



# University of HUDDERSFIELD

## University of Huddersfield Repository

Joseph, Debra

Psychosocial Issues and Support for Children who Acquired HIV/AIDS from their Mothers in Trinidad and Tobago

### Original Citation

Joseph, Debra (2013) Psychosocial Issues and Support for Children who Acquired HIV/AIDS from their Mothers in Trinidad and Tobago. Doctoral thesis, University of Huddersfield.

This version is available at <http://eprints.hud.ac.uk/id/eprint/18056/>

The University Repository is a digital collection of the research output of the University, available on Open Access. Copyright and Moral Rights for the items on this site are retained by the individual author and/or other copyright owners. Users may access full items free of charge; copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational or not-for-profit purposes without prior permission or charge, provided:

- The authors, title and full bibliographic details is credited in any copy;
- A hyperlink and/or URL is included for the original metadata page; and
- The content is not changed in any way.

For more information, including our policy and submission procedure, please contact the Repository Team at: [E.mailbox@hud.ac.uk](mailto:E.mailbox@hud.ac.uk).

<http://eprints.hud.ac.uk/>

Psychosocial Issues and Support for Children who Acquired HIV/AIDS from  
their Mothers in Trinidad and Tobago

DEBRA JOSEPH

A thesis submitted to the University of Huddersfield in partial fulfilment of  
the requirements for the degree of Doctor of Philosophy

The University of Huddersfield

May 2013

## **Copyright statement**

- i. The author of this thesis (including any appendices and/or schedules to this thesis) owns any copyright in it (the “Copyright”) and s/he has given The University of Huddersfield the right to use such copyright for any administrative, promotional, educational and/or teaching purposes.
- ii. Copies of this thesis, either in full or in extracts, may be made only in accordance with the regulations of the University Library. Details of these regulations may be obtained from the Librarian. This page must form part of any such copies made.
- iii. The ownership of any patents, designs, trademarks and any and all other intellectual property rights except for the Copyright (the “Intellectual Property Rights”) and any reproductions of copyright works, for example graphs and tables (“Reproductions”), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property Rights and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property Rights and/or Reproductions

## Abstract

The HIV/AIDS prevalence rate in the Caribbean is second only to Sub-Saharan Africa and higher than the global rate. HIV/AIDS presents a real threat to children as they account for one in six global AIDS-related deaths and one in seven new global HIV infections. Furthermore, the number of new cases of children in the region is growing. Despite the impact of HIV/AIDS on Caribbean children, few research studies have been undertaken on the psychosocial issues that affect them and studies that include children's perspectives seem to be even more lacking. This thesis is based on original research carried out in the Republic of Trinidad and Tobago.

This study has examined the psychosocial issues that exist for children living with HIV in Trinidad and Tobago and has explored, from the perspectives of both children and their mothers, the types of supports that are available or accessed. The aims of the research were to 1) examine the psychosocial issues that affect children with acquired HIV/AIDS in Trinidad (the children in this research acquired HIV from their mothers) and 2) to explore the support that exists and gaps that may be necessary for their improved quality of life. It is hoped that intervention strategies will be gleaned from this research to assist future interdisciplinary teams that interact with this population.

The methodology was based on a grounded theory approach (Strauss & Corbin 1990), and consisted of theoretical sampling and constant comparison throughout data analysis (open, axial, and selective coding) using a case triad (triad refers here to perspectives of three different actors). Four cases were purposively selected, each 'case' comprising a mother who was HIV positive, an "HIV Friend" (primary support figure, 4 in total) identified by the mother, and a child living with HIV -(there were two children in one family, making five children in total, aged between five and thirteen years) – each of whom was interviewed. In addition, three mothers who did not tell their children of their status were also interviewed. These additional interviews were the result of theoretical sampling to explore two themes that emerged as significant in the first stage of analysis: 1) How "secrecy" was manifested in the lives of families coping with HIV and 2) The role of mothering. In total sixteen persons were interviewed.

The findings produced three core categories, namely 1) the cyclical and complex nature of secrecy as a strategy to protect children from stigma and discrimination, 2) the impact on children of living with HIV-AIDS, including their role as protectors of HIV-positive mothers and 3) Mothering with HIV-AIDS. The study showed that these families, though impacted by uncertainty about the future, fear of dying and societal rejection, and for the large part financially and materially disadvantaged, were in-tact and functioned well. Furthermore these families had created a 'new normal' in which the secrecy about HIV was central and around which a range of behaviours, social codes and perceived consequences for breaches (of the secret) shaped relationships in both explicit and implicit ways. This indicates a high level of resourcefulness and resilience on the part of the women and their children. However the pressure to maintain the secret created additional challenges for women and children already impacted by a high level of stress because of HIV. Additionally, the rules of secrecy meant that women were unable to talk

about their circumstances or needs and consequently had very little support either for themselves or their children. From the child's point of view, the secret required them to be conscious of what they said and to whom and although not able to talk about HIV, paradoxically the secret had the effect of making HIV more dominant in their lives. This was despite the fact that children themselves did not seem to regard HIV as central in their everyday worlds. Mothering was also a significant theme to emerge from the study and it appeared that such was the importance of the role of mother, as a primary signifier of Caribbean womanhood, that the decision to have children was more important than the risk of passing on HIV. Two of the mothers had gone on to have more children even though their first child had been born with the virus. The study showed that being a good mother in a family affected by HIV means being able to protect children from the implications of the virus being known about outside the family and thus mothering was intertwined with the creation and maintenance of the secret.

New understandings about the effects of HIV/AIDS on children and several recommendations aimed at improving services and resources for these children and their families have emerged from the study. Implementation of these recommendations would auger well for improved quality of life in the future, as children continue to live with the chronic illness of HIV/AIDS.

The sample was small (16 participants in all) and as a qualitative study, no claims are made about with respect to any generalisations of the findings.

# Table of Contents

Copyright statement.....	1
<b>Abstract.....</b>	<b>2</b>
<b>Table of Contents.....</b>	<b>4</b>
<b>List of Figures .....</b>	<b>18</b>
<b>List of Tables .....</b>	<b>20</b>
<b>Dedications.....</b>	<b>21</b>
<b>Acknowledgements.....</b>	<b>22</b>
<b>List of abbreviations .....</b>	<b>23</b>
<b>Chapter 1: Introduction to Study .....</b>	<b>24</b>
1.1 My Interest in this Study .....	24
1.2 Context of Trinidad and Tobago.....	24
1.3 Country Profile .....	26
1.4 Policy .....	27
1.4.1 Treatment and Support .....	31
Health Care and Treatment Facilities.....	32
Social Work and HIV-AIDS .....	33
Social Welfare Policies.....	34
Children and HIV .....	35
1.4.2 Legal Support, Advocacy and Human Rights.....	37
In the UNGASS report, it was found that persons living with HIV/AIDS encounter discrimination based on their HIV status in the workplace, in health care settings, and in the provision of goods and services such as credit and insurance services. There is no protection in the law against discrimination on the grounds of ‘HIV status or suspected HIV status’. General anti-discrimination legislation (the <i>Equal</i>	

<i>Opportunity Act 2000</i> ) exists, but ‘HIV status or suspected HIV status’ is not included as one of the prohibited grounds of discrimination.....	37
1.5 United Nations General Assembly Special Session (UNGASS) report.....	39
Summary.....	40
1.6 Research Aims .....	41
1.7 Issues of Definition .....	41
1.7.1 Definition of ‘Children’ .....	41
1.7.2 Stages of Development.....	41
1.7.3 Perinatal Transmission.....	42
1.8 Thesis Structure.....	42
<b>Chapter 2: Literature Review.....</b>	<b>45</b>
2.1 Introduction.....	45
2.3 Structure of literature review .....	46
2.4 Methods used to obtain data .....	46
2.5 Key Issues and Debates about the Topic .....	47
2.5.1 Globally .....	47
2.5.2 The Caribbean .....	49
2.5.3 The Face of HIV/AIDS in Children- Developing versus Developed Countries. .....	50
2.5.4 Summary.....	52
2.6 Three Main Reviews .....	52
2.6.1 Summary.....	54
2.7 Key Theories, Concepts and Ideas on the Topic .....	55
2.7.1 Children.....	55
2.7.2 Disclosure .....	57
2.7.3 Theoretical Framework .....	58

Child Right's Perspective .....	58
Resilience .....	60
Stigma .....	60
2.7.4 Summary.....	60
2.8 Women and HIV .....	60
2.8.1 Coping Aspects of HIV/AIDS.....	62
2.8.2 Summary.....	63
2.9 Caribbean Culture and Socialisation: HIV/AIDS in the midst of Culture.....	63
2.9.1 Summary.....	65
2.10 Conclusion .....	65
<b>Chapter 3: Methodology .....</b>	<b>66</b>
3.1 Introduction.....	66
3.2 Epistemology .....	66
Justification for the Use of Grounded Theory .....	68
3.3 Research Design .....	69
3.4 Research Design Phase .....	72
3.4.1 Personal Frame of Reference .....	72
3.4.2 The Literature Review .....	73
3.4.3 Methods Framework .....	74
3.4.4 Overall Research Aim .....	75
3.5 Data Collection Phase .....	76
3.5.1 Data Collection Tools .....	76
3.5.2 Theoretical Sampling .....	78
3.5.3 Study Participant Criteria.....	79
<i>Mothers Inclusion Criteria</i> - mothers who were HIV positive .....	79



Children’s’ Inclusion Criteria.....	79
<i>Exclusion Criteria-</i> .....	79
Children born with any other condition; children outside the age range and children who do not know of their status.....	79
3.5.4 Recruitment.....	79
3.5.6 Study Setting.....	80
3.5.7 Creation of a Case Triad Database.....	80
3.5.8 Conducting Interviews.....	81
3.5.9 Transcriptions.....	82
3.6 Data Analysis Phase.....	83
The Story & Story Line.....	85
3.6.1 Literature Comparison Phase.....	87
3.6.2 Ethical Considerations and Access.....	87
3.6.3 Reliability and Validity.....	90
a) Credibility – Reflection of conceptual grounding.....	90
b) Originality- Significance of study.....	90
c) Resonance- Meaning and scope.....	90
d) Usefulness- Knowledge development and practical application.....	91
3.7 Reflection.....	92
3.8 Conclusion.....	93
<b>Chapter 4: Findings Mothers- Part 1.....</b>	<b>94</b>
4.1 Introduction.....	94
4.2 Demographic profiles of the women Who Told.....	94
4.3 Mothers Who Told.....	95
Participant 1 - Mary:-.....	95

Participant 2 - Bertha .....	96
Participant 3- Petra .....	96
Participant 4 - Martha.....	97
4.4 Initial themes- Mothers .....	97
<b>Major theme .....</b>	<b>97</b>
<b>Sub-theme.....</b>	<b>97</b>
<b>Sub-sub-theme .....</b>	<b>97</b>
Axial coding & Selective coding .....	99
4.5 The final five main themes that emerged were: .....	99
4.5.1 Living with HIV-AIDS .....	100
Worry about children’s future; issues around dying; hope for the future .....	100
Disclosure for children.....	102
4.5.2 Social circumstances .....	106
Poverty.....	106
4.5.3 Mothering and HIV .....	108
4.5.4 Stigma and discrimination and secrecy .....	112
4.5.6 Coping and resilience .....	116
4.6 Conclusion.....	118
<b>Chapter : Findings Mothers Part 2.....</b>	<b>120</b>
4.7 Introduction.....	120
Participant A - Maxine .....	121
Participant B - Anne .....	122
Participant C - Candy .....	122
4.8 Themes.....	122
4.8.1 Mothering with HIV-AIDS - Non-disclosure .....	123

4.8.2 Adherence.....	126
4.8.3 Social Support .....	130
4.9 Similarities in findings for women in parts 1 and 2.....	133
Secrecy to Protect.....	133
4.10 Conclusion .....	133
<b>Chapter 5: Findings Children .....</b>	<b>135</b>
5.1 Introduction.....	135
5.2 Socio-demographic table of children.....	135
5.2 Child-Participant 1 – Amy 13 years.....	136
Mother- Mary.....	136
Demographic information and economic issues .....	136
Emotional and Behavioural Issues: Thoughts on Being HIV Positive.....	137
Social Issues- School & Relationship with Peers .....	138
Relationship with Mother.....	139
Health Issues .....	140
Miracle Question .....	140
5.3 Activities .....	140
Amy’s “Drawing” .....	140
Amy’s “All About Me” Worksheet.....	141
Amy’s “Picture of Different Faces of Expressions and Action” .....	142
5.3.1 Summary of Case .....	144
5.4 Participant 2 – Brian 11 years.....	144
Mother- Bertha .....	144
Demographic Information & Economic Issues .....	144
Emotional and Behavioural Issues- Thoughts on HIV .....	144

Social Issues- School and relationship with peers .....	145
Health Issues .....	145
Miracle Question .....	146
5.5 Activities .....	146
Brian’s “Drawing” .....	146
Brian’s “All About Me” Worksheet .....	147
Brian’s “Picture of Different Faces of Expressions and Action” .....	148
5.5.1 Summary of Case .....	150
5.6 Participant 3 – Cathy 10 years.....	150
Mother- Bertha .....	150
Demographic Information & Economic Issues .....	150
Emotional and Behavioural Issues: Thoughts on HIV .....	151
Social Issues- School and relationship with peers .....	151
Health Issues .....	152
Miracle Question .....	152
5.7 Activities .....	152
Cathy’s “Drawing” .....	152
Cathy’s “All About Me” Worksheet .....	153
Cathy’s “Picture of Different Faces of Expressions and Action” .....	154
5.8 Summary of Case .....	155
5.9 Participant 4 – Dawn 9 years.....	156
Mother – Petra .....	156
Demographic Information & Economic Issues .....	156
Emotional and Behavioural Issues- Thoughts on HIV .....	156
Social Issues- School and relationship with peers .....	157

Health Issues .....	157
Miracle Question .....	158
5.9 Activities .....	158
Dawn’s “Drawing” .....	158
Dawn’s “All About Me” Worksheet.....	158
Dawn’s “Picture of Different Faces of Expressions and Action” .....	159
5.10 Summary of Case .....	160
5.11 Participant 5 – Evan 12 years .....	161
Mother- Martha.....	161
Demographic Information and Economic Issues .....	161
Emotional and Behavioural Issues- Thoughts on HIV .....	161
Social Issues- School and relationship with peers .....	162
Health Issues .....	163
Miracle Question .....	163
5.12 Activities .....	163
Evan’s “Drawing” .....	163
Evan’s “All About Me Worksheet” .....	164
Evan’s “Picture of Different Faces of Expressions and Action” .....	165
5.13 Summary of Case .....	167
5.14 Themes.....	167
Three main themes emerged:.....	168
5.14.1 Living with HIV .....	168
Social and emotional issues.....	168
Illness and Medication.....	169
Limited Knowledge of HIV .....	170

Feelings of Sadness.....	170
Feeling no different from others .....	171
Coping with HIV .....	172
Children generally happy despite HIV .....	173
5.14.2 Children as Carers.....	174
5.14.3 Mother/Child Bond of Secrecy .....	176
5.15 The Development of the Storyline.....	177
5.16 Conclusion .....	180
<b>Chapter 6 – HIV Friends.....</b>	<b>182</b>
6.1 Introduction.....	182
6.2 Definition of Social Support .....	182
Informal support .....	183
Formal Support .....	183
Informational Support.....	183
Theoretical Reflection of Social Support .....	183
6.3 Interviews .....	188
6.4 Themes.....	188
6.4.1 Social support.....	189
Support role .....	190
HIV Friend 1 .....	190
HIV Friend 2 .....	191
HIV Friend 3.....	192
HIV Friend 4.....	192
6.4.2 Coping: mothers and children .....	194
Mary and her daughter Amy .....	194

Mary .....	194
Amy.....	195
Bertha and her children Brian and Cathy .....	196
Bertha .....	196
Brian and Cathy .....	196
Petra and her daughter Dawn .....	196
Dawn.....	197
Martha and her son Evan.....	198
Evan.....	198
6.4.3 How the HIV Friend viewed the mother and the child .....	200
6.4.4 Health issues .....	202
6.4.5 Overall future support .....	203
Social services needs of women and children with HIV/AIDS .....	205
6.5 Summary .....	206
<b>Chapter 7.....</b>	<b>210</b>
7.1 Introduction.....	211
7.2 The Paradigm Model .....	211
How The Paradigm Model was Used.....	212
7.3 Causal Condition of Phenomena .....	215
7.3.1 Being an HIV positive mother .....	215
7.3.2 Caribbean Cultural Norms .....	217
Theoretical Ideas and Concepts.....	220
Patriarchy.....	221
7.4 Phenomenon Resulting from a) Being an HIV positive mother and b) Caribbean cultural norms .....	222

7.4.1 Core Category- Secrecy- Mothers who told and Mothers who did not tell their Children.....	222
7.4.2 Children’s feelings about being HIV Positive.....	226
7.5 Context.....	229
7.5.1 Context with respect to secrecy .....	229
7.5.2. Stigma and Discrimination.....	230
7.5.3 Concern for Future of Children.....	231
7.5.4 Context- Children’s Feelings about HIV/AIDS.....	232
7.5.5 Environment of Care .....	232
7.5.6 Young Carers .....	234
7.5.7 Non-Disclosure & Non-Discussion (Double Negative) .....	235
7.5.8 Adults minimise the impact of HIV/AIDS on Children .....	235
7.6 Intervening Conditions- Cultural Values & gender relations.....	236
7.6.1 Poverty.....	237
7.6.2 Adherence.....	238
7.6.3 Informal and Formal Support.....	239
7.7 Strategies .....	239
Managing Stigma and Discrimination.....	240
Mothers who did not tell .....	240
Mothers who told their Children.....	241
Non-Discussion of HIV/AIDS- Topic Avoidance .....	241
7.7.1 Children’s Feelings on Having HIV/AIDS.....	242
7.8 Consequences of Strategies for Children Living with HIV/AIDS .....	242
Living and Coping with HIV/AIDS- Mothers.....	243
Aspects of Religion .....	244



Living and Coping with HIV/AIDS- Children .....	244
Normalisation .....	245
Self-Blame .....	245
Resiliency - Mothers.....	246
Resiliency - Children .....	246
7.9 Conclusion.....	247
<b>Chapter 8- Essential Findings and Recommendations.....</b>	<b>249</b>
8.1 Introduction.....	249
8.2 Situating the Study within a Caribbean Cultural and Social Context with Respect to HIV-AIDS .....	249
8.3 Aims of the Research .....	251
8.4 Grounded Theory - Appropriateness for Study .....	252
Credibility .....	253
New Insights .....	254
Resonance.....	255
Usefulness .....	256
8.5 The Phenomenon of “Secrecy to Protect”.....	256
8.6 Mothers Mothering with HIV - the New Normal.....	260
8.7 Young Carers with HIV-AIDS in Trinidad and Tobago: Children Living with HIV-AIDS .....	263
8.8 Practice and Policy Implications and Recommendations.....	266
8.8.1The Macrosystem .....	267
Update on Policies in Trinidad and Tobago .....	267
The Rights of the Child.....	269
Education .....	270
Health.....	270

Social Development .....	274
Community Development.....	274
8.8.2 The Exosystem .....	275
8.8.3 The Mesosystem .....	276
8.8.4 The Microsystem .....	276
Advocacy .....	278
8.9 Limitations of Study .....	279
8.10 Further Research.....	280
8.11 Reflections .....	280
8.12 Conclusion .....	282
<b>References.....</b>	<b>283</b>
<b>Appendix 1 .....</b>	<b>313</b>
<b>Appendix 2.....</b>	<b>314</b>
<b>Appendix 3.....</b>	<b>315</b>
<b>Appendix 4.....</b>	<b>316</b>
<b>Appendix 5.....</b>	<b>317</b>
<b>Appendix 6.....</b>	<b>318</b>
<b>Appendix 7.....</b>	<b>319</b>
<b>Appendix 7 (cont'd).....</b>	<b>320</b>
<b>Appendix 8.....</b>	<b>321</b>
<b>Appendix 9.....</b>	<b>322</b>
<b>Appendix 9 (cont'd).....</b>	<b>323</b>
<b>Appendix 10.....</b>	<b>324</b>
<b>Appendix 11 .....</b>	<b>325</b>
<b>Appendix 12.....</b>	<b>326</b>

<b>Appendix 13.....</b>	<b>327</b>
<b>Appendix 14.....</b>	<b>328</b>
<b>Appendix 15.....</b>	<b>329</b>
<b>Appendix 16.....</b>	<b>330</b>
<b>Appendix 17.....</b>	<b>331</b>
<b>Appendix 18.....</b>	<b>332</b>

**WORD COUNT: 84, 439**

## List of Figures

Figure 1.3a: Picture of the country of Trinidad and Tobago .....	27
Figure 1.4a: Estimate of children needing ART CD4<200 (Trinidad and Tobago UNGASS country progress report, March 2010, p. 30) .....	30
Figure 1.4b: Estimate of children needing ART with a CD4 threshold of 350 (Trinidad and Tobago UNGASS country progress report, March 2010, p. 31) .....	31
Figure 3.4.3: Depiction of the case triad.....	75
Figure 3.6: The Paradigm Model of this Study (expanded in Chapter 7).....	86
Figure 5.3a : Amy’s Drawing .....	141
Figure 5.3b: Amy’s Worksheet .....	142
Figure 5.3c: Amy’s Picture of Different Faces of Expressions and Action .....	144
Figure 5.5a: Brian’s Drawing .....	147
Figure 5.5 b: Brian’s “All about me worksheet” .....	148
Figure 5.5c: Brian’s Picture of Different Faces of Expressions and Action .....	150
Figure 5.7a: Cathy’s drawing.....	153
Figure 5.7b: Cathy’s “All About Me” Worksheet .....	154
Figure 5.7c: Cathy’s “Picture of Different Faces of Expressions and Action” .....	155
Figure 5.9a: Dawn’s Drawing .....	158
Figure 5.9b: Dawn’s “All About Me” Worksheet.....	159
Figure 5.9c: Dawn’s “Picture of Different Faces of Expressions and Action” .....	160
Figure 5.12a: Evan’s drawing .....	164
Figure 5.12b: “All About Me Worksheet” .....	165
Figure 5.12c: Evan’s “Picture of Different Faces of Expressions and Action” .....	166
Figure 5.15a: Mothers and HIV case.....	179
Figure 5.15b: Case studies .....	179
Figure 6.5: Diagram of case triad .....	207
Figure 7.0: Paradigm Model- Culmination of themes and sub-themes for the case triad .....	210
Figure 7.2: How Paradigm model was used.....	215
Figure 8.4: Birks & Mills (2011) - Grounded Theory Approach.....	252
Figure 8.8: Bronfenbrenners’s ecological theory .....	267

Figure 8.8.4: The Top-down Approach for Intervention for Mothers and Children with HIV-AIDS..... 278

## List of Tables

Table 1.4 National Strategic Plan Priorities and Strategies .....	28
Table 1.5 Major challenges and remedial actions taken.....	39
Table 1.8: Stages of development.....	41
Table 3.3: Process of building an understanding of research topic .....	70
Table 4.2: Socio- demographic profile of mothers .....	94
Table 4.4a- Coding for mothers.....	97
Table 4.5b - Final Main themes and sub-themes for mothers .....	100
Table 4.8 Demographic table of women who did <b>not tell</b> .....	120
Table 5.2 Socio-demographic table of children .....	135
Table 5.14 Themes for Children .....	167
Table 6.3 Mothers and HIV Friends .....	188
Table 6.4 Themes of HIV friends.....	189

## **Dedications**

I dedicate this thesis to my family: My husband Keith Joseph and my sons Liu and Jeremy. They were my rock, especially my husband. I would not have completed this work without them. You guys are the best.

