input type="checkbox"/> |
| vi. 其他（请注明）：_____ |                          |                          |

### 第三节:

以下问题涉及您对生活质量、健康、或生活其他方面的看法。请您做出选择。请在最适当的格子勾(√)您的答案。如果您暂时不能确定,则头脑中的第一反应往往是最正确的。

所有问题都请您按照自己的标准、愿望或自己的感觉来回答。注意所有问题都是您最近4周内的情况。

		很差	差	一般	好	很好
1.	您如何评价您的生活质量?	1	2	3	4	5

		非常 不满意	不满 意	一般	满意	很满意
2.	您对自己健康状况满意吗?	1	2	3	4	5

下列问题是有您在过去4周中经历某些事情的感觉:

		根本没有	有点	中等	很大	极其
3.	您因躯体疼痛而妨碍您去做需要做的事感到有多烦恼?	1	2	3	4	5
4.	您对保持日常生活的医学治疗的需求程度有多大?	1	2	3	4	5
5.	您觉得生活有乐趣吗?	1	2	3	4	5
6.	您觉得自己的生活有意义吗?	1	2	3	4	5

		根本不	有点	中等	很大	极其
7.	您能集中注意力吗?	1	2	3	4	5
8.	日常生活中您感觉安全吗?	1	2	3	4	5
9.	您的生活环境对健康好吗?	1	2	3	4	5

下列问题有关您在过去4周中做某些事情的能力。

		根本没有	有点	中等	多数有(能)	完全有
10.	您有充沛的精力去应付日常生活吗?	1	2	3	4	5
11.	您认为自己的外形过得去吗?	1	2	3	4	5
12.	您有足够的钱来满足您的需要吗?	1	2	3	4	5
13.	在日常生活中,您需要的信息都能得到吗?	1	2	3	4	5
14.	您有机会进行休闲活动吗?	1	2	3	4	5

		很差	差	一般	好	很好
15	您行动的能力如何?	1	2	3	4	5

		非常不满意	不满意	一般	满意	很满意
16.	您对自己的睡眠情况满意吗?	1	2	3	4	5
17.	您对自己做日常生活事情的能力满意吗?	1	2	3	4	5
18.	您对自己的工作能力满意吗?	1	2	3	4	5
19.	您对自己满意吗?	1	2	3	4	5
20.	您对自己的人际关系满意吗?	1	2	3	4	5
21.	您对自己的性生活满意吗?	1	2	3	4	5
22.	您对自己从朋友那里得到的支持满意吗?	1	2	3	4	5
23.	您对自己居住地的条件满意吗?	1	2	3	4	5
24.	您对您能享受到的卫生保健服务满意吗?	1	2	3	4	5
25.	您对自己的交通情况满意吗?	1	2	3	4	5

下列问题是关于您在过去 4 周中经历某些事情的频繁程度:

		从不	很少	有时	经常	总是
26.	您有消极感受吗? 如情绪低落、绝望、焦虑、忧郁。	1	2	3	4	5

请您填写提供 (如有) 任何方面的意见或建议:

---



---

**非常感谢您的时间和对本次调查研究工作的精力。**

### **Instrumentation C: Computer assisted qualitative data analysis software NVivo 7.0**

**NVivo (7.0):** a Computer Assisted Qualitative Data Analysis Software (CAQDAS) which has made the qualitative data management and analysis procedure much easier due to the various software features. Textual data from interview transcripts which were processed and saved in rich text files could be easily imported into NVivo 7.0 as documents for data coding and further text formatting purposes. It has many of the versatile features which made the supposedly tedious task of coding easier. These include features such as ‘code and retrieve’, ‘uncode’, ‘merge’, ‘highlight’ of coded items and ‘show nodes coding items’ within one document (transcript).

The availability and use of computer assisted qualitative data analysis software (CAQDAS) NVivo 7.0 (QSR International, 2009) had made the qualitative data management and analysis procedure much easier due to the various software features. Textual data from interview transcripts which were processed and saved in rich text files were imported into NVivo 7.0 as documents for data coding and further text formatting purposes. It has many of the versatile features which made the supposedly tedious task of coding easier. These include features such as ‘code and retrieve’, ‘uncode’, ‘merge’, ‘highlight’ of coded items and ‘show nodes coding items’ within one transcript document (Boeije, 2010, QSR International, 2009).

It has features such as ‘showing of all the coded segments of selected data’ from within one document which allows an overview of all coded segments. ‘Showing coding references’ allows the data source where data segments can be located from across the whole data set (Boeije, 2010). The criticism about coding with the computer software that ‘retrieved segments of data were de-contextualized’, or taken out of the context did not

hold any truth, however, as the various NVivo 7.0 features enabled retrieval of the various ‘referenced’ data segments “to enable the locating of the original source document to view its context” (Boeije, 2010, p. 144).

Besides these, there was the flexibility of writing annotations at any segment of the main text while reading through it, and writing memos, which could then be linked to a particular node or on its own regarding any thoughts or reflections that arise during the course of data analysis. The software with the many features makes many of the repetitive and mechanical aspects of qualitative data analysis easier and more efficient. It removed much of the stress and tedium of data analysis (Jones, 2007).

Concerning the use of computer software in qualitative data analysis, while it facilitated the management and analysis process efficiently, it is to be cautioned that the technical aspect of its usage could be challenging at the initial period in learning to use the software. When came to a time when the computer hard ware encountered problem and the unit of computer needed to be replaced, the hassle of re-installation of the software program and compatibility issue was an issue of concern (Jones, 2007).

## **Glossary of terms**

- 1. Coping resources:** include: physical resources—health, energy, stamina; utilitarian resources—finance, employment, housing; social resources—social networks and support systems; psychological resources—belief systems, problem solving skills, personality (Folkman, 1984 cited in Slopper et al., 1991, p.656).
- 2. Coping strategies:** the cognitive and behavioral efforts used to manage a stressful situation, and to manage the negative emotions that result from the stressful situation'. Refers to what people do to manage stressful events or situations in their lives. It includes any attempt or effort to manage stress, regardless of how well it works (Paster, Brandwein & Walsh, 2009, p. 1338).
- 3. 'Feng Shui':** an ancient Chinese belief which uses the law of Heaven and Earth to help one improve life (Marie, 2007).
- 4. Household income:** refers to the average gross income earned by all income recipients of the household per month.
- 5. Household:** it is defined as a group of people, living together, pooling their financial resources and eating from the same pot.
- 6. Quality of life (QOL):** In this study, QOL refers to individuals' perceptions of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns"; it is related to



the individuals' perceived physical health, psychological well being, social relationship with others, and their environmental support.

- 7. Resilience:** “a term to mean that some individuals have a relatively good psychological outcome despite suffering risk experiences that would be expected to bring about a serious outcome. 'Resilience is an interactive concept that refers to a relative resistance to environmental risk, experiences, or the overcoming of stress or adversity. It is the positive behavioral patterns and functional competence individuals and families demonstrate under stressful or adverse circumstances, which determine the family's ability to recover by maintaining integrity as a unit while ensuring and, where necessary, restoring the well-being of family members and the family unit as a whole” (McCubbin, Thompson, and McCubbin, 1996 in Van Riper, 2007, p.117).
  
- 8. Rural:** It refers to the large and isolated region of a country, often with low population density (email communication with Sarawak Land & Survey Department @ email address tseusk@sarawaknet.gov.my, 2 May, 2010). In the present study, some of the participants were accessed from the smaller, rural administrative districts of Bau, Lundu, Asajaya and Serian which are categorized as rural regions within the Kuching and Samarahan Divisions of Sarawak (Sarawak, State Planning Unit. (2009). The rural region or locality, in comparison with the urban, have less socio-economic structures such as residential buildings, limited road access, limited public transport system, commercial and industrial activities.

- 9. Urban:** It refers to the more built-up area of a region. Settlements are usually zoned or designated as urban once they have grown large enough to support the components of socio-economic structures such as residential, commercial and industries which are not rural in nature. However, no common figure can be put on the *necessary size as settlements function differently in different countries/areas due to local circumstances* (email communication with Sarawak Land & Survey Department @ email address tseusk@sarawaknet.gov.my, 2 May, 2010).
- 10. Social support network:** defined as including those relationships and larger societal interactions occurring outside the nuclear family system, such as friends, other parents, church, or support group; it functions primarily to nurture and sustain linkages among persons who are supportive on an everyday basis, and in times of need or crisis (Grant & Ramcharan, 2001).
- 11. Social support:** a coping resource (the availability & quality) and a coping strategy (the usage of it as a mean of coping) (Resch, et al., 2010, p. 182); defined in relation to physical and emotional content, attitude transmission and information sharing (Grant & Ramcharan, 2001).
- 12. Stigma:** a discrediting attribute assigned by society to those who differ in some manner from society's expectations, customs, and mores. It results from a social categorization process that allows for the quick identification of those who are similar and those who are different and can therefore be considered as "others"; the coupling of negative value judgments with particular characteristics that results in

an adverse reaction to difference. The adverse reaction takes the form of discrimination, or beliefs, attitudes, and actions directed at individuals due to “phenotypic characteristics or ethnic group affiliation” that result in disparate life chances or unequal outcomes (McHatton & Correa, 2005).

**13. Perspectives:** a way of regarding facts and their relative importance, point of view.

## Appendix A

Table 1.1 Statistics of Down's syndrome (new cases) from year 2004-2006

	Year		
	2006	2005	2004
	N (%)	N (%)	N (%)
Children with special needs (new cases)	2538 (100)	2681 (100)	2752 (100)
Causes: <b>Down's syndrome</b>	596 (24)	665 (25)	640 (23)
Distribution among Malaysian states:			
Sarawak state	62 (10.4)	117 (18)	187 (29)
Selangor state	32 (5.4)	199 (30)	67 (10)

Note: Statistics from year 2004 to year 2006: reported new cases of *Kanak Kanak Berkeperluan Khas (Children with Special needs)* in Malaysia for 0-12 years old (as registered in the Family Health Division, Ministry of Health Malaysia)

Source: Information System & Documentation Unit, Ministry of Health, Malaysia.  
Retrieved 4 August 2008, from  
[http://fh.moh.gov.my/uploads/laporan\\_tahunan\\_kesihatan\\_keluarga.pdf](http://fh.moh.gov.my/uploads/laporan_tahunan_kesihatan_keluarga.pdf).

**Appendix B: Sarawak Facts and Figure 2009**

**ADMINISTRATIVE DIVISIONS AND DISTRICTS**

<b>DIVISION</b>	<b>DISTRICTS</b>	<b>SUBDISTRICTS</b>	<b>DIVISION</b>	<b>DISTRICTS</b>	<b>SUBDISTRICTS</b>
<b>KUCHING</b>	Kuching Bau Lundu	Padawan  Sematan	<b>SIBU</b>	Sibu Kanowit Selangau	
<b>SAMARAHAN</b>	Samarahan Asajaya Serian Simunjan	Tebedu Sebuyau	<b>MUKAH</b>	Mukah Dalat Daro Matu	Balingian Oya Belawai Igan
<b>SRI AMAN</b>	Sri Aman Lubok Antu	Lingga, Pantu Engkilili	<b>BINTULU</b>	Bintulu Tatau	Sebauh
<b>BETONG</b>	Betong  Saratok	Maludam, Debak, Spaoh, Pusa Kabong, Roban, Budu	<b>KAPIT</b>	Kapit Belaga Song	Ng. Merit Sg. Asap
<b>SARIKEI</b>	Sarikei Meradong Julau Pakan		<b>MIRI</b>	Miri  Marudi	Sibuti Niah-Suai Beluru, Long Lama
			<b>LIMBANG</b>	Limbang Lawas	Ng. Medamit Sundar, Trusan

Source: Sarawak State Planning Unit (2009)

## FACTS ON SARAWAK

<b>TOTAL AREA</b>	: 124,449 square kilometres
<b>LOCATION</b>	: Between latitude 0° 50' and 5° N and longitude 109° 36' and 115° 40' E
<b>SYSTEM OF GOVERNMENT</b>	: Parliamentary democracy with a constitutional monarch
<b>CAPITAL OF SARAWAK</b>	: Kuching
<b>MAJOR ETHNIC GROUPS</b>	: Malay, Iban, Chinese, Bidayuh, Melanau, Orang Ulu, Indian, and other indigenous groups
<b>MAJOR LANGUAGES</b>	: Malay (official language), English, Mandarin, Iban, others local dialects
<b>MAJOR RELIGIONS</b>	: Islam (official religion), Buddhism, Christian, and Hindu
<b>TIME</b>	: GMT + 8 hours : US Eastern Standard Time + 13 hours
<b>CLIMATE</b>	: Tropical : warm and sunny throughout the year. Daily temperature range from 33° C (90° F) in the afternoon to 22° C (70° F) during the night.
<b>CURRENCY</b>	: Ringgit Malaysia (RM) which is divided in 100 cent.
<b>EXCHANGE RATE</b>	: Pegged at US\$1 = RM3.80 on 2 September 1998. Ringgit depeg on 21 July 2005. US\$1 = RM3.60 for January - May 2009

Source: Sarawak State Planning Unit (2009)

## Appendix C

### Keyword combinations used for the literature searches:

- ('behavioral problems' AND 'parental stress' AND (child OR children) AND Down's syndrome)
- ('perceived health' AND (parents OR mothers) AND ( child OR children) AND 'Down's syndrome')
- (mothers OR parents) AND (children OR child) AND ('Down's syndrome' OR disabilities) AND experience AND 'quality of life' AND ('care provision' OR 'care giving' OR care)
- ALL(The impact on mothers of bringing up a child with intellectual disabilities a cross-cultural study)
- ((parents OR mothers) AND child AND (disability OR "down's syndrome")) AND "psychological well-being"
- ((mothers AND child AND Down's syndrome AND pregnancy) AND fear AND recurrence)
- (('self-blame AND guilt' AND (child OR children) AND disabilities AND parents) AND Down's syndrome)
- ('environmental supports' AND (parents OR care-giver) AND (child OR children) AND disability AND needs)
- ('formal support services' AND (child OR children) AND (disability OR disabilities) AND (parents OR mothers))
- ('quality of life' AND definition)

**Appendix D: Summary of key articles reviewed**

<b>Author/Title/ year/country</b>	<b>Focus of study</b>	<b>Study design</b>	<b>Conclusions</b>	<b>Limitations</b>
1. Azar & Badr (2010). Predictors of coping in parents of children with an intellectual disability: comparison between Lebanese mothers and fathers. (Middle-east)	Exploring predictors of coping in parents of children with an intellectual disability:	- comparison study between 101 Lebanese mothers and 46 fathers of children with disabilities, using parenting stress index and coping health inventory.	Social acceptance and supports to parents of child with disability was reported to be more directly associated to their stress regardless of severity of child's disability; higher parenting stress index was related to lower level of informal social support.	Those fathers who were not the main care givers of the child, but they reported similar level of stress; quantitative study approach did not permit further probing.



Table 2.1, continued

<p>2. Beck, A., &amp; et al. (2004). Pro-social behaviour and behaviour problems independently predict maternal stress. (UK)</p>	<p>Aims to find out whether child's behavior problem is related to maternal stress level.</p>	<p>74 mothers and their children with intellectual disabilities. (26 had a diagnosis of Down syndrome) were assessed using: Vineland Adaptive Behavior Scale (VABS/ Strengths and Difficulties Questionnaire/ Hospital Anxiety and Depression scale/ Parenting Stress Index/ Dysfunctional Parent-Child Interactions</p>	<p>-child's behaviour problems were an independent positive predictor of maternal stress, the child's pro-social behaviour was a negative predictor of maternal stress, Thus, mothers of children with intellectual disabilities at most risk of stress may be those whose children show high levels of behaviour problems and also a lack of pro-social behavior.</p>	<p>Recruitment method led to the participation of mothers from more socioeconomically advantaged backgrounds only.</p>
<p>3. Buzatto, L. L. &amp; Beresin, R. (2008). Quality of life of Parents with Down's syndrome Children. A Brazilian study</p>	<p>To study the QOL of parents who have children with DS, and to verify the influence that the care of these children has on the QoL of their parents.</p>	<p>Descriptive study: on a sample of 30 parents of child having DS. Using the WHOQOL-BREF questionnaire.</p>	<p>QOL was described as good by 60% of sample. There were 12 responses of which 58.3% reported about major involvement with the education and care of the children, which resulted in satisfaction. The psychological domain had the lowest score in the QOL evaluation.</p>	<p>The complexity of parental experiences related to care giving of child with disabilities, using quantification process to obtain a QOL score is a limited way of gaining understanding.</p>

Table 2.1, continued

<p>4. Chang, M.Y. &amp; McConkey, R. (2008). Perceptions and Experiences of Taiwanese Parents who have Children with an Intellectual Disability.</p>	<p>Exploring perceptions and experiences of parents who have children with an intellectual disability.</p>	<p>117 parents (98 mothers and 19 fathers) of child having various intellectual disabilities, whose aged ranged between 7 and 17 years old were interviewed.</p>	<p>-findings of strengthened family cohesiveness, appreciation of life and opportunity for growth and achievement though some indicated stress and pessimism about the future reported.</p>	<p>- not stated how long data collection took place using interviews which took two to three hours for each participant. - participants of the study were self-selected and hence sample could not be assumed to be representative.</p>
<p>5. Dyson, L. (2010). Unanticipated effects of children with learning disabilities on their families. (Canada )</p>	<p>To examine the unanticipated effects that children with learning disabilities have on the life of their families.</p>	<p>Eleven parents of students aged 8 to 16 years old participated in two separate focus group interviews.</p>	<p>Findings showed that children with learning disabilities had a range of effects on their families. These included family stress, parenting discrepancies, negative reactions from extended family members, difficulty in interacting with the school, and mixed effects upon siblings. Patterns of family coping also emerged.</p>	
<p>6. Ekas, et al. (2009). Religiosity, spirituality &amp; socio-emotional functioning in mothers of children with autistic disorder.</p>	<p>to examine the effects of religious beliefs, activities, and spirituality as coping resources in parents of child with disability .</p>	<p>questionnaire study among 119 mothers (95% Caucasian) of children with disability ( USA)</p>	<p>Findings indicated that higher scores on the religious beliefs and spirituality measures were associated with higher scores in self esteem, life satisfaction, positive life events, positive affect, psychological well-being, optimism, and internal locus of control.</p>	<p>-quantitative approach of study is a limited way of gaining further understanding the topic; whereas qualitative approach using open-ended questions would provide individualized, in-depth findings.</p>

Table 2.1, continued

<p>7. Green (2007) We're tired, not sad": benefits and burdens of mothering a child with a disability. USA</p>	<p>-exploring aspects of experience of mothering child</p>	<p>-mixed method research approach in which quantitative measure 'Perceived Stigma' was used to survey among the 81 mothers, and interviewing with seven of them.</p>	<p>-most of them moved beyond the initial grief or sadness relatively soon after the initial trauma to move on to love and care for their child.</p>	<p>- limitation in generalization of findings as only those participants whose children were receiving some form of therapy services during the time of the survey were recruited, and thus those who were not receiving therapy were not represented.</p>
<p>8. Gupta, V. B. (2007). Comparison of Parenting Stress in Different Developmental Disabilities. (USA study)</p>	<p>To explore the relation between the type of disability and parenting stress.</p>	<p>Parenting stress data on the Parenting Stress Index (PSI) were collected from parents of four cohorts of children: 50 children with ADHD, 28 children with developmental disabilities, 46 children with medical conditions and 22 typically developing children (control).</p>	<p>Parents of children with disruptive behaviors (ADHD) and parents of children with developmental disabilities (DD) reported higher total stress than parents of children with typically developing children. High scores in the isolation domain are produced when the parents are socially isolated from formal and informal emotional support systems.</p>	