## **Acknowledgements**

I want to thank the women and children who volunteered to take part in this study. It was difficult to identify women and children who were living with HIV and these women stepped forward to be heard. They also encouraged their children to speak to me and also allowed someone they identified as a support person to be interviewed.

I also want to thank my supervisory team, Professor Adele Jones and Professor Eric Blyth for their encouragement and dedication to my completion of this thesis. Also, thanks to the other PhD. students in my year. I will never forget our times together and our outings, it certainly helped me to realise that we were in the 'same boat' and faced the same challenges along the path of gaining our doctorate.

I want to thank my colleagues who assisted me in finding the respondents for the study, namely: Jocelyn Daniel, Maria Cruickshank, Cynthia Greenidge and Madonna. In the end their help was invaluable.

Special thanks my friends Annette Joseph and Dorian Porter who stood behind me every inch of the way.

Most of all, I want to thank God for without Him I would not have completed this work. He gave me the strength and grace to focus on my goal and complete it.



## **List of abbreviations**

Anti-RetroVirals (ARVs)

National Strategic Plan (NSP)

Men having Sex with Men (MSM).

Mother To Child Transmission (MTCT)

Voluntary Counselling and Treatment (VCT)

Sexually Transmitted Infections (STIs)

People Living with Human Immunodeficiency Virus (PLHIV)

National Aids Coordinating Committee (NACC)

Faith Based Organisation (FBO)

Non-Governmental Organisation) (NGO)

Anti-Retroviral Therapy (ART)

Regional Health Authorities (RHAs)

Civil Society Organisations (CSOs)

National AIDS Coordinating Committee (NACC)

The Trinidad and Tobago Health Training Centre (TTHTC)

Tobago HIV & AIDS Coordinating Committee Secretariat (THACC)

United Nations General Assembly Special Session (UNGASS)

Provider Initiated Counselling and Testing (PITC)

The Health Public Lab (THPL)

# **Chapter 1: Introduction to Study**

## **1.1 My Interest in this Study**

My interest in this study stemmed from being a practitioner in the field of HIV/AIDS. As a masters' student, I did my practicum in the area of HIV/AIDS and this opened up my eyes to a brand new world of intervention. There was interaction with clients from mainly the lower economic strata of society in the east, west, north and south of the country. When I completed my practicum, I was asked by one of the Non-Governmental Organisations (NGO) to continue the work as a social work clinician in their organisation. This I did, and again, I had clients both male and female. In counselling these clients, although I realised that they had children, the children were never my clients. It appeared that little thought was given to how the children were functioning in families where one parent or both parents had HIV/AIDS. As I continued to build my clientele, I recognised this more and more. I asked myself the question, how are children managing in these homes? No answers were forthcoming. I concluded my Masters in Social Work in 2005.

## **1.2 Context of Trinidad and Tobago**

In the Caribbean, adult prevalence of HIV-AIDS is approximately 1%, higher than any region outside of sub-Saharan Africa and Trinidad and Tobago has one of the highest annual HIV prevalence rates, ranking midway between Haiti, which has the highest rate, and Cuba, which has the lowest rate in the region (UNAIDS 2009).

The Republic of Trinidad and Tobago is a small twin-island state with a population of 1.3 million (including 407,097 children), comprising largely people of African and East Indian descent (37 percent and 40 percent, respectively), with other ethnic groups making up 23 percent (Central Statistics Office of Trinidad and Tobago 2000). Trinidad and Tobago is one of the wealthiest countries in the Caribbean, however despite positive macroeconomic indicators, poverty continues to present a significant threat to the life chances of particular sections of the population, with women, young people, and children disproportionately affected (Health Economics Unit 2001).

HIV in Trinidad and Tobago is spread largely through heterosexual sexual intercourse. It is fuelled by several intersecting socioeconomic factors such as migration, urbanization, lack of safe sex practices, and gender inequality (United Nations Population Fund 2002). Fifty-seven percent of reported infections are in the 25- to 49-year-old age group, 18 percent are among young people ages 15 to 24, 9 percent are in the 50 and over age group, 5 percent are children zero to four years of age, and 1 percent are among children ages five to 14 (Caribbean Epidemiological Centre 2004). Although more men are infected overall than women, women become infected at a younger age than men and, now outnumber men. In the 15 to 24 age group, for instance, there are more infected women than men, and young women 15 to 19 years of age are three times more likely to be infected than young men of the same age (UNICEF 2005). This gender shift is a global phenomenon, and for the first time since international surveillance began, women now account for 51 percent of all HIV cases worldwide (UNAIDS, 2006). Internationally, gender inequality and the fact that transmission of the virus is several times more efficient from men to women than from women to men (Bain 2001) are among the reasons that account for this. Within Trinidad and Tobago, other factors include patriarchal values, gender roles in sexual decision making, and the economic dependence of women. In addition, multiple sexual partnering and the reportedly high incidence of domestic violence, rape, and sexual abuse are factors that increase risk for women (Health Economics Unit 2001). There are no reliable statistics on the number of children affected by HIV/AIDS in Trinidad and Tobago. Among confirmed AIDS cases, 7 percent are children, and 93 percent are adults. Mother-to-child transmission accounts for 69 percent of the total reported AIDS cases among children, with 7 percent classified as other modes of transmission and 24 percent unknown (Caribbean Epidemiological Centre 2004).

In The Trinidad and Tobago National Strategic Plan 2004-2008/10 in 1.6, it is noted that the priority areas listed prevention as a primary goal, including the provision of “youth friendly” sexual and reproductive health services. Treatment, care and support was second on the list with the government stating that its aim was to ‘provide appropriate economic and social support to the People Living with Human Immunodeficiency Virus (PLHIV)’ and to those affected by the virus. The second policy area of relevance to my

study is that pertaining to children's rights. Trinidad and Tobago, as with all Caribbean countries is a signatory of the 1989 UN Convention on the Rights of the Child. However, while there has been some progress in promoting children's rights in general, public policy is not fully aligned with the principles of the CRC and consequently, the rights of especially marginalized children (such as children living with HIV) are easily overlooked. (See chapter 3 Section 3.6.2 for a fuller discussion of children's rights).

As the first study to focus on the experience of living with HIV for children in Trinidad, from the perspectives of children themselves, the translation of the knowledge produced into meaningful policy and interventions may go some way to helping the government achieve its objectives in respect of strategic aims on HIV prevention and AIDS care *and* in ensuring that rights of children affected by HIV are fully promoted and protected.

My motive for conducting the study was to find out what issues impacted on children's lives in the midst of HIV/AIDS. I wanted to hear how they felt and learn how they coped. Sometimes we get absorbed in the issues that affect adults and the children are left out completely; this is reflected in the literature on HIV/AIDS too, with the views of children rarely being represented. In addition to focusing on children's perspectives, it was also crucial that the mothers be part of the picture since the impact of HIV on mothers is inextricably linked to children's experiences.

### **1.3 Country Profile**

The country of Trinidad and Tobago constitutes a twin-island Republic situated northeast of Venezuela. It is the most southerly of the Caribbean islands and is located at geographic coordinates 11 00N & 61 00 W.<sup>2</sup> The total area covered is 5,128 sq km. The population, as of July 2011, is estimated to be 1,227,505 with 72.1% being between the ages of 15 and 64 years old; there are an estimated 455,148 males and 429,990 females. (<https://www.cia.gov/library/publications/the-world-factbook/geos/td.html>)



<http://www.worldatlas.com/webimage/countrys/namerica/caribb/tt.htm>

Figure 1.3a: Picture of the country of Trinidad and Tobago

Almost 27 years have elapsed since the first case of AIDS was diagnosed in Trinidad in 1983. By the end of the third quarter of 2009, the number of new HIV positive cases reported had reached 20,255. These figures were obtained from the Ministry of Health for the period 1983 to September 2009 (Ministry of Health, the Republic of Trinidad and Tobago, National Surveillance Unit, 2009). The most recent modelling of the available surveillance data for Trinidad and Tobago indicates a steady, though small, increase in the HIV prevalence rates from 1.2% at the end of 2006 to 1.5% in 2009. This slow rate of increase can be attributed to the expansion of treatment services, and more specifically, to the free provision of Anti-Retrovirals (ARVs), which was initiated in 2002. The period under review also saw further extension of same-day testing at multiple sites throughout Trinidad and Tobago.

## 1.4 Policy

The United Nations General Assembly Special Session (UNGASS) Country Progress Report 2010 gave an updated status of HIV/AIDS in Trinidad and Tobago from January 2008 to December 2009. This is the latest report with respect to HIV/AIDS in Trinidad and Tobago, and mainly addresses issues at a macro level. The Trinidad and Tobago National Strategic Plan (NSP) 2004-2008/10 played a key role in this report. This plan

had its genesis in the situation and response analysis conducted in Trinidad and Tobago in 1999 and 2001, respectively. It was a product of a highly collaborative process. As such, there is a strong sense of ownership among government, civil society, UN agencies, development organisations and the corporate sector. These partners founded the NSP on four key principles: inclusion, sustainability, accountability, and respect for human rights. Below are the main priorities and strategies:

**Table 1.4 National Strategic Plan Priorities and Strategies**

Priority Areas	Strategies
<b>Prevention</b>	<ul style="list-style-type: none"> <li>• Heighten HIV/AIDS education and awareness</li> <li>• Improve the availability and accessibility of condoms.</li> <li>• Extend the responsibility for the prevention of HIV to all sectors of government and civil society.</li> <li>• Introduce behaviour change intervention programmes targeted to young females.</li> <li>• Introduce behaviour change interventions targeted to youths in and out of school.</li> <li>• Support behaviour change programmes targeted to Men having Sex with Men (MSM).</li> <li>• Implement a nationwide Mother To Child Transmission (MTCT) programme.</li> <li>• Develop a comprehensive national Voluntary Counselling and Treatment (VCT) programme.</li> <li>• Promote VCT services.</li> <li>• Ensure the availability of adequate post exposure services.</li> <li>• Increase knowledge and awareness of the symptoms of STIs</li> <li>• Ensure effective syndromic management of Sexually Transmitted Infections (STIs).</li> <li>• Provide “youth friendly” sexual and reproductive health services.</li> </ul>
<b>Treatment, Care and Support</b>	<ul style="list-style-type: none"> <li>• Implement a national system for the clinical management and treatment of HIV/AIDS</li> <li>• Improve access to medication, treatment, and care for persons with opportunistic infections.</li> <li>• Provide appropriate economic and social support to the People Living with Human Immunodeficiency Virus (PLHIV) and to the affected.</li> </ul>
<b>Advocacy and Human Rights</b>	<ul style="list-style-type: none"> <li>• Promote openness and acceptance of PLHIV in the workplace and in the wider community.</li> <li>• Create a legal framework that protects the rights of the PLHIV and other groups affected by HIV/AIDS.</li> <li>• Monitor human rights abuses and implement avenues for redress.</li> <li>• Mobilize opinion leaders on HIV/AIDS and related human rights issues.</li> </ul>

<b>Surveillance and Research</b>	<ul style="list-style-type: none"> <li>• Understand the linkage between psychosocial issues and vulnerability to HIV/AIDS.</li> <li>• Conduct effective epidemiological research and clinical trials</li> </ul>
<b>Programme Management, Coordination and Evaluation</b>	<ul style="list-style-type: none"> <li>• Develop an appropriate management structure for the national expanded response.</li> <li>• Gain wide support for the NSP.</li> <li>• Mobilize adequate and sustained resources to support implementation of the NSP</li> <li>• Monitor the implementation of policies and programmes as outlined 23 in the NSP.</li> <li>• Strengthen the key constituents of National Aids Coordinating Committee (NACC).</li> <li>• Strengthen support groups for PLWHIV to better respond to the epidemic and increase the number of these support groups.</li> </ul>

The UNGASS Country Progress Report 2010

Under the first priority of **prevention** is the Prevention of Mother-to-Child Transmission (PMTCT) programme, which is the main prevention strategy employed by the Ministry of Health. The largest providers of treatment and care for paediatric AIDS patients are the Eric Williams Medical Science Complex (government owned) and the Cyril Ross Nursery, NGO treating 79 and 78 patients, respectively, at the end of 2009.

The Cyril Ross Nursery is a residential facility operated by the Society of St. Vincent de Paul, a Roman Catholic Institution that receives some funding from the government. It houses thirty-five children and it is responsible for the medical management of thirty other children living with their parents and or guardians in various parts of Trinidad and Tobago. There are once-monthly clinics held at the home to ensure that children are receiving the best possible care, especially with ART (Society of St. Vincent and DePaul 2013).

The graph below shows the estimated number of children needing Anti-Retroviral Therapy (ART) or Anti-Retrovirals (ARVs) (terms used interchangeably).

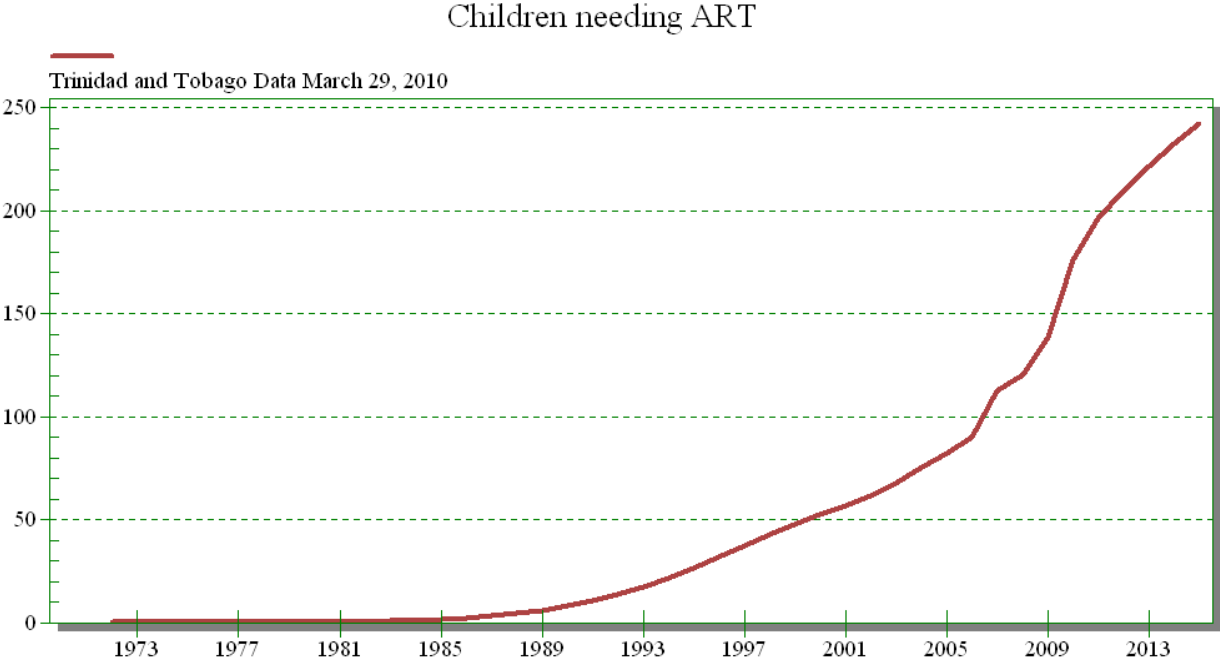


Figure 1.4a: Estimate of children needing ART CD4<200 (Trinidad and Tobago UNGASS country progress report, March 2010, p. 30)

As shown in the graph above, it is projected that 222 children will require ART in 2013 if a CD4<sup>2</sup> - a measure of the number of T-helper cells per cubic millimetre of blood, used to analyse the prognosis of patients infected with HIV- threshold of less than 200 - is used. The increase in the number of children requiring ART when a CD4 threshold of 350 is used is negligible, rising from 222 to 223.



## Children needing ART

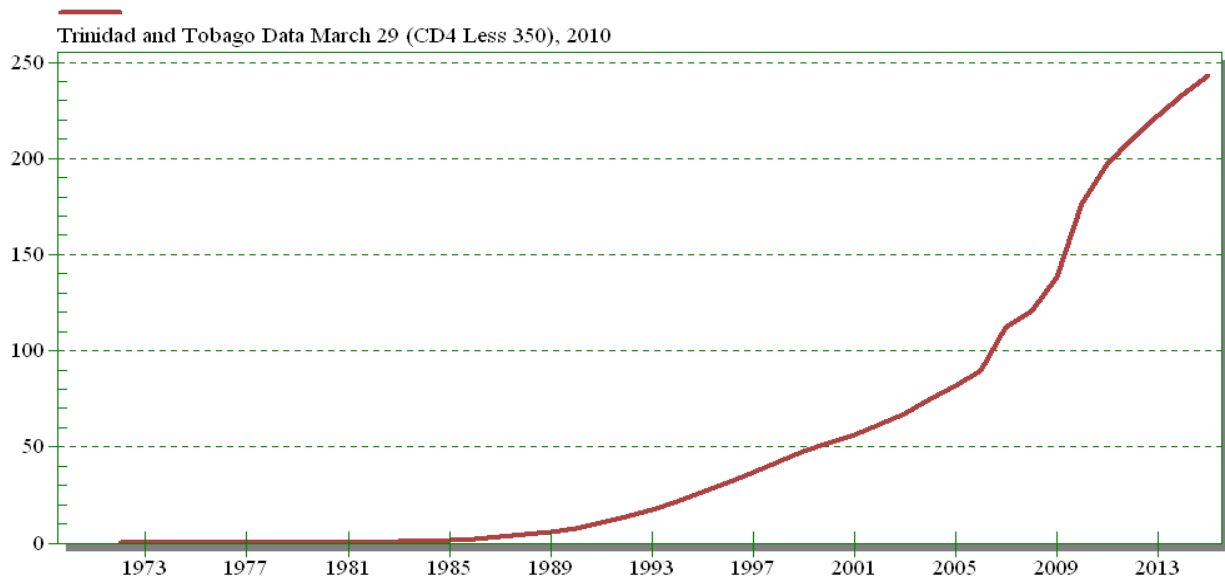


Figure 1.4b: Estimate of children needing ART with a CD4 threshold of 350 (Trinidad and Tobago UNGASS country progress report, March 2010, p. 31)

Dried blood spot testing was introduced in 2008 and 98 infants were tested using this method with 91 negative and seven HIV positive results. Between January to September 2009, 65 infants were tested using the dried blood spot testing and seven infants were determined to be positive.

### 1.4.1 Treatment and Support

Another feature of the epidemic that separates it out from other diseases is that while it affects all sections of society, young people and those in their most economically productive years are most at risk. The consequences of this aspect of AIDS are felt at the micro and meso level and will increasingly have repercussions at the macro level. Hence the reason for the structure of Chapter 8 where recommendations were done according to Bronfenbrenner's Ecological theory which addressed the microsystem, mesosystem, exosystem and macrosystem levels of society. We are facing an unprecedented phenomenon, which profoundly transforms family life. In some families parents are losing their children prematurely and in others children are losing their parents prematurely. We can predict (based on what has happened in other countries) that there will be an increase in child-headed and grandparent-headed households, an

increase in abandoned children and a wide-scale loss of skills and human resources which will deplete productivity and undermine development in every sphere of public life. In families this will place the burden of care on those with least ability and resources to provide it.