Table 2.1, continued

<p>9. Hatton &amp; Emerson (2009). Does socioeconomic position moderate the impact of child behavior problems on maternal health in South Asian families with a child with intellectual disabilities? (UK)</p>	<p>To examine the moderating effect of socioeconomic position on parental health.</p>	<p>123 South Asian (mostly of Pakistani) mothers (who were materially disadvantaged and having a child with intellectual disabilities) were assessed with various parental mental health measures, and all were interviewer-assisted.</p>	<p>-the lack of economic or material resources had strong association with families' perceived dissatisfaction with life, higher levels of psychological stress, and decreased level of well-being.</p>	
<p>10. Hastings, R. P, Kellyanne, R. &amp; et al. (2002). Factors Related to Positive Perceptions in mothers of Children with Intellectual Disabilities</p>	<p>To explore the factors related to the mothers' positive perceptions of their child with intellectual disability. (UK)</p>	<p>Mothers of 41 children with intellectual disabilities completed a self-report questionnaire that measured demographic factors, child demographic variables (including care-giving demand), social support, coping strategies and dimensions of positive perceptions.</p>	<p>Mothers' perceptions of the child as a source of happiness/fulfillment and as a source of strength and family closeness were positively associated with reframing coping strategies. Mothers' perceptions of the child as a source of personal growth and maturity were also positively associated with reframing coping strategies, the helpfulness and usefulness of support from family and friends, and the care-giving demand.</p>	

Table 2.1, continued

<p>11. Hedov, G., Anneren, G. &amp; Wilblad, K. (2000). Self-perceived health in Swedish parents of children with DS.</p>	<p>To investigate the self perceived health of parents of children with DS. (Swedish)</p>	<p>Questionnaire study using the Swedish version of the SF-36 exploring the 8 different life domains. among 165 parents of 86 children with DS and a control group of parents of children without DS.</p>	<p>Mothers of children had significantly lower, less favorable scores than did the fathers of DS children in the vitality domain. DS mothers spent more time in caring for child with DS than the fathers (P&lt;0.001). DS mothers also had lower scores than mothers of control group in vitality and mental health domains (P&lt;0.001). It is concluded that DS mothers showed poorer health than their spouses and the control mothers.</p>	
<p>12. Hsieh, R. L. &amp; et al. (2009). Quality of life, health satisfaction and family impact on caregivers of children with developmental delays</p>	<p>To study the quality of life, health satisfaction and family impact on caregivers of children with developmental delay. (Taiwan)</p>	<p>Cross-sectional study, main caregivers of 48 male and 22 female children with developmental delays were recruited. WHOQOL-BREF for health-related quality of life (HRQOL), other quantitative measures were evaluated.</p>	<p>The HRQOL of Chinese main caregivers (mostly mothers) with developmental delays was not affected by the sex and age of children, parental age, employment status, family structure or the children's developmental domains. Participants from the nuclear family had higher score than that of the extended family.</p>	<p>In view of complexity of parental responses and impacts related to care giving of child with various disabilities or developmental delay, using quantification process to obtain findings in term of a score is a limited way of gaining further understanding.</p>
<p>13. Kate, K. &amp; Sinéad, M. (2007). Caring for children with learning disabilities: exploratory study of parental strain</p>	<p>Exploring parental of children with disabilities &amp; their strain &amp; coping. (Ireland)</p>	<p>32 parents of children (&lt;16) with learning disabilities completed the Caregiver Strain Questionnaire, an adapted version of the Carers Questionnaire; Qualitative analysis examined factors affecting carers ability.</p>	<p>Participants showed high levels of objective and subjective caregiver strain and most were receiving inadequate support. However, parents employed a range of strategies to help them cope more effectively. The qualitative data highlighted the difficulties and rewards of care-giving and the inadequacies of current service provision.</p>	

Table 2.1, continued

<p>14. Kearney P.M. &amp; Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. (Australian)</p>	<p>This study explored the experiences of parents who have children with significant developmental disability.</p>	<p>Using an interpretive methodology informed by phenomenology, intensively explored the experiences of six parents of children with significant developmental disability</p>	<p>Although they experienced much anguish and sorrow, the parents also spoke of hope, love, strength and joy. Parents' experiences revealed the themes of 'joy and sorrow', 'hope and no hope', mediated by 'the tensions': findings provides insight and understanding into the parents' experiences and has implications for practice, education and research in nursing.</p>	
<p>15. Kenny &amp; McGilloway (2007). Caring for children with learning disabilities: an exploratory study of parental strain and coping. (Irish)</p>	<p>To explore the nature and consequences of care and coping of parents of child with learning disabilities.</p>	<p>- 24 mothers and 8 fathers of child with learning disabilities were assessed using mainly the Caregiver Strain Questionnaire and adapted version of the Carers Questionnaire.</p>	<p>The majority of the parents indicated their tiredness and strained related to care giving of the child.</p>	<p>- using quantitative measures to obtain a summative score is a limited way of gaining further understanding related to care giving experience; generalization of findings with a relatively small sample size is cautioned.</p>

Table 2.1, continued

<p>16. King, G. A. &amp; et al. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or DS (Canadian)</p>	<p>investigation of changes in the belief systems of families of children with autism or Down syndrome</p>	<p>-focus groups were 15 parents (12 mothers and 3 fathers) of children with autism spectrum conditions or Down syndrome, and 4 service providers working in the childhood disability field. Ethics.</p>	<p>Although parents may grapple with lost dreams, over time positive adaptations occurred in the form of changed world views concerning life and disability, and an appreciation of the positive contributions made by children to family members and society as a whole.</p>	
<p>17. Lam, L.W. &amp; Mackenzie, A.E. (2002). Coping with a child with Down Syndrome: the experiences of mothers in Hong Kong.</p>	<p>Chinese mothers' experiences of parenting a child with Down syndrome were explored.</p>	<p>through semi-structured interviews with 18 key informants whose children diagnosed with Down syndrome and aged between 2 and 6 years selected by purposive sampling.</p>	<p>Seven major themes were identified: unexpected birth of an abnormal child, (shock) acceptance of the child, special needs of the child, worry about the future, knowledge deficit, effect on the marital relationship, and social restriction</p>	<p>Recruitment of key informants whose children diagnosed with Down syndrome and aged between 2 and 6 years implied those experiences immediately after child's birth would not be explored.</p>
<p>18. Larson, E. (1998). Reframing the meaning of disability to families: the embrace of paradox</p>	<p>Study of occupation and subjective wellbeing of mothers of children with disabilities.</p>	<p>Case study: in-depth study of 6 Mexican origin mothers of children with disabilities. (USA)</p>	<p>Mothers expressed apparently contradictory emotions of grief and joy, hope and fear that influenced their subjective well being.</p>	

Table 2.1, continued

<p>19. Lindblad, et al., (2007). A life enriching togetherness-meanings of informal support when being a parent of child with disability. Sweden</p>	<p>Exploring informal supports received by parents of child with disability.</p>	<p>-using in-depth interviews with eight mothers and five fathers of child having disability;</p>	<p>-significant supports came from the grandparents of children with disabilities in the provision of a broad range of practical helps such as child minding and emotional supports, with maternal grandparents provided more support than paternal grandparents, and grandmothers provided more support than grandfathers.</p>	
<p>20. Lloyd &amp; Rosman (2005). Exploring mental health outcomes for low-income mothers of children with special needs: implications for policy and practice.</p>	<p>Exploring the mental health outcomes for low-income mothers of children with special needs.</p>	<p>A case study among a few singled, unsupported mothers of child with disability;</p>	<p>- financial strain of the lower income group parents parenting a child with disability was exacerbated due to reduced earning, and extra financial burden related to accessing needed service of various therapies for child, for transportation and for babysitting of other siblings.</p>	



Table 2.1, continued

<p>21. Margalit, M., Ankonina, D. B. (1991). Positive and negative affect in parenting disabled children. (Israel study)</p>	<p>To explore the positive and negative affect in parenting of disabled children.</p>	<p>Quantitative survey : Parental affect (positive and negative), coping strategies (active and avoidant), and family climate (relationships, personal growth, and system maintenance) among 71 families with disabled children were compared (using MANCOVA) to parental measures of 77 families with nondisabled children,</p>	<p>-significant differences: Parents of disabled children reported higher levels of negative (distressed) affect, adopted more avoidant coping strategies, and differed in their familial interrelations and the opportunities for personal growth available to them in their families.</p>	
<p>22. Masood, A. F., Turner, L. A. &amp; Baxter, A. (2007). Causal attributions and parental attitudes toward children with disabilities in the United States and Pakistan.</p>	<p>explored parents' causal attribution for their child's disabilities</p>	<p>A cross-cultural study; 60 parents from Pakistan and 45 from the USA recruited; using questionnaires and open-ended questions.</p>	<p>More Pakistani than the USA parents reported self-blame such as 'something I did or did not do' or as sins' punishment, besides being their fate or the will of God. Parents from the USA who had different educational levels attributed child's disabilities to causes such as inheritance, medical problems during pregnancy and birth, and God's will.</p>	

Table 2.1, continued

<p>23. McConkey, R. &amp; et al. (2008). The impact on mothers of bringing up a child with intellectual disabilities: a cross-cultural study</p>	<p>Exploring the impact on mothers of bringing up a child with intellectual disabilities</p>	<p>-mixed method study: recruited 209 mothers of child having intellectual disabilities, inclusive of the Irish (30%; n=62), Taiwanese (47%; n=98) and Jordanian (23%; n=49). The 12-item Family functioning scale, questionnaire on resources and stress and the General Health Questionnaire were used.</p>	<p>Among the three groups of mothers from the different cultures and settings, mothers had poorer family functioning whose children have higher levels of problem behaviours. Maternal mental health was poorer in single mothers, and those who experienced greater child-related stress</p>	
<p>24. Minder K. Parthama. (2007). Speech problems of Malay Down's syndrome children</p>	<p>To explore on the language-communication of children with DS (Malaysia)</p>	<p>(N=14) children with DS was explored regarding problem of language development in which recommendations were made for emphasis on interventional program in this aspect for these children.</p>	<p>Though capable of producing nearly all the consonantal phonemes, correct production of the consonants are limited to a particular position within the words; phonological process which account for speech errors of children with DS are similar to DS children's of other language. This supports the view that mis-articulation are the results of deviant and delay in language development.</p>	

Table 2.1, continued

<p>25. Moyle, J., Iacono, T. &amp; Liddell, M. (2006). Experiences of Parents of Children with Development Delays in Obtaining Assessment and Diagnosis from Med Practitioner (Malaysia)</p>	<p>What parents think about traditional beliefs about the cause of child's disabilities, sources they received advice</p>	<p>Questionnaire survey/ parents from EIP (with children with different learning disabilities, including DS)</p>	<p>Parents thought about the traditional beliefs about causes of child's disability were: fate; bad Feng Shui, family curse; spirits, stayed near a poison factory husband went fishing- killing living thing brings a curse, punishment for wrong acts of parents, punishment for eating something forbidden, exposure to animals when pregnant; watching a movie about disability when pregnant; baby brought it upon himself. Parent perceptions of attitudes toward disability in community were generally negative.</p>	
<p>26. Myers, B. J., Mackintosh, V. H. &amp; Goin-Kochel, R. P. (2009). 'My greatest joy and my greatest heartache'. (USA)</p>	<p>To find out how having a child in the autism spectrum has affected their lives and their families' lives</p>	<p>Using an online questionnaire to the question, 'How has your child in the autism spectrum affected your life and your family's life?' (N = 493). Analysis using a qualitative content analysis,</p>	<p>15 negative themes and 9 positive themes were identified. Themes are subsumed into five clusters: Stress; Child's behavior; Parents' personal well being, work, and marital relationship; Impact on the whole family; and Social isolation. The mix of negative and positive themes is interpreted as a dialectical viewpoint of finding positive meaning to life even while acknowledging the stress and difficulties of having a child with autism.</p>	

Table 2.1, continued

<p>27. Mugno, D., Ruta, L., Arrigo, V.G. &amp; Mazzone, L. (2007). Impairment of QOL in parents of children and adolescent with pervasive developmental disorder (Italy)</p>	<p>To evaluate the QOL in parents of children affected by developmental disorders as compared with a control group.</p>	<p>Using the WHOQOL-BREF questionnaire: 212 parents (115 mothers and 97 fathers) of 135 children affected developmental disorders were recruited; 77 parents (42 mothers and 35 fathers of 48 healthy children were included as control group.</p>	<p>Parents of children with developmental disorders display a higher burden; a significant impairment of QOL as compared to the control group; suggested that policy making to take into consideration this to provide better and more specific supports and interventions for this group of parents.</p>	
<p>28. Olsson, M. B. &amp; Hwang, C. P. (2008). Socioeconomic and psychological variables as risk and protective factors for parental well-being in families of children with intellectual disabilities. (Sweden)</p>	<p>To estimate the extent to which differences in wellbeing of parents of children with and without intellectual disability (ID) in Sweden can be accounted for by differences in the presence of the risk factors.</p>	<p>Parents of children with ID (62 mothers and 49 fathers) and control children (183 mothers and 141 fathers) completed postal surveys on wellbeing, socioeconomic situation, health, sense of coherence, satisfaction with participation in different areas of life and the child's impact on the family.</p>	<p>Well-being of parents with a child with ID is dependent upon the interplay of risk and protective factors .</p>	

Table 2.1, continued

<p>29. Ong, et al, (1998). Parenting stress among mothers of Malaysian children with cerebral palsy: predictors of child and parent-related stress.</p>	<p>To examine parenting stress among mothers of children with disability due to cerebral palsy  (Malaysian study)</p>	<p>Hospital survey study among 87 mothers of children with C.P, and a control group of children without CP; questionnaire using Parenting Stress Index associated with child and parent domain stress.</p>	<p>Mothers of children with CP scored significantly higher than control subjects on all sub scales of CDS and PDS (P&lt;0.01); increased care giving demands, low education level and ethnicity (Chinese) are modifying factors.</p>	<p>Complex parental response related to impacts of care giving child on families may be measured only superficially by one quantification process to obtain an index on a questionnaire.</p>
<p>30. Ong, L. C., Chandran, V., &amp; Peng, R. (1999). Stress experienced by mothers of Malaysian children with mental retardation. (Malaysian study)</p>	<p>To examine parenting stress among mothers of children with mental retardation</p>	<p>Hospital survey study using self-administered Parental Stress Index (PSI) which yielded the child and parent-domain stress scores among 75 mothers of child with mental retardation and 75 mothers of child without disability as control.</p>	<p>Mothers who were unemployed, Chinese ethnicity, intelligence quotient and number of siblings were significant predictors of stress.</p>	<p>Parental experiences related to care giving child may be measured only superficially by one quantification process using a questionnaire. Parental experiences of child with DS maybe different from disability of other origin.</p>

Table 2.1, continued

<p>31. Plant, K. M. &amp; Sanders, M. R. (2007). Predictors of stress in care-giver stress in families of children with developmental disabilities.</p>	<p>examine the predictors, of stress in families of preschool-aged children with disability</p>	<p>One hundred and five mothers of preschool-aged children with developmental disability completed assessment measures addressing the key variables. (Australia).</p>	<p>Difficulty of care-giving tasks, difficult child behaviour during care-giving tasks, and level of child disability are the primary factors which contribute to parent stress.).</p>	<p>This study had the constraints in recruiting enough fathers as participants, and so findings did not include data from the fathers.</p>
<p>32. Resch, et al. (2010) Giving Parents a Voice: A Qualitative Study of the Challenges Experienced by Parents of Children With Disabilities</p>	<p>To explore challenges Experienced by Parents of Children With Disabilities  USA</p>	<p>-using focus group discussion among 36 mothers and four fathers of children with physical and intellectual disabilities,</p>	<p>Findings indicated that some parents' experience of distress and denial related to loss of a dream child related to child's disability.</p>	<p>- only part of the parent experience is captured in relation to data collection using a focus group discussion. Furthermore, the difference in the types of child's disabilities could influence parental experiences.</p>
<p>33. Rogers, C. (2007). Disabling a family? Emotional dilemmas experienced in becoming a parent of a child with LD</p>	<p>-to highlight some of the emotional dilemmas that parents experience. UK</p>	<p>Qualitative interview with parents (mostly mothers) of children with Down's syndrome, language difficulties, emotional and behavioural difficulties.</p>	<p>Without the right levels of support and understanding, having a child with a diagnosis of learning disability can disable the whole family.</p>	

Table 2.1, continued

<p>34. Shin &amp; et al. (2006). Parenting stress of mothers and fathers of young children with cognitive delays.</p>	<p>Examine the effects of child and family variables on stress of ppts of child with cognitive delay.</p>	<p>The mothers (n=106) and fathers (n=93) whose children (age range=3-6 years) were identified as having cognitive delays participated in the Interviewer-assisted questionnaires survey. (Vietnam.)</p>	<p>The findings revealed traditional gender roles. Mothers were more affected by the child's characteristics and the spouse's functioning; they anticipated future problems related to the child's functioning more than fathers did. Fathers were more affected by concerns about the family's connection to the wider world such as economic issues and the social support network.</p>	
<p>35. Tarakeshwar &amp; Pargament (2001). Religious coping in families of children with autism. USA</p>	<p>To explore religious coping of families of children with disability.</p>	<p>- mixed method study, involved questionnaire study with 45 parents who were mostly mothers of child with disability, and semi-structured interviews with 21 of the parents.</p>	<p>Findings showed religious beliefs were associated with greater stress-related growth, such as social relationship, personal resource and coping. Interviews finding showed that parents perceived their religious beliefs provided alternative ways of interpreting the meaning of the seemingly incomprehensible challenges of raising a child with disability.</p>	
<p>36. Van Riper, M.V. (2007). Families of children with DS: responding to 'a change in plans with resilience (U.S)</p>	<p>-to describe maternal perceptions of family adaptation in raising a child with DS..</p>	<p>Seventy-six mothers completed various mailed questionnaires</p>	<p>-most mothers reported that their family was doing well or very well. Three family variables (i.e., family demands, family resources, and family problem-solving communication) were significantly associated with family adaptation. These results provide support for the belief that many families of children with Down syndrome respond to a change of plans with resilience; they are able to endure, survive, and even thrive in the face of ongoing challenges associated with raising a child with DS.</p>	

Table 2.1, continued

<p>37. White, N. &amp; Hastings, R.P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. (UK study)</p>	<p>Aims to explore on the Social and Professional Support for Parents of Adolescents with Severe Intellectual Disabilities.</p>	<p>Thirty-three parents of adolescent children with moderate–profound intellectual disabilities completed measures of parental well-being (stress, anxiety and depression, and care-giving satisfaction), social support (informal and formal sources, and practical and emotional support), and child characteristics).</p>	<p>- parental wellbeing was associated with the child’s adaptive and problem behaviours and with the child’s diagnosis. Parents’ ratings of the helpfulness of informal sources of support (spouse, extended family, friends, etc.) was most reliably associated with parental well-being, and remained so after controlling for child characteristics.</p>	
<p>38. Worcester &amp; et al. (2008). Giving Voice to Parents of Young Children With Challenging Behavior Exceptional Children</p>	<p>Aims to give voice to parents of children with challenging behavior. (USA)</p>	<p>Qualitative interview with 7 participants include the fathers, mothers or guardians of children with various developmental delay/using interviews</p>	<p>Obtaining useful and accurate information; obtaining service and supports; financial stress; stress among members of family; community isolation. Participants reported they are being listened to and being given voice. Suggested future research: recruiting participants from various socioeconomic background;</p>	<p>Guardian’s experiences of care giving may be different from the biological parents (father or mother). Monolingual interviewer limited in recruiting participants, therefore could be biased, missed out those who are not recruited because of language criteria.</p>
<p>39. Yuen &amp; et al. (2003). QOL of parents who have Child With Disabilities.</p>	<p>To survey on QOL of parents who have children with disabilities.</p>	<p>A survey study using WHOQOL-BREF on parents of children with developmental disabilities and without disabilities (Hong Kong)</p>	<p>Parents of child with disabilities had lower QOL scores compared to control. Social life domain was affected as they spent much of their time with child’s Rx, therapy &amp; assessments; QOL were correlated to children’s level of functional independence.</p>	



## **Appendix E:**

Verification of translation of key interview guide

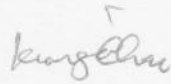
(i) from English to Bahasa Malaysia

(ii) from English to Mandarin

Dear Mr. Lis anak Chin chong,

I, Chan Kim Geok, a doctoral student from University of Malaya would like to request your assistance with the verification of translation of key interview guide from English to Bahasa Malaysia. Attached herewith is a copy of the translation. Please comment and verify regarding the accuracy of the translation in the section below.