Goal 6 of the Millennium Development Goals (MDGs) states: to combat HIV-AIDS and other diseases. The target is to have this reduced by 2015 and halt the progression of HIV-AIDS. In the report for Trinidad and Tobago (2005) there is no mention of children and the issues they face having HIV-AIDS. The main focus is on contraceptive use for adults and knowledge of HIV-AIDS. There is need for reports emanating from the country to include children with HIV-AIDS and ways to improve their quality of life as these children will eventually become adults with HIV-AIDS. The 'Millennium Development Report 2011' states that on an average only 33 percent of young males and 20 percent of young women in developing countries have a comprehensive and correct knowledge of HIV-AIDS (MDGs Report 2011). The importance of understanding and knowledge of HIV-AIDS will be necessary as they approach adulthood in terms of reducing the spread of HIV-AIDS.

### **Health Care and Treatment Facilities**

Five Regional Health Authorities (RHAs) in Trinidad and Tobago are responsible for the dispensation of health care services throughout the country. Each region has its cadre of health professionals who assist in the care and treatment of persons with HIV/AIDS. Apart from other services (counselling for persons infected by HIV/AIDS) provided by medical social workers, the Eastern Regional Health Authority and the South West Regional Health Authority have implemented support groups for infected mothers and expanded their services to provide care and support to affected families. The other regional authorities have not done so to date. The UNGASS report - the most current report on HIV/AIDS in Trinidad and Tobago that incorporates all sources that pertain to HIV/AIDS - did not expand or explain what 'provision of care and support' entailed. This was very vague.

The main care and treatment facilities are operated by the Government of Trinidad and Tobago. In the north of the country, this is the Medical Research Foundation (MRF),

Here clients are seen by an interdisciplinary team that consist of a social worker, nurses, doctors and a nurse counsellor. A person can walk into this facility to get tested, receive counselling, ARVs and treatment from doctors on staff all under one roof. In the South, the service is more clinical where on Ward 2 at the San-Fernando General Hospital these services are rendered. However, these are not all under one roof. The client can access help from the social worker once their case is referred from the doctor in attendance. Most clients prefer to visit the MRF. In the East and West there are clinics whereby clients can be tested, however they are referred to the MRF for ARVs and follow-up. Once clients are tested positive for HIV at MRF, they are given a letter of introduction to attend the Community Action resource (CAre).

CAre is an NGO that supports persons living with the virus and their families. They provide professional counselling services both individual and group. This NGO serves a wide cross-section of the population of Trinidad and Tobago.

### **Social Work and HIV-AIDS**

Social work is concerned primarily with addressing the social problems of vulnerable populations, in minimizing unacceptable risks and in helping people to overcome the effects of harm. While not clearly defined, 'vulnerability' is a term that has widespread usage within the discourses of social and human development. Defining socially constructed concepts such as vulnerability, risk and resilience can have the effect of reducing meanings so that they become functional categories rather than the expressions of people's lived experiences that provide complexity and context to the ways in which those experiences are represented. Rather than define these terms then, it is more helpful to understand the ways in which they are used within social work. Vulnerability is commonly understood as the 'potential for disruption or harm' while 'risk' refers to the probability (not simply potential) for disruption or harm and introduces the notion of hazard (Wisner 2001). Children and young people are among the most vulnerable members of our society and are therefore a major locus of social work attention.

What makes them particularly vulnerable is that their emotional, social and physical dependence upon adults, their status within families and society more widely and that

their level of development may lead to them being subject to increased hazards such as exploitation, exposure to disease, neglect or abuse. While all children are in a sense vulnerable, the key to understanding when and why children may become more vulnerable to HIV lies in assessing multiple connections among different factors. What the effects of particular hazards may be and what specific action is needed to target unacceptable risks can be addressed by adopting a systems approach. This was recommended in chapter 8.

Social work services are provided for children at the Cyril Ross Residential home an (NGO). A professional social worker is attached to that establishment. The home houses children are mostly infected with HIV. The National Family Services, a government department provides counselling services for families with children with HIV-AIDS. Social workers in schools provide counselling and intervention services for families inclusive of children with HIV-AIDS. There are Guidance Officers attached to both primary and secondary schools that deliver guidance programmes that address HIV-AIDS. While many of these departments do not provide specialist services for children living with HIV, they are available to children. However, there are some specialist services, for example, a social worker attached to the Paediatric AIDS clinic at the Mt. Hope Hospital.

Vulnerability to HIV/AIDS is clearly then both universal and specific. Addressing the psychosocial implications of the epidemic therefore requires universal preventative and support social work services as well as targeted preventative and support social work services.

### **Social Welfare Policies**

The major grants administered by the Social Welfare Division are governed by the Public Assistance Act Chapter 32:03 and Senior Citizens' Pension Act Chapter 32:02. In 1996 amendments were made to the Public Assistance Act to introduce the Disability Assistance Grant (DAG) (Act #23 of 1996). This grant was introduced in commemoration of the International Year of the Disabled.

Social Welfare caters for persons who cannot work because of the virus by giving them

a Disability Grant upwards of TT\$1000. These welfare offices are located throughout the country. Such persons must be citizens or legal residents of Trinidad and Tobago and must have been residing in the country for at least three (3) years immediately prior to the date of claim provided that the person did not spend more than six (6) months out of the country during this period. A person who has fulfilled the above criteria but who spent in excess of six (6) months out of the country but who has lived for one continuous year in Trinidad and Tobago preceding the date of application may qualify for Disability Assistance Grant. However, if in the future they become employed this is revoked. Families can also receive a 'cash card' for purchase of grocery items provided a means test is passed in terms of income per month.

The Public Assistance Grant aims to provide financial support to meet the needs of necessitous persons who are prevented by some disability from earning a living. It is normally paid to the head of the household whose needs shall be deemed to include those of his dependents. Others within the family can also receive Public Assistance, a monthly grant for help with family expenses. This is also means tested.

### **Children and HIV**

According to Rao *et al.* (2007), HIV/AIDS in children has been transformed from the category of an acute lethal disease to that of a chronic illness because of the advent of HIV/AIDS medication. However, the stigma and discrimination experienced by these infected children make it unique compared to other chronic illnesses. This is so because stigma and discrimination fosters non-disclosure of HIV-AIDS and there is the fear of societal rejection by those infected with HIV-AIDS. With respect to chronic illnesses, there are psychological adjustments of the child and family to both the physical nature of the illnesses and to the important management factors such as adherence to medication and treatment and lifestyle changes. Thus, Rao *et al.* reiterate that there was need for all the specialists dealing with HIV-infected children, including health care experts, to be aware of the psychological manifestations of HIV infection so that proper management and referral might be considered.

Worldwide, most of the transmissions of HIV infection to children occur from mother to child through perinatal vertical transmission (70-80% of all HIV positive cases) (Burns &

Mofenson 1999). In high-income countries, the rate of transmission from an infected mother to child has drastically decreased because of the provision of antiretroviral therapy to HIV infected pregnant women, and the practice of conducting delivery by caesarean section (Blattner 2000). In low-income countries<sup>1</sup>, however, the transmission rates continue to remain high (Lodha *et al.* 2000). The World Health Organisation (WHO) (2003) in their report states that most people in developed countries have access to affordable and free health care, including various Anti-Retroviral Therapies (ART) and treatments for opportunistic infections. However, in contrast, in the developing world, 40% of women lack access to adequate antenatal care. Moreover, the proportion of people without access to health care ranges from over 40% in some parts of Latin America and Asia and eighty percent (80%) in the poorest parts of Africa.

Blanche *et al.* (1997) state that the presentation of Acquired Immune Deficiency Syndrome (AIDS) in children was different compared to that of an adult; in children, the presentation tends to be bimodal as some children become seriously ill in infancy as children are rapid progressors. Rapid progressors are individuals who develop the symptoms of AIDS, or end-stage HIV disease, within two to three years after infection Phair *et al.* (1992). The term 'bimodal' according to Spira *et al.* (1999) indicate children who progress to AIDS and who die within the first two years of life as opposed to those who live longer than two years. Adults tended to remain relatively healthy for prolonged periods, as they are slow progressors. Forsyth (1995) concludes that children could have a number of clinical manifestations secondary to HIV infection, which might cause noticeable features such as growth stunting or chronic dermatological conditions. This may lead to psychological problems in HIV-infected children as growth stunting may

---

<sup>1</sup> The least developed countries (LDCs) represent the poorest and the weakest of the international community. They comprise 880 million people (about 12% of the world's population, but account for less than 1% of the world's Gross Domestic Product (GDP). The identification of LDCs is currently based on three criteria: per capita gross national income (GNI), human assets and economic vulnerability to external shocks. The latter two are measured by two indices of structural impediments, namely the human assets index and the economic vulnerability index. To be included in the list of LDCs, a country must satisfy all three criteria. <http://www.unohrls.org/en/ldc/related/59/02/10/2011>.

lead to a disturbed body image, which in turn, may lead to significant psychosocial problems for the school-going child.

Other psychosocial issues can involve the history of repeated hospitalisation and isolation from peers, which has been shown to have an adverse effect on the child's social, cognitive, and communicative development (Task Force on Paediatric AIDS, 1998). The knowledge of HIV status through disclosure of HIV infection, fear of death and suffering, and family conflict because of the illness may all cause attendant stress on the child (Trad *et al.* 1994). Family and other aspects of the social environment play an integral part in the psychological health of the infected child as the loss of a parent or sibling due to AIDS also affects the child (Pelton & Forehand 2005). Other factors to note that affect the psychological well-being of the child are: the inability of parents to provide care for their HIV infected child because of their own physical ill health, bereavement made difficult because of the loss of adult support for their grieving or because of ill parents (Medlins & Erhardt 1994), and discrimination and stigma as a result of society's attitude to HIV (Trad *et al.* 1994). The parent-child relationship and the family environment play an important part in the psychological well-being of the infected child. While few published studies have been carried out, it is likely that the issues affecting HIV positive children in other countries as highlighted in this brief overview, also impact the lives of children in Trinidad and Tobago, the country in which my study was situated. In the next section, I provide a country profile and identify some of the social factors that intersect with HIV to produce specific childhood experiences.

#### **1.4.2 Legal Support, Advocacy and Human Rights**

In the UNGASS report, it was found that persons living with HIV/AIDS encounter discrimination based on their HIV status in the workplace, in health care settings, and in the provision of goods and services such as credit and insurance services. There is no protection in the law against discrimination on the grounds of 'HIV status or suspected HIV status'. General anti-discrimination legislation (the *Equal Opportunity Act 2000*) exists, but 'HIV status or suspected HIV status' is not included as one of the prohibited grounds of discrimination.

There is no law that governs persons living with HIV-AIDS specifically. All laws serve

the general public. The Ant-Discrimination Act 2011, has included the class of age and HIV status, however, it has not been proclaimed by the President as such it cannot be used in a court of law. Thus, in its present state it cannot be used as a legally binding document. Even if it was operational, it would not affect the rights of individuals with HIV-AIDS or suspected HIV-AIDS. Awareness of legal, treatment, and reproductive rights among persons living with HIV and health workers can appear to be deficient, as information on rights is not posted at health facilities and other pertinent sites.

In dealing with the needs of children it is important for adults to be aware and also for children to be aware of their rights. The United Nations Convention on the Rights of the Child (UNCRC) (1990) has guiding principles that include non-discrimination; adherence to the best interests of the child; the right to life, survival and development; and the right to participate. Trinidad and Tobago ratified the Convention in 1991, thus agreeing to be legally bound by the terms of the treaty and fulfil its own legislative requirements. Presently there is a legislative package adopted by this country since 2000 that includes the Children (Amendment) Act, The Children's Authority Act and the Children's Community Residences, Foster Homes and Nurseries Act. The Children's (Amendment) Act includes a schedule that contains a list of rights to which children are entitled. At the time of writing, this legislation was in the process of being updated. The Committee on the Rights of the Child has repeatedly expressed concern that the legislation of the Caribbean region does not adequately incorporate the 'general principles' recognised in the Convention, that is, decisions taken in the best interest of the child. It also does not address the 'civil rights and freedom of children' such as the right to be heard in decisions affecting them. Legislators and politicians thus far have not succeeded in putting the child at the centre of law reform efforts concerning children. This can prove to be a negative for children with acquired HIV as focus may not be on their needs as their right to be heard could be compromised (UNICEF (2004)). Over the last five years there has been a sharp decline in the volume of government resources allocated to the implementation of the NSP because of contractions in the national economy. The European Commission provided a grant of TT\$23.84 million to support the implementation of the NSP. Delays in project start up and the complex procurement procedures led to only TT\$8.30 million, or 34.81% of the grant, being utilized. The use



of the rest of the funds was delayed. The fact that HIV is slipping off the agenda is of grave concern. Regarding the specific allocation of resources for the funding of HIV programmes, there is poor understanding of the role of management accounting in the public sector, especially of identifying cost centres and beneficiary populations. Civil Society organisations (CSOs) have also expressed serious concern with the very limited resources, and in some instances, no resources being made available to them by the National AIDS Coordinating Committee (NACC) to implement community projects and programmes. NACC is the coordinating authority for Trinidad and Tobago’s national HIV and AIDS monitoring and evaluation framework, but presently, the NACC has been disbanded, and there is a plan to make it a statutory authority. At the time of writing this thesis, all activities were on hold.

## **1.5 United Nations General Assembly Special Session (UNGASS) report**

Thus far, the following has been accomplished for the 2008 United Nations General Assembly Special Session (UNGASS) report

Table 1.5 Major challenges and remedial actions taken

<b>Challenges</b>	<b>Action Taken</b>
<b>Limited sites which provide youth-friendly services</b>	Tobago HIV & AIDS Coordinating Committee Secretariat (THACC) Secretariat has procured 7 modified porta cabins (pre-fabrication buildings) and these will be located throughout the island to house youth healthy spaces.
<b>Absence of a comprehensive surveillance system for HIV/AIDS that covers both the public and private sectors</b>	An Information Technology (IT) platform has been established at the National Surveillance Unit to support the collation and compilation of data.
<b>Large numbers of persons, particularly among the most at risk population segments, remain reluctant to access testing and treatment and care services</b>	Many of the cultural and structural issues which deter these groups from accessing services were identified in recent studies and the manner in which services are delivered will be reviewed with relevant considerations

<b>Record-keeping and documentation of services provided are not routine</b>	Attempts have been made to introduce electronic record keeping but there have been delays in addressing data entry for old records
<b>Policy guidelines for service delivery are not readily available nor diligently adhered to</b>	National Treatment and Care Guidelines have been approved and circulated
<b>Anti-retroviral Therapy (ART) services remain centralized</b>	One additional treatment delivery site has been added
<b>Availability and willingness of clinicians to provide HIV/AIDS care and treatment services</b>	An Infectious Disease Specialist has been recruited by the South West Regional Health Authority who also services the Sangre Hospital treatment site.
<b>Enough training opportunities to update the skills of all the members of the treatment team</b>	The Trinidad and Tobago Health Training Centre (TTHTC) has implemented several training courses. Donors have also supported the participation of treatment providers at 38 regional and international training events.
<b>Provider stigma is still evident</b>	Workshops on Stigma and Discrimination have been conducted in Trinidad and Tobago and the issue receives attention in all training workshops conducted by the TTHTC.
<b>Interventions tend to be targeted to the general population with limited interventions specially designed and directed at high- risk groups</b>	Interventions tend to be targeted to the general population with limited interventions specially designed and directed at high risk groups

The UNGASS Country Progress Report 2010

## Summary

A look at the above highlights some of the problems, as clinicians are still unwilling to treat HIV/AIDS patients and provider stigma is still evident. The last point is very important, as the interventions tend to target the general population with limited interventions specially designed and directed at high-risk groups. The lack of specially designed interventions for children is particularly noticeable.

## 1.6 Research Aims

The broad aims of the study were to explore 1) the psychosocial issues that affect children with acquired HIV/AIDS in Trinidad and 2) to explore the support that exists and that is needed for an improved quality of life. It is hoped that intervention strategies will be gleaned from this research to assist future interdisciplinary teams that interact with this population

## 1.7 Issues of Definition

### 1.7.1 Definition of ‘Children’

In this research the definition of ‘children’ used by UNICEF and UNAIDS was used and therefore ‘children’ are defined as persons under the age of 18 years who were living with HIV or had lost one or both parents due to AIDS or whose survival, well-being or development was threatened or altered by HIV (UNAIDS 2008).

### 1.7.2 Stages of Development

The following stages of development were used to determine the scope of this research. The President’s Emergency Plan for AIDS Relief PEPFAR (2006, p. 2)

Table 1.8: Stages of development

<b>AGE (years)</b>	<b>STAGE</b>
Under 2 years	Infancy
2-4	Early Childhood/Toddler
5-11	Middle Childhood
12-17	Late Childhood/Adolescence

The children interviewed in this research were mainly from middle childhood and adolescence.

### **1.7.3 Perinatal Transmission**

The guidelines for the use of antiretroviral agents in paediatric HIV infection (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children, 2009) sought to define the vertical transmission of HIV from mother to child.

Transmission of HIV can occur during the prenatal period, during delivery or after birth via breast milk. HIV can be definitely diagnosed in most infected infants by age one month and nearly in all by four months by the use of virologic assays. The guidelines (Working Group on Antiretroviral Therapy and Medical Management of HIV-Infected Children 2009) state that HIV in an infant can be diagnosed by a positive virologic test before age 48 hours and that the infant is seen as being infected 'in utero' (before delivery). Those infants who have a negative virologic test during the first week of life but test positive after 6 to 8 weeks are considered to have been infected around the time of delivery (peripartum). Those who do not test positive until 4-6 months later are seen as being infected via breast milk. HIV infection can be definitely excluded if tests for HIV antibodies are negative at the age of 18 months.

In Trinidad and Tobago there is no mandatory testing of pregnant women for HIV. Pregnant women are however asked to undertake a test voluntarily while attending the public clinics. The Ministry of Health in Trinidad and Tobago developed a comprehensive counselling and testing policy to include Voluntary Testing & Counselling (VCT), rapid testing, and Provider Initiated Counselling and Testing (PITC). As a result, rapid testing is now available at several sites. In 2007, 7,842 rapid tests had been completed at the various sites with all positive tests being referred to The Health Public Lab (THPL) for confirmation. These are the latest data available (UNAIDS/UNGASS 2008).

### **1.8 Thesis Structure**

In order to explore the psychosocial issues and support for children with perinatally acquired HIV/AIDS, the use of a grounded theory approach was adopted. This approach led to a theory about the nature of secrecy in the lives of affected children. HIV/AIDS in any particular culture is a complex issue and needs to be examined in a way that facilitates the unearthing of various aspects that may not be known to date.

Thus, the research aims and questions determined the approach for conducting this study. The research explored these issues through interviews with a triad of individuals - mother, child and HIV friend – which I describe as constituting one case. I use the term ‘case’ throughout the thesis for ease of reference and in all instances I mean this triad of persons; this is different from conducting case study research, and which was not the approach adopted.

Chapter 2 contains a preliminary literature review. While it is not common to review the literature in advance of the research in a grounded theory study, a preliminary review was carried out to ascertain gaps in knowledge and provide greater theoretical sensitivity. The review is presented under the following headings: Section 1: methods used to obtain data, Section 2: definitions of perinatal transmission, children, and stages of development. Section 3: Major issues and debates about the topic. Section 4: three main reviews on the topic, Section 5: critical theories, concepts, and ideas on the topic and disclosure. Section 6: Women and HIV/AIDS, and the coping aspects of HIV/AIDS, and Section 7: Caribbean culture and socialisation.

Initially I conducted a broad-based literature review to shed some light on the topic and to expose gaps that may be present. Strauss & Corbin (1990) explain that in grounded theory one wants to discover relevant categories and the relationships among them, so that these can be put them together in new, rather than standard, ways. In order to facilitate this, the discussion of findings and the exploration of the literature took place simultaneously and the substantive review of literature is thus integrated into the findings chapters.

Chapter 3 discusses the methodology. It cites prior research using this methodology to give the study more rigour. The chapter gives an outline of the research design, the process, the interviews and the data analysis. The chapter also describes how ethical issues were managed.

Due to the complexity of the case triads, 3 chapters are devoted to the findings:

Chapter 4 outlines the findings related to the mothers. It discusses the main themes that emerged in relation to existing literature on the subject. Chapter 4 also includes

data from the further theoretical sample of three women who had not disclosed to their children that they were HIV-positive. The reason for this further theoretical sampling was to explore the core category 'secrecy' that emerged from interviews with the mothers who had disclosed to their children. Chapter 5 summarizes the findings related to the children. As in Chapter 4, the main themes are discussed in reference to existing literature. This chapter also employs eco-maps of the children's support systems, drawings, and other activities that help to produce more complete understandings of children's lives. Chapter 6 discusses the findings related to the HIV friends, the individuals identified by the mothers as their main supports.

Chapter 7 pulls together all the main themes of the findings chapters and offers a theoretical conceptualisation on the nature of secrecy. This theoretical model is presented in diagram form, based on the paradigm model used by Strauss & Corbin (1990). It gives a full explanation of the emergent phenomenon and draws conclusions from the findings.

In Chapter 8, based on Charmaz (2006) 'guidelines for evaluation of a study's grounded theory approach', I reflect on the research process and outcomes and suggest recommendations for improved interventions in terms of services, resources, and implications for practice. The aim is to help foster a better quality of life for mothers and children who are HIV positive.

## Chapter 2: Literature Review

### 2.1 Introduction

In order to heighten my sensitivity to the topic (Strauss and Corbin, 1998), I undertook a preliminary review of the literature. Many grounded theorists argue that the review of literature should only be conducted in relation to the emerging themes in a study and not before this. However I believed a preliminary review of other studies was necessary in order to sensitise myself to some of the key issues in the maternal transmission of HIV and its impact on the child. This preliminary review of the literature helped to justify the need for this research. Strauss and Corbin (1998, p. 49) state that there is no need to review all of the literature beforehand as in grounded theory studies it will be impossible to know prior to the investigation what the salient problems will be or what theoretical concepts will emerge. Also, the grounded theory researcher should not be so steeped in the literature that he or she is constrained or stifled by it.

However, it was important to identify some of the gaps in knowledge with respect to the psychosocial issues and support of children with acquired HIV. Thus, I had to ask myself the question, how rigorous and thorough should the review be. Smith & Bailey (1997) state that a comprehensive literature review is not the first point of call in grounded theory, they go on to say that some reading can occur prior to data collection but it should not be too extensive.

A good source of research questions in grounded theory studies is the 'technical literature', that is, reports of research and characteristics of professional and disciplinary writing on the general problem area (Strauss and Corbin 1990, p. 52). I used this as my guide. The bulk of the literature review was conducted during the emergence of the core phenomenon and main themes. It is via this route that data from the extant literature contribute to the study (Eisenhardt 1989). It must be clear here that this is not a neglect of literature but the awareness that the researcher should be free as possible of influences that could restrict the freedom and objectivity necessary for theoretical discovery. In this literature review I was mindful of this, thus, readings about mothers

with HIV, support systems and culture of Trinidad and Tobago with respect to HIV/AIDS and the raising of children comprised the initial literature review.

### **2.3 Structure of literature review**

This review is presented under the following headings: 1) methods used to obtain data. 2) Key issues and debates about the topic; global & Caribbean figures; the face of HIV/AIDS in children; developing versus developed countries. 3) Three main reviews on the topic. 4) Key theories, concepts and ideas on the topic and disclosure. 5) Women and HIV/AIDS; coping aspects of HIV/AIDS. 6) Caribbean culture and socialisation. Each section ends with a summary.

### **2.4 Methods used to obtain data**

Studies were sourced between October 2008 and September 2009.

A search was undertaken for studies on the topic, also reports from the international websites such as UNAIDS, USAIDS, UNICEF, UNIFEM, WHO and PAHO. The online library at [www.questia.com](http://www.questia.com) was used to source journal articles, books and reports. The 'Google Books' site was used to source books written by Caribbean authors. Electronic databases EbscoHost and Proquest were used both at The University of Huddersfield, United Kingdom and The University of the West Indies, St. Augustine, Trinidad for journals on the topic. As journals were sourced, those bibliographies were perused for further data. Journals were then further sourced from 'Metalib' at the University of Huddersfield.

Information on HIV/AIDS is vast, so the search had to be narrowed down to actually find what was needed on the topic. This created a funnel effect with the following terms being used to filter the search: Vertical Transmission of HIV/AIDS, mother- to-child transmission of HIV/AIDS, perinatal transmission of HIV/AIDS, children and HIV/AIDS, psychosocial issues and children with HIV/AIDS, women living with HIV, HIV-infected women and their families and care and support for children living with HIV/AIDS. As this information was sought, the bibliographies at the end of sourced journals provided for new searches. This formed a very important aspect of the literature search.



However, it was discovered that even though several studies had been carried out on the psychosocial issues relating to children born with HIV, most used a quantitative method and did not capture the experience of living with HIV from children's perspectives.

## **2.5 Key Issues and Debates about the Topic**

### **2.5.1 Globally**

Globally in 2007 there were 2 million children living with HIV, 370,000 new infections and of the estimated 2.3 million infected children, more than 90% are thought to have been infected through MTCT (UNAIDS, UNICEF & WHO 2007).

On the cusp of the fourth decade of the AIDS epidemic, the world had turned the corner and has begun to reverse the spread of HIV (UNAIDS/WHO 2010). It is reported that more than 25million people worldwide have died of AIDS since 1981 and approximately another 33.3million (as of 2009) were living with HIV/AIDS. While cases have been reported in all regions of the world, almost all those living with HIV (15 million) reside in low and middle income countries (UNAIDS/WHO 2010 pg. 7). HIV primarily affects people in their most economically productive years and more than half of new infections are among those under the age of twenty five (UNAIDS/WHO 2008). Of all people living with HIV worldwide, 50% are women (the other 50% consists of young persons, men and children less than 15 years of age) and more than 59% are found in Sub-Saharan Africa. Chang *et al.* ( 2003) and Royce *et al.* (1997) note that the predominant mode of transmission of HIV worldwide is via heterosexual contact and that women were more susceptible to HIV because the efficiency of HIV transmission from male to female was greater than for the reverse. There are few means by which women can actively protect themselves against HIV infection, particularly in the absence of a protective vaccine. Gender inequalities, differential access to services and sexual violence have increased women's vulnerability to HIV and women, especially younger women are more biologically susceptible to HIV than men (UNAIDS/WHO 2008).

UNAIDS & UNICEF, (2005 p. 4) reports that HIV/AIDS was a serious threat to children as children younger than 15 years accounted for one in six global AIDS-related deaths and one in seven new global HIV infections. One child under 15 is said to die of an AIDS-related illness every minute of every day and a young person between the ages of 15-24 contracts HIV every 15 seconds. The UNICEF 2005 report further stated that there were nearly 1800 new infected HIV infections in children under five mostly from MTCT - and after more than twenty years, less than 10% of pregnant women were being offered services to prevent transmission of HIV to their infants. Added to which, fewer than 10% of the children who had been orphaned or made vulnerable by AIDS received public support or services. The estimated number of children living with HIV-AIDS globally has increased to 2.5million in 2009 (UNAIDS/WHO 2010 p. 23). In the Caribbean the estimated number of children living with HIV-AIDS has decreased marginally from an estimated 18,000 in 2001 to an estimated 17,000 in 2009 (UNAIDS/WHO 2010, p. 40). However, decreasing HIV incidence and slowly widening access to services that prevent MTCT have led to a steep drop in the number of children newly infected. An estimated 22,000 children between the ages 0-14 became infected in 2009, a 15% decrease as compared to an estimated 26,000 in 1999. AIDS-related deaths have declined by 15% since 2004, from 18,000 to 15,000 (UNAIDS/WHO, 2010 p. 35).

According to UNICEF (2005), AIDS redefines the very meaning of childhood for millions of children; depriving them of their human rights in the form of lack of care, love and affection of their parents and of their teachers and other role models. This had a domino effect; eventually affecting their education and options for the future.

Even though AIDS has been the focus of the international community for over two decades the number of children infected with HIV/AIDS was not counted until recently (UNICEF 2005). One of the first global estimates of the number of children who had lost 1 or both parents to HIV/AIDS appeared in 1997 (Hunter & Williamson 1997).

### **2.5.2 The Caribbean**

The HIV/AIDS adult prevalence rate in the Caribbean was 1.0% in 2009, second only to Sub-Saharan Africa (5%) and higher than the global rate of 0.8% (UNAIDS/WHO 2010). In the Caribbean region there were approximately 17,000 new HIV infections in 2009 and 12,000 deaths. Women aged fifteen years and over comprised the majority of those infected with HIV/AIDS and accounted for an estimated 53% of adults aged fifteen and over (up from 46% in 2001). The Caribbean remains the only region besides Sub-Saharan Africa, where women and girls outnumber boys and men among people living with HIV (UNAIDS/WHO 2010). In 2001, the fastest growing group of HIV/AIDS positive individuals was females aged 15-24 years (Jack 2001). Sexual patterns and norms, which in the past had contributed to teenage pregnancy in the Caribbean, now contribute to increasing HIV/AIDS. Some factors that may have contributed to this include tolerance for multiple sexual partners, women's lack of negotiating power for condom use, and low condom use (Jack 2001).

The Caribbean Epidemiology Centre (CAREC) (2006) reports that risky sexual behaviour still abounded in the Caribbean. Results of the 12 household-based general population surveys in six eastern Caribbean countries showed that more than half of the surveyed males aged 15 to 24 years had had more than one non-regular sex partner in the preceding 12 months, compared to approximately one-quarter of surveyed females in the same age group. Approximately 7 in 10 males reported using a condom the last time they had sex with a non-regular partner; this result was consistent with the data from the younger and older populations. Less than half of the men reported using a condom every time they had sex with a casual partner. Although at least 8 out of 10 respondents (male & female) knew that using a condom during sex was protective against HIV infection, fewer than half of the sexually active respondents reported consistent condom use with casual partners. The gender differences highlight the vulnerability of women to HIV due to low level usage of known effective prevention methods. For females, condom use at last sex with a casual partner was reported by approximately half of the women aged 15 to 24 (CAREC 2006).

There were approximately 11,000 children under the age of fifteen living with HIV/AIDS in the Caribbean region (UNAIDS/WHO 2007). The number of new cases of children in the region with HIV/AIDS in 2007 was approximately 1,800 (UNAIDS/WHO 2007).

### **2.5.3 The Face of HIV/AIDS in Children- Developing versus Developed Countries.**

Sub-Saharan Africa is home to 24 out of 25 countries with the world's highest level of HIV prevalence (UNAIDS/UNICEF/USAID 2004). The UNAIDS 2004 report states that it was estimated globally that 15 million children were orphaned by HIV/AIDS with more than 12 million in Sub-Saharan Africa alone, fewer than 10% of whom received public support and services. Magder *et al.* (2002) stated that North America and Europe have reduced HIV infections in young children to 1- 2% by combining antiretroviral treatment with elective caesarean-section delivery and avoidance of breastfeeding (Levine et al. 2005; Kind et al. 1998). However, in Sub-Saharan Africa, testing levels and medication have been neither available nor affordable (UNICEF 2005). In 2003 only 10% of low and middle income countries with data reported coverage of services to prevent MTCT and fewer than 10% of all pregnant women were being offered services to protect their children from transmission of HIV (USAID/UNAIDS/WHO/UNICEF 2004).

UNICEF (2005) reports that some pharmaceutical companies that produced anti-retroviral drugs have hesitated to invest in the development of paediatric products because HIV infection among children in industrialised countries was almost eliminated. However, there is still a demand for anti-retroviral drugs for children in low-income countries. Another issue pertaining to medicine for children in some low-income countries is the lack of trained medical staff to treat children. The 2005 UNICEF report reiterates the need for more effort to provide counselling and psychosocial support to children with HIV/AIDS. This report further provided recommendations for action for helping women and children with HIV/AIDS; however research on issues affecting children and women was not mentioned as a platform for action.

Richter (2008) points out that children remained "small issues" for policymakers and scholars, and highlighted several factors accounting for this relative invisibility:

1. HIV positive children have remained a blind spot in the care and treatment for two decades in low-resource countries (Domek 2006). However, despite recently scaled-up treatment access programmes, a large majority of the 2.3 million children living with HIV/AIDS do not have access to the antiretroviral treatment they need (WHO/UNAIDS & UNICEF 2008).
2. The complex reality of the impact of HIV/AIDS on both infected and affected children has often been undermined by the media because of the emphasis on the “orphan crisis” (Bicego, Rutstein & Johnson 2003; Foster, Levine & Williamson 2005; UNICEF/UNAIDS & WHO 2007).
3. Children and childhood have not been recognised as significant areas of study even though over the last two or three decades they have gained increased attention (Qvortrup 1994; James & Prout 1997; James, Jenks & Prout 1998; Mayall 2002). Hejoaka (2009) reported that there is still a dearth of scholarship examining children as social actors and exploring the sense that children make of their world.

Presently, according to the World Bank classification of low, middle and high income countries ([World Bank 2011](#)) Trinidad and Tobago falls into the category of high income. The threshold for this classification is \$US12, 275 and above Gross National Income (GNI) per capita. The threshold for “high income” is set fairly low so that there is an extensive range within the high income classification. Trinidad, although as the richest country in the Caribbean and with free, universally available ARVs, the outcomes for children should be closer to those in income-rich countries. As discussed in 1.6., the way that the UNCRC is being adopted in Trinidad and Tobago, may explain why the country has not made significant inroads into treating children as subjects and putting them high on the agenda for treatment and care. Also, there are still gaps that persist in the MTCT programme, such as challenges in accessing all the babies who need to be tested, adherence of mothers and children to the prescribed treatment regime, disclosure to partners, testing of partners and other children and lack of follow-up of mothers and babies (Trinidad and Tobago UNGASS 2010 Report, P. 29)

#### **2.5.4 Summary**

After the 4<sup>th</sup> decade of HIV/AIDS this epidemic has become a major health challenge throughout the world, more so in developing countries especially Sub-Saharan Africa where resources and services are in limited supply. The pandemic has affected women disproportionately as they are more susceptible to contracting the virus because of gender inequalities and domestic violence. Children face a severe health challenge and as recently as 2005, they accounted for one in six AIDS-related deaths and one in seven new infections. Care and support for children is mostly focused on their material needs as opposed to their social and psychological needs. Platforms for action to help children infected by HIV/AIDS have been recommended however, research on issues affecting children is not among them. Richter (2008) mentions that children still remained “small issues” to policy makers and scholars and went on to list several reasons why. The Caribbean’s prevalence rate of 1.1% is second to that of Sub-Saharan Africa (5%) and this highlights the seriousness of the pandemic in the region. In Trinidad and Tobago (a country that according to the terminology of ‘development’ is classified as ‘in-transition’) from being a middle income country, that is, the country has fairly recently become classified as “high income” and it is found in the lower ranks of the “high income league”, research on the psychosocial issues and support pertaining to children is integral to achieving the best care and support for this generation and the generation to come. If this can be accomplished in the near future, then the livelihood and quality of life of this nation’s children can register some improvement.

#### **2.6 Three Main Reviews**

In the review of literature on children and HIV/AIDS, three main reviews were found: Sherwen and Boland (1994); Brown and Lourie (2000) and UNDP/UNFPA/WHO (2003).

Sherwen & Boland (1994) provide an overview of psychosocial research concerning paediatric HIV. They looked at approximately 30 research papers grouped according to the child’s environment and family and those concerning the child. They noted that improved medical treatments helped children with acquired perinatal HIV to live longer and as a result children needed to be integrated into the mainstream of life. They added

that caregivers needed to be aware of the psychosocial issues faced by children living with HIV; however, there was minimal research concerning children's relationship with the psychosocial aspects of HIV/AIDS. A keen observation made was that models available for research on paediatric HIV/AIDS came out of models developed for other chronic childhood illnesses creating a pool of intervention approaches and knowledge from a medical standpoint. They went on to use an interactionist model of chronic illness that grouped research into studies that related to the child's environment, family and those family members involved with the child. Emerging from this exercise were areas of psychosocial research that concerned resiliency and coping, family concerns and interventions.

Browne *et al.* (2000) reviewed 140 studies from 1981 to 1999 which addressed HIV infection and its psychological and social implications for children and adolescents. They focused on 1) epidemiology of HIV, 2) neurocognitive development among those infected, 3) psychological impact of infection and 4) the family and social context of HIV. They highlighted the fact that the social context for many children with HIV consisted of poverty, lack of resources and multiple family losses. These variables may have had an impact on adherence to medications, delivery and utilisation of treatment services, family relationships, bereavement and disclosure of illness. Another important point noted was that cultural beliefs influenced how people coped with illness and loss.

In their review Brown & Lourie (2000) noted that the transition of HIV/AIDS from an acute lethal disease to a sub-acute chronic disease had enormous implications for the emotional development of children. Thus, as children born with HIV continued to live longer, normal developmental milestones and educational needs will take on new significance. Furthermore, the mental health needs of those born with HIV may have to be studied independently in order to ascertain what effects living longer with HIV/AIDS entail; also, they argue there is need for research to be directed at the quality of life and other psychological concerns of children. They said that in the future, psychosocial research into HIV as a chronic disease may benefit the care of other chronic disorders in children. Cohen (1994) as quoted by Brown *et al.* suggested that paediatric HIV treatment should be understood in terms of 3 systems: 1) individual characteristics of

the child, 2) disease characteristics of HIV/AIDS, 3) family processes which addressed HIV/AIDS. Mellins & Ehrhardt (1994) had advocated for a family-centred approach to the treatment for HIV positive children while Brown & Lourie (1994) suggest that the ideal model for children living with HIV is the integration of medical, psychological and social services by both primary clinicians and community based staff although this requires the cooperation of paediatricians, social workers, psychologists, psychiatrists, medical ethicists, psycho-educational specialists, occupational, physical and language therapists and case managers. In a multidisciplinary treatment approach, they argue, the psychosocial elements can be identified and addressed.

In their review of HIV-infected women and their families (UNDP/UNFPA/WHO 2003) note that the psychosocial needs of the woman and her family are given very little consideration. Bennetts *et al.* (1999) report that most research on HIV-infected women focused on risk behaviour and vertical transmission and that social and psychological studies of mothers were rare. Ingram & Hutchinson (1999) note that little research exists about the psychological aspects of mothering when HIV-infected. Further to these three reviews, Hejoaka (2009) speak about the need for policies and programmes to value the role of caregivers and pay specific attention to their specific support needs. She further added that to date, there was still need for more research on the social and psychological issues facing women infected with HIV/AIDS.

### **2.6.1 Summary**

The three reviews discussed above highlight the need for more emphasis on the social and psychological experiences of and implications for mothers and children in the face of the HIV/AIDS. Both groups (children and women) demand more attention in this area. As children continue to live longer more attention must be paid to their developmental and psychosocial needs as they continue to live and be part of the mainstream of society. Most research on women in general has focused on risk-behaviour and vertical transmission. Thus, there is a gap with respect to both groups on the psychosocial issues that confront them on a daily basis. These research reviews gave an overall picture during the period 1994-2003 on women and children with HIV/AIDS.



## 2.7 Key Theories, Concepts and Ideas on the Topic

### 2.7.1 Children

It is important to recognize that cure rates for many illnesses that were once highly lethal for children have changed from coping with dying to living with a life-threatening illness (Adams & Deveau 1993; Doka 1996; Koocher & O'Malley 1981; Spinetta 1981).

Children often have psychosocial needs focused around the importance of love and security, with freedom from pain, freedom from deep-seated feelings of anxiety or guilt, a sense of belonging, a feeling of self-respect and understanding of self (Masera *et al.* 1999; Morgan & Murphy, 2000). Waechter (1984) notes that from a developmental standpoint, school-aged ill children most often have concerns about the future, education, social relationships, body image and issues related to hospitalization and procedures. He added that much of their anxiety focused on relief from pain or other forms of distress, intervention procedures and security both within themselves and in relationship to family members, peers and other significant others. Attig (1996a) and Sourkes (1995) also supported this claim.

According to Dane (1996) and Bluebond-Langner *et al.* (2001) there may be some similarities between the way that children with HIV/AIDS cope with this life threatening illness and the way that children cope with other childhood illness such as cancers and cystic fibrosis. Issues that are often central for survivors of a life threatening illness are: 1) normalising or incorporating the disease experience into their life history; (2) learning to live with uncertainty, which may lead to a heightened sense of vulnerability, over-protectiveness by adults, or a transformation of personal priorities, values and goals; (3) learning to live with compromise and on-going repercussions of disease and (4) overcoming stigma in the social world (Ruccione 1994). According to Rao *et al.* (2007) HIV/AIDS in children has transformed from the category of an acute lethal disease to that of a chronic illness because of the advent of HIV/AIDS medication. However, the stigma and discrimination experienced by infected children make it unique compared to other chronic illnesses. In a chronic illness there is a psychological adjustment of the child and family to both the physical nature of the illness as well as the important management factors such as adherence to medication and treatment and lifestyle

changes. Thus, Rao *et al.* (2007) reiterate that there is need for all the specialists dealing with HIV-infected children, including health care experts, to be aware of the psychological manifestations of HIV infection so that proper management and referral for other services as may be considered necessary can be made.

Blanche *et al.* (1997) state that the presentation of AIDS in children was different compared to that of adults. In children, the presentation tended to be bimodal as some children become seriously ill in the infancy period (being rapid progressors); while others remain relatively healthy for prolonged periods (being slow progressors). Forsyth (1995) concludes that children can have a number of clinical manifestations secondary to HIV infection which may cause noticeable features such as growth stunting or chronic dermatological conditions. This may lead to psychological problems in HIV-infected children because both conditions may manifest a disturbed body image, in turn, leading to significant psychosocial problems in the school-aged child.