Thank you,




Chan Kim Geok

1/4/2008

General comment:

I hereby acknowledge that the translation  
of the key interview guide is accurate.

Verification by:

Signature:  \_\_\_\_\_

Name: LIS ANAK CHIN CHONG

Date: 15/4/2008

Dear Mr. Kho Choon How,

I, Chan Kim Geok, a doctoral student from University of Malaya would like to request for your assistance with the verification of translation of key interview guide from English to Mandarin. Attached herewith is a copy of the translation. Please comment and verify regarding the accuracy of the translation in the section below.

Thank you,

*Kim Geok*

Chan Kim Geok

1/4/2008

General comment:

I hereby acknowledge that this translation  
is accurate.

Verification by:

Signature: *[Signature]*

Name: KHO CHOOH HAW

Date: 16/4/2008



**Appendix F: Verification of translation of questionnaire (Section I and II)**

**(i) from English to Bahasa Malaysia**

**(ii) from English to Mandarin**

Dear Mr. Lis anak Chin cheng,

I, Chan Kim Geok, a doctoral student from University of Malaya would like to request your assistance with the verification of translation of key interview guide from English to Bahasa Malaysia. Attached herewith is a copy of the translation. Please comment and verify regarding the accuracy of the translation in the section below.

Thank you,

Kim Geok

Chan Kim Geok

1/4/2008

General comment:

I hereby acknowledge that the translation  
of the key interview guide is accurate.

Verification by:

Signature: 

Name: LIS ANAK CHIN CHONG

Date: 15/4/2008

Dear Mr. Kho Choon How,

I, Chan Kim Geok, a doctoral student from University of Malaya would like to request for your assistance with the verification of translation of the questionnaire Part I and II from English to Mandarin. Attached herewith is a copy of the translation.

Please comment and verify regarding the accuracy of the translation in the section below.

Thank you,



Chan Kim Geok

1/4/2008

Comments:

I hereby acknowledge that this translation  
is accurate.

Verification by

Signature: 

Name: KHO CHOON HAW

Date: 18/4/2008



## **Appendix G:**

- Request for permission to use the WHOQOL-BREF

Ms Volkan, Sibel,  
Health Statistics and Informatics  
The World Health Organization  
20 Avenue Appia  
CH-1211 Geneva 27  
Switzerland  
Tel.: +41 22 791 2334  
Fax: +41 22 791 4328

Dear Ms,

**Re: WHOQOL-BREF survey**

Refer to your email on request of the Bahasa Malaysia version of the WHOQOL-BREF survey instrument dated 12/10/09.

Please find the signed copy of the 'User Agreement for WHOQOL Bref' (total of 4 pages, including this cover page).

Thank you.



Chan Kim Geok

University Malaysia Sarawak  
Faculty of Medicine and Health Sciences,  
Lot 77, Section 22, Kuching Town Land District,  
Jalan Tun Ahmad Zaidi Adruce,  
93150 Kuching, Sarawak



On Fri, Oct 23, 2009 at 11:31 PM, permissions <[permissions@who.int](mailto:permissions@who.int)> wrote:

Dear Sibel,

Could you please assist Mrs Chan in obtaining the necessary documents?

Thanks and best regards,

Carla, WHO Press

**From:** Chan Kim Geok [mailto:[kimgeokchan@gmail.com](mailto:kimgeokchan@gmail.com)]

**Sent:** Wednesday, October 21, 2009 4:09 AM

**To:** permissions

**Subject:** Re: 40534 Form to request permission to reproduce or reprint WHO copyrighted material

Dear Charla,

Thank you for your kind assistance regarding my request for the WHOQOL- BREF questionnaire.

I have sent the doc regarding 'user Agreement'.

I hope to start distributing the questionnaire on the 1/11/09.

I have a few questions to ask you:

1.How long will it take for the requested questionnaire to be sent to me? Will it be sent through the email or by post to the address we have given?

2. Will there be any problem if I have requested for the 2 version of the questionnaire (i.e. Bahasa Malaysia and Mandarin) in one form in the 'user agreement form' ?

Thank you very much for help,

Chan Kim Geok

On Wed, Oct 14, 2009 at 7:43 PM, permissions <[permissions@who.int](mailto:permissions@who.int)> wrote:

Dear Mrs Chan,

We thank you for your enquiry regarding WHOQOL-BREF survey. Please note that we are forwarding your request to the technical unit responsible for this material and the responsible officers will contact you shortly.

Should you wish to contact them directly, please send an email to [chatterjis@who.int](mailto:chatterjis@who.int) and [volkans@who.int](mailto:volkans@who.int)

Kind regards,

Carla

## **Appendix H: Information to the mothers (in three languages)**

- In English
- In Bahasa Malaysia
- In Mandarin

**(in English)**

## **Information to mothers**

**To all mothers,**

You are kindly invited to participate in this survey study titled ‘*Care-giving Experiences and Perceived Quality of life of Mothers of Child with Down’s Syndrome*’.

This survey aims to find out more about your experiences and your life as mothers in giving care to your child with Down’s Syndrome.

By participating in this study, we would like to give this opportunity to invite you to share your experiences of care giving of your child with Down’s syndrome, and to express your opinions, for the attention of those in the higher authorities concerned. We hope that this information can be disseminated to those involved in policy making for the improvement of care provision in the communities.

It is hope that this information will help to minimize any discomfort related to questions that are being asked. Your decision to answer the questionnaire is voluntary. All information given will be kept confidential and anonymous, and will be used for this survey purpose only.

Thank you very much for your time and efforts in responding to all the questions. Your contribution to this part of the survey is very much appreciated.

You are most welcomed to contact any members of the research team for clarification or additional information related to this study:

**Project leader:**

Chan Kim Geok  
Faculty of Medicine (Nursing  
Department),  
University Malaya  
Email address:  
kgchan@fmhs.unimas.my  
HP: 016-8709494

**Supervisor of project**

Dr. Khatijah Lim Abdullah  
Faculty of Medicine (Nursing  
Department),  
University Malaya  
Email address:  
katlim@um.edu.my  
HP: 016-3609146

**Co-supervisor of project:**

Dr Ling How Kee  
Faculty of Social Sciences  
University Malaysia Sarawak  
Email address:  
[lhkee@fss.unimas.my](mailto:lhkee@fss.unimas.my)  
HP: 0138181522



Ref: (65) UPN/S/G1/110.Vol.11



**(In Bahasa Malaysia)**

## **Maklumat kepada ibu ibu**

**Kepada ibu ibu yang dihormati:**

Puan,

Anda dijemput untuk mengambil bahagian dalam soal selidik yang bertajuk '*Kualiti Kehidupan Ibu ibu kepada Anak yang ada Down's Syndrome*' dengan menjawab soalan yang di dalam kertas soal-jawab ini.

Tujuan soal selidik ini adalah untuk memahami sedikit sebanyak tentang kualiti kehidupan seseorang ibu kepada anak yang ada Down's syndrome.

Dengan mengambil bahagian dalam soal selidik ini, anda diberi peluang untuk berkongsi pengalaman menjaga anak yang ada Down's syndrome, dan juga mengemukakan pendapat anda. Kami berharap supaya kefahaman dan pengetahuan ini dapat dimaklumkan kepada pihak atasan yang berkaitan dan mereka yang terlibat dalam pembentukan polisi, supaya dapat memperbaiki lagi perkhidmatan penjagaan dalam komuniti.

Di harap penerangan dan maklumat yang diberi di sini dapat mengurangkan sebarang ketidakselesaan berkaitan dengan soalan yang ditanya dalam kertas soal-jawab ini. Keputusan anda untuk menjawab kertas soal-jawab ini adalah sukarela dan sangatlah dihargai. Semua maklumat yang diberi akan disimpan rahsiakan dan hanya untuk tujuan kajian ini saja, dan hanya penyelidik yang berkenaan yang mengetahui maklumat tersebut.

Diucapkan banyak terima kasih atas masa dan usaha anda untuk menjawab semua soalan. Sumbangan anda terhadap kaji selidik ini amatlah dihargai.

Sila menghubungi ahli projek selidik yang di bawah untuk sebarang penjelasan yang lanjut berkaitan dengan kajian ini:

**Ketua Projek**

Chan Kim Geok  
Faculty of Medicine (Nursing  
Department),  
University Malaya  
Email address:  
kgchan@fmhs.unimas.my  
HP: 016-8709494

**Penyelia Projek**

Dr. Khatijah Lim Abdullah  
Faculty of Medicine (Nursing  
Department),  
University Malaya  
Email address:  
katlim@um.edu.my  
HP: 016-3609146

**Penyelia Projek Bersama:**

Dr Ling How Kee  
Faculty of Social Sciences  
University Malaysia Sarawak  
Email address:  
[lhkee@fss.unimas.my](mailto:lhkee@fss.unimas.my)  
HP: 0138181522



**(In Mandarin)**

## 给母亲们的信

亲爱的母亲们,

您被邀请参加本次调查问卷, 让我们了解更多关于您的经验和身为唐氏症儿童患者母亲的生活经历.

通过回答问卷调查的研究, 也让您有机会分享您的经验和说出您所遇到的问题. 我们希望能够把所得到资料和信息传达给那些在社区里参与决策和护理的有关单位.

我们希望, 这些所得到的资料和信息将有助于减轻一些在调查问卷里提到的负担和问题.

您所参与这项回答调查问卷是自愿的. 所有的调查资料均会保密和匿名. 并只将用于这项研究为目的.

非常感谢您抽出您的时间和精力来回答所有的问题. 我们非常赞赏您对这份调查所给予的贡献.

若有需要, 您也可以与任何研究小组成员澄清或讯问与此研究相关的事项.

**研究组长:**

Chan Kim Geok  
Faculty of Medicine (Nursing  
Department),  
University Malaya  
Email address:  
kgchan@fmhs.unimas.my  
HP: 016-8709494

**研究监督员:**

Dr. Khatijah Lim Abdullah  
Faculty of Medicine (Nursing  
Department),  
University Malaya  
Email address:  
katlim@um.edu.my  
HP: 016-3609146

**研究助理监督员:**

Dr Ling How Kee  
Faculty of Social Sciences  
University Malaysia Sarawak  
Email address:  
[lhkee@fss.unimas.my](mailto:lhkee@fss.unimas.my)  
HP: 0138181522



Ref: (65) UPN/S/G1/110.Vol.11



**Appendix I: Consent form (in three languages)**

- In English
- In Bahasa Malaysia
- In Mandarin

**(in English)**

PARTICIPANT CONSENT FORM

I, .....mother of ..... of  
(name) (name of child)

.....  
(Address)

give my consent to participate in this survey titled below:

*Title of Study: Care-giving Experiences and Quality of life of mothers of Child with Down's syndrome.*

I have read (or it has been read to me) the information sheet about the nature and purpose of the study.

I understand that participation in this questionnaire is voluntary. I have also been informed that all information given will be kept confidential and anonymous, and will be used for this research purpose only.

Signature of participant: .....

Date: .....

Name .....

Signature of researcher: .....

Date: .....

Name.....



Ref: (65) UPN/S/G1/110.Vol.11



**(in Bahasa Malaysia)**

KEIZINAN UNTUK PENYERTAAN

Saya, ..... ibu kepada .....  
(Name) (Nama anak)

beralamat di .....  
(alamat)

dengan ini bersetuju menyertai dalam kajian soal-selidik yang bertajuk

*‘Kualiti Kehidupan Ibu Ibu kepada Anak yang ada Down’s Syndrome’*

Saya telah baca surat maklumat tentang tujuan kajian selidik. Saya faham bahawa penyertaan saya dalam kajian selidik ini adalah sukarela. Saya telah pun diberitahu bahawa semua maklumat yang diberi akan disimpanrahsiakan dan hanya untuk tujuan kajian ini saja, dan hanya penyelidik yang berkenaan yang mengetahui maklumat tersebut.

Tandatangan peserta.....

Tarikh: .....

Nama: .....

Tandatangan ketua projek.....

Tarikh: .....

Nama: .....



Ref: (65) UPN/S/G1/110.Vol.11





(in Mandarin)

## 参加者同意书

我, ..... 身为 ..... 的母亲  
(母亲姓名) (孩子姓名)

.....  
(地址)

同意参加以下的问卷调查:

研究题目: 唐氏症儿童患者母亲的护理经验和生活质量.

我已经详读 (或有人已为我朗读) 有关的信息表并理解研究的性质和宗旨.

据我所知, 参与这项问卷调查是自愿的. 我也被告知所有资料均会被保密和匿名, 并只将用于研究用途.

参与者签名: ..... 日期: .....

姓名: .....

研究员签名: ..... 日期: .....

姓名: .....



Ref: (65) UPN/S/G1/110.Vol.11

## **Appendix J**

### **Institutional ethics approval letters from:**

- Sarawak State Education Department
- Ministry of Education Malaysia
- Sarawak State Social Welfare Department
- Sarawak State Health Department
- Sarawak State Planning Unit



JABATAN PELAJARAN NEGERI SARAWAK  
BANGUNAN TUN DATUK PATINGGI  
TUANKU HAJI BUJANG  
JALAN SIMPANG TIGA  
93604 KUCHING  
SARAWAK

Telefon: 082-243201  
FAX: 082-246750  
Kawat : PENDIDIKAN

Ruj Kami : JPS(W)/SPPP/(Lat)153/08/02/05, Jld. 25 (28)

Tarikh : 29 JULAI 2009

**Chan Kim Geok**

448, Lorong 15, Jalan Upper Chawan,  
93300 Kuching  
Sarawak

Tuan/puan

**KEBENARAN UNTUK MENJALANKAN KAJIAN DI SEKOLAH-SEKOLAH, INSTITUT-  
INSTITUT PERGURUAN, JABATAN-JABATAN PELAJARAN DAN BAHAGIAN-  
BAHAGIAN DI BAWAH KEMENTERIAN PELAJARAN MALAYSIA**

Dengan hormatnya saya diarah merujuk kepada perkara di atas.

2. Sukacita dimaklumkan bahawa pada dasarnya Jabatan Pelajaran Negeri Sarawak tiada sebarang halangan untuk membenarkan tuan menjalankan kajian bertajuk :

**" Care-Giving Experiences Of Parents Of Children With Down's Syndrome And Their Perceived Quality Of Life"**

3. Sayugia diingatkan bahawa sepanjang tempoh kajian tersebut, tuan adalah tertakluk kepada peraturan yang sedang berkuatkuasa dan menjalankan kajian seperti tajuk yang diluluskan oleh Bahagian Perancangan dan Penyelidikan Dasar Pendidikan, Kementerian Pelajaran Malaysia bil. KP(BPPDP)603/5/JLD.07(041) bertarikh 20 Julai 2009.

4. Jabatan ini memohon agar sesalinan laporan kajian dihantar ke Unit Perkhidmatan, Latihan Dan Kemajuan Staf, Jabatan Pelajaran Negeri Sarawak sebaik sahaja selesai untuk tujuan rekod dan rujukan. Dengan surat ini, Pegawai berkenaan adalah dimohon untuk memberi bantuan dan kerjasama yang sewajarnya bagi menjayakan kajian tersebut.

Sekian. Terima kasih.

**"BERKHIDMAT UNTUK NEGARA"**

Saya yang menurut perintah,

  
[KUSWADY BIN CHIL]

Sektor Khidmat Pengurusan Dan Pembangunan  
b.p Pengarah Pelajaran  
Sarawak.

Surat Kebenaran Kajian/J... KC/NMS/GW

s.k.

Pegawai Pelajaran Daerah Kuching  
Pegawai Pelajaran Daerah Padawan  
Pegawai Pelajaran Daerah Lundu.  
Pegawai Pelajaran Daerah Bau  
Pegawai Pelajaran Daerah Samarahan  
Pegawai Pelajaran Daerah Simunjan  
Pegawai Pelajaran Daerah Serian

Guru Besar, SK Semerah Padi, Kuching  
Guru Besar, SK Rampangi, Kuching  
Guru Besar, SK Semenggok, Kuching  
Guru Besar, SK Petra Jaya, Kuching  
Guru Besar, SK Astana, Kuching  
Guru Besar, SK Buntal, Kuching  
Guru Besar, SK Bau, Kuching  
Guru Besar, SK Tan Sri Datuk Haji Mohamed, Kuching  
Guru Besar, SK Tabuan Ulu, Kuching  
Guru Besar, SK Laksamana, Kuching  
Guru Besar, SK Stungkur, Kuching  
Guru Besar, SK Bumiputera, Kuching  
Guru Besar, SK Grogo, Kuching  
Guru Besar, SK Jalan Arang, Kuching  
Guru Besar, SK Dato Mohd. Musa, Samarahan  
Guru Besar, SK Tuanku Bagus, Samarahan  
Guru Besar, SK Serian, Samarahan  
Guru Besar, SK Tebedu, Samarahan  
Guru Besar, SK Abang Man, Samarahan  
Guru Besar, SK Tuanku Bagus, Samarahan  
Guru Besar, SK Serian, Samarahan  
Guru Besar, SK Tebedu, Samarahan  
Guru Besar, Abang Man, Samarahan  
Guru Besar, SK Haji Kelali, Semera, Samarahan

Pengetua, SMK Tabuan Jaya, Kuching  
Pengetua, SMK Demak Baru, Kuching  
Pengetua, SMK Matang Jaya, Kuching  
Pengetua, SMK Tarat, Samarahan

**Fail (Latihan)**



BAHAGIAN PERANCANGAN DAN PENYELIDIKAN DASAR PENDIDIKAN  
KEMENTERIAN PELAJARAN MALAYSIA  
ARAS 1 - 4, BLOK E - 8,  
KOMPLEKS KERAJAAN PARCEL E  
PUSAT PENTADBIRAN KERAJAAN PERSEKUTUAN  
62604 PUTRAJAYA

Telefon : 03-88846591  
Faks : 03-88846579

Rujuk. kami : KP(BPPDP)603/5/JLD.7 (041 )  
Tarikh : 20 Julai 2009

Puan Chan Kim Geok  
448, Lorong 15, Jln Upper Chawan  
93300 Kuching  
Sarawak

IC: 610927135436

Tuan/Puan,

**Kelulusan Untuk Menjalankan Kajian Di Sekolah, Institut Perguruan, Jabatan Pelajaran Negeri dan Bahagian-Bahagian di Bawah Kementerian Pelajaran Malaysia**

Adalah saya dengan hormatnya diarah memaklumkan bahawa permohonan tuan/puan untuk menjalankan kajian bertajuk:

***Care-Giving Experiences Of Parents Of Children With Down's Syndrome And Their Perceived Quality Of life***

diluluskan.

2. Kelulusan ini adalah berdasarkan kepada cadangan penyelidikan dan instrumen kajian yang tuan/puan kemukakan ke Bahagian ini. Kebenaran bagi menggunakan sampel kajian perlu diperolehi dari Ketua Bahagian / Pengarah Pelajaran Negeri yang berkenaan.
3. Sila tuan/puan kemukakan ke Bahagian ini senaskah laporan akhir kajian setelah selesai kelak. Tuan/Puan juga diingatkan supaya mendapat kebenaran terlebih dahulu daripada Bahagian ini sekiranya sebahagian atau sepenuhnya dapatan kajian tersebut hendak dibentangkan di mana-mana forum atau seminar atau diumumkan kepada media

Sekian untuk makluman dan tindakan tuan/puan selanjutnya. Terima kasih.

**"BERKHIDMAT UNTUK NEGARA"**

Saya yang menurut perintah,

(DR. SOON SENG THAH)

Ketua Sektor,  
Sektor Penyelidikan dan Penilaian  
b.p. Pengarah  
Bahagian Perancangan dan Penyelidikan Dasar Pendidikan  
Kementerian Pelajaran Malaysia

s.k.