Other psychosocial issues can involve the history of repeated hospitalisation and isolation from peers which have been shown to have an adverse effect on the child's social, cognitive and communicative development (Task Force on Paediatric AIDS, 1998). Also, knowledge of HIV status through disclosure of HIV infection, fear of death and suffering and family conflict because of the illness and the attendant stress on the child from these factors, all play a part in the psychological well-being of the child (Trad *et al.* 1994). Additionally, family and other social issues play an integral part in the psychological health of the infected child as a loss of a parent or sibling due to AIDS can affect the child (Pelton & Forehand, 2005). The inability of parents to provide care to their HIV infected child is also an important issue and occurs for several reasons such as parental physical ill health; bereavement made even more difficult because of the loss of support of a spouse or partner (Mellins & Erhardt, 1994) and discrimination and stigma as a result of society's attitude to HIV (Trad *et al.* 1994).

The parent-child relationship and the family environment also play an important part in the psychological wellbeing of the infected child. Healthy family functioning has been shown to be associated with positive outcomes in children with a serious illness. Sprenkle (2002) identifies nine positive family characteristics that are associated with

good outcomes for children. Those that emphasised psychological well-being included maintaining social supports, maintaining family flexibility, maintaining family cohesiveness and engaging in active coping efforts.

### **2.7.2 Disclosure**

Abadia-Barrero & LaRusso (2006) worked with a group of 7- 9 year olds with perinatal HIV who perceived that the word AIDS or being sick were considered negative attributes but could not relate these to their lives. Thus, at primary school they eventually learned a lot more about HIV/AIDS as information was available. These children were also exposed to the negative messages and discriminatory labels and continued to be confused about the difference between HIV positive and HIV negative children. At this age, children interacted with more environmental spaces in which AIDS had different biologic, social and emotional meaning; however the lack of information impeded children from making sense of these different meanings. As a result, children exhibited inadequate knowledge about AIDS and were not prepared to address AIDS-related stigma and began to feel uneasy about their illness experience (Abadia-Barrero & LaRusso 2006).

Preadolescents' growing awareness of the relationship between their lives and negative social values associated with AIDS produces shame and anger, that is, a growing self-stigma. The inability of adults to adequately explain what HIV/AIDS is about continues to add to this stigma and misunderstanding. At the pre-adolescence stage, however young people begin to have a better understanding of AIDS in its biologic and social environments. This stage is crucial for awareness and capacity for understanding the self in relation to others (Selman 2003). However, an environment of secrecy and disclosure tends to perpetrate AIDS as a shameful part of self, leading to children reacting negatively in their social environment (Selman 2003).

Other studies show that prolonged silence and poor adult-child communications result in psychosocial distress, self-stigma and adherence problems (Johann-Liang 1999; Instone 2000; American Academy of Paediatrics 1999; Mellins et al. 2004). Despite poor communication these studies showed that children still learned a lot about the disease.

According to Lewis (2001) the decrease in rates of perinatal transmission makes the wellbeing of affected children even more prominent. Lewis suggests that investigation of services and interventions aimed at enhancing coping and adjustment over time and permanency planning should be a priority. Further, she argues that there is need for an integrated, multidisciplinary service in paediatric primary care along with mental health, social and policy interventions that seek to improve quality of life for all families.

### **2.7.3 Theoretical Framework**

In pulling the different strands of the literature together I have identified the theoretical framework which underpins this study. This informed this researcher's epistemology and philosophical stance. Denzil and Lincoln (2003) state that the theoretical framework can guide the researcher's actions and his/her methodological premises. Crotty (1998 p. 3) posit that epistemologies are embedded in theoretical perspectives. He claimed that the "philosophical stance informs the methodology and provides context for the process". He continued that methodologies can include a wide range of approaches, (for example, grounded theory as used in this research) and constitute research designs that affect the choice of methods to be used. Flinders and Mills (1993) assert that a theoretical framework is more than methodologies and epistemologies and that theory includes "any general set of ideas that guide action" (p. 12). They also said that theory is pragmatically bound up with the activities of planning a study, gaining entry into the field, recording observations, conducting interviews, sifting through documents and writing up research" (p. 14). These ideas helped to inform the methodology and comprised of three distinct concepts.

1. Child-right's perspective
2. Resilience (coping)
3. Stigma

#### **Child Right's Perspective**

The researcher's view of children is very important to the power relations that take place between researcher and participant. Christensen and Prout (2002) outline four ways that children and childhood have been identified in research: the child as object, the child as subject, the child as social actor and the child as participant/co-researcher. I

have used the second viewpoint where children are positioned as subjects putting them more in the forefront of the research process in a child-centred setting with child centred activities. These activities are recorded in Appendices 15 and 16 along with the drawings that each child completed on his/her family. The information for the children (Appendix 8) was done on coloured paper for child friendly purposes. As stated in 5.1, it was important for the child to understand that they were not being viewed only in relation to being HIV positive but as non-pathologised individuals with complete lives. Their childhoods being affected by living with HIV but not defined by the virus.

The Convention on the Rights of the Child treaty lists the basic human rights that children everywhere have the right to including survival and the right to develop their fullest potential. Ensuring beneficence based on children's rights was an ethical principle that was used in the research. The Australian Health Ethics Committee (2007: 4.2) outlines the principle of beneficence whereby research involving children should only be conducted where:

- The research is important to their health and well- being.
- Their participation is indispensable to the research.
- The research method is child appropriate and
- The research conditions provide for their physical, emotional or psychological safety.

Attached to this principle of beneficence is the principle that for children to benefit from the participation in research, they should be seen and heard in research (Australia's Seen and Heard Report 1997). Winter (2004) articulates that the obligations of professionals and ethical obligations of research are to provide children with authentic opportunities to have their views heard and considered in respective ways. Woodhead and Faulkner (2000) see respect for children as social actors in the research places new responsibilities on the adult community to structure children's environments, guide their behaviour and enable their social participation in ways consistent with their understanding, interests and ways of communicating, especially in the issues that most directly affect their lives. All of this was taken into consideration before entrance into the field to interview the children.

## **Resilience**

Jones (2009) states that the literature on HIV-AIDS emphasises issues of risk and vulnerability and while it is important to minimise risk, it is just as important to focus on resilience of persons living with HIV-AIDS. This can foster social work interventions that promote empowerment rather than reinforce victimhood. Resilience in its broad meaning is viewed as the capacity of individuals and groups, to prevent, minimise, adapt to or overcome the damaging effects of adversity (Masten & Coatsworth 1998). It was important to see in this research how children and mothers coped with the virus in their daily lives and the measures they may have utilised to combat same. This was addressed in 4.5.6 in the mother's chapter and in 6.4.2, the children's chapter.

## **Stigma**

Goffman (1963 pg. 3) defined stigma as an "attitude that is deeply discrediting, within a particular social interaction". In the Caribbean many governments are committed to the achievement of human rights, however, stigma and discrimination in relation to HIV-AIDS seems to retard the process. Stigma and discrimination operate at every level of society (Jones 2009). This was acknowledged and it emerged as a theme with the mothers in this research and is discussed in depth in 4.5.4.

### **2.7.4 Summary**

HIV/AIDS has moved from an acute lethal disease to a chronic illness in children. The main difference between this chronic illness and others is the stigma and discrimination experienced by children and the psychological issues encountered which may be a major stressor in their lives. Lack of open communication about HIV/AIDS can create confusion and mistrust and compromised disease knowledge can lead to increase in vulnerable risk behaviours.

## **2.8 Women and HIV**

Wiener (1991, p. 375) writes about women and their experiences with HIV; she alluded to the fact that these women - gay and straight, rich and poor, of all ethnicities and from varying backgrounds - were the 'invisible participants' who shouldered the burden as caregivers both in and outside the home. Anastos & Marte (1989) describe how society's display of sexism, racism and classism had affected the public perception of

HIV/AIDS in women. McKenzie (1989) continues that since 1981, little attention had been paid to research or public discussion of the medical, social and emotional needs that accompany women's multiple roles in society. Wofsky (1987) asserts that with HIV-infected women, stigma and discrimination were intensified. He added that women needed a community of support especially at the time of diagnosis to buffer the impact of such information.

Gillman & Newman (1996) also address women and the discrimination they experience based on poverty, gender, race and lack of opportunities as well as having a potentially life-threatening infection. Yet, strength, courage, kindness, devotion to family and children and a determined will to live also characterised the women in Gillman and Newman's study. With respect to children, women often express tremendous guilt over unintentionally transmitting the disease to their children coupled with fears of the stigma that their children may experience because of their mother's disease (Kneisl 1993). Kneisl stated that HIV-infected women coped with sources of stress and anxiety differently from infected men as they have fewer economic resources, more household responsibilities and fewer social and community supports than do men. However, Gillman & Newman (1996) conclude that despite women's concerns for issues such as finances and housing, HIV health, discrimination, death and dying, women showed strength, resilience, flexibility, endurance, courage and compassion under these circumstances when they interacted with their HIV-positive children.

The dual challenge of women being both patient and caregiver was examined. Hackl *et al.* (1997) discover several factors that impacted on HIV positive women. These included the impact of stigma, disbelief at the diagnosis, lack of a guardian for their children, the paucity of women's groups and barriers associated with seeking services. All of the women (8) in Hackl *et al.*'s study exhibited evidence of clinical depression.

Home care has become a main component of the response of the AIDS epidemic, hence shifting the care-giving work onto women who are the majority of informal and unpaid caregivers. In recent years there has been an increasing amount of literature on AIDS-related care, with particular focus on care for ailing adults (Hamra *et al.* 2005; Nkosi *et al.* 2006; Campbell *et al.* 2008) and foster care of orphaned children

(Nyamukapa & Gregson 2005; Meintjes & Giese 2006; Abebe & Aase 2007; Heymann *et al.* 2007; Hosegood *et al.* 2007). So far, however, with the exception of a few studies (Brouwer *et al.* 2000; O'Hare *et al.* 2005; Van Graan *et al.* 2007) there has been little discussion among social scientists about caring for children living with HIV.

In order to understand the daily AIDS care provided by women to HIV positive children, the issue of stigmatisation must be explored. AIDS-related stigma has received some attention (Stein 2003; Parker & Aggleton 2003; Castro & Farmer 2005; Deacon *et al.* 2005; Mahajan 2008) and some research has shown how stigma may prevent access to and provision of care (Turan *et al.* 2008).

In the western world, recent examples of literature have attempted to explain the complexity of HIV disclosure to children and to stress the need for formal supports (Tompkins 2007; Wiener 2007). However, a limited number of studies conducted in low resource countries show a lack of assessed interventions and institutional support for children (Bikaako-Kajura *et al.* 2006; Rwemisisi *et al.* 2008; Vaz *et al.* 2008). In spite of all this research, interventions which support HIV/AIDS disclosure to children in low-resource countries is still missing from the AIDS policy agenda (Hejoaka 2009).

Hejoaka (2009) reports that mothers' isolation challenged AIDS policies and programmes since these tended to undervalue the central role of caregivers and their social support needs. Hejoaka (2009) concludes in her research that there was further need to investigate family and community-based care and that further research should integrate individual approaches in order to emphasise the experience of both caregivers and children in a context where care is shaped by secrecy. Furthermore, the feminist ethic of care (Tronto 1993) provides a challenging framework with which to examine the role of informal care givers and care recipients; thus, by placing relationships at the heart of care, the ethic of care may increase our understanding of the complex role of gender in the process of AIDS care.

### **2.8.1 Coping Aspects of HIV/AIDS**

Coping is an issue that is integral to mothers, children and family members when faced with the stark reality of an HIV positive diagnosis. Silva *et al.* (2008) explore this area



and examined the coping strategies of women with HIV positive children in order for them to live better with the disease. These consisted of fear of the disease and death, fear of expected prejudice and uncertainty regarding the future. Consequently, mothers reacted with excessive concern and phobic/controlling behaviour with respect to their parenting of their children. Silva *et al.* added however, that mothers tended to exhibit total dedication to ensuring that their children adhered to their anti-retroviral medication. In the public perception AIDS as a disease is still associated with death. Some ways in which a number of mothers cope include denial and underestimation of the virus. On the other hand comparison of their HIV positive children with other seropositive children makes them feel better. That is, they observe other children who are in worse situations than their children and compared them both. These comparisons may be considered as positive and beneficial as adjustments to HIV are made easier.

Religious belief has also proved to be another way of coping. In Silva's 2008 study, spirituality, faith and beliefs gave the mothers the necessary strength to care and for self-care, thus reducing the effects of loneliness in their struggle for life (Silva *et al.* 2008).

### **2.8.2 Summary**

In the review of literature, it can be seen that having a HIV positive diagnosis evokes psychological stress on the part of mothers. Issues of coping and living with HIV become a central part of their existence and stigma seems to be always at the forefront of their lives. Where children are involved, normalizing the situation for these mothers is a key aspect of ensuring their children are cared for in the best way possible. However, children's experiences with HIV have not been explored enough, especially with respect to the psychosocial issues and support that permeate their daily lives.

## **2.9 Caribbean Culture and Socialisation: HIV/AIDS in the midst of Culture**

Thomas (2001:40) said that culture is a unified set of values, ideas, beliefs and standards of behaviour shared by a group of people; it is a way a person accepts orders, interprets and understands experiences throughout the life course. Williams &

Ponton (1992) state that the cultural context of HIV transmission was an important factor in the care of infected youth and that cross-cultural studies of the psychological processes triggered by HIV suggested that people of different backgrounds coped with HIV/AIDS according to their own social mores and cultural practices. In India, for example, HIV infection has been associated with extreme reactions of shame, fear, humiliation and anger (Ponton & Lees 1998). However, Ponton & Lees also mention that because of greater social acceptance of HIV infection among young people, combined with advances in drug therapies, HIV diagnosis in the United States today does not have such a profound negative impact as it once did.

Many of the research studies on Caribbean families are dated. Evans & Davies (1997) state that although there was substantial research on Caribbean families, much of the research related to low-income African-Caribbean families in Jamaica and Trinidad and Tobago. A common thread running through the literature is that children are seen as desirable and highly valued and much status is placed on the “mother role” (Barrow 2008). Child bearing has long been linked to the emergence of a strong self-image and a sense of womanhood that serves as a ‘rite of passage’ (Durant-Gonzales 1982).

In the Caribbean, there are certain cultural beliefs that influence child-rearing practices and the socialisation process. The biblical injunction not to “spare the rod and spoil the child” and the idea that children “should be seen and not heard” are adhered to by many Caribbean parents (Evans & Davies 1997). Caribbean men who have several sexual partners are tolerated, while females are expected to remain virgins until married (Le Franc *et al.* 1996) and more recent studies suggest this is still the case (Holschneider & Alexander 2003). Men have been expected to ‘father’ as many children with ‘as many women as possible’ to show their ‘macho-ness’ (maleness) as it improves their image with their friends consequently, children are produced ‘inside’ and ‘outside’ the primary union (Ortiz-Torres *et al.* 2000). This is a potentially dangerous practice especially with respect to HIV/AIDS prevention as condom use in relationships often implies lack of intimacy and suspicion of infidelity on the part of the male and leads to non-protection which in turn, can increase the risk of HIV infection.

Due to the downturn in the economy and the need to migrate for employment, the Caribbean family has gone through a series of changes over recent decades where women have taken on more responsibility of managing the household financially (Ortiz-Torres et al. 2000). In addition to becoming at times, head of the household, women are expected to continue with their traditional care-giving roles (Neely-Smith 2003). In the past, the Caribbean had been a community where the extended family - aunts, cousins, grandparents, God-parents and neighbours- played a significant role in the nurturing of children. Children were seen as being raised by the community (Evans & Davies 1997). However, Dudley-Grant (2001) reports that the values of Caribbean families were changing and the nuclear family now seemed to be the ideal.

### **2.9.1 Summary**

The culture of a country provides important information that is pertinent in the understanding of the impact of HIV/AIDS on the family. Certain cultural practices and beliefs influence the way children are viewed and nurtured and this in turn can impact on care and support in their unique situation with HIV/AIDS. The family in the Caribbean presently seems to more 'nuclear' than 'extended' and this can also influence the type of informal support systems available to women and children in the midst of HIV/AIDS crisis.

### **2.10 Conclusion**

The literature review has revealed gaps in what is known about children with perinatally acquired HIV. It was found that children with HIV-AIDS were not placed high enough on the agendas of countries and that children's experiences were not explored enough especially their psychosocial issues. In addition to heightening my sensitivity to the subject, the literature review also provides justification for research on the topic in Trinidad and Tobago. The next chapter looks at the methodology, methods and research design for the study.

## Chapter 3: Methodology

### 3.1 Introduction

This chapter addresses the research design of the project undertaken and the epistemology that guided the philosophical framework, the methodological approach and methods used. My position as the researcher situated in the research process is discussed and I show how the research was conceptualised with respect to the research questions, aims and conceptual framework. In addition I hope to make explicit some of the theoretical positions that underpin my value base as a researcher. The chapter also describes the procedures used to recruit participants, and collect, transcribe and analyse data. Finally, the ethical issues and reflections on the rigour of the research are discussed.

### 3.2 Epistemology

'Research is a systematic process of investigation, the general purpose of which is to contribute to the body of knowledge that shapes and guides academic and or practice disciplines' (Powers & Knapp 1995, p. 148). However, all research has an epistemological basis, that is, a particular viewpoint/understanding about the ways in which knowledge is constructed; in other words, a philosophical framework. Higgs *et al.* (2009 p. 16) state that 'a philosophical framework of a research project establishes the research paradigm within which the project is situated and provides guidance concerning the type of knowledge that will be generated and the tools and rules that are appropriate to use'. The framework used was that of the social constructivist which views knowledge interests as pragmatic, the knowledge product as negotiated understanding, the approaches to reality as social interpretation and the research paradigm as interpretive (Higgs *et al.* 2007). This is the philosophical stance I adopted and provides the rationale and justification for the chosen research methodology, which was a qualitative theoretical inquiry via a Grounded Theory (GT) approach. Qualitative research offers a spectrum of methods for enquiring into the behaviour and experiences of individuals and groups of people within specific cultural settings (Hall *et al.* 2009).

Theoretical inquiry utilising a grounded theory approach as summarised by Higgs and Cherry in Higgs *et al.* (2009 p.10) is concerned with the way theory can be built from the observed behaviours and lived experiences of individuals and groups. It is often referred to as theory grounded in data. This approach to producing knowledge about social phenomena stands in contrast to theory that is first derived from the world of ideas and then tested in action. The data collected through grounded theory is then coded and analysed using a specific set of procedures to build theory that helps us to understand human experiences. Grounded theory is particularly useful for helping to bring to the surface and articulate complex aspects of human behaviour and experience that may be outside the consciousness of the people who demonstrate it but which have emerged through other forms of theorising.

The grounded theory approach was also used because I have professional experience in this area of study and the rigorous procedures required for a 'true' grounded theory study provided a means of controlling the risk of bias in the study. This was achieved through the constant comparison aspect of the research as themes were generated only from the data (and not from my previous experiences) with assurance of fidelity being provided through the use of written memos which were constantly compared with subsequent emerging data. In other words, the Grounded Theory approach generated data via constant comparison, validated or rejected my own observations and proved to be a vital tool as it reduced the risk of bias- induced conclusions.

The generation and development of concepts and categories was an iterative process. Theory was not generated *a priori* and then subsequently tested but rather, the process carried out was as described by Strauss and Corbin (1990, p. 23) as one of theory being inductively derived from the study of the phenomenon. That is, themes are discovered, developed and provisionally verified through systematic data collection and analysis of data pertaining to the phenomenon and thus lead to theory that helps to explain the phenomenon. Therefore, data collection, analysis and theory stand in reciprocal relationship with each other. One does not begin with a theory and then prove it. Rather, one begins with an area of study and what is relevant in that area is allowed to emerge.

The case study method as a tool for generating theory has been tested and detailed by Eisenhardt (1989). She posited that using case data to build grounded theory has three major strengths:

- 1) 'Theory building from case studies is likely to produce novel theory; this is so because creative insight often arises from juxtaposition of contradictory or paradoxal evidence. The process of reconciling these accounts using the constant comparative method forces the analyst to a new gestalt, unfreezing thinking and producing theory with less researcher bias than theory built from incremental studies' (p. 546).
- 2) The emergent theory 'is likely to be testable with constructs that can be readily measured' (p. 547). Due to close connection between data and theory, it is likely that the theory can be further tested and expanded by subsequent studies.
- 3) The 'resultant theory is likely to be empirically valid' (p, 547). This is so because the level of validation is performed implicitly by constant comparison, questioning the data from start to finish of the process. 'This closeness can lead to an intimate sense of things' that often produces theory which closely mirrors reality' (p. 547).

### **Justification for the Use of Grounded Theory**

Grounded theory as originally described by Glaser and Strauss (1967) (the 'pure' school of grounded theory) suggest that there is some observable reality waiting to be discovered from the data. "Glaser (1998) emphasises the importance of not taping interviews, as recordings, transcribing and analysing the interaction between researcher and participant work against a post-positivistic positioning of relying on field-notes as data. In so doing, that is, writing a one-sided account of the interview in this format it effectively separates the researcher and participant as the constant comparison of abstract categories done by the researcher during the interview is pursued at the cost of participants' voices" (Birks & Mills 2011 p. 56). The position I adopted in this study is in line with Charmaz (2006); Clarke (2005); Morse et al. (2009) who as second-generation grounded theorists argue that it is in the interpretation of data that the findings emerge.

They argue that the study of the data in the form of recordings and transcripts exposes more about the ‘nuances of language and meaning’ Charmaz (2006:34) than field notes were able to reveal. Each methodological position places a different value on the contribution that various forms of data can make to a grounded theory, although essential grounded theory methods for analysing data remain the same no matter what constitutes the data (Birks & Mills 2011).