Institute Of Postgraduate Studies  
Jabatan Kejururawatan  
Universiti Malaya  
50603 Kuala Lumpur

Pengarah  
JPN Sarawak



JABATAN KEBAJIKAN MASYARAKAT NEGERI SARAWAK  
(KEMENTERIAN PEMBANGUNAN SOSIAL & URBANISASI)  
WISMA KEBAJIKAN,  
LOT 4273, BLOK 14,  
OFF JALAN SIOL KANAN,  
93050 KUCHING, SARAWAK



Kawat: "WELDEP"

Tel: 082 - 449577/444139/444152/444121/444077

Faks: 082 - 445710/448741

Ruj. Kami : JKMNS/ 30031(25)

Ruj. Tuan :

Tarikh : 2 Januari 2009

Puan Chan Kim Geok,  
448, Lorong 15, Jln Upper Chawan,  
93300 KUCHING.

Puan,

**KEBENARAN UNTUK MEMBUAT LAWATAN KE INSTITUSI KEBAJIKAN  
NEGERI DI BAHAGIAN KUCHING DAN SAMARAHAN UNTUK TUJUAN KAJIAN.**

Dengan hormatnya surat Puan bertarikh 22 Disember 2008 berhubung perkara di atas adalah dirujuk.

2. Sukacita dimaklumkan bahawa permohonan cik/puan untuk melawat institusi-institusi kebajikan Negeri untuk tujuan menjalankan kajian bagi memenuhi pengajian secara tesis adalah diluluskan.

3. Sehubungan dengan itu Puan dikehendaki untuk melengkapkan borang akuan yang berkepil dan kembalikan ke pejabat ini secepat mungkin.

Sekian, terima Kasih.

**"BERSATU BERUSAHA BERBAKTI"  
"BERKAT BERJASA"**

**(HJH NORHAYATI HJ ABDUL RAHMAN)  
b.p Pemangku Pengarah  
Jabatan Kebajikan Masyarakat Negeri Sarawak.**

ars/ars

TELAH DIFAX

PADA 5.1.2009

Sk Penolong Pengarah,  
Jabatan Kebajikan Masyarakat Bahagian, Kuching.

Penolong Pengarah,  
Jabatan Kebajikan Masyarakat Bahagian, Samarahan.

Pengerusi,  
Persatuan Bagi Kanak-Kanak Terancat Akal Sarawak (PERKATA),  
Lot 1652, Blk 10, Jalan Ridgeway,  
Off Jalan Ong Tiang Swee,  
93250 KUCHING.

Pengerusi  
Pertubuhan IbuBapa Kanak-Kanak Keperluan Istimewa Sarawak  
(PIBAKAT)  
NO.9 Jalan Ridgeway,  
Off Jalan Ong Tiang Swee,  
93250 KUCHING.

(Sesalinan surat Cik/Puan Chan Kim Geok bertarikh 22 Desember  
2008 dikepilkan bersama)





PEJABAT PENGARAH,  
(DIRECTOR'S OFFICE)  
JABATAN KESIHATAN NEGERI SARAWAK,  
(STATE HEALTH DEPARTMENT SARAWAK)  
JALAN TUN ABANG HAJI OPENG,  
(TUN ABANG HAJI OPENG ROAD)  
93590 KUCHING, SARAWAK,  
(93590 KUCHING, SARAWAK)  
MALAYSIA.

Tel : 082 - 256566  
Faks : 082 - 424959  
E-mel : shd@sarawak.health.gov.my



Ruj.kami: JKNSWK/K/QDU/2A Jld 3 (5)  
Tarikh: 7 Januari 2008

Puan Chan Kim Geok  
c/o Dr Khatijah Lim Abdullah  
Jabatan Sains Kejururawatan,  
Fakulti Perubatan,  
50603 Universiti Malaya

Puan,

**Per: Pemohonan Menjalankan Penyelidikan Di Sarawak Oleh Pn Chan Kim Geok  
Dari Jabatan Sains Kejururawatan, Fakulti Perubatan, Universiti Malaya**

Adalah saya merujuk kepada surat puan bertarikh 26 Disember 2007 mengenai perkara yang  
tersebut di atas.

Sukacita dimaklumkan bahawa Jabatan Kesihatan Negeri Sarawak tidak ada halangan  
terhadap projek penyelidikan puan bertajuk "Parents of Child with Down's Syndrome: Their  
Care-giving Experiences and the Parent-Child Communicative Pattern" dijalankan di klinik  
kesihatan ibu dan kanak-kanak di Bahagian Kuching, Samarahan dan Sri Aman.

Walaupun bagaimanapun, penyelidik perlu mematuhi syarat-syarat yang di kemukakan dalam  
Lampiran 1

Sekian terima kasih

"BERKHIDMAT UNTUK NEGARA"

"PENYAYANG, BEKERJA BERPASUKAN DAN PROFESIONALISMA A  
DALAH BUDAYA KERJA KITA"

DR ANDREW KIYU  
Pengarah Kesihatan Negeri  
Sarawak

Sk: Pegawai Kesihatan Bahagian Kuching, Samarahan & Sri Aman

copy 1-2  
cc



STATE PLANNING UNIT  
CHIEF MINISTER'S DEPARTMENT  
6<sup>th</sup> & 7<sup>th</sup> Floor, Wisma Bapa Malaysia  
93502 Kuching  
Sarawak, Malaysia



SARAWAK MAJU DALAM MALAYSIA

Tel : (6)082 – 492276/492285

Fax : (6)082 – 449481/442536

Website : <http://www.spu.sarawak.gov.my>

Our Ref. : ( 65 ) UPN/S/G1/II/10 Vol.11

Date : 08 JANUARY 2009

Chan Kim Geok  
448, Lorong 15  
Jalan Upper Chawan  
93300 Kuching, Sarawak

**URGENT**

Dear Ms Chan Kim Geok,

**APPLICATION TO CONDUCT RESEARCH IN SARAWAK**

I am pleased to inform you that approval is hereby given to enable you to conduct a research project in Sarawak entitled "Experiences of Parents during the Care-giving Process of Child With Down's Syndrome, child-parent interaction patterns and Their Perceived Quality of Life: the Malaysian Perspectives" from 01.01.2009 to 31.12.2010 (24 months).

This approval is subject to the following terms and conditions:-

- (i) The research will not involve any financial aid from the State Government of Sarawak;
- (ii) You are to complete your study within the stipulated time as indicated in this letter of approval;
- (iii) Any data provided should be used for this particular research only,
- (iii) The Government has the right to withdraw this approval should you deviate from the original scope of your study based on the application form submitted to us; and
- (iv) Upon completion of your research, printed copies of the final report of your study are to be extended free to the State Planning Unit; State Welfare Dept, Sarawak State Library, (that is designated as the State Depository Centre); and, other departments/agencies connected with your study at no cost.

Thank you.

**"BERSATU BERUSAHA BERBAKTI"**

(DATU HAJI ISMAWI BIN HAJI ISMUNI)  
Director  
State Planning Unit  
for State Secretary Sarawak

c.c: Director

State Welfare Department (your memo ref NPW 907 4 (III)-19 dated 23.07.2008 is referred)

**Appendix K: Response slip (in English)**

**Response slip**

I, ..... , mother of .....  
(child's name)

Agree/ disagree to be interviewed.

I can be reached at:

Hand phone number: .....

House/office phone number .....

Address: .....

Signature:..... Date: .....

**(in Bahasa Malaysia)**

**Slip maklumbalas**

Saya, ....., ibu kepada .....  
(nama anak)

Setuju / tidak setuju untuk ditemubuai.

Saya boleh dihubungi:

Nombor hand phone: .....

Nombor telefon (rumah/pejabat) .....

Alamat: .....

Tandatangan : ..... Tarikh: .....

## **Appendix L**

### **Preparation for conducting interview at participant's home**

1. Follow the cultural practice of the participant (mother), such as waiting to be asked to be seated, either on the floor or on the sofa.
2. Build rapport, social chat and interact with mother and child, ensure both are comfortable.
3. Introduce about my background: a registered nurse, a nursing lecturer, studying on 'experience of mothers of child having Down syndrome.
4. Explain about the purpose of the session to learn from mothers their experience and other related details, such as duration and no. of time of visits requested. Show the relevant ethic approval letters.
5. Give a copy of the 'information sheet' to mother. Obtain 'Informed Consent' from mothers after explanation for interviewing.
6. Obtain permission for audio-recording and for making brief notes.
7. Ask for other support documents which might provide a broader understanding of the mothers' care giving experience such as OKU card, child health card, hospital discharge certificate, etc.
8. Obtain related background information guided by the part I and II of the questionnaire for quantitative study (refer to Appendix on Questionnaire).
9. Conduct interview as guided by 'interview guide'.

## Appendix M: email from a participant

**Date:** Thu, 12 Mar 2009 21:56:26 +0800 [12 Mar 09 09:56 pm MYT]

**From:** Julia <julia@streamyx.com>

**To:** chankimgeok@perdana.um.edu.my

**Subject:** Re:

**Part(s):** Download All Attachments (in .zip file)

**Headers:** Show All Headers

Click [HERE](#) to view HTML content in a separate window.

1. Show tantrum when he cannot get what he wants, or when he did something that is not correct and I have to discipline him by giving him a smack with my wooden Spoon. Also when he is over demanding in his own ways and no one include the Kids who will also not give in to him .Then he will start to throw anything that is near him.

Sometimes he does it with the kids in the centre and sometimes with the family.

\*\* For your information : Jo seldom throw things around now unless he is really angry when his brother disturb him.  
Now when he is angry, he will usually just sit and not

move

I guess he had grown up to be more understanding and he can communicate with us easily . Once we understand what he wants to tell us and we are able to communicate with him,, there is no problems.

2. The other children knows who he is and understand him, they will usually give in to Him, unless we say no. Sometimes they will just live him there and let him get over. Sometimes they will use other things to cool him down and Jo will get over.
3. When he starts to show his anger by throwing things, I will let him sit at the corner on a chair . I will tell him why I punish him and reason with him. Jo can understand very well. Jo had been well train that when he is punish he will not go away from his chair unless we tell him to do so.

I should say he is Obedient at times. Praise the Lord as he had been taking Good care of Jo's life be it health or discipline.

This morning, when I fetch him home from school, Josiah's teacher told me that

he can communicate very with them now.

By the way, feel free to ask anything, as it is wonderful when we are able to share our joy with others as it will always encourage and bring joy to others.

God bless you. Take care. Matthew 25:15 - God gives gift (Jo) to me according to each one's unique and ability. God knows that I'm able to take good care of his child(Jo) and that is why he gave me Jo. These word had been given to me by my Pastor wife and had encourage me to move on. God Bless you.

-----Original Message-----

**From:** chankimgeok@perdana.um.edu.my

**Date:** 3/11/2009 10:33:45 PM

**To:** julia@streamyx.com

**Subject:** your child

Hi Julia,

Is such a good thing to get to know you, I am reflecting on those experience you had just shared with me...

Just want to further understand those experience of yours. May I ask you: when you mentioned that those plastic chairs near the tables were broken or cracked as Josiah dropped them out of anger, what actually trigger his behaviour that time? Was it during the time when he was with the other children?

How did the other children react to when they had seen Jo acted that way?

What did you do when he was in such a stage of anger?

There are lots of things that I can learn from the above.

Thank you so much for sharing with me your experience and insights and hear from you again,

Chan Kim Geok

## **Appendix N: A sample of journaling**

### **(i) interview with Ziah's parents (28/5/08)**

#### **Initial contact:**

*Initial contact with this parents (both father and mother) was made through the CBR staff as the staff had good rapport with the family who sent the child with DS to the CBR. The researcher went to the CBR in the morning to meet the father who came over to the nearby health centre adjacent to the CBR to deliver to the staff some cakes ordered from the mother as day was near to the local Gawai festival. Later researcher's car driven by the husband followed from behind his to visit and interview the family. The researcher was later left to spend time to interact and interview the family.*

#### **Description of participant, settings, details of their actions, personal impression of situations:**

*Address: Kampung Tanah Putih, 17<sup>th</sup> Mile, Siburan, Sarawak*

*Mother of Ziah (5-year-old girl with DS): age 43 years old, Malay (a Muslim).*

*Education: till Primary 3.*

*A house wife, doing a small scale domestic business by setting up a small hawker stall in front of the house in the kpg, selling keropok, sweets. She also made cake for sale during festive seasons, Gawai, Hari Raya. She had 8 children. The child, Ziah, aged 5 years old with DS is the youngest of them all.*

**The interview setting: House environment:**

Floor appeared dirty. The house was still not fully constructed, bath room did not door; wall was semi painted; father informed when they have money he would continue with the work on the house.

The house had 'open' bedroom without bed; only mattress and pillows were seen stacked up at the side of the partially partitioned room. There was a shelf with the family's clothes and a few soft toys given by people to the child. When the child wanted to sleep, she was placed on the rolled up carpet placed at the side of sitting room as a pillow to sleep.

*Thoughts: regarding their house environment, are there other things that are more important in their lives, for the day to day living than this?) To relate to the house condition with that of Hazeline from another kampong, kampong Turon, the Iban kampong, they were quite similar.*

***Other family members present***

*The mother's brother, aged > 20 years old, stayed together as part of the family was smoking on and off outside the house.*

***After the 'formal interviewing session:***

*After the actual semi-structured in-depth interviewing guided by the key interview question guide at the chairs with the mother was completed, the mother moved to the kitchen for something, while I moved to interact with the child. On seeing this, the mother moved to further informal activities while the researcher was there with the child.*



### ***Interaction: child and parents***

*When her auntie came to the house to visit them, Ziah stood in front of the door and saw her. She came in to call 'ma ma'. Mother taught her to 'salam'. She followed her teaching. The auntie called her from far: 'ba ba'. Ziah sat down with the auntie and mother.*

*She played cards with the father, took turns with the father, if she lost, she put her fist in front of the father and wait for him to grab her fist, father was really happy she was able to communicate and respond to her. She played with me and my husband who came to the house to visit her.*

*Mother sang 'jangan tunggu lama lama ' and child followed her. Child played with tambourin, mother sang; when child stopped playing, mother took over. They seems to be a happy family.*

### ***Child's previous health condition***

*Father informed that Ziah was seen by occupational therapist (OT) to make 'splint' (shoes said by father) for both feet, as she could not walk, to prevent foot-drop, ; he informed that he still keep the 'shoes' made for her by the OT; as this served to show to Ziah when she grew bigger to let her know she used it when young (he had the hope of her growing up and to know things); He said the family hard life before this, often went to SGH specialist clinic. He further informed that child started to walk at 3 years old.*

**Thought:** will request for child's health record card for further verification of child's health.

### ***Invitation for lunch***

*The researcher was invited to have lunch with the family in their house. All sat down together on the floor to have the meal over a few simple dishes. Ziah sat down next to her father and he fed her food with rice and fish. He said she like to eat fish but not crab meat or prawn; the mother also said the same thing.*

*The father said that she was 'anak istimewa' ('special child' in Bahasa Malaysia), take care of her also must be 'istimewa' ('special' in Bahasa Malaysia).*

### **Further informal conversation after lunch**

#### ***Involvement in the CBR centre***

*Mother talked about their involvement in the CBR centre: mother cooked during the recent meeting among the parents; She helped the CBR centre staff workers to take care of other children when the other two teachers went for courses.*

*They helped to raise funds through ticket sales, CD sales, biscuits sales etc to buy a van for the PDK, to pick children from various places around CBR.*

#### ***Financial burden***

*Mother could not drive, father is the one who sent the child and mother to PDK; mother normally stayed with child there. the father would pick them back again few hours later.*

*Mother informed about the need to change pampers for her child at least twice a day (morning and night). Mother informed that in order to earn some extra money to meet end needs, she set up stall in front of their kampong house to sell some junk food to people passing by. Child will be following her to the stall. During festive seasons, she made cookies, cakes for sale, to the staff in the health Clinic at RCBM, CBR and friends. She*

*had been making and selling cakes for the last 20 years; she made less now because of caring for the child with DS.*

***Child over friendly, no fear of stranger***

*The mother wanted to put Ziah to sleep on the carpeted floor, but she came close to me, bringing her own pillow, went to sleep with her 2 legs placed on my lap while I was sitting down on the chair. (thoughts: relate to what the mother informed about her concern and fear for Ziah's safety if she went out to the outside of the house, that other stranger may took her away as she was very friendly).*

***Mother was relaxed***

*While the researcher was still staying around waiting for transport to go back, she observed the mother repaired the child's soft toy (which was given by people) while child went to sleep. She then placed it near to the child at the side.*

***Reflections of researcher's social experience:***

*My effort to interact with child while she was in the participant's home had helped the participant to have more confidence and trust in the researcher. I was well received by the family: being invited to have lunch with the family was a gesture of their acceptance, friendliness and generosity. My reciprocal response in following their cultural practice (e.g. washing hands in the basin of water prepared for visitor, sitting down on the floor while eating lunch with family) in their home further established the building up of rapport with the participants, gave further opportunity to know their settings and increase the chance of hearing their 'true story'.*

**(ii) Interview session with Kho's mother (29/9/08)**

*As the CBR staff –in-charge had a good rapport with the mother, she got mother to come to meet the researcher in the CBR, though it was not scheduled for her to bring the son to the CBR. The mother did not hesitate to accept invitation for the interview. Without wasting the opportunity and the time the mother was given the explanation right away regarding the nature of the study and the objectives, which she had no problem in giving the consent to be interviewed.*

*As child was taken care of by a volunteer who was around, researcher saw the opportunity available to straight away start the interview with the mother.*

*In order to have time to interview her further in her home, I started the negotiation with mother for a time to visit them in their home, asking if it was ok to visit them in the house which she finally agreed to my request to follow her from behind while I drove my own vehicle: I supposed my ability to talk with her using a common dialect helps to build rapport and trust with her.*

**2<sup>nd</sup> visit to Ziah's home (3 days after the first visit) (30/5/08)**

***Family photos: as another source of data***

*Mother: took out the family photos to show me the family photos of Ziah from young;*

*Ziah joined in the fun of looking at the photo, she called 'mama' to get her attention;*

*She responded 'oi' while she arranged the photos. Ziah was included in their family*

*birthday celebration photo session with other sisters and brothers or of she herself alone.*

*Mother: said that while in Bintulu with her brother, he bought milk powder which she gave*

*her; she really put on weight; but came back home to kampong she lost wt, said maybe too*

*active; she informed the elder sister who worked in the nearby crocodile farm used to buy milk powder but not anymore; now she gave milo with condensed milk to Ziah, due to lack of money. Said she was surprised Ziah put on wt when given milk powder to drink. While looking at Ziah's **photos** at 7 months old, she mentioned her face looked very chubby, that time she gave S26 milk; so she changed to give breast milk.*

### ***Playing with child***

*While the mother arranged and showed the photos, Ziah sat behind me.*

*I played with her by moving with she running behind me.*

*I on and off asked if she wanted to pass urine, while she touched her pampers, mother also asked, 'mahu kencing?'; she informed that sometimes while bathing she was able to walk to toilet bowl to pass motion, but cannot inform her about it; she said this with a smile.*

*Mother suggested to bathe Ziah in the bathe room, she clung to me and refused to come down (weather was slightly cooling after the rain).*

### ***Child health card: another data source***

*The mother showed the child's child health record on my request: record indicated that child was very underweight for her age; was on follow-up care with the nearest child health clinic since last year; was given vitamins supplement and milk supply, she did not go back for follow-up again for the last few months. Child health card indicated she had cardiac abnormality (heart murmur) or patent ductus arteriosus and was on medical follow-up at hospital cardiac clinic; had been to OT follow-up and treatment.*

***Mother making choices of attendance to service provisions:***

*Choosing between clinic-based rehabilitation (interventional), or CBR centre:*

*Ziah was only brought to PDK Mambong one month ago; she went to the 10<sup>th</sup> mile child health clinic-based rehabilitation program once a month only.*

*Parents preferred to send child to CBR centre at 13<sup>th</sup> mile: more frequent attendance for 2 x's a week.*