My epistemological position on the construction of knowledge is in line with these views. This explains why I have not followed the Glaser and Strauss model described in their early text (1967). I have not sought to extend grounded theory in any way – since I am influenced by the grounded theory approach rather than in being tied to its principles in a restrictive, pure or prescriptive fashion. I wanted to hear the ‘voices’ of the participants. I also found that the grounded theory approach was appropriate as the area of study is unique, that is listening to the children on how HIV-AIDS impacted their lives and the support that exists. The grounded theory methods gave me the confidence that the data was being thoroughly analysed by way of purposive sampling, initial coding, concurrent data generation and collection, theoretical sampling, constant comparison analysis, theoretical sensitivity and core categories. I hoped to generate knowledge that was relevant and significant. My personal frame of reference is found in Section 3.4. I have applied my approach to Grounded Theory in the execution of this research in Sections 3.3 (Research Design) where the steps, phases, activity and rationale were outlined in a table and also in the Methods Framework in Section 3.4.3.

### **3.3 Research Design**

Easterby-Smith *et al.* (1990. p. 21) define research design as ‘the overall configuration of a piece of research: what kind of evidence is gathered from where, and how such evidence is interpreted in order to provide good answers to the basic research question[s]’. The process of building an understanding of the psychosocial issues and support available for children with acquired HIV via a Grounded Theory Approach was carried out in four phases. This was patterned after Eisenhardt (1989) and Pandit (1996) and was not strictly sequential. The table below shows the phases of the study, the activities carried out and the rationale underpinning the approach used.

Table 3.3: Process of building an understanding of research topic

<b>Phases</b>		<b>Step</b>	<b>Phase</b>	<b>Activity</b>	<b>Rationale</b>
1.	<b>RESEARCH DESIGN PHASE</b>	1	Personal Frame of reference  Review of technical literature	<ul style="list-style-type: none"> <li>a) Situating myself in the research.</li> <li>b) Developing a conceptual framework.</li> <li>c) Defining research questions and aims.</li> </ul>	Focused efforts
2	<b>DATA COLLECTION PHASE</b>	2	Develop rigorous data collection protocol	<ul style="list-style-type: none"> <li>a) Creating case study database (EZ-Text)</li> <li>b) Employing multiple data collection methods (interview guide, clustering tool, observations, field notes)</li> </ul>	<p>Increased validity</p> <p>Strengthened grounding of theory by triangulation of evidence.</p> <p>Enhanced internal validity</p>
		4.	Entering the field	<ul style="list-style-type: none"> <li>a) Simultaneously collecting and analysing data</li> <li>b) Flexible data</li> </ul>	<p>Sped analysis and revealed helpful adjustments to data collection</p> <p>Allowed the researcher to</p>



				collection methods, for example, constant comparison	take advantage of emergent themes and unique case features
3.	<b>DATA ANALYSIS PHASE</b>	5	Analysing the data relating to the first case	<p>a) Employing open coding</p> <p>b) Employing axial coding</p> <p>c) Employing selective coding</p>	<p>Facilitated development of concepts and categories</p> <p>development of connections between a category and its sub-categories</p> <p>Facilitated development of integrated categories to build theoretical framework</p> <p>All coding enhanced internal validity</p>
		6	Theoretical sampling	Literal and theoretical replication across cases. Step 2 used until theoretical saturation was found	Confirmed, extended and sharpened theoretical framework
		7	Closure process	Theoretical saturation when possible	Ended process when marginal improvement became small

4.	<b>LITERATURE COMPARISON PHASE</b>	8	Compare emergent theory with extant literature	a) Undertaking comparison with conflicting frameworks  b) Undertaking comparison with similar frameworks	Improved construct definitions and therefore internal validity  Improved external validity by establishing the domain to which the study's findings can be generalised.

### 3.4 Research Design Phase

This consisted of steps 1 and 2, that is, articulating my personal frame of reference and producing a cogent plan for the literature review. The purpose of the activities conducted in this phase was to situate myself as the researcher in relation to epistemological and methodological issues and to provide the justification for the literature review and the selection of cases. The rationale for these activities helped to focus efforts on the research process.

#### 3.4.1 Personal Frame of Reference

This study emerged from my professional stance of a social worker through which I realised that children were being omitted from the overall picture of HIV-AIDS in Trinidad and Tobago. They were not accorded the same level of attention as adults who are HIV positive and their needs and concerns were not being addressed. Furthermore, children's own views appeared to be ignored; it was as if the words emanating from their mouths were muffled and no one was listening. Thus, the primary motivating factor underpinning the study was my belief that research in this area could assist in creating

more equity, enable the voice of children living with HIV to be heard and influence the provision of better intervention strategies that would have a positive impact on their lives. I was particularly interested in discovering or unearthing the psychosocial issues that affect children and mothers who are living with HIV and the types of support that exist.

I utilised my professional experience and the research interests derived from this experience as a potential source of sensitivity. Strauss and Corbin (1990) refer to 'theoretical sensitivity' as important context for grounded theory research and categorise this into three broad areas: personal experience; professional experience and the literature. However, Strauss and Corbin (1998) caution that professional experience as a source of sensitivity can block perception even though it can also enable the researcher to move into the area being studied more quickly as he/she would already be familiar with research environment. Strauss and Corbin add that two points must be remembered. The first is to 'always compare what one thinks one sees to what one sees at the property level because this enables the analyst to use experience without putting the experience itself in the data'. The second is that 'it is not the researcher's perception or perspective that matters but rather how research participants see events or happenings' (p. 47). I maintained a state of awareness of these two points throughout the study and through constant reflection ensured that my prior perceptions did not affect the emerging themes.

### **3.4.2 The Literature Review**

As a further source of sensitivity (Strauss and Corbin, 1998), I also undertook a preliminary review of the literature. Many grounded theorists argue that the review of literature should only be conducted in relation to the emerging themes in a study and not before this. However I believed this was necessary in order to sensitise myself to some of the key issues concerning maternal transmission of HIV and its impact on the child. However, it was discovered that while there were other studies on the psychosocial issues relating to children born with HIV most of these used a quantitative method and did not capture the experience of living with HIV from children's perspectives. This preliminary review of the literature helped to justify the need for this

research. Strauss and Corbin (1998, p. 49) state that there is no need to review all of the literature beforehand as in grounded theory studies it will be impossible to know prior to the investigation what the salient problems will be or what theoretical concepts will emerge. Also, the grounded theory researcher should not be so steeped in the literature that he or she is constrained or stifled by it. For these reasons the major review of literature was carried out following data collection and analysis.

### **3.4.3 Methods Framework**

During the next phase of the process a methods framework for this research was developed. Glaser and Strauss (1967, p. 45) state that 'the initial decisions for data collection are not based on a preconceived theoretical framework'. Benton (1996) also proposes that the researcher should not have a pre-conceived framework when using grounded theory as important data collected may be missed as one tries to fit what was gathered into that framework.

However, I agreed with Miles and Huberman (1994) who state that something may be known about the phenomenon, even if this is not enough to develop theory. They add that the researcher may know of some of these things, for example, a) where to look, b) in which settings c) among which actors and d) how to gather information. Miles and Huberman argue that all researchers are likely to have some general research questions, and some idea about sampling and about data-gathering devices and together with ideas about the research site and actors, these factors can be said to comprise a rudimentary framework. This was true in this study. Thus, the following conceptual framework was created. Based on my initial review of the literature, I determined that the focus of the study would be on psychosocial issues of maternal transmission of HIV and support for children's wellbeing. Support in relation to HIV is likely to consist of a small group of key actors and I therefore conceptualised the support network for the child as a triangular 'case' which consisted of the mother who was HIV positive, the child who was also HIV positive and an HIV friend identified by the mothers.

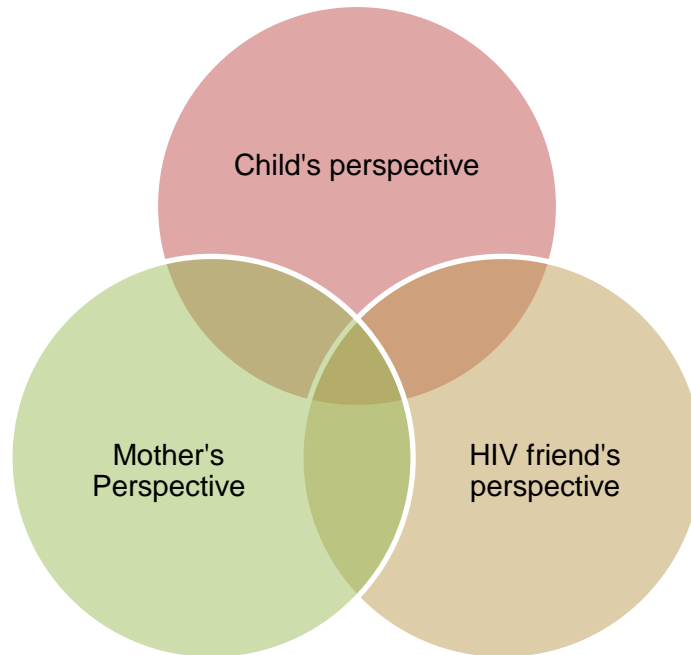


Figure 3.4.3: Depiction of the case triad

#### **3.4.4 Overall Research Aim**

The research topic chosen was grounded in professional sensitivity, the literature and a preliminary framework and this gave birth to the overall aim which was to examine the psychosocial issues that affect children with acquired HIV/AIDS in Trinidad.

The rationale for the use of a grounded theory approach was based on the aim to discover patterns and processes and to understand how the participants define their reality via social interactions (Stern *et al.* 1982).

Strauss and Corbin (1998, p. 11) applied this approach to the lived experiences of persons experiencing chronic illness and stated that the act of 'coming out' lends itself to getting out into the field and finding out what is happening with persons affected by these circumstances. This process of research can be used to obtain intricate details about phenomena such as feelings, thought processes and emotions that may be difficult to obtain or learn about through other conventional research methods.

Grounded Theory as explained by Strauss and Corbin (1998, p. 12) means theory that is derived from data systematically gathered and analysed through the research process. This means that data collection, analysis and theory stand in close relationship

with each other. Thus, there is no preconceived theory, but rather an area of study that allows for the emergence of theory from the data.

### **3.5 Data Collection Phase**

This phase dealt with the development of data collection tools. The activities consisted of the creation of a 'case study' (this term is 'borrowed from case study research but in this instance refers to the triad; the unit of inquiry comprised of mother, child and support person) sampling and selection criteria based on theoretical sampling. These activities aimed to increase reliability and construct credibility and by strengthening the approach through triangulation (gathering data from the perspectives of three different sets of key actors) I sought to enhance internal credibility.

In see order to gain access to children, I had to respect the parental role (a cultural consideration as well as one of courtesy), to lessen the anxiety of the child. Also, I wanted the children to know that the interview was done with their mothers first so they can begin to trust the process.

#### **3.5.1 Data Collection Tools**

These consisted of demographic forms for the mothers, children and HIV friend (see Appendices 1, 2, 3); semi-structured interview guidelines for all three persons in the triad (see Appendices 4, 5,6); Information sheets for all participants in the triad (see Appendices 7, 8, 9); consent forms for all participants (see Appendices 10,11,12) and a clustering tool titled "Me, Myself and HIV" (see Appendix 13) for mothers and children. Official letters were sent to various agencies which had access to mothers that fit the criteria for this research. (see Appendix 14). Specific activities for the children were designed; these consisted of drawings of themselves and their families, a written exercise entitled "Who Am I" (see Appendix 15) and a series of pictures for children to choose how they viewed themselves (see Appendix 15).

I made notes directly after the interviews. These notes included my reflections of the interview process.

The clustering tool entitled "Me, Myself and HIV" (Appendix 13) developed by Rico (1983) and used by Karpiak in Anfara & Mertz (2006, p. 87) as a technique to elicit

feelings and to enable the participants to tell their stories. Accordingly, participants were asked to talk about feelings and experiences that the phrase evoked. It was a simple plain white paper with the words “Me, Myself and HIV” written in the middle in different colours. I asked the mothers and children at their interviews to tell me all the issues that came to their minds when they think of themselves as having HIV. Whatever answer that was given was written on the paper. These were the issues that the participants considered most important in their lives. These were then followed-up in the interview with mothers and children. This tool generated phrases and words that came to the mind of the participants which I clustered into thematic areas. Using an interview guide as a probing aid, I then asked the participants to expand on the words they used enabling them to talk at a deeper level. I analysed these data by paying close attention to the language of the participants, the context in which the data was conveyed and the significance as it related to their life experiences with HIV. This technique brought to the fore pertinent issues that were important to the women’s lives. This information helped to situate the women within their frame of reference that is, the social and cultural context within which they were living with HIV.

The semi-structured interview protocol was used as a guide for the first interview in order to elicit information for the open coding stage of the data analysis. The issues emanating from this initial interview were carried forward to the next interview to facilitate the process of constant comparison. In so doing the interview protocol changed over the course of subsequent interviews to help unearth the main categories that were emerging. Berg (2004) stated that questions used in a semi-structured manner reflect an awareness demonstrated by individuals of their world. Additionally, the grounded theory approach requires the researcher to approach the world from the interviewee’s perspective.

The tools used for the children were varied as the purpose was to gain an insight into the child’s feelings and individual experiences living with HIV. Drawings can be a communicative tool for children but also in their production, pictures are discovered (Andersson 1994) and they can also offer a representation of children’s worldview

(Gloom 1992). The drawings were used as a probing guide to explore how children viewed themselves living with HIV.

### **3.5.2 Theoretical Sampling**

Sutcliffe (2000) argues that grounded theory uses non-probability sampling to facilitate the emergence of concepts and categories during data analysis and that the need to recruit participants continues until each category is saturated. Thus at the beginning of this study no limits were set on the number of participants and although the total number of respondents interviewed was quite small, I continued to recruit interviewees until nothing new emerged about the concepts being explored.

Glaser and Strauss (1967) see sampling within grounded theory as 'theoretical' as opposed to purposeful, as it is driven by emerging theory while Lincoln and Gobi (1985) and Morse (1991) suggest that the terms theoretical and purposeful sampling are interchangeable. Hutchinson (1993) purports that individuals are chosen initially who can provide a relevant source of data and as such, generate and delimit the theoretical codes. Thus, a researcher about to collect data commences with purposive sampling, which is then superseded by theoretical sampling as the data or theory highlight the direction for further sampling. This position is supported by Sandelowski *et al.* (1992) and Coyne (1997).

Cutcliffe (2000) deliberates that if the first participant of a sample has only limited experience of the issue being investigated then subsequent theoretical sampling would also reflect the limited experience. Data collected and analysed from this source may not yield the full understanding of the issues being examined. Morse (1991) highlights that the selection of an adequate and appropriate sample is critical in qualitative research and the outcome quality hinges on data selection. Thus, in her opinion, participants must be knowledgeable about the topic and be experts in their own right with respect to their lived experiences on the topic being researched.

This process was followed in my own study with the first case being selected through purposive sampling and subsequent cases being selected on the basis of theoretical sampling to explore the themes that emerged from the data. This approach led to me



interview a further three women in addition to the four from the case studies to explore specific issues relating to mothering and women's HIV-AIDS secrets (this is discussed in more detail below).

### **3.5.3 Study Participant Criteria**

#### ***Mothers Inclusion Criteria - mothers who were HIV positive***

Further theoretical sampling - mothers who did not tell their children that they were HIV positive.

#### **Children's' Inclusion Criteria**

Children with acquired HIV and they know that they are positive, ages from 5-13 (The middle stage of development).

#### ***Exclusion Criteria-***

Children born with any other condition; children outside the age range and children who do not know of their status

### **3.5.4 Recruitment**

Study participants were recruited via NGOs and medical health institutions. I made contact with nursing personnel and social workers to ascertain whether they were in contact with individuals eligible to participate in the study. So, information on the research was given to professional workers and they in turn told the women about the research. The women then decided whether to volunteer. Once this happened, I was given their phone numbers and followed up with a phone call to make initial contact. I then explained what the research was about and asked if it was possible to also interview their child who was HIV positive. Once this was agreed upon, I arranged for the interview for both mother and child on the same day. After the mother was interviewed, she was asked to identify one person whom she had told about her status and who provided support. I then called that person and arranged an interview with him or her for another date. These interviews were done via telephone and recorded as it was difficult for the person to meet. Four women, five children and four support persons

(otherwise called HIV friends) were recruited and, thus, 13 interviews completed. Each case consisted of, mother, child/children and support person.

### **3.5.6 Study Setting**

The women were asked where they would like the interview conducted. Subsequently, two interviews (mother and child) were conducted at a social worker's office and the other seven interviews with mothers and their children were conducted at the home of the women. The interviews for three support persons were conducted on the phone as it was difficult to meet with them at the times suggested. The fourth interview with the support person was conducted at his home. He was the partner of one of the women.

### **3.5.7 Creation of a Case Triad Database**

Data sources were in-depth interviews with participants: mother, child and support persons. Field notes were made after the interviews. These recorded reflections on what occurred. This triangulation of data strengthened the grounding of theory and enhanced internal credibility of the study. Glaser and Strauss (1967 p. 65) states that in 'theoretical sampling, no one kind of data on a category or technique for data collection is necessarily appropriate. Different kinds of data give the researcher different views or vantage points from which to understand a category and to develop its properties: these different views are called 'slices of data'.

Construct validity and reliability were further enhanced through the preparation of a case study database which stored all the evidence collected. Yin (1989 pp. 98-99) says that 'every case study should strive to develop a formal retrievable database, so that other investigators can review the evidence directly and not be limited to the written reports. In this manner, the database will increase the reliability of an entire case study'. Thus, a case study database was constructed systematically using the EZ-Text Software package from The Centre for Disease Control (CDC) in the United States.

"CDC EZ-Text" version 3.07 is a qualitative software programme developed to assist researchers in creating, managing and analysing semi-structured databases. EZ-Text was jointly designed and developed by staff from Conwal Incorporated and CDC. (See Appendix 16 & 17 for an example of the code book). Its primary purpose is to meet

CDC's own public health research needs. It is in the public domain and can be used freely without restriction (Carey *et al* 1998).

EZ-Text helps solve the problem of consistency across interview write-ups by allowing a researcher to design a series of qualitative data entry templates tailored to his/her questionnaire. After data entry the investigator can create online codebooks, apply codes to specific response passages, develop case studies, and conduct database searches to identify text passages.

This programme simplified the speed and mechanical aspect of the data analysis and helped me as the researcher to focus on the more creative aspects of theory building. Tesch (1991, pp. 25-26) says that the thinking, judging, deciding, interpreting, etc., are still done by the researcher. The computer does not make conceptual decisions, such as which words or themes are important to focus on, or which analytical step to take next. The data from the transcriptions in Microsoft Word were copied into this data base to help develop codes and categories.

### **3.5.8 Conducting Interviews**

As a researcher, I adhered to the following procedure to ensure protection of participants. First, I introduced myself to participants and told them of the purpose of the study. I also explained that I am not affiliated with any local agency, was accountable to the University of Huddersfield, Centre for Applied Childhood Studies and that data would be used only for research purposes, conference presentations and articles in peer reviewed journals. No individually identifiable information would be reported in the final written report, maintaining complete participant anonymity. A unique identifier was assigned to each person and all names were immediately removed during transcription. A single list, matching name to identifier has been securely kept and is accessible only to me.

I read and explained the contents of the consent form in clear language and clarified any questions participants asked. Participants signed and retained a copy of the consent form for their records. Even though consent was given by the mothers for the

children, when I met with the child I also sought the child's assent. If the child had not agreed to do the interview, I would have had to disallow that case and try to find another. It was important for the child to give assent as this is in line with children's rights and also shows the willingness of the child to participate and to answer questions pertaining to the research. The consent form stated that participation in the study was entirely voluntary and that participants could withdraw from the study at any time or refuse to answer any question. The consent form also explained the circumstances whereby there would be a need to reveal confidential information to local authorities. Thus, during the interview, if a woman revealed that she planned to harm another person, was in danger, or if a child was in danger, there was a requirement by law for this to be reported to the appropriate authorities.

I was aware that participants can be harmed psychologically as talking about sensitive issues in their lives could make them uncomfortable, emotional and perhaps face issues that they had not addressed in their lives. Counselling was made available to the participants through prior arrangement with a social worker at one of the health institutions.

Cross referencing my study findings with studies carried out using quantitative methods helped to corroborate my data and added a new dimension to understanding the issues at hand although clearly the different methodological approaches meant that studies themselves are not comparable.

### **3.5.9 Transcriptions**

Interview guides and information sheets were developed for each person in the case triad. The interview took about an hour for each person. A total of 16 interviews in all were carried out. All the interviews were recorded and transcribed verbatim. This provided the following benefits as Hansen & Kautz (2005) report: 1) recording the interviews captured all the information given by the participants, 2) the data provided the categories and themes, 3) reading the transcriptions meant that I revisited the conversations again making the content clearer, 4) having the transcripts in electronic form enabled me to search for key words across transcripts. Having the participant's exact words were useful for quotations in the thesis used to illustrate findings.

### **3.6 Data Analysis Phase**

Data analysis included activities such as open coding, axial coding and selective coding to assist in the development of concepts and categories, to develop connections between categories and sub-categories and the integration of categories to build the theory. All forms of coding and the reporting of the actual process sought to enhance internal credibility.