*(Mothers' dilemma: can go by bus from Siburan to 10<sup>th</sup> mile, more convenient; more troublesome to go to CBR Mambung at 13<sup>th</sup> mile); at times she walked from the Siburan town to the kampong if nobody to send them.*

*(thoughts: parents were more interested to send child to attend program when it is more frequent. Reflecting on another participant, parent of Aryana's choice: he chose to send child to CBR instead of clinic-based program as CBR program is more frequent.*

*However, from what the parents said, there was no provision for speech related therapy in the CBR centre. Speech related activities in the clinics was also rare, according to what another mother described when she sent her child to the clinic-based rehabilitation program (more of assessment, as was said).*

*Relating to the findings about resources where participants look for information, health professionals were most sought for. Therefore, the implication for the findings is for provision of speech therapy related stimulation programs for the children with DS.*

## Appendix O: NVivo 7.0 data analysis illustrations

Figure 3.5 Coding from one document

Figure 3.6 Review the context of segments of coded text

Figure 3.7 Select a node to be merged with another node

Figure 3.8 Merging one node into another node

Figure 3.9 Uncoding

Figure 3.10 Writing memo to be linked to a selected tree node

Figure 3.11 Memo with file name 'support' was written and linked to tree node 'support network'

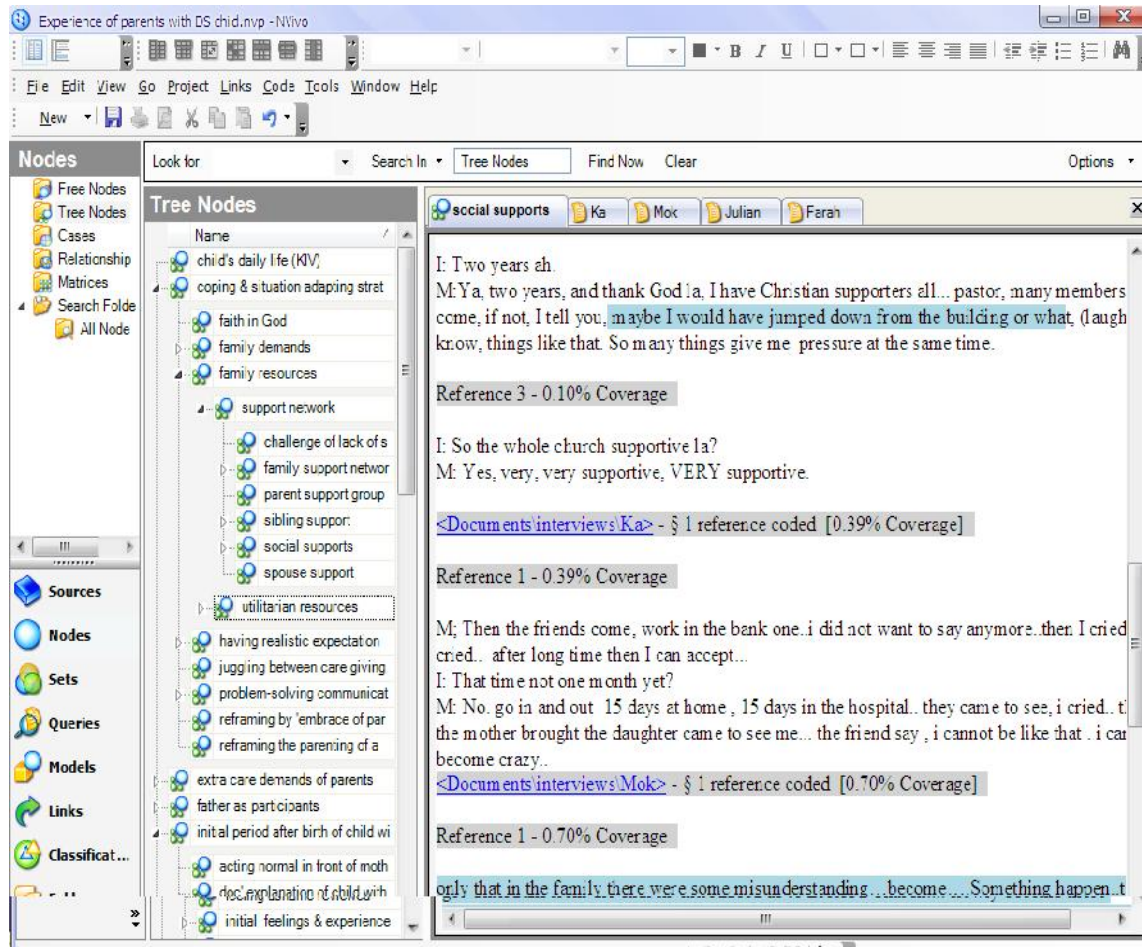


Figure 3.5 Coding from one document

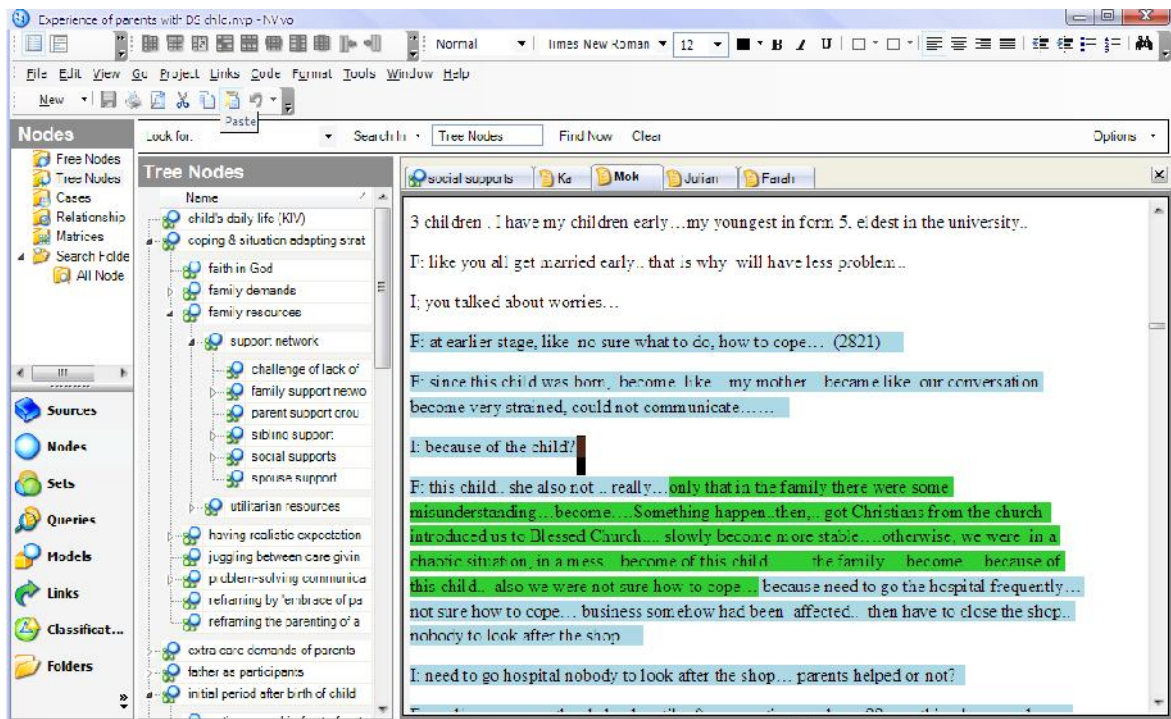


Figure 3.6 Review the context of segments of coded text

Decide on the most suitable code if two or more similar codes (synonyms) had been used by 'merging' one code into the other. E.g. the node below 'sadness' 'very sad' had been 'cut' and 'merged into the selected node 'sadness' as these two were synonyms.

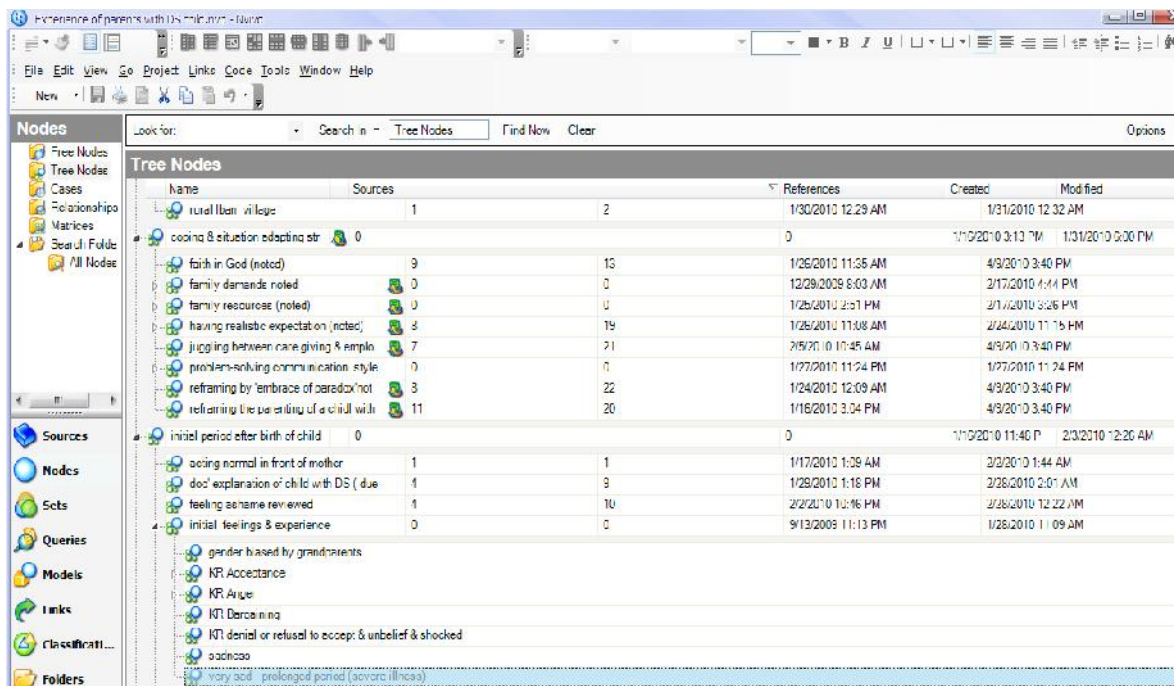


Figure 3.7 Select a node to be merged with another node



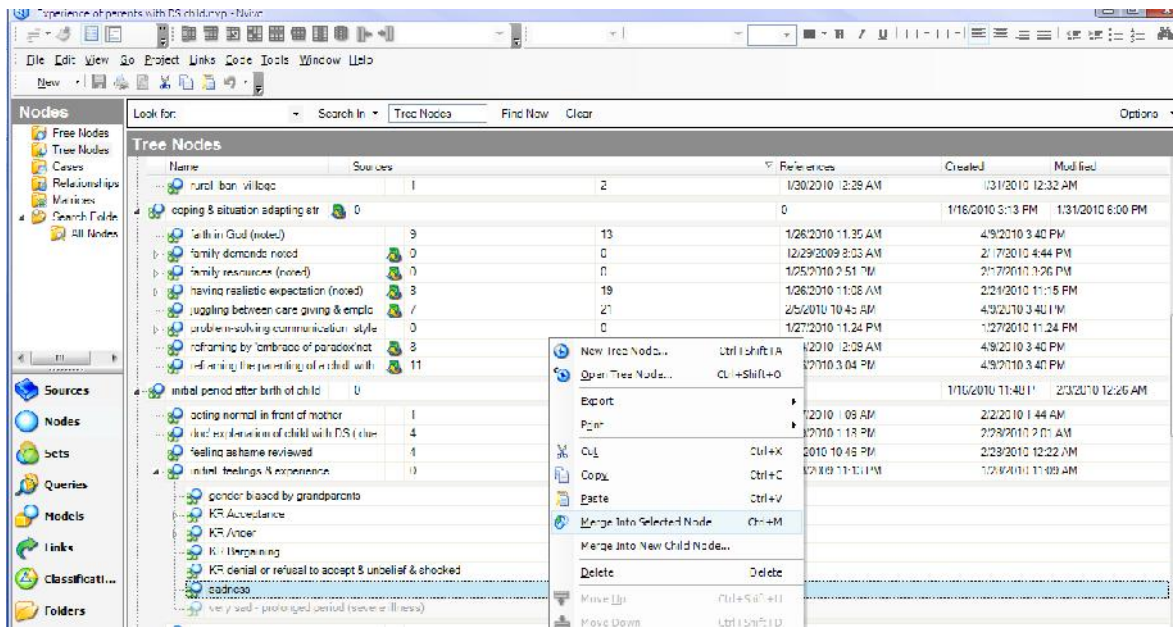


Figure 3.8 Merging one node into another node

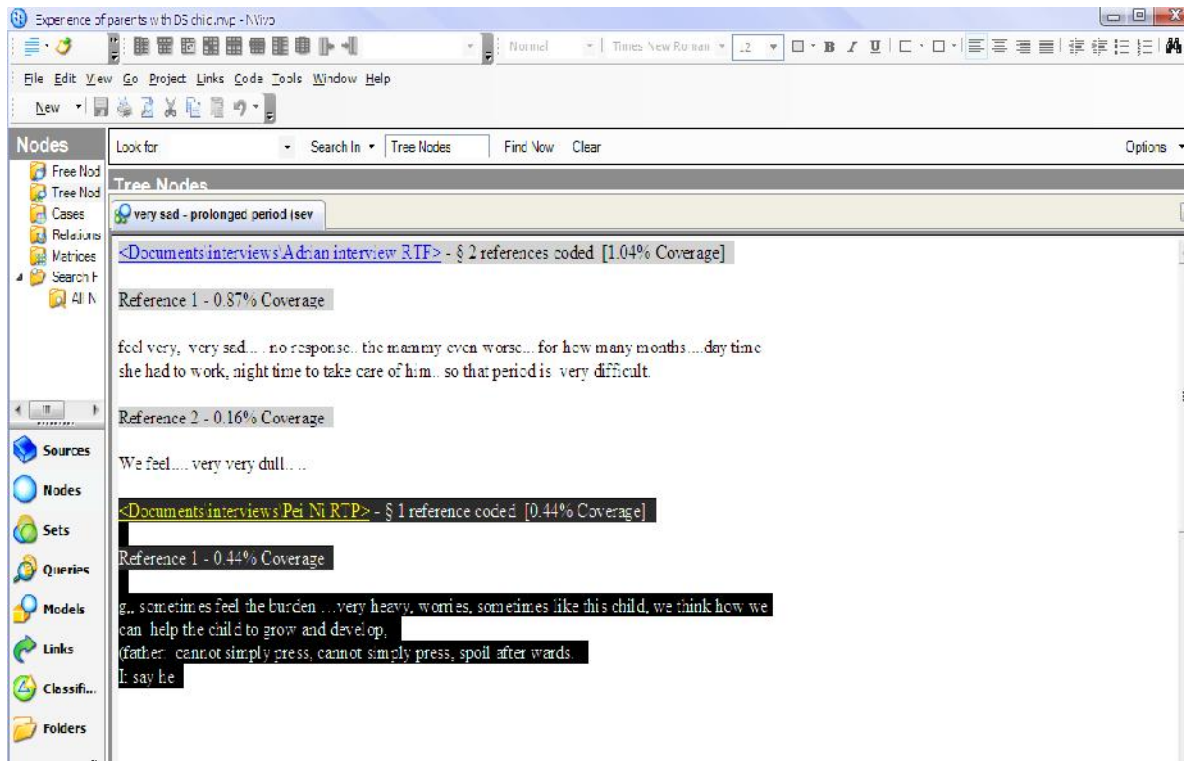


Figure 3.9 Uncoding

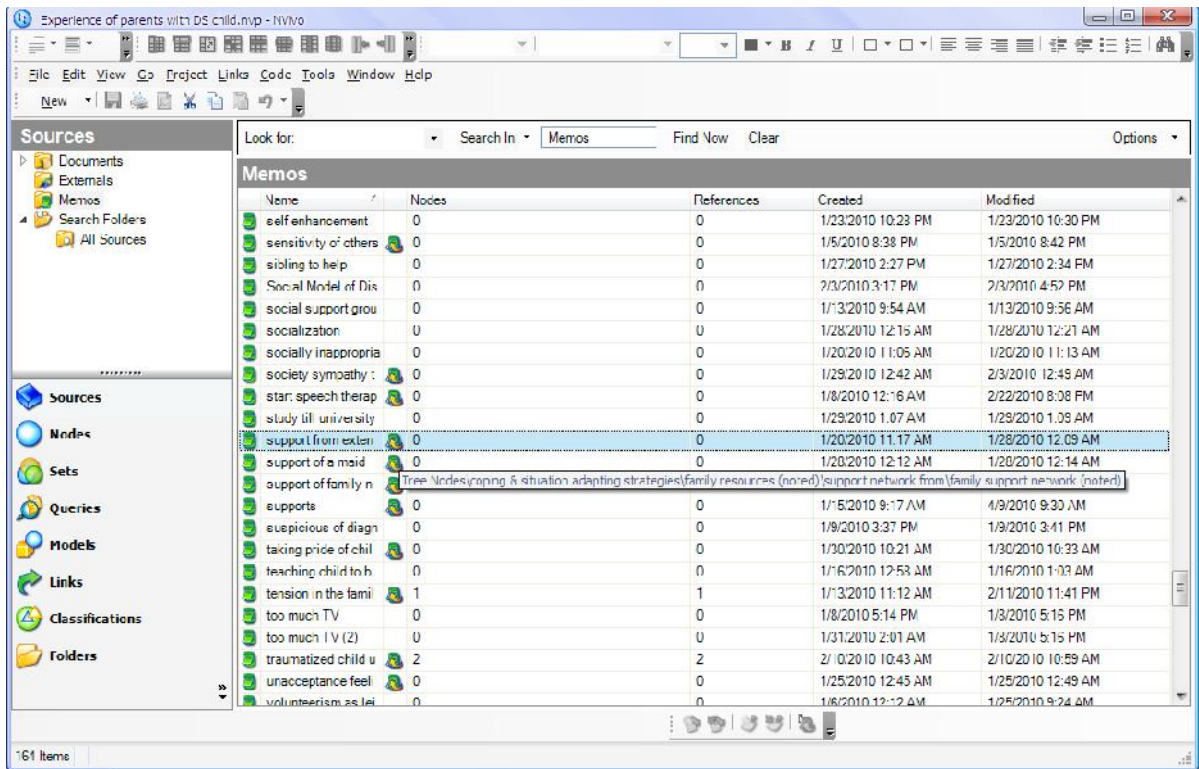


Figure 3.10 Writing memo to be linked to a selected tree node

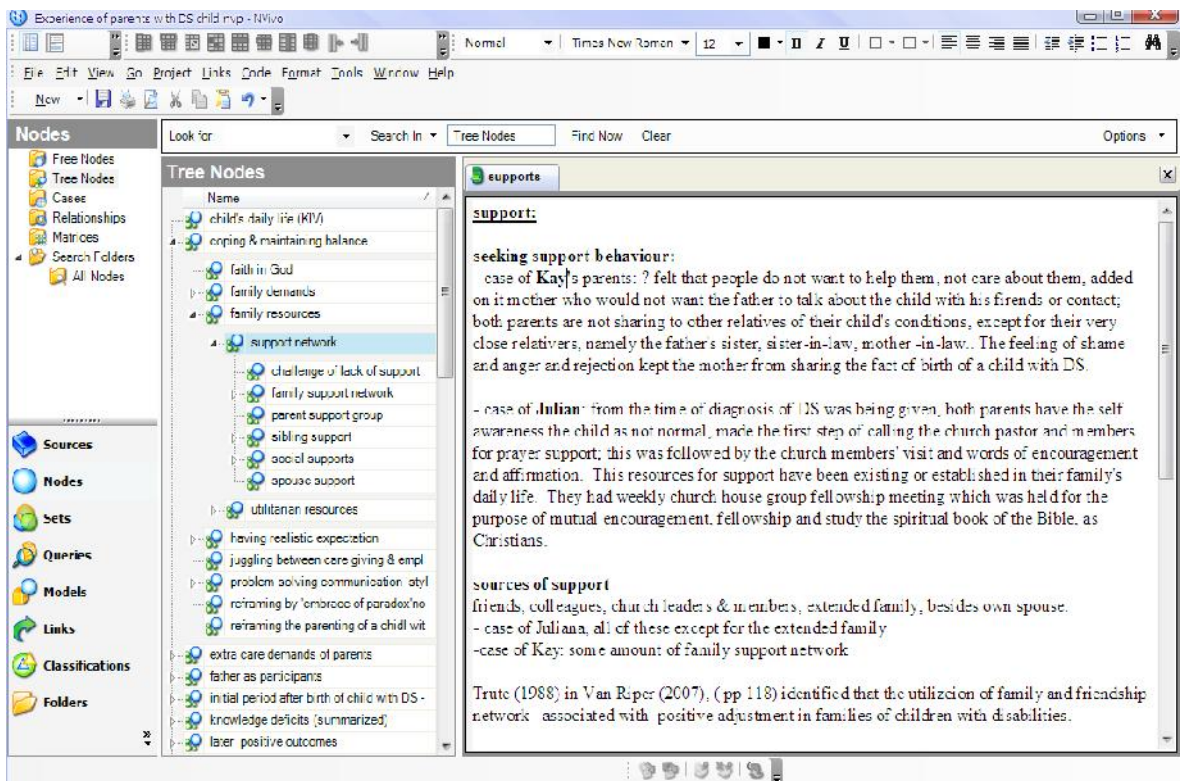


Figure 3.11 Memo with file name 'support' was written and linked to tree node 'support network'

**Appendix P: Coding summary report (p.1-4)**

**Coding Summary Report**

**Project:** Experience of parents with DS child

**Generated:** 6/16/2011 11:06 PM

**1 Adrina**

Document

**Total References 2**

<u>Node Coding</u>	<u>Tree Nodes\Initial responses\sadness</u>	<u>References</u>	<u>Coverage</u>	<b>1.03 %</b>
<i>Reference 1</i>		<i>Character Range</i>	930 - 1,112	
	feel very, very sad... no response.. the mammy even worse... for how many months....day time she had to work, night time to take care of him.. so that period is very difficult.			
<i>Reference 2</i>		<i>Character Range</i>	3,439 - 3,473	
	We feel.... very very dull..			

**17 Kua**

Document

**Total References 4**

<u>Node Coding</u>	<u>Tree Nodes\initial responses\sadness</u>	<u>References</u>	<u>Coverage</u>	<b>3.57 %</b>
<i>Reference 1</i>		<i>Character Range</i>	5,535 - 5,676	
	'it is so tough; so sad to see her suffered; I wished that I could take on the burden from her. (she shed tears as she shared about this).			
<i>Reference 2</i>		<i>Character Range</i>	5,821 - 5,965	
	..had suicidal thoughts when she was about 2 years old; ..At the beginning when I had her, I thought I was going to die...could not take it..			
<i>Reference 3</i>		<i>Character Range</i>	7,488 - 7,623	
	....had suicidal thoughts (depressed, meaninglessness of life) when she was about 2 years old; ....felt like crazy (distressed)....			
<i>Reference 4</i>		<i>Character Range</i>	8,652 - 8,720	
	M: You cry you cry alone, you laugh the whole world laugh with you..			

**16 Kay**

Document

**Total References 10**

<u>Node Coding</u>	<u>Tree Nodes\initial responses\Anger</u>	<u>References</u>	<u>Coverage</u>	<b>2.27 %</b>
<i>Reference 1</i>		<i>Character Range</i>	18,088 - 18,365	
	The male nurse also came to check me...ask where the baby was.. baby is it not in the nursery?... keep asking!.. one by one keep asking. i was already so so sad.. not that I hide the baby.. still keep asking... (full of fire)..so angry that time ... they kept asking..			
<i>Reference 2</i>		<i>Character Range</i>	20,762 - 21,830	
	M: I felt sad.. receive this type of message, before I called Dr Lim,,, asked him, 'Dr Lim, why I always check in your clinic and you always said child was ok, ok ..no problem.. why I delivered baby like this one?' He can see, si ya... study .. got certificate cannot see?..then he said, like this, when full month already,			

bring her for him to see a while. I argued with him..he meant that it cannot be checked.. I asked why the first daughter i delivered ok, why this one like this? He said this cannot be detected, to tell the truth. if want to do amniocentesis, let me know.. then I go and do the test..true or not?...when i went to look for him , he said he did not expect it .. ai si..he did not expect it..si ya.. did not realize my age.. did not expect it and asked me to do amniocentesis ..

Reference 3 Character Range 21,937 - 22,207

...later, i put down the phone and i went back... that day ..i meant to phone him.. that day received the message, I could not wait any more... he meant he could not detect it... later , said can go back....i went back.. other day go and look for him..went back..

Reference 4 Character Range 76,094 - 76,713

I: Do you have any suggestion, any opinion or any thing that you would like to add in we have not discussed ?  
 M: My comment is why the doc did not check properly, if i was at that age already , he should have done the amniocentesis ..explain to me..I must talk about it...u listen to me...  
 I: But you did think about it la?  
 M: the doc, studied so much already, he saw me above 35 years old, should do the amniocentesis.. ask me ok or not or ,,should ask whether ok or not... otherwise advise me not to deliver any more.. this should..he should let me know..

**Node Coding** Tree Nodes\initial responses\sadness **References** 6 **Coverage** 2.44%

Reference 1 Character Range 16,507 - 17,383

M: ...during confinement..after I came back.. myself just cannot accept.... later.. ..inside the Nursery.. the specialist there. she herself sucking milk...si loh... I was at the bed.. si loh..  
 I: Can you do breast feeding or not?  
 M: Breast feeding her ya.. no energy..I was too weak ..  
 I: You mean that time after you got the news lah?  
 M: ar.. she was in one place...I in one place lo..i slept.. baby if hungry, the nurse fed her ..  
 I: You really are weak la..  
 M: ... true one... not lying one..I was really weak, no strength..went to sleep.. i was so weak i went to sleep... no strength. if she cried.. want to feed, the nurse did the feeding..  
 I: U go back t your place to sleep ?  
 M: I Go back to sleep..see.. yah... what to do... no strength..She could cry.. could drink.. want to drink the nurse give feed..  
 i no need to go, do not want to go.. what to do?

Reference 2 Character Range 17,625 - 17,889

M: I slept in my bed..The nurse said come to feed her when it was the time.. they know how to feed..the nurse knew how to feed the baby when it was time to feed. ... got milk bottle.. i did not care for her.. I was weak.. just went to sleep..could not got up ..

Reference 3 Character Range 22,278 - 22,512

M: Later went back.. so weak... went BACK TO the house.. felt weak..went to sleep..no mood to breast feed the baby..  
 mother asked give her milk or not.. ya, she did not cry, always sleep..ok.. she did not cry.. both went to sleep..

Reference 4 Character Range 22,618 - 23,017

M: Later came back (to the house)..so weak.. no energy to give breast feeding.. no energy already..mother freq sneaked in to have a look at me.. you gave milk to baby or not?  
 I: You yourself ate or not?  
 M: I, if i ate, i ate, it did not matter.. frustrated..mother said you must eat.

I kept crying..kept crying.. kept crying ; mother said cannot keep crying.. otherwise you can become blind., she said to me.

Reference 5 Character Range 23,188 - 23,318

Reference 6 Character Range 24,620 - 25,107

M: Later, at the bed, I kept looking at the book ( the child health card), how, keep looking at the card, later big sister in law scolded me, 'keep away this card', ah ya... (mother showed me the writing on the card, where it was written the DS diagnosis...) ... cannot eat, breast feeding also no need... cannot do anything, came back, also ... keep on holding the child card, kept looking at it... the big sister in law saw me... scolded me..keep away this card, can or not?

**19 Wang**

Document

Total References 1

**Node Coding** Tree Nodes\initial responses\sadness **References** 1 **Coverage** 0.27 %

Reference 1 Character Range 35,966 - 36,145

M: At first when the doctor told me that she has down syndrome, I, of course, cried. ... cried until some time...  
I: How long did you cry?  
M: Not too long. About a couple of days.

**9 Farah**

Document

Total References 1

**Node Coding** Tree Nodes\initial responses\sadness **References** 1 **Coverage** 0.08 %

Reference 1 Character Range 57,394 - 57,479

M: Memang, because, ah, sedih memang sedih la, because.. how come I got two? (laugh)

**13 Jen**

Document

Total References 2

**Node Coding** Tree Nodes\initial responses\sadness **References** 2 **Coverage** 0.65 %

Reference 1 Character Range 34,962 - 35,118

T: Because last time when he was just born, when the doctor explained this one is a child with special condition. How do you feel?  
M: Of course very sad.

Reference 2 Character Range 35,446 - 35,699

T: Your first one, your first child? So after delivery...confinement time..1 month. How u cope it? How you cope like this, feel sad? Did you eat or not?  
M: Yes yes. Confinement time is ok. Sometimes during the night, I 'll keep thinking and feel sad..

**25 Tan**

Document

Total References 1

**Node Coding** Tree Nodes\initial responses\sadness **References** 1 **Coverage** 0.22 %

Reference 1 Character Range 2,814 - 2,914

Cried only... we..did not know what to do... ..you also... cannot explain to the family.... now...

**11 Harris**

Document

Total References 1

**Node Coding** Tree Nodes\initial responses\sadness **References** 1 **Coverage** 2.36 %

Reference 1 Character Range 13,987 - 14,468

T: Diatu kati asal insan, diatu?  
Helplessness, cannot count on child,  
M: Nadai, endang peda (just leave him like that , what to do...)..Susah ati, memang susah... memang

suseli. Kati kital enda tuseli, (why not feel sad), Iya enda ulih kerja, gari enda ulih muat ha..(cannot even collect the clothes). ...tapak ati ie bagus muat gari. ...tapak ati enda manah enda muat gari..(If he is in good mood, he collects, if not no..). pida nuan nya..macam ariembikbah, umur Iya udah tua.

Key		Document	
Total References	1	References	1
Node Coding	Tree Nodes\initial response\Anger	Coverage	3.15 %
Reference	1	Character Range	11,201 - 11,742
<p>The mother insisted that the doctor (obstetrician) whom she had been going to during her antenatal check up should have checked properly and detected the problems when she was pregnant with Karen. According to her, the doc had admitted he did not realize about her age was 36 years old then, thus overlooked the risk of pregnancy with DS.... she expressed her anger against the doc still. She mentioned if the doc did the test to withdraw some fluids from her abdomen (Amniocentesis), he would be able to detect the abnormal pregnancy.</p>			

## **Appendix Q: Verification of translation of transcripts**

- Verification of translation of transcripts from Iban to English
- Verification of translation of transcripts from Bahasa Malaysia to English



**(i): Verification of translation of transcripts from Iban to English**

Dear Mr Lis Anak Chin Chong.

I, Chan Kim Geok, a doctoral student from University of Malaya would like to request for your assistance with verification of the translation of transcripts from Bahasa Iban to English.

Please comment and verify regarding the accuracy of the translation in the section below.

Thank you,

Chan Kim Geok  
Chan Kim Geok  
11/12/2009

Comments:

I hereby acknowledge that the translation  
of the transcripts from Iban to English is  
accurate.

Verification by

Signature: Lis

Name: LIS ANAK CHIN CHONG

Date: 15/12/2009

**(ii): Verification of translation of transcripts from Bahasa Malaysia to English**

Dear Mr Lis Anak Chin Chong,

I, Chan Kim Geok, a doctoral student from University of Malaya would like to request for your assistance with verification of the translation of transcripts from Bahasa Malaysia to English.

Please comment and verify regarding the accuracy of the translation in the section below.

Thank you,

Kim Geok

Chan Kim Geok

1/12/2009

Comments:

I hereby acknowledge that the translation of  
the transcripts from Bahasa Malaysia to English  
is accurate

Verification by

Signature: Li

Name: LIS ANAK CHIN CHONG

Date: 15/12/2009



## Appendix R: SPSS syntax for data checking and computing domain mean scores

**Table 3 - Steps for checking and cleaning data and computing domain scores**

<b>Steps</b>	<b>SPSS syntax for carrying out data checking, cleaning and computing total scores</b>
1. Check all 26 items from assessment have a range of 1-5	RECODE Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12 Q13 Q14 Q15 Q16 Q17 Q18 Q19 Q20 Q21 Q22 Q23 Q24 Q25 Q26 (1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS). (This recodes all data outwith the range 1-5 to system missing).
2. Reverse 3 negatively phrased items	RECODE Q3 Q4 Q26 (1=5) (2=4) (3=3) (4=2) (5=1). (This transforms negatively framed questions to positively framed questions)
3. Compute domain scores	COMPUTE DOM1=MEAN.6(Q3,Q4,Q10,Q15,Q16,Q17,Q18)*4. COMPUTE DOM2=MEAN.5(Q5,Q6,Q7,Q11,Q19,Q26)*4. COMPUTE DOM3=MEAN.2(Q20,Q21,Q22)*4. COMPUTE DOM4=MEAN.6(Q8,Q9,Q12,Q13,Q14,Q23,Q24,Q25)*4. (These equations calculate the domain scores. All scores are multiplied by 4 so as to be directly comparable with scores derived from the WHOQOL-100. The '.6' in 'mean.6' specifies that 6 items must be endorsed for the domain score to be calculated).
4. Delete cases with >20% missing data	COUNT TOTAL=Q1 TO Q26 (1 THRU 5). (This command creates a new column 'total'. 'Total' contains a count of the WHOQOL-100 items with the values 1-5 that have been endorsed by each subject. The 'Q1 TO Q26' means that consecutive columns from 'Q1', the first item, to 'Q26', the last item, are included in the count. It therefore assumes that data is entered in the order given in the assessment). FILTER OFF. USE ALL. SELECT IF (TOTAL<=&21). EXECUTE. (This second command selects only those cases where 'total', the total number of items completed, is greater or equal to 80%. It deletes the remaining cases from the data set).
5. Check domain scores	DESCRIPTIVES VARIABLES=DOM1 DOM2 DOM3 DOM4 /STATISTICS=MEAN STDDEV MIN MAX. (Running descriptives should display values of all domain scores within the range 4-20).
6. Save data set	Save data set with a new file name so that the original remains intact.

Source: WHOQOL Group (1996).

## Appendix S: Descriptive exploratory data analysis

### Descriptives

		Statistic	Std. Error
DOM 1 QOL	Mean	14.4561	.17808
of phy health	95% Confidence Interval for Mean	Lower Bound	14.1044
		Upper Bound	14.8078
	5% Trimmed Mean	14.4592	
	Median	14.2857	
	Variance	5.105	
	Std. Deviation	2.25953	
	Minimum	9.14	
	Maximum	20.00	
	Range	10.86	
	Interquartile Range	4.00	
	Skewness	-.041	.191
	Kurtosis	-.418	.380

### Descriptives

		Statistic	Std. Error
DOM 2 QOL of	Mean	14.2070	.16025
psycho well-being	95% Confidence Interval for Mean	Lower Bound	13.8906
		Upper Bound	14.5235
	5% Trimmed Mean	14.2022	
	Median	14.0000	
	Variance	4.135	
	Std. Deviation	2.03338	
	Minimum	9.33	
	Maximum	19.33	
	Range	10.00	
	Interquartile Range	3.33	
	Skewness	.021	.191
	Kurtosis	-.634	.380

**Descriptives**

		Statistic	Std. Error	
DOM 3 QOL of social relationship	Mean	14.9017	.16619	
	95% Confidence Interval for Mean	Lower Bound	14.5735	
		Upper Bound	15.2299	
	5% Trimmed Mean	14.8997		
	Median	14.6667		
	Variance	4.446		
	Std. Deviation	2.10865		
	Minimum	9.33		
	Maximum	20.00		
	Range	10.67		
	Interquartile Range	2.67		
	Skewness	-.160	.191	
	Kurtosis	.181	.380	

**Descriptives**

		Statistic	Std. Error	
DOM 4 QOL of environmental supports	Mean	13.2857	.16705	
	95% Confidence Interval for Mean	Lower Bound	12.9558	
		Upper Bound	13.6156	
	5% Trimmed Mean	13.2933		
	Median	13.5000		
	Variance	4.493		
	Std. Deviation	2.11964		
	Minimum	8.50		
	Maximum	18.50		
	Range	10.00		
	Interquartile Range	3.00		
	Skewness	-.087	.191	
	Kurtosis	-.457	.380	

**Descriptives**

		Statistic	Std. Error
Overall perceived QOL	Mean	14.0539	.14509
	95% Confidence Interval for Lower Bound	13.7673	
	Mean Upper Bound	14.3404	
	5% Trimmed Mean	14.0497	
	Median	14.1538	
	Variance	3.389	
	Std. Deviation	1.84102	
	Minimum	10.00	
	Maximum	18.77	
	Range	8.77	
	Interquartile Range	2.69	
	Skewness	.000	.191
	Kurtosis	-.496	.380

**Appendix T**

Table 5.15 Linear regression analysis

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.380 <sup>a</sup>	.145	.117	1.72987

a. Predictors: (Constant), mothers' age, marital status, localities, education 2 categories, income 3 categories

ANOVA<sup>b</sup>

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	78.467	5	15.693	5.244	.000 <sup>a</sup>
	Residual	463.829	155	2.992		
	Total	542.297	160			

a. Predictors: (Constant), mothers' age, marital status, localities, education 2 categories, income 3 categories

b. Dependent Variable: Overall perceived QOL

Coefficients<sup>a</sup>

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	12.481	1.164		10.727	.000
	localities	.689	.321	.188	2.148	.033
	marital status	1.366	.568	.180	2.403	.017
	education	.471	.332	.126	1.419	.158
	income	.129	.196	.059	.661	.509
	mothers' age	-.024	.017	-.111	-1.387	.167

a. Dependent Variable: Overall perceived QOL

## REFERENCE

- Amir, M., Marcelo, F., Herrman, H., Lomachenkov, A., Lucas, R. & Patrick, D. (2000). *Reliability, validity and reproducibility of the WHOQOL.BREF in six countries*. Retrieved 30 August, 2010, from [http://www.hrinc.net/pdf/ISOQOL\\_2000\\_Vancouver\\_BREF.pdf](http://www.hrinc.net/pdf/ISOQOL_2000_Vancouver_BREF.pdf).
- Anfara, V. A. & Mertz, N. T. (2006). *Theoretical Frameworks in Qualitative Research*. London, UK: Sage Publications.
- Askheim, O. P. (2008). Personal Assistance in Sweden and Norway: From Difference to Convergence? *Scandinavian Journal of Disability Research*, 10(3): 179-190.
- Azar, M. & Badr, L. K. (2010). Predictors of coping in parents of children with an intellectual disability: comparison between Lebanese mothers and fathers. *Journal of Pediatric Nursing*, 25(1), February, 46-56. Retrieved 20 April 2010, from ScienceDirect database.
- Baldassar, L., Baldock, C.V. & Wilding, R. (2007). *Families caring across borders*. New York: Palgrave Macmillan.
- Barnes, C. (2001). *Rethinking care: from the perspectives of disabled people*. World Health Organization Disability and Rehabilitation Team. Conference Report and Recommendations, August. Retrieved 29 March, 2012 from <http://whqlibdoc.who.int/hq/2001/a78624.pdf>.
- Barr, O. & Millar, R. (2003). Parents of children with intellectual disabilities: their expectations and experience of genetic counseling. *Journal of Applied Research in Intellectual Disabilities*, 16(3), Sept, 189-204. Retrieved 20 May 2009, from Medical Database @ EBSCOhost (Psychology and Behavioral Sciences Collection).
- Baum, R. A., Nash, P. L., Foster, J. E. A., Spader, M. S., Schaub, K. R. & Coury, D. L. (2008). Primary care of children and adolescents with Down's syndrome: an update. *Current Problems of Pediatric Adolescent Health Care*, 38, September, 241-261.
- Beck, A. & Hastings, R. P. & Daley, D., Stevenson, J. (2004). Pro-social behaviour and behaviour problems independently predict maternal stress. *Journal of Intellectual & Developmental Disability*, 29(4), December, 339-349.
- Benzies, K., & Mychasiuk, R. (2009). Fostering family resiliency: a review of the key protective factors. *Child & Family Social Work*, 14(1), Feb, 103-114.
- Beresford, B. A. (1994). Resources and strategies: how parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry*, 35(1), Jan, 171-209. Retrieved 13 May 2009, from Medical database @ EBSCOhost (Psychology and Behavioral Sciences Collection).