Analysis and coding began simultaneously with the interviews. This can be termed an iterative process as the first set of data collected were analysed and reflected upon as issues came to the fore. These issues needed further clarification with the second participant and so constant comparison as advocated by Strauss and Corbin (1998) was used. As new information emerged, new questions were added as the participants were asked to elaborate on these issues. This helped me to 'follow a lead' for clarification on an issue that may have been relevant to the overall research.

Grounded theory relies heavily on data which reflect the respondents' interpretation of their reality. However data analysis reflects the researcher's interpretation of the participants' reality. Thus, the results were influenced by three perspectives from each case study and also by the theoretical framework used by the researcher to interpret meaning (Strauss & Corbin 1998). Grounded theory helped to explain the main concepts in this study. It generated results from the data via the interviews and the respondents' explanation of their reality. Conclusions were based on this. Thus, the investigation of subjective realities of individuals provided the rationale for the use of a grounded theory approach.

Open coding (Appendix 16 & 17 gives an example of open coding with the HIV Friend's aspect of the triad) involved breaking down, examining, comparing, conceptualising and categorising data (Strauss & Corbin 1990, p. 61). I examined the interviews via the transcripts and listened to them again via the audio recordings. Key notes were made at the side of the transcribed copies. These were based on the repetitive nature of the issues discussed by the women via the "find" mechanism in Microsoft Word. A list of codes was developed manually and page numbers from the transcription were assigned to the codes for ease of location. This helped me to examine the context in which the

words were used. The visual perusal of codes enabled me to see the relationship between responses. The interviews transcripts were then arranged in EZ-Text and codes recorded. These codes were labelled and categorised, forming concepts which provided the building blocks for theory construction. Axial Coding is a set of procedures whereby data are put back together in new ways after open coding, by making connections between categories. This is done by utilising a coding paradigm involving conditions, context, action/interactional strategies and consequences (Strauss & Corbin 1990, p. 96).

Based on the iterative process, categories were created. These were then written separately on a new sheet of paper to produce a visual representation of themes and sub-themes. In this process relationships between participants' responses emerged and new codes again applied. Reports were produced on EZ-Text and associations between codes and respondents were developed. Each report provided the link between the code and the participant's responses and enabled me to further narrow down the main concepts emerging out of the data. Concepts and categories were put together in a new way by making connections between categories and sub-categories. Thus main categories emerged with corresponding sub-categories.

Selective coding is the process of selecting the core categories and systematically relating these to other categories, validating relationships and filling in categories that need further refinement and development (Strauss & Corbin 1990, p. 116).

After all data have been collected and analysed, categories pointed towards a constructed theory. In this study several themes emerged, for example, the dichotomy of 'fear of dying which existed alongside hope for the future', the cyclic nature of stigma and discrimination and the cultural influence of childbearing, the sad feelings with respect to HIV that the children expressed, the disparity between how the children viewed HIV and their general demeanour of positivity, the issue of fear that fuelled the stigma and discrimination and the secrecy (core category) that was birthed. These main themes helped to structure the findings of the study.

While no new themes were emerging from the children's transcripts, the mothers' data suggested the need for theoretical sampling to explore the perspectives of mothers who had not disclosed to their children. Clearly under these circumstances it was not appropriate (or possible) to seek to interview the children of *these* mothers and one limitation of the study therefore is that we can never know whether children who know their status fare better or worse than children who do not.

### **The Story & Story Line**

The coding called for me to ask what stood out about this study. What was the story behind this research? Pandit (1996) states that the story is simply a descriptive narrative about the central phenomenon of the study and the storyline is the conceptualisation of this story. When analysed, this story line becomes the core category or the phenomenon that emerged. This was also mentioned by Strauss & Corbin (1990, p. 124) who say that the core category must be the sun, standing in orderly systematic relationships to its planets.

In order for me to think systematically about the data and relate them in complex ways a paradigm model was used as suggested by Pandit (1996). The basic idea was to help organise the data and their complexities and look at the linkages between them. In grounded theory a lot of data can be generated and this was the case in my study, thus mentally it was important to construct a pathway that could help delineate the data and get to the core categories. The basic features of this model are depicted in Figure 3 below.

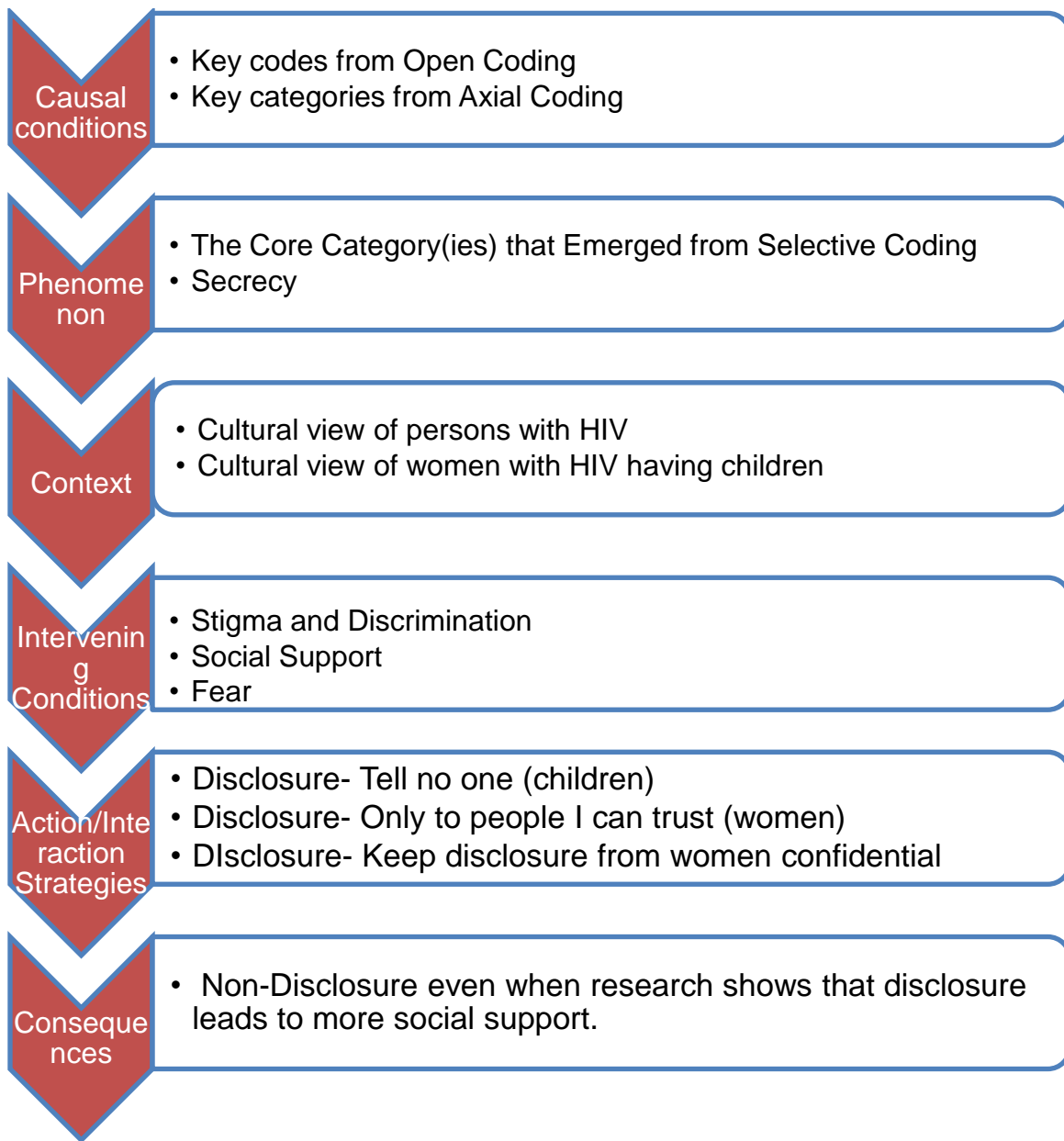


Figure 3.6: The Paradigm Model of this Study (expanded in Chapter 7)

The core categories (central idea) were defined as the phenomenon. The other activity that assisted greatly with revealing the core categories was memo writing. Strauss & Corbin (1990, pp.198-199) state that memos and diagrams are important elements of analysis and should never be omitted; regardless of how pressed the analyst might be for time. The diagramming begins at the inception of a research project and continues to final writing. This process helped me to gain an analytical distance from the data to help



with abstract thinking, then in returning to the data I was able to ground these abstractions in the findings. Memos and diagrams can take several forms: code notes, theoretical notes, and operational notes. Pandit (1996) explains that coded memos relate to open coding and are thus focus on conceptual labelling; theoretical memos relate to axial and selective coding and thus focus on paradigm features and indications of process and finally operational memos contain directions relating to the evolving research design. The paradigm model In Figure 3 was as a consequence of coding.

### **3.6.1 Literature Comparison Phase**

The literature at his stage was used as supplementary validation (Strauss & Corbin 1990, p. 52). This meant that as the theory was developed and the findings written, reference to the literature in appropriate places was used to support and refine the findings. Extant literature was used to look at conflicting studies which helped to enhance internal credibility and similar studies to improve external credibility.

Eisenhardt (1989, p. 545) states that overall, tying the emergent theory to existing literature enhances the internal validity, generalisability and theoretical level of the theory building as the findings often rest on a very limited number of cases. Glaser (1998) posits that in Grounded Theory re-immersion in the literature occurs at two levels: 1) constant reading of material to increase theoretical sensitivity and 2) conceptual emergence, which is reviewing of convergent and diverging literature in the field related to the developing concepts. He adds that because emerging theoretical construction drives the literature review, the extant literature is incorporated into the study as data. Thus, most of the relevant reviewed literature finds its way into and becomes integrated with the substantive theory. This was the process adopted in this study, as the findings were discussed.

### **3.6.2 Ethical Considerations and Access**

Ethical approval was received from the University of Huddersfield in July 2009. I then proceeded to conduct interviews.

Since this research is about children, it was important to look at the ethical considerations carefully. The perspective I took was to ensure that children were active

participants in the research. This is in line with the UN Convention of the Rights of the Child which recommends that children be informed, involved and consulted about all activities that affect their lives, inclusive of research. Alderson in Fraser et al (2008) identify three levels of involvement of children in research which reveal the power and status children hold in research projects. These are: 1) using children as unknown objects of research 2) children as aware subjects and 3) children as active participants who willingly take part in research that have flexible methods, such as semi-structured interviews. In this research children were seen as active participants; not as passive research objects but as individuals who possessed agency.

Two main frameworks were used: 1) the principles of respect and justice which concerned doing 'good' research because it is the right thing to do, for example, respecting children as sensitive and dignified human beings, being fair and using resources effectively and 2) 'rights based research' which involved children's rights which have been cited as the '3Ps': *providing* for basic needs, *protection* and *participation* (United Nations 1989; Franklin 2002). Participants' rights were vital to ensure ethical research as children had to be well informed, have their own views listened to and be respected by me as the researcher.

It was not enough for me to obtain consent from the mother of the child being interviewed but to obtain assent from the child as well. I explained the research to the children and asked them if they understood what it was about. They were then asked if they were willing to talk to me about the topic and the interview proceeded only if they agreed. If not, I would have been obliged to abandon that case triad.

Jones in Fraser et al (2008, p. 129) provides a list of principles for involving children in research including:

- 1) Clarity about the role and purpose of children's involvement
- 2) Consent from the child, and where appropriate , parents or other caregivers
- 3) The language, methods and processes of research are made accessible to children
- 4) Adequate support to facilitate children's participation

- 5) Children are not subject to harm, exploitation, coercion or adult manipulations
- 6) Adequate support systems in place
- 7) Understanding and agreement about how far the study (and the child-researcher) should go in prying into the lives of children

These principles were adhered to as far as possible.

Salvi & Damania (2006) speaks about ethics in research with women and HIV. She said that in many countries HIV-AIDS is encountered amongst vulnerable populations, who may be poor, uneducated and hence powerless. To approach women to be part of a research with HIV-AIDS calls for proper administration of the informed consent procedure and the implications. The women must understand fully what the research is about and volunteer to be part of it. Salvi & Damania said that the issue of protection for the women will be a major concern and it is necessary to ensure that the rights of participants are not trampled upon and that the research is conducted in conformity with the highest ethical standards.

The issues of confidentiality and voluntary participation were very crucial for this research as the mothers and HIV friends had to be assured of confidentiality to dispel fears of inadvertent disclosure. Thus, it must be reiterated that the informed consent procedure and the implications were administered and explained in a proper manner so as to ensure that the mothers and HIV friends were clear as to what the research entailed. HIV-AIDS is a highly sensitive topic and gaining entry into these mothers' lives was challenging at the start. It was important to help the mothers and HIV friends trust the research process. Once the mothers identified an HIV friend, this person was contacted. The mere fact that the mothers identified these persons was a positive entrance to the interview as some measure of trust was established between myself and the HIV friends. Ethical principles were also adhered to with the HIV friends.

Inclusion of mothers and HIV-Friends were important in this study as it help to strengthen the research process and the findings from interviews with the children. It also served to ascertain the support present for the children and the gaps in that support that existed.

### **3.6.3 Reliability and Validity**

Gulafshani (2003) said that reliability and validity in qualitative research is conceptualised as trustworthiness, rigour and quality. The elimination of bias increases the researcher's truthfulness about the social phenomenon using triangulation of data (Denzin 1978) as a means of searching for convergence among multiple and different sources of information, to form themes or categories in a study (Creswell and Miller 2002, p. 126). Therefore Gulafshani (2003) concludes that reliability, validity and triangulation if they are to be relevant research concepts from a qualitative paradigm, must be redefined to reflect the multiple ways of establishing truth.

Charmaz (2006) posits that there are different quality assurance criteria for grounded theory studies. She suggests these are credibility, originality, resonance and usefulness and that a strong combination of originality and credibility increases resonance and usefulness. This adds to the overall value of the contribution. A summary is given below.

#### **a) Credibility – Reflection of conceptual grounding**

- Has the research achieved intimate familiarity with the setting or topic?
- Has the research provided enough evidence to allow the reader to form an independent assessment—and agree with claims made?

#### **b) Originality- Significance of study**

- Do categories offer new insights?
- Does the analysis provide a new conceptual rendering of data?
- What is the social and theoretical significance of this work?
- How does your grounded theory challenge, extend, or refine current ideas, concepts, and practices?

#### **c) Resonance- Meaning and scope**

- Does this study make sense to the participants or others who share their circumstances?
- Do the categories portray the fullness of the studied experience?

#### **d) Usefulness- Knowledge development and practical application**

- Does the analysis offer interpretations that people can use in their every-day worlds?
- Can the analysis spark further research in other substantive areas?
- How does this work contribute to knowledge? How does it contribute to making a better world?

(Charmaz, 2006, p. 162-163)

In Chapter 8 'Conclusions and Recommendations', these four criteria were used to address how the study met each category (sections 8.4.1 to 8.4.4).

The study was directed by Strauss and Corbin's (1990, 1998) and Charmaz' (2006) view of grounded theory and used the guidance of Strauss and Corbin (1990, 1998) to gather and analyse data. Charmaz (2006) summarised her stance on grounded theory by the following:

- The grounded theory research process is fluid, interactive and open-ended.
- The research problem informs initial methodological choices for data-collection.
- Researchers are part of what they study, not separate from it.
- Grounded theory analysis shapes the conceptual content and direction of the study; the emerging analysis may lead to adopting multiple methods of data collection and to pursuing inquiry in several sites.
- Analytic directions arise from how researchers interact with and interpret their comparisons and emerging analyses rather than from external prescriptions.
- Successive levels of abstraction through comparative analysis constitute the core of grounded theory analysis.

(Charmaz, 2006, p. 178)

I agree with Charmaz when she said that the cloak of objectivity surrounding grounded theory of the past reduced visibility of its interactive strengths. She continued that enlisting grounded theory in a contemporary more reflexive mode, keeps you interacting with your data and emerging ideas. This then fosters more abstract interpretations.

Along the line of continuum from the tentative interpretations in initial coding and memos to the finished project, grounded theory captures fleeting thoughts and immediate questions and prompts you to give ideas concrete form in analytic writing. This was my experience in this study.

### **3.7 Reflection**

This methodology chapter was quite challenging as the process of grounded theory was daunting at times with the sheer volume of data. At times I was uncertain as to how to proceed with the data. However, the reading of theorists on the topic aided the understanding of the process immensely. This took time and effort and the writing of notes to facilitate understanding of the process. The incorporation of the case study method and its alliance to grounded theory was another hurdle to cross and the conceptualisation of this required extensive reading. The technique of memo writing helped to sift out the codes and categories as constant comparison occurred and the use of the qualitative software assisted in the organisation of data and the development of a case study database.

Interviewing children was new to me and I had to utilise different data collection tools appropriate to their ages and stages of development. Negotiating entrance into the lives of the participants on such a sensitive topic had to be handled with care. The dominant aspect of this research was the development of theory from the data as the data collected were alive with richness. However using the techniques of grounded theory proved to be vital in extracting the categories that eventually developed into the theory. I thought the process was never ending. I took a hiatus from the analysis to refresh myself. This helped as I revisited the analysis of data renewed and enthused.

The writing of this chapter describes the structure of the research process. This is important for reliability and credibility. I was always aware that if someone should take this same journey elsewhere they should be able to follow this process as a map and should get similar results. Thus, the development of grounded theory had to be documented in a table and each phase highlighted to be clear as to the direction. This serves as a Global Positioning System (GPS) for anyone to follow as it gives the exact location of each step in the process of the building of the theory in this study.

### **3.8 Conclusion**

This chapter has outlined the methodology and methods applied in this study and provide detailed explanation of the four phases of the study (research design, data collection, and data analysis and literature comparison) with the associated activities and the rationale for their use. I have shown how I used ethical considerations for all participants throughout the study with particular attention to ensuring that children were treated as active participants in this study.

## Chapter 4: Findings Mothers- Part 1

### 4.1 Introduction

This chapter consists of part 1 and part 2 of the findings of the study in relation to the mothers who participated. Part 1 concerns the findings with respect to four mothers who told their children that they were HIV positive and Part 2 describes the findings of three mothers who did not tell their children of their status. Part 2 came about as there was a need for theoretical sampling of mothers who did not tell to further explore the phenomenon of secrecy that emerged as a core theme. The mothers in part 1 were participants in the four case studies in the study. As explained earlier each case study comprises three individual systems: a mother who is HIV positive, child/children of the family who is/are HIV positive and who know their status and a support system (family member or worker, identified by the mothers). In-depth interviews were conducted with each member of this triad. The mothers are introduced and the themes that emerged explored.

### 4.2 Demographic profiles of the women Who Told

Table 4.2: Socio- demographic profile of mothers

NAME	AGE	M S	ET H	REL	EDLVL	CHLD	EMPST AT	YR DIAG	WA	CD4	MED	AREA
1. Mary	35	S	A	B	S	4	E	2003	NO	861	YES	WEST
2. Bertha	34	C	M	RC	S,O	4	E	1994	NO	>1000	YES	SOUTH
3. Petra	34	C	A	B	P	5	U	2000	YES	NOT KNOWN	YES	EAST
4. Martha	41	M	A	P	S	2	U	1998	YES	NOT KNOWN	YES	NORTH

**Table Legend:**

**NAME** - Name and name of Participants

**MS**- Marital Status,

**M**-Married, **S**-Single, **C**-Common-law,

**ETH**- Ethnicity



**A**-African, **M**-Mixed

**REL**- Religion/Faith

**RC**-Roman Catholic, **B**-Baptist, **P**-Pentecostal,

**EDLVL**- Educational Level

**P**-Primary, **S**-Secondary, **O**-Ordinary Level, **CHLD**- Number of Children

**2**-Two Children, **4**-Four Children, **5**-Five Children

**EMPSTAT**, Employment Status

**E**-Employed, **U**-Unemployed

**YRDIAG**- Year Diagnosed

Four figures for the year, e.g. 1980

**WA**-Welfare Assistance

**Y**-Yes, **N**-No

**CD4**- CD4 Cell Count

Three figures reflecting the Cell Count

**MED**- Medication. **Y**-Yes, **N**-No

### **4.3 Mothers Who Told**

#### **Participant 1 - Mary:-**

Mary was diagnosed HIV Positive in 2003. She is receiving ART which will have been prescribed by the MRF, where she attends for check-ups and monitoring; She was not in receipt of Public Assistance (Welfare) – she was expecting to become unemployed because of her health, this is likely to change.

Partner- Never told partner of her last two children that she is HIV Positive.

Mary is an Afro-Trinidadian who is 34 years old, single and had schooling up to secondary level (no Ordinary levels). She is a helper in the Forestry Division. She has

four children ranging in ages from 4 years to 21 years. The 13 year old (Martha) is HIV positive. Two children born after Martha were HIV negative. Mary belongs to the Baptist religion and lives in the western part of Trinidad. Martha is also receiving a service from MRF (ART and follow up care) however they are not accessing support from any other agency (such as Care).

### **Participant 2 - Bertha**

Bertha was diagnosed HIV Positive in 1994. She is receiving ART which will have been prescribed by the MRF, where she attends for check-ups and monitoring; She was not in receipt of Public Assistance (Welfare).