- Berma, M., Shahadan, F. & Gapor, S. A. (2006, June). *Alleviating Bumiputera Poverty in Sarawak: Reflections and Proposal*. Paper presented at the Malaysian Research Group International Congress, Salford, England. Retrieved 3 May, 2009, from <http://eprints.usm.my>.
- Bloom, J. (2005). Breaking bad news. In: G. Grant, P. Goward, M. Richardson & P. Ramcharan (Eds), *Learning disability: A life cycle approach to valuing people* (pp. 198-221). England, Berkshire: Open University Press.
- Boeije, H. (2010). *Analysis in qualitative research*. London: Sage Publications.
- Boo, N.Y., Hoe, T. S., Lye, M. S., Poon, P. K. & Mahani, M. C. (1989). Maternal age specific incidence of Down's syndrome in Malaysia neonates. *The Journal of the Singapore Paediatric Society*, 39, 138-42.
- Borneo Post (2011). *Review Social System for Special Children – Council*. May, 24. p.11.
- Brannen, J. (2009). Prologue: mixed methods for novice researchers: reflections themes. *International Journal of Multiple Research Approaches*, 3(1), 8–12.
- Buckley, S. J. (2000). Speech, language and communication for individuals with Down syndrome: An overview. *Down Syndrome Issues and Information: The Down Syndrome Educational Trust*.
- Burden, R. (1991). Psycho-social transitions in the lives of parents of children with handicapping conditions. *Counseling, Psychology Quarterly*, 4(4), 331-344.
- Buzatto, L. L. & Beresin, R. (2008). Quality of life of parents with DS children. *Einstein*, 6(2), 175-81.
- Cable, A. (n.d.). Why I put my Down's syndrome baby up for adoption... and the loving mother who took him in. Retrieved 30 April, 2012 from <http://www.dailymail.co.uk/femail/article-1090103/Why-I-Downs-syndrome-baby-adoption-loving-mother-took-in.html#ixzz1tTbaphJx>
- Calman, K. C. (1984). Quality of life in cancer patients-a hypothesis. *J. Med Ethics*, 10(3), September, 124–127.
- Chan, K. G. (2010a). *Experiences of UK parents in care giving of children with disabilities*. In: Towards a culturally sensitive disability studies: interconnections of disability studies in and across Malaysia and the UK. Unpublished research report, Manchester Metropolitan University-University Malaysia Sarawak collaborative research project ([www.rihsc.mmu.ac.uk/malaysiauk](http://www.rihsc.mmu.ac.uk/malaysiauk))
- Chan, K. G. (2010b). *Experiences of UK parents in care-giving of child with disabilities: A Malaysian perspectives*. Paper presented at the International Conference: Perspectives on inclusive development, Sarawak, Malaysia.

- Chang, M. Y. & McConkey, R. (2008). The perceptions and experiences of Taiwanese families who have children with intellectual disability. *International Journal of Disability, Development & Education*, 55(1), Mar, 27-41. Retrieved 21 June, 2009, from Academic Source Premier@ EBSCOhost.
- Chataika, T. (2009). *The social model and postcolonial analyses of disability in Malaysia: engaging with disabled people in Sarawak, Malaysia*. In: Towards a culturally sensitive disability studies: interconnections of disability studies in and across Malaysia and the UK. Unpublished research report, Manchester Metropolitan University-University Malaysia Sarawak collaborative research project ([www.rihsc.mmu.ac.uk/malaysiaiuk](http://www.rihsc.mmu.ac.uk/malaysiaiuk)).
- Chou, Y. C., Pu, C.Y., Lee, Y. C., Lin, L.C. & Kroger, T. (2009). Effect of perceived stigmatization on the quality of life among ageing female family carers: a comparison of carers of adults with intellectual disability and carers of adults with mental illness. *Journal of Intellectual Disability Research*, 53(7), July, 654-664.
- Coakes, S. J. & Steed, L. G. (2003). *SPSS version 11.0: Analysis without anguish*. Queensland: John Wiley & Sons.
- Coakes, S. J. & Steed, L. G. (2007). *SPSS version 14.0: Analysis without anguish*. Queensland: John Wiley & Sons.
- Coleman, D. (2006). *Emotional intelligence* (10<sup>th</sup> anniversary re-issue ed.). New York: Bantam Books.
- Couper, D. (1989). *Aging and our families*. New York: Human Sciences Press, Inc.
- Creswell, J. W. (2003). *Research design: qualitative, quantitative, and mixed method approaches* (2<sup>nd</sup> ed). California, USA: Sage Publication.
- Cunningham, S. J. (2002). *Assessing family context of children with disabilities*. Master Thesis, Trinity Western University, South Africa. Retrieved 9 May, 2012 from <http://www2.twu.ca/cpsy/assets/studenttheses/cunninghamsteve.pdf>.
- Cuskelly, M., Hauser-Cram, P. & Van Riper, M. (2008). Families of children with Down's syndrome: What we know and what we need to know, *Down's syndrome Research and Practice*, 105-112. Retrieved 7 April, 2012 from [www.down-syndrome.org/research](http://www.down-syndrome.org/research).
- Danielle, H. (2003). A holistic theoretical model for examining welfare reform: quality of life. *Public Administration Review*, Jan/Feb, 63 (1), 90-104. Retrieved 9 February 2011, from Medical database @ EBSCOhost (Health Business Full text Elite).
- Dalvie, S., Barua, A., Choong, S., Chin, O. & Ramasami, S. (n.d.). *A study of knowledge, attitudes and understanding of legal professionals about safe abortion as a women's rights*. The Asia Safe Abortion Partnership. Retrieved 4 April 2012,

from [www.asap-asia.org](http://www.asap-asia.org).

- Driedger, D. (1991). *Disabled People in International Development*. Retrieved 31 October 2010, from <http://www.independentliving.org>.
- Dyson, L. (2010). Unanticipated effects of children with learning disabilities on their families. *Learning Disability Quarterly*, 33, Winter, 43-55.
- Economic Planning Unit (n. d.). *The Malaysian Economy in Figures 2009 (Quality of Life)*. Retrieved 12 October 2009, from <http://www.epu.gov.my/malayisaeconomyfigures2009>.
- EEM. (2012). *Pantang larang semasa mengandung*. Artikel. Retrieved on 3 March, 2012 from [www.mengandung.com/artikel/artikel06-05.html](http://www.mengandung.com/artikel/artikel06-05.html).
- Ekas, N. V., Whitman, T. L. & Shivers, C. (2009). Religiosity, spirituality and socio-emotional functioning in mothers of children with autism spectrum disorder. *Journal of Autism Developmental Disorder*, 39, 706–719. Retrieved 15 June 2009, from Medical database @ EBSCOhost.
- ‘Every Disabled Child Matters Campaign’ (2007). *Movement’s objectives*. Retrieved 18 June 2009, from <http://www.edcm.org.uk>.
- Felce, D. & Perry, J. (1995). Quality of Life: its definition and measurement. *Research in Developmental Disabilities*, 16(1), 51-74. Retrieved 15 June 2009, from ScienceDirect database.
- Fernandez, R.S. & Griffiths, R. (2007). Portable MP3 players: innovative devices for recording qualitative interviews. *Nurse Researcher*, 15(1), 7-15. Retrieved 13 May 2009, from Medical database @ EBSCOhost (CINAHL Plus with Full Text).
- Ferrans, C. E. & Powers, M. (1984). *Quality of Life Index*. Retrieved 17 November, 2010, from <http://www.uic.edu/orgs/qli>.
- Fidler, D. J. (2005). The emerging Down’s syndrome behavioral phenotype in early childhood: Implications for practice. *Infants and Young Children*, 18(2), Apr-Jun, 86-103. Retrieved 10 May, 2009, from Medical database @ EBSCOhost (CINAHL Plus with Full Text).
- Finlay, L. (2006). The embodied experience of multiple sclerosis: an existential-phenomenological analysis. In L. Finlay & C. Ballinger (Eds.), *Qualitative research for allied health professionals: challenging choices* (pp. 185-199). Chichester, East Sussex: John Wiley.
- Flaherty, M. & Glidden, M. (2000). Positive adjustment in parents rearing children with Down Syndrome. *Early Education & Development*, 11(4), July, 407-422.
- Fraenkel, J. R. & Wallen, N. E. (1993). *How to design and evaluate research in education*. (International ed.). Singapore: McGraw-Hill Book Co.

- Gatford, A. (2001). Learning disability nursing: Down's syndrome: experiences of mothers from different cultures. *British Journal of Nursing*, 10(18), 1193-1199. Retrieved 10 May 2009, from Medical database @EBSCOhost (CINAHL Plus with Full Text).
- Gibbs, E.D. & Carswell, L.E. (1991). Using total communication with young children with Down syndrome: A literature review and case study. *Early Education and Development*, 2, 306-320.
- Glidden, L. M. & Schoolcraft, S. A. (2003). Depression: its trajectory and correlates in mothers rearing children with intellectual disability. *Journal of Intellectual Disability Research*, 47, Part 4/5, May/June, 250-263. Retrieved 13 April 2009, from Medical database @ EBSCOhost (Psychology and Behavioral Sciences Collection).
- Goodley, D. (2011, July). *Researching the lives of others: qualitative data collection and analysis*. Paper presented at the 'Engaging & Empowering Marginalized Communities: Towards a Critical Social Science Research' Conference, Sarawak, Malaysia.
- Grant, G. & Ramcharan, P. (2001). Views and experience of people with intellectual disabilities and their families, the family perspectives. *Journal of Applied Research in Intellectual Disabilities*, 14, 364-380.
- Grant, G. (2005). Experiences of family care: bridging discontinuities over the life course. In: G. Grant., P. Goward, M. Richardson & P. Ramcharan (Eds.), *Learning disability: A life cycle approach to valuing people* (pp. 222-239). England, Berkshire: Open University Press.
- Grant, G., Ramcharan, P. & Flynn, M. (2007). Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psychosocial model. *Journal of Applied Research in Intellectual Disabilities*, 20, 563-575.
- Green, J. & Thorogood, N. (2009). *Qualitative Methods for Health Research* (2<sup>nd</sup> ed.). London: Sage Publications.
- Green, S. E. (2007). "We're tired, not sad": benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, 64(1), Jan, 150-63. Retrieved 15 June 2010, from ScienceDirect database.
- Greening, K. (2001). *Grief: the toothache of the soul* (2<sup>nd</sup> Ed). Australia: Kingswood Press.
- Gupta, V. B. (2007). Comparison of parenting stress in different developmental disabilities. *Dev Phys Disability*, 19, 417-425.
- Hasanah, C. I. & Razali, M. S. (1999). The pilot study of WHOQOL-100 (Malay version). *Malaysian Journal of Medical Sciences*, 6(2), July, 21-25.

- Hasanah, C. I. (2003). Approaches and methodological as well as interpretative issues in quality of life research in Malaysia. *Malaysian Journal of Medical Sciences*, 10(2), July, 60-65.
- Hastings, R. P., Kellyanne, R. A., McDermott, K. & Still, D. (2002). Factors related to positive perceptions in mothers of children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 15, 269–275. Retrieved 20 June 2009, from Medical database @ EBSCOhost (Psychology and Behavioral Sciences Collection).
- Hastings, R. P., Thomas H. & Delwiche, N. (2002). Grandparent support for families of children with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities*, 15, 97-104. Retrieved 20 June 2009, from Medical database @ EBSCOhost (Psychology and Behavioral Sciences Collection).
- Hatton, C. & Emerson, E. (2009). Does socioeconomic position moderate the impact of child behavior problems on maternal health in South Asian families with a child with intellectual disabilities? *Journal of Intellectual & Developmental Disability*, 34(1), March, 10–16. Retrieved 20 June 2009, from Medical database @ EBSCOhost (MEDLINE with Full Text).
- Hedov, G., Anneren, G. & Wikblad, K. (2000). Self-perceived health in Swedish parents of children with Down's syndrome. *Quality of Life Research*, 9, 415-422. Retrieved 21 June 2009, from Medical database @ EBSCOhost (MEDLINE with Full Text).
- Hodapp, R. M., Ly, T. M., Fidler, D. J. & Ricc, L. A. (2001). Less stress, more rewarding: parenting children with Down's syndrome. *Parenting: Science and Practice*, 1(4), Oct-Dec, 317-337. Retrieved 21 June 2009, from Medical database @ EBSCOhost (Academic Source Premier).
- Hsieh, R. L., Huang, H. Y., Lin, M. I., Wu, C.W. & Lee, W. C. (2009). Quality of life, health satisfaction and family impact on caregivers of children with developmental delays. *Child Care, Health and Development*, 35(2), 243–249. Retrieved 23 June 2009, from Medical database @ EBSCOhost (MEDLINE with Full Text).
- Janet, C. (2005). Families of 30-35 years olds with Down syndrome. *Journal of Applied Research in Intellectual Disabilities*, 18 (1), 75-84, DOI:10.1111/j.1468- 3148.2004.00226.x.
- Jang, Y., Hsieh, C. L., Wang, Y. H. & Wu, Y. H. (2004). A validity study of the WHOQOL- BREF assessment in persons with traumatic spinal cord injury. *Arch Phys Med Rehabil*, 85(11), Nov, 1890-1895.
- Japan Bank for International Cooperation. (2001). Poverty Profile executive summary: Malaysia. Retrieved 11 May, 2012, from [www.jica.go.jp/activities/issues/poverty/profile/pdf/malaysia\\_e.pdf](http://www.jica.go.jp/activities/issues/poverty/profile/pdf/malaysia_e.pdf)

- Johnson, R. B. & Onwuegbuzie, A. J. (2004). Mixed methods research: a research paradigm whose time has come. *Educational Researcher*, 33(7), 14-26.
- Jones, M. L. (2007). *Using software to analyze qualitative data*. Retrieved 5 December, 2010, from <http://ro.uow.edu.au/commpapers/429>.
- Kagan, C., Lewis, S. & Heaton, P. (1997). *The context of work and caring for parents of disabled children*. Interpersonal & Organization Development Research Group: Department of Psychology and Speech Pathology, Manchester Metropolitan University: IOD Occasional papers: 1/97.
- Karppinen, J. & Buschark, W. (2006). *First European quality of life survey: urban-rural differences*. Dublin: Office for Official Publication of the European Communities. Retrieved 2 May, 2012, from [www.eurofound.europa.eu/pubdocs/2006/63/en/1/ef0663en.pdf](http://www.eurofound.europa.eu/pubdocs/2006/63/en/1/ef0663en.pdf).
- Kate, K. Sinéad, M. (2007). Caring for children with learning disabilities: an exploratory study of parental strain and coping. *British Journal of Learning Disabilities*, 3 (4), Dec, 221-228.
- Kearney, P. M. & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34(5), 582-592. Retrieved 23 June 2009, from Medical database @ EBSCOhost (Academic Source Premier).
- Kearney, K. S. & Hyle, A. E. (2006). A look through the Kubler-Ross Theoretical Lens. In V. A. Anfara, & N. T. Mertz (eds.), *Theoretical Frameworks in Qualitative Research* (pp. 109-128). London: Sage Publications.
- Kenny, K. & McGilloway, S. (2007). Caring for children with learning disabilities: an exploratory study of parental strain and coping. *British Journal of Learning Disabilities*, 35(4), Dec, 221-228. Retrieved 23 June 2009, from Medical database @ EBSCOhost (Academic Source Premier).
- Kiger, A. M. (2004). *Teaching For Health* (3<sup>rd</sup> ed). Churchill Livingstone: London.
- King, G. A., Zwaigenbaum, L., King, S., Baxter, D., Rosenbaum, P. & Bates, A. (2006). A qualitative investigation of changes in the belief systems of families of children with autism or Down syndrome. *Child: Care, Health & Development*, 32(3), 353-369. Retrieved 23 June 2009, from Medical database @ EBSCOhost (Psychology and Behavioral Sciences Collection).
- Kitto, S., Chesters, J. & Grbich, C. (2008). Quality in qualitative research: criteria for authors and assessors in the submission and assessment of qualitative research articles for the Medical Journal of Australia. *Medical Journal of Australia*, 188(4), 243-246.

- Korenromp, M. J., Page-Christiaens, G. C., van den Bout, J., Mulder, E. J. & Visser, G. H. (2007). Maternal decision to terminate pregnancy in case of Down's syndrome. *Am J Obstet Gynecol*, 196, Feb, 149.e1-11.
- Kumin, L. (1998). Comprehensive speech and language treatment for infants, toddlers, and children with Down's syndrome. In J. Terry & P. David (eds), *Down's syndrome: a promising future, together*, Wiley-Liss. Retrieved 25 August 2008, from <http://www.ds-health.com/speech.htm>.
- Lai, J. (2011, July). *Grace court: an experience of living together*. Paper presented at the International Conference on Intellectual and Developmental Disabilities 2011, Sabah, Malaysia.
- Lalor, J., Begley, C. M. & Galavan, E. (2009). Recasting hope: a process of adaptation following fetal anomaly diagnosis. *Social Science & Medicine*, 68, 462–472. Retrieved 15 June 2009, from ScienceDirect database.
- Lam, L. W. & Mackenzie, A. E. (2002). Coping with a child with Down's syndrome: the experiences of mothers in Hong Kong. *Qual Health Res*, 12, 223-237. Retrieved 23 June 2009, from Medical database @ EBSCOhost (CINAHL Plus with Full Text).
- Lam, C. K. (2006). *The Iban population of Sarawak: 1947-2000*. Working Paper Series No. 13 (May). Institute Of East Asian Studies (I.E.A.S.). Universiti Malaysia Sarawak.
- Larson, E. (1998). Reframing the meaning of disability to families: the embrace of paradox. *Social Science & Medicine*, 4 (7), 865-75. Retrieved 15 June 2009, from ScienceDirect database.
- Laws, G. & Bishop, D. (2004). Pragmatic language impairment and social deficits in Williams syndrome: a comparison with Down's syndrome and specific language impairment. *International Journal of Language Communication Disorders*, 39(1 January–March), 45–64. Retrieved 23 June 2009, from Medical database @ EBSCOhost (MEDLINE with Full Text).
- Lazzarini, I. G. M. (2009). *Intergenerational financial transfers: Filipino migrants caring for parents overseas*. Unpublished thesis: The University of Queensland, Australia.
- Lee, L., Harrington, R. A., Louie, B. B. & Newschaffer, C. J. (2008). Children with autism: quality of life and parental concerns. *Journal of Autism & Developmental Disorders*, Jul(38), 1147-1160.
- Leininger, M. M. (1985). Nature, rationale, and importance of qualitative research methods in nursing. In Leininger, M. M. (Eds.), *Qualitative Research Methods in Nursing* (pp. 1-25). Orlando: Grune & Stratton, Inc.
- Liamputtong, P., Yimyam, S., Parisunyakul, S., Baosoung, C. & Sansiriphun, N. (2004). When I become a mother! Discourses of motherhood among Thai women in Northern Thailand. *Women's Studies International Forum*, 27(5-6),

November-December, 589-601.

- Lim, Abdullah. (2007). *Mothers' experiences of their babies' transfer to a regional neonatal unit*. Unpublished thesis: University of Southampton, UK.
- Lim, G. E. (2012). BN minimum monthly wage is below Poverty Line Indicator (PLI) for Sabah and Sarawak. Retrieved 8 May, 2012 via [http://www.facebook.com/note.php?note\\_id=417556254934758](http://www.facebook.com/note.php?note_id=417556254934758).
- Lindblad, B. M., Rasmussen, B. H. & Sandman, P. P. (2007). A life enriching togetherness-meanings of informal support when being a parent of child with disability. *Scand J Caring Science*, 21, 238-246. Retrieved 23 June 2009, from Medical database @ EBSCOhost (Psychology and Behavioral Sciences Collection).
- Ling, H. K. (2000). *Towards developing culturally appropriate social work practice: insights from a study of help-seeking and help-giving experiences in Sarawak, Malaysia*. Unpublished thesis, University of Queensland, Brisbane.
- Ling, H. K. (2007). *Indigenising social work: research and practice in Sarawak*. Petaling Jaya, Malaysia: Strategic Information and Research Development Centre.
- Link, B.G. & Phelan, J, C. (2006). Stigma and its public health implications. *Lancet*, 367, 528-29.
- Lloyd, C. M. & Rosman, E. (2005). Exploring mental health outcomes for low-income mothers of children with special needs: implications for policy and practice. *Infants and Young Children*, 18(3), Jul-Sep, 186-199. Retrieved 24 June 2009, from Medical database @ EBSCOhost (CINAHL Plus with Full Text).
- Lloyd, T. J. & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 53, part 12, Dec, 957-968.
- Lupton, D. & Fenwick, J. (2001). 'They've forgotten that I'm the mum': constructing and practicing motherhood in special care nurseries." *Social Science & Medicine*, 53(8), Oct, 1011-1021.
- Lupton, D. & Schmied, V. (2002). "The right way of doing it all": first-time Australian mothers' decisions about paid employment. *Women's Studies International Forum*, 25(1), January-February, 97-107.
- Majd, M. A. (2011, July). *A comparative study on quality of life among parents of children with Down syndrome and parents of normal children*. Paper presented at the International Conference on Intellectual and Developmental Disabilities 2011, Sabah, Malaysia.



- Malaysia, Department of Statistics. (2010). *The demographics of Sarawak: population*. Retrieved 1 April, 2012 from <http://www.sarawak.gov.my/en/about-sarawak/demographics>.
- Malaysia, Economic Planning Unit (n.d.). *Map of Malaysia*. Retrieved 16 May 2012, from [http://www.epu.gov.my/c/document\\_library](http://www.epu.gov.my/c/document_library).
- Malaysia, Economic Planning Unit (n.d.). *The Malaysian Economy in Figures 2009 (Quality of Life)*. Retrieved 12 October 2009 from <http://www.epu.gov.my/malaysiaeconomyfigures2009>.
- Malaysia, Ministry of Health. (n.d., a). *Year 2004 Annual Report, Family Health Development Division*. Retrieved 4 August 2008, from [http://fh.moh.gov.my/uploads/laporan\\_tahunan\\_kesihatan\\_keluarga.pdf](http://fh.moh.gov.my/uploads/laporan_tahunan_kesihatan_keluarga.pdf).
- Malaysia, Ministry of Health. (n.d., b). *Year 2005 Annual Report, Family Health Development Division*. Retrieved 4 August 2008, from [http://fh.moh.gov.my/uploads/laporan\\_tahunan\\_kesihatan\\_keluarga.pdf](http://fh.moh.gov.my/uploads/laporan_tahunan_kesihatan_keluarga.pdf).
- Malaysia, Ministry of Health. (n. d. c). *Year 2006 Annual Report, Family Health Development Division*. Retrieved 4 August 2008, from [http://fh.moh.gov.my/uploads/laporan\\_tahunan\\_kesihatan\\_keluarga.pdf](http://fh.moh.gov.my/uploads/laporan_tahunan_kesihatan_keluarga.pdf).
- Malaysia, Ministry of Health. (2004). *Manual on the management of children with communication problems*. Family Health Development Division.
- Malaysia, Ministry of Health. (2006). *Garis panduan Pelaksanaan Program Penjagaan Kanak-Kanak Berkeperluan Khas di Klinik Kesihatan*. Public Health Department, Family Health Development Division.
- Malaysia, Ministry of Women, Family & Community Development. (2008). *Persons with Disabilities Act 2008*.
- Malaysia, National Early Childhood Intervention Council (2012). *4<sup>th</sup> National Early Childhood Intervention Conference (2012)*. Retrieved 1 March 2012, from <http://www.agapesibu.org/about-us/necic2012>.
- Malaysia, Social Welfare Department. (2009). *Financial assistance scheme for people with disabilities*. Retrieved 1 August 2009, from <http://www.jkm.gov.my>.
- Manisah Mohd Ali, Ramlee Mustapha & Zalizan Mohd Jelas. (2006). An empirical study on teachers' perceptions towards inclusive education in Malaysia. *International Journal of Special Education*, 21(3), 36-44.
- Margalit, M. & Ankonina, D. B. (1991). Positive and negative affect in parenting disabled children. *Counselling Psychology Quarterly*, 4(4), 289-300.
- Mason, L. & Cunningham, C. (2008). An exploration of issues around menstruation for

women with down syndrome and their carers. *Journal of Applied Research in Intellectual Disabilities*, May, 21(3), 257-267.

- Masood, A. F., Turner, L. A. & Baxter, A. (2007). Causal attributions and parental attitudes toward children with disabilities in the United States and Pakistan. *Exceptional Children*, Summer, 73(4), 475-487. Retrieved 24 June 2010, from Medical database @ EBSCOhost (Psychology and Behavioral Sciences Collection).
- Mbekenga, C. K., Christensson, K., Lugina, H. I. Olsson, P. (2011). Joy, struggle, and support: postpartum experiences of first-time mothers in a Tanzanian suburb. *Women and Birth*, 24, 24-31.
- McCubbin, M. A. & McCubbin, H. I. (1993). Family coping with illness: The Resiliency Model of Family Stress, Adjustment, and Adaptation. In C. Danielson, B. Hamell-Bissell, P. Winstead-Fry (Eds.). *Families, health & illness: Perspectives on Coping and intervention* (pp. 21 – 63). St. Louis: Mosby.
- McConkey, R., Truesdale-Kennedy, M., Chang, M., Y., Jarrah, S. & Shukri, R. (2008). The impact on mothers of bringing up a child with intellectual disabilities: a cross-cultural study. *International Journal of Nursing Studies*, 45(1), Jan, 65-74.
- McHatton, P. A. & Correa, V. (2005). Stigma and discrimination: perspectives from Mexican and Puerto Rican mothers of children with special needs. *Topics in Early Childhood Special Education*, 25(3), Fall, 131-142. Retrieved 24 June 2010, from Medical database @EBSCOhost (Psychology and Behavioral Sciences Collection).
- Merriam, S. B. (2001). *Qualitative research and case study applications in education*. San Francisco: Jossey-Bass.
- Meyer-Rochow, V. B. (2009). Food taboos: their origins and purposes. *Journal of Ethnobiology and Ethnobiology and Ethnomedicine*, 5(18), doi:10.1186/1746-4269-5-18. Retrieved 3 March 2012, from <http://www.ethnobiomed.com/content/5/1/1>.
- Miles, B. M. & Huberman, A. M. (1994). *An expanded sourcebook: qualitative data analysis* (2<sup>nd</sup> ed.). London: Sage Publications.
- Minder Kaur Parthama. (2007). *Speech problems of Malay Down's syndrome children*. Unpublished doctoral dissertation, Universiti Malaya, Kuala Lumpur. Retrieved 30 September 2009, from <http://www.diglib.um.edu.my/umtheses/browse.asp>?
- Minichiello, V., Aroni, R., Timewell, E. & Alexander, L. (1990). *In-depth interviewing: researching people*. Melbourne: Longman Cheshire Pty Limited.

- Moyle, J., Iacono, T. & Liddell, M. (2006, Nov). *Experiences of parents of children with developmental delays in obtaining assessment and diagnosis from medical practitioner*. Paper presented at the National Early Childhood Intervention Conference, Penang, Malaysia.
- Mugno, D., Ruta, L., D'Arrigo, V. G. & Mazzone, L. (2007). Impairment of quality of life in parents of children and adolescent with pervasive developmental disorder. *Health and Quality of Life Outcomes*, 5(22), 1-9.
- Myers, B. J., Mackintosh, V. H. & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heart ache." Parents' own words on how having a child in the autism spectrum has affected their lives and their families' lives *Research in Autism Spectrum Disorders*, 3(3), July-September, 670-684.
- Norizan, A. & Shamsuddin, K. (2010). Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal of Intellectual Disability Research*, 54(11), Nov, 992-1003, DOI: 10.1111/j.1365-2788.2010.01324.x
- Olsson, M. B. & Hwang, C. P. (2008). Socioeconomic and psychological variables as risk and protective factors for parental well-being in families of children with intellectual disabilities. *Journal of Intellectual Disability Research*, 52(part 12), December, 1102–1113.
- Ong, L. C., Afifah, I., Sofiah, A. & Lye, M. S. (1998). Parenting stress among mothers of Malaysian Children with cerebral Palsy: predictors of child and parent-related stress. *Annals of Tropical Paediatrics*, 18, 301-307.
- Ong, L. C., Chandran, V. & Peng, R. (1999). Stress experienced by mothers of Malaysian children with mental retardation. *Journal of Pediatric Child Health*, 35, 358–362
- Östlund, U., Kidd, L., Wengström, Y. & Rowa-Dewar, N. (2010). Combining qualitative and quantitative research within mixed method research designs: a methodological review article. *International Journal of Nursing Studies*, In press, corrected proof, available online 16 November 2010.
- Pallant, J. (2007). *SPSS Survival Manual* (3<sup>rd</sup> ed). Sydney: Allen & Unwin.
- Parahoo, A. K. (1997). *Nursing Research: principles, process and issues* (1<sup>st</sup> ed.). London: MacMillan Press Ltd.
- Parnes, P. (2008). *Research on Disability and development*. International Centre for Disability and Rehabilitation University of Toronto. Report submitted to CIDA. Project number: 7048320, April.
- Phelps, K. W., Jennifer, I., Hodgson, J. I., Mccammon, S. I. & Lamson, A. I. (2009). Caring for an individual with autism disorder: A qualitative analysis. *Journal of Intellectual & Developmental Disability*, 34(1), March, 27–35.

- Plant, K. M. & Sanders, M. R. (2007). Predictors of care-giver stress in families of preschool aged children with developmental disabilities. *Journal of Intellectual Disability Research*, 51(II), 109-124. Retrieved 17 April 2011, from Medical database @ EBSCOhost (Psychology and Behavioral Sciences Collection).
- Polit, D. F. & Hungler, B. P. (1999). *Nursing research: principles and methods* (6<sup>th</sup> ed.). Philadelphia: Lippincott Williams & Wilkins.
- QSR International (2009). *NVivo 7.0*. Retrieved 30 October 2009, from <http://www.qsrinternational.com>.
- Queensland Government. (2011). *Multicultural health: community profiles for health care providers: cultural profiles*: Retrieved 17 April 2011, from [http://www.health.qld.gov.au/multicultural/health\\_workers/cultdiver\\_guide.asp](http://www.health.qld.gov.au/multicultural/health_workers/cultdiver_guide.asp)
- Resch, J. A., Mireles, G., Michael, R., Benz, R., Grenwelge, C., Peterson, R., et al. (2010). Giving parents a voice: a qualitative study of the challenges experienced by parents of children with disabilities. *Rehabilitation Psychology*, 55(2), May, 139-150.
- Rogers, C. (2007). Disabling a family? Emotional dilemmas experienced in becoming a parent of a child with learning disabilities. *British Journal of Special Education*, 34(3), Nov, 148-157.
- Runswick-Cole, K. (2008, Sept). *Luminal lives: non-disabled mothers and the disability world*. Paper presented at the Disability Studies Conference: Lancaster, U.K.
- Safii, R. (2007). *Expanded Scope in Sarawak-the Wellness Activities*. Family Health Development Unit, Sarawak Health Department (Unpublished write-up for the Sarawak Heritage).
- Sarawak, Government Official Portal. (2010). *About Sarawak*. Retrieved 15 November 2010, from <http://www.sarawak.gov.my>.
- Sarawak, Health Department. (2007a). *Statistics of Admission of children to the government hospitals*. Information and Documentation Unit.
- Sarawak, Health Department. (2007b). *Expanded Scope in Sarawak- The Wellness Activities*. Unpublished report. Family Health Development Unit.
- Sarawak, State Planning Unit. (2009). *Sarawak Facts & Figure 2009*. Chief Minister's Department: Sarawak State Planning Unit Publications.
- Sarawak, Welfare Department. (2012). List of Community-Based Rehabilitation Centres. Retrieved 7 July 2012, from <http://www.welfare.sarawak.gov.my/modules/web/page.php?id=147>
- Schalock, R. L. (2005). Special issue on quality of life: an introduction and overview. *Journal of Intellectual Disability Research*, 49(Part 10), Oct, 695-8.

- Schrojenstein, H. M., Lantman-de Valk, M. J., Haveman, H. F., Crebolder, J. M. (1996). Review: co-morbidity in people with Down's syndrome: a criteria-based analysis. *Journal of Intellectual Disability Research*, 40(5), October, 385-399.
- Shakespeare, T. (2006). *Disability rights and wrongs*. New York: Routledge.
- Sharot, T. (2011). The optimism bias: those rose-colored glasses? Adapted from The Optimism Bias Pantheon Books, a division of Random House Inc. *Time*, June 6, 34-39.
- Sheldon, R., Traustadottir, R., Beresford, P., Boxall, K. & Oliver, M. (2007). Disabilities rights and wrongs? Review symposium. *Disability Society*, 22(2), March, 209-234.
- Shin, J., Nhan, N. V., Crittenden, K. S., Hong H. T. D., Flory M. & Ladinsky, J. (2006). Parenting stress of mothers and fathers of young children with cognitive delays in Vietnam. *Journal of Intellectual Disability Research*, 50, part 10, October, 748-760.
- Silverman, D. (2005). *Doing qualitative research* (2<sup>nd</sup> ed). London: Sage Publications.
- Skevington, S. M., Lotfy, M. & O'Connell, K. A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial: A Report from the WHOQOL Group. *Quality of Life Research*, 13, 299–310.
- Skevington, S. M., Sartorius, N., Amir, M. & The WHOQOL-Group. (2004). Developing methods for assessing quality of life in different cultural settings: The history of the WHOQOL instruments. *Soc Psychiatry Psychiatr Epidemiol*, 39, 1–8.
- Sloper, P., Knussen, C., Turner, S. & Cunningham, C. (1991). Factors related to stress and satisfaction with life in families of children with Down's syndrome. *Journal of Child Psychological Psychiatry*, 32(4), 655-676.
- Stewart, D., Law, M., Burke-Gaffney, J., Missiuna, C., Rosenbaum, P., King, G., Moning, T. & King, S. (2006). Keeping It Together TM: an information KIT for parents of children and youth with special needs, *Child: Care, Health & Development*, 32(4), 493–500.
- Stone, D. (1989). A parent speaks, professional perceptions of parental adaptation to a child with special needs. *Children's Health Care*, summer, 18(3), 174-178.
- Streubert, H. J. & Carpenter, D. R. (1995). *Qualitative research in nursing*. Philadelphia: J. P. Lippincott.
- Superstitions of Malaysian Chinese. (n.d.). Retrieved 27 March 2012, from [wikipedia.org/wiki/Superstitions\\_of\\_Malaysian\\_Chinese](http://wikipedia.org/wiki/Superstitions_of_Malaysian_Chinese).
- Tarakeshwar, N. & Pargament, K. I. (2001). Religious coping in families of children with autism. *Focus on Autism and Other Developmental Disabilities*, 16, 247–260.

- Teddlie, C. & Tashakkori, A. (2009). *Foundations of mixed methods research: integrating quantitative and qualitative approaches in the social and behavioral sciences*. California, USA: Sage Publications.
- Tess, B. & DeLuca, D. A. (1996). Families of children with disabilities: positive adaptation across the life cycle. *Social Work in Education, 18*(1), Jan, 31-44.
- Tong, A., Sainsbury, P. & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19*(6), 349-357.
- Tully, M. P. & Cantrill, J. A. (2000). The validity of the modified patient generated index: a quantitative and qualitative approach. *Quality of Life Research, 9*, 509-520.
- Unger, D. G., Tressell, P. A., Jones, C. W. & Park, E. (2004). Regarding low-income single caregivers' involvement in child-focused early intervention services: Implications for care giver-child interaction, *Family Relations Minneapolis, 53*(2), Mar, 210-218.
- United Nations General Assembly (1989). *Convention on the Rights of the Child* (Document A/RES/44/25). Retrieved 2 February 2012, from [http://www.hakani.org/en/convention/Convention\\_Rights\\_Child.pdf](http://www.hakani.org/en/convention/Convention_Rights_Child.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.
- Verdugo, M. A., Schalock, R. L., Keith, K. D. & Stancliffe, R. J. (2005). Quality of life and its measurement: important principles and guidelines. *Journal of Intellectual Disability Research, 49*(10), 707-717.
- Wang, M., Summers, J. A., Little, T., Turnbull, A., Poston, D. & Mannan, H. (2006). Perspectives of fathers and mothers of children in early intervention programmes in assessing family quality of life. *Journal of Intellectual Disability Research, 50*, 977-988.
- Ware, J. E. & Sherbourne, C. D. (1992). The MOS 36-item Short-Form Health Survey (SF-36). *Medical Care, 30*(6), June, 473-483.
- Ware, J. E., Kosinski, M. M. & Keller, S. D. (1996). A 12-item Short Forms Health Survey (SF-12): construction of scales and preliminary tests of reliability and validity. *Medical Care, 34*(3), 220-233.
- Webster, J., Nicholas, C., Velacott, C., Cridland, N. & Fawcett, L. (2010). Validation of the WHOQOL- BREF among women following childbirth. *The Australian & New Zealand Journal of Obstetrics & Gynaecology, 50*(2), 132-137.

- Weiss, T. C. (2009). *Commentary on the convention on the rights of people with disabilities*. Retrieved 2 September 2010, from <http://www.disabled-world.com/editorials/political/convention-disabilities>.
- Wells, G. L., Barker, S. E., Finley, S. C., Colvin, E. V. & Finley, W. H. (1994). Congenital heart disease in infants with Down's syndrome. *Southern Medical Journal*, 87(7), Jul, 4338-4343.
- White, N. & Hastings, R. P. (2004). Social and professional support for parents of adolescent with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17, 181-190.
- WHOQOL Group. (1995). The World Health Organization Quality of Life assessment: position paper from the World Health Organization. *Social Science and Medicine*, 41, 1403-1409.
- WHOQOL Group. (1996). *WHOQOL-BREF: Introduction, administration, scoring and generic version of the assessment*. Geneva: Program on Mental Health, WHO.
- Wong, D. L. (1993). *Whaley & Wong's essential of pediatric nursing* (4<sup>th</sup> ed.). St Louis, Missouri, USA: Mosby-Year Book.
- Worcester, J. A., Raffaele, L. M. M.; Keller, H. R. (2008). Giving Voice to Parents of Young Children With Challenging Behavior, *Exceptional Children*, 74(4), summer, 509-525.
- World Health Organization. (2009). *WHOQOL-BREF, Health Statistics and Informatics*, Geneva 27, Switzerland.
- World Health Organization. (2010). *Process of translation and adaptation of instruments*. Retrieved 16 November 2010, from [http://www.who.int/substance\\_abuse/research\\_tools/translation/en/print.html](http://www.who.int/substance_abuse/research_tools/translation/en/print.html).
- Yahya, H. (n.d.). *Belief in karma*. Retrieved 12 December 2011, from <http://www.islamandbuddhism.com/w.html>.
- Yao, G., Chung, C. W., Yu, C. F. & Wang, J. D. (2002). Development and verification of validity and reliability of the WHOQOL-BREF Taiwan version. *J. Formos Med Assoc.*, 101(5), May, 342-51.
- Yuen, C. S. L. & Li-Tsang, W. P. C. (2003). Quality of life of parents who have children with disabilities. *Hong Kong Journal of Occupational Therapy*, 13(1), 19-24.