Partner- Told Partner she was HIV positive after the birth of their son

Bertha is 34 years old, of mixed descent and was in a common-law relationship. She had schooling up to secondary level and obtained her Ordinary Levels. She was employed but did not know how long she could remain this way as she felt tired all the time. She has four children ranging in ages from 10 to 10 years (the 15 year old was abducted from hospital following her birth and was never found,) . The three youngest children (aged 10, 11 and 14 years) are HIV positive. The 14 year old lives at a residential facility for children who are HIV positive and the youngest two (Bill and Betsy) live with Betsy and their father. Bertha belongs to the Roman Catholic religion and lives in the southern part of Trinidad.

### **Participant 3- Petra**

Petra was diagnosed HIV Positive in 2000. She is receiving ART which will have been prescribed by the MRF, where she attends for check-ups and monitoring; She was in receipt of Public Assistance (Welfare).

Partner- Told Partner she was HIV positive after the birth of their son.

Petra is 34 years old, Afro-Trinidadian and in a common-law relationship. She had schooling up to primary level. She is unemployed. She has five children ranging in ages from 4 to 12 years. The 9 year old (Patty) is HIV positive. A younger son who is 4 years

old (HIV negative) currently lives with his father. Petra belongs to the Baptist faith and lives in the eastern part of Trinidad.

**Participant 4 - Martha**

Martha was diagnosed HIV Positive in 1998. She is receiving ART which will have been prescribed by the MRF, where she attends for check-ups and monitoring. She was in receipt of Public Assistance (Welfare)

Partner- Told current Partner she was HIV positive.

Martha is 41 years old, Afro-Trinidadian and married. She had schooling up to Secondary Level but no Ordinary Levels (O’Levels) passes. She is unemployed and has two children aged 4 and 12 years. The 12 year old (Mark) is HIV positive. Her younger son is HIV negative and she is married to his father. She lives in the northern area of Trinidad.

**4.4 Initial themes- Mothers**

Interviews were recorded and transcribed verbatim. The first interview was coded in the qualitative software EZ-Text as discussed previously in 3.4.7. Table 4.2 shows the result of this coding in terms of open coding (sub-sub theme). This helped to ascertain the main issues that were being highlighted and provided the basis for subsequent interviews. Thus similarities and dissimilarities in responses were further noted in following interviews. The use of the software helped me to see the responses of the women to similar questions. These codes were applied to the relevant respondent and a report generated to show who said what and how it was said. This organisation of the codes allowed for ease of recognition of the participants and the relationships between the various responses.

Table 4.4a- Coding for mothers

<b>Major theme</b>	<b>Sub-theme</b>	<b>Sub-sub-theme</b>
<b>1. LIVING WITH HIV-AIDS</b>	Diagnosis And Disclosure	Pre-diagnosis awareness
		Diagnosis – how status was

		discovered
		Diagnosis of child
		Feelings and reactions
		Decisions and fears about disclosure- links with domestic violence
		What to tell the children
		Reactions to disclosure
	Illness and Medication	Access
		Effects
		Body image
		Depression
<b>2. SOCIAL CIRCUMSTANCES</b>	Relationships with partners	Supportive partners
		Non-supportive partners
		Role of partners in dealing with HIV
	Family	Family composition
		Family changes due to HIV
		Impact on family life of HIV
	Poverty	Financial circumstances
		Impact of HIV on finances
		Providing for the family
<b>3. PARENTING</b>	Mother –to- Child Transmission	Guilt
		Decisions about having children
		Preventing transmission to child
		Dealing with infected child
<b>4.</b>	Mothering	Protecting children, telling children about sex
		Caring for children
		Planning for the future
<b>5. STIGMA AND</b>	Self-Stigmatisation	

<b>DISCRIMINATION</b>	Discriminatory Treatment by Health Professionals	
	Employer Discrimination	
	Family Discrimination	
	Discrimination Faced by Children	
<b>6. COPING AND RESILIENCE</b>	Isolation/Withdrawal	
	Religion	
	Positive Life Changes	
	Support Services	
	Family Support	
<b>7. THE FUTURE</b>	Dying	
	Planning for Children	Fears
		Challenges
	Strengths	

### **Axial coding & Selective coding**

The generated reports from the qualitative software as each participant was interviewed were used to develop sub-themes (axial coding) and main themes (selective coding) as in table 4.2a based on the arrangement of the codes. After theoretical saturation occurred some codes stood out from the responses given by the participants and these were grouped together for similarity. They were then organised into final sub-themes and main themes in table 4.5b.

### **4.5 The final five main themes that emerged were:**

1. Living with HIV-AIDS
2. Social circumstances
3. Parenting
4. Stigma and discrimination
5. Coping and resilience

Table 4.5b - Final Main themes and sub-themes for mothers

Main themes	Sub-themes
1. Living with HIV-AIDS	<ul style="list-style-type: none"> <li>• Worry about their children’s future:               <ul style="list-style-type: none"> <li>-Issues around dying</li> <li>-Hope for the future</li> </ul> </li> <li>• Disclosure:               <ul style="list-style-type: none"> <li>- for children</li> <li>-outside the workplace</li> </ul> </li> </ul>
2. Social circumstances	<ul style="list-style-type: none"> <li>• Poverty</li> </ul>
3. Mothering with HIV	<ul style="list-style-type: none"> <li>• Value of mothering</li> </ul>
4. Stigma and discrimination	<ul style="list-style-type: none"> <li>• Management via secrecy</li> </ul>
5. Coping and resilience	<ul style="list-style-type: none"> <li>• Coping strategies:               <ul style="list-style-type: none"> <li>- Isolation withdrawal, religion.</li> </ul> </li> </ul>

### 4.5.1 Living with HIV-AIDS

The sub-themes were disclosure; illness and medication; issues around dying, planning for their children’s future and hope for the future. The women talked about their diagnosis and associated feelings and reactions, their fears and what to tell their children.

#### **Worry about children’s future; issues around dying; hope for the future**

The women were generally concerned about others discovering not only their status but also that of children who were HIV positive. They tended to worry a lot about the future of their children and being able to provide for them.

*I just want to be able to provide for them and to ensure that they are well taken care of..yuh know, I want to be able to have more time for them, [Mary]*

*I would like to live to see my sons reach a certain age where they could handle themselves because people laugh and talk with you but when your eyes close it is something else and I would not really like my sons to be out here suffering.[Martha]*

*I want them to be like ordinary children; to live. Not that they are not like other children but knowing that they have to do certain things and stay away, and it kind of hard for them. [Petra]*

'Provide' was the operational word as the women referred to this mainly from a financial view point. All the women were from the lower socio-economic strata of society and had financial problems. Two were employed in blue collar jobs while two were unemployed. 'Provide' also implied 'being alive and present' in their children's lives. Thus, 'alive' meant being physically there and 'present' meant being active in the lives of their children; these features of mothering were very important to the women. This also led to a discussion on the issue of 'death and dying' on the part of the mothers. Even though the mothers spoke of 'hope for the future', in the same breath, they were constantly reminded that because of the nature of their illness death could occur in the future sooner than expected, hence being 'alive' was very important. A dichotomy between 'death and dying' and 'hope for the future' emerged.

The main bridge between these two positions appeared to be the children. The mothers wanted to be alive and present in their lives as much as possible even though they knew death was a possibility in the future because of the nature of their illness. They nevertheless needed to have that hope for the future in order to protect and provide for their children.. This pointed to the importance that the mothers placed on mothering and responsibility towards their children's well-being. The mothers however, had made no plans for the future of their children, they cited lack of finances as the reason for non-planning.

Pittiglio & Hough (2009) purported that mothers wanted to live to prolong their parenting role as they believed that there would be no one willing to take care of their children. This is similar to this study where the mothers felt a need to provide, that is, be a part of their children's lives for as long as possible. Asander *et al.* (2009) found that most mothers in their study had planned for someone to take care of their children. Some had discussed it with someone in their family network, others spoke to someone directly about actually caring for their children, some sought to get help in identifying foster families while some made out a last will and testament. Most of the mothers in their

study were dependent on social welfare and other benefits and could not see how they could plan for the future of their children without the financial means to do so.

### **Disclosure for children**

The mothers were convinced that disclosure to others was an issue of risk and they prevented their children from revealing their positive status to anyone, especially at school. One mother had to lie in order to maintain that non-disclosure.

*She went to the teacher and asking the teacher “ Miss if you take care of yourself, would you live with HIV “ So I had to cover that in school now to make my child look like she was a liar because of the people you dealing with by way of the teachers, their behaviour. [Mary]*

*if they find out your child is that way in the school to me I feel they would put you out. They would...they would put you out. [Martha]*

*(If they found out your child is HIV positive I feel that they will put them out of the school. They would, they would put them out).*

*Well, the school might not want them. Children might start to discriminate them and would not want to be around them. [Bertha]  
(The school may not accept them and children may show discrimination against them)*

McLean *et al.* (2009) found that in Trinidad and Tobago schools were unwilling to accept children who were infected with HIV or whose parents were also living with HIV/AIDS. They added that parents had resorted to withholding information on the status of the child in order that he or she may get an equal chance at education. This was shown in this research and became apparent in the interviews. Non-disclosure was used by the mothers to protect their children from discrimination. A recurring theme in the realm of felt stigma (fear of being discriminated against) was parental worry about children experiencing discrimination (Vallerand *et al.* 2005).

Siegal *et al.* (2005) asserted that emotional support may foster stress-related growth that is, help persons with HIV to better deal with stress as family and friends can help the person re-evaluate what is important in their lives by providing the necessary support. However, not all stressful events are easy to disclose because of the risks involved. Persons who disclose may encounter avoidance by others, be ridiculed or experience gossip (Moore *et al.* 2008). Sharing one's seropositive status is a difficult



process that can lead to stress (Serovich *et al.*1998) as persons living with HIV-AIDS tend to be stigmatized and discriminated against compared to people with other chronic illnesses. As such, sharing one's positive status becomes a challenge and one has to decide to whom, when and how to disclose. On the other hand, in some instances, disclosure of personal and secret information is necessary to garner resources needed to survive and overcome the daily and stressful demands of conditions such as HIV-AIDS. Disclosure can be challenging but social support decreases depressive symptoms among persons with HIV-AIDS and leads to better psychosocial functioning (Klein *et al.* 2002).

Despite evidence that social support helps, mothers did not want to risk attracting discrimination into their homes as they felt that their children and they themselves would not be able to cope. The thought of being discriminated against outweighed the benefits of disclosure. Non-disclosure to others was an important strategy used by these mothers and the sentiment was passed on to the children.

### **Disclosure outside the workplace**

The two mothers who were employed were very careful as to not disclose to anyone in the work place.

*No---hell no. This forestry is contracts awarded to communities, community groups ...right so my community get the contract for St.Anns that is like telling my neighbour. I can't do that ---my name will be all over like wildfire ---I can't do that [Mary]*

*(Mary swore that she will never disclose as work contracts awarded to the communities were in the St. Anns district where she lived and it was like telling her neighbour that she was HIV positive. She cannot disclose as her name will be the subject of gossip all over the community)*

The cloak of fear of stigma and discrimination was always worn. All the women were cautious as to whom they revealed their positive status. Three of the women disclosed to a close family member, namely a sister who they thought would understand. They were adamant that disclosure to a friend would have definite outcomes. In this study one of the women feared disclosing because she thought that domestic violence was a

consequence. She recalled that someone she knew was subjected to this from their partner.

*It had a time I see my friend in the hospital dripping blood. He use to beat that girl like a dog, break she hand, break she foot---hmmm [Mary]  
(There was this instance where she saw her friend in the hospital bleeding as her partner physically abused her terribly by breaking her hand and foot).*

Jones (2009) stated that disclosure of a woman's positive status can lead to domestic violence. Jones and Rogers (2007) also found that, compared to men, women diagnosed as HIV positive were more likely to fear rejection and violence on disclosure.

In this research, three women did not initially disclose their positive status to their partners, and one of these never did so. Mary never disclosed her positive status to her partner who was the biological father of her last child. She also did not reveal her status to her daughter's Amy biological father either. Thus both men do not know that she is HIV positive. Amy's father does not know that she is HIV positive. Mary has managed to keep this information a secret. Bertha did not initially reveal her status to her partner; however she felt she had to as when Brian was born HIV positive she had to register him at the clinic which he had to attend regularly. She felt that she could not lie about it as it could be discovered so she eventually told her partner. She went on to have Cathy with her partner. Cathy was born HIV positive. Petra did not tell her partner about her status either; she waited, however she also had to reveal her status as she had bouts of HIV-AIDS related illnesses that caused her to be hospitalised at times. She felt she had to say something as her status could have been revealed at some point. Petra went on to have a child (HIV negative) with her partner. Martha has revealed her status to her husband. He knew of her status before they were married. She also went on to have a child with her husband. The fear of rejection was so great that it superseded the risk that the partners could contract a life-threatening virus. Three of the mothers were dependent on their partners for financial support. Jones (2009) found that women who were economically dependent on their partners may also fear disclosure as they believe this will lead to them becoming financially destitute. These are the issues with which the

women had to grapple and in the end decided not to disclose initially. Fear emerged as a very strong emotion at in the lives of the women.

The World Health Organisation (WHO) (2004) carried out a comprehensive review of published abstracts and journal articles from 1990 to 2001 on gender dimensions of status disclosure to sexual partners. They found that disclosure to partners in the developing world was less (52%) than in the developed world (71%). It is ironic that the four barriers to HIV status disclosure in that review consisted of the word 'fear', that is, fear of rejection, fear of discrimination, fear of violence, fear of abandonment and fear of upsetting family members. The word fear loomed largely in the lives of the women in this research. The lone woman (Mary) who never disclosed to her partner cited fear of domestic violence. The other two (Bertha and Petra) who disclosed after a while were those who felt they had no other choice as their partners eventually would have discovered their status. Martha disclosed upfront with partner.

*They wanted me to join him in the clinic so I had to tell him where I going with the baby. [Bertha] (waited after birth of child) (The nurses wanted her to bring the baby to the clinic on a regular basis so she had to tell her partner where she was taking the baby).*

*(Asked nurse to disclose to partner) - No, because hearing people saying that when they told their spouse and thing, they just left them there. Because the father of my child (HIV), he is this person I got sick from and when I told him about it he told me he would stand up with me, he would be there for me, and up to this day he was never there, he not even there for his daughter.[Petra] (waited after birth of child).*

*(Did not want to disclose to her present partner as she believed she would have been abandoned as before. If the partner who allegedly gave her the virus rejected her maybe anyone else could).*

The WHO (2004) report also stated that the motivating factors for disclosure by women included minimising the stress of non-disclosure and to access social support. The two women (Bertha & Petra) who disclosed did it to minimize the stress of non-disclosure and the fear that their partners would eventually discover their status. The lone woman (Martha) who disclosed before having a child did so for social support. It must be noted here that the two women who disclosed waited for more than nine months to reveal their status to their partners. The actual birth of the child seemed to have been the impetus

for disclosure as this new born baby attracted a new set of needs and support. When the two partners found out, they stayed to support the women. The WHO (2004) study found that positive outcomes to disclosure to partners were common and that these outcomes included increased support, minimized anxiety and strengthening of relationships. This was found in this study from the women who eventually disclosed and also the one who told from the onset of her relationship.

#### **4.5.2 Social circumstances**

##### **Poverty**

All the women spoke about the inadequacy of finances to meet their needs. Two were receiving welfare while the other two had jobs that assisted with household expenses, but these proved to be insufficient.

*I send me daughter by meh mother because of financial reasons and she not on medication, they tell me if I continue to how I going with her she will not have to go on medication. I can't provide for her so I have to send her up the road. [Mary] (I sent my daughter by my mother because of financial reasons. She is not on medication. They told me if I do not provide for her adequately inclusive of proper nutrition she will have to go on medication)*

*Oh Lord. Finance in this country, that is a no no. [Martha]  
(Finances are inadequate in this country)*

The two working women were uncertain as to if they would continue being employed. They were Mary, because of an additional illness (diabetes) and Bertha, because of tiredness as a result of being HIV positive. It was clear that if the women were unable to continue working it would impose additional financial strain on inadequate finances and compound the poverty in their families.

Nabyonga-Orem *et al.* (2008) found that HIV/AIDS can increase poverty. They discovered that an HIV affected household had expenses that were four times greater than non-affected households. Rodrigo & Rajapakse (2010) revealed that HIV can affect a household financially in two ways, that is, direct costs and indirect costs. The direct costs were attributed to drugs (anti-retroviral and other medication) and illness related issues and the indirect costs due to loss of work and loss of productivity of patients. In Trinidad antiretroviral therapy is free, thus the cost for drugs is nil. However, illness

related issues created additional expenses with respect to transportation, as the women had to take more trips to the clinic or doctor for help for themselves or their children. Indirect costs are also incurred because of the higher nutritional needs of infected children.

The United Nations (2005) stated that poverty and HIV/AIDS are interrelated. Poverty is a key factor leading to behaviours that expose people to the risk of HIV infection, and poverty exacerbates the impact of HIV/AIDS. Households and families bear most of the burdens of HIV-AIDS as they are the primary units of coping with the disease and its consequences. The disease strikes young adults in their most productive years, thus, there is a particular destructive effect on families' and households' ability to generate income and the long-term development of a country.

Scott *et al.* (2011) lamented that with both the presence of poverty and HIV-AIDS deterioration of economic and health circumstances may occur as the two situations impact each other. Ganyaza-Twalo and Seager (2005) acknowledged this previously when they showed that the relationship between HIV-AIDS and poverty was synergistic and symmetrical. In addition, as much as HIV-AIDS exacerbates poverty, through morbidity and mortality of productive adults, poverty on the other hand could facilitate the transmission of HIV. Ganyaza-Twalo and Seager states that this can occur because the poor live in high risk environments and HIV positive persons experience adverse economic impacts. Typically poor people have less access to the services they need most, such as health care, welfare support and education. The problem is compounded by indirect costs of access such as transport and time. Poverty increases the risk factors of an individual by engagement in unsafe sex and possibly non-treatment of Sexually Transmitted Diseases.

These are important points to note as poverty is an important variable in families with HIV-AIDS and can be a factor that can impinge on the quality of life of individuals and households. In this study it was a factor that affected nutrition and available resources and in two of the cases the possibility of unemployment in the future was likely to decrease quality of life further.

### **4.5.3 Mothering and HIV**

Mothering was found to be a valued and important responsibility of all the mothers interviewed and was a dominant theme. This was the single most important role for the women in this study and being the best mother formed a major part of living with HIV-AIDS. The “clustering tool” used to obtain information from the women produced responses that alluded to the importance of providing adequately for their children and their future. It emphasised the importance of being present in their children’s lives especially those who were HIV positive.

Mothering is seen as a continuous struggle requiring super-ordinate efforts against great odds for all mothers (Ruddick 1989). Many women consider the caregiver role as their first priority (Williams 2003). Maintaining this traditional role while simultaneously dealing with symptoms of HIV and issues related to the stigma of the disease can be overwhelming. For African American women, the diagnosis of HIV is often embedded in societal problems including poverty, single parenting, and internalized oppression (Gilbert & Wright, 2003).

Ingram & Hutchinson (2000) spoke about the double-bind of mothers with HIV. On one hand the predominant role of women in society is to bear children, while on the other society frowns upon the idea of an HIV positive women becoming pregnant. This suggests that if you do not have children, it is seen as a disgrace but if you do while being HIV positive it is also a disgrace. Two societal messages being prescribed, however one negates the other.

From a Caribbean viewpoint, Evans & Davies (1997) asserted that children are seen as desirable and highly valued by all societies in the Caribbean region. They added that there is much value placed on the ‘mother role’. Child-bearing is seen as evidence of the emergence of a strong self-image and motherhood has long been identified as a rite of passage (Durant - Gonzales, 1982). Thus, child-bearing at times is seen as an enhancement of self-image instead of simply the psychological and economical readiness to bear children. In the Caribbean, women and men perform different roles, the male role being primarily economic whilst the woman’s primary role has long been regarded as the nurturer even though she also provides for the home (Brown, 1993;

Senior, 1991). Barrow (2010) reiterates that child-bearing continues to be perceived as a natural part of the life course for Caribbean women and motherhood the pivotal signifier of womanhood. This was discovered in my study.

Other international studies have shown that a woman's HIV status does not necessarily influence her reproductive decisions (da Silveira Rossi, Amaral, & Bahamondes, 2005; Sowell, Murdaugh, Addy, Moneyham, & Travokoli, 2002). Women's decisions to have children are more likely to be influenced by the culturally constructed meaning of motherhood than by other factors (Cooper, Harries, Myer, Orner, & Bracken, 2007; Heard, Sitta, Lert, & the VESPA Study Group, 2007). This appears to be so in Trinidad and Tobago. Having children was seen culturally as a positive function for a woman and which gives the person a strong self-image in the eyes of society.

Strongly embedded in Caribbean history and in low income Afro-Caribbean families is the issue of 'child-shifting', where the child is shifted from his or her residence and is forced to live with another family unit because of economic issues (Senior, 1991). Because of economic hardship, Mary had to let her 13 year old HIV positive daughter, Amy, lived with her maternal grandmother periodically so that she could receive nutritious meals on a daily basis. Mary felt she could not provide adequately for Amy because of economic hardship. Mary kept her other children with her who were HIV negative. It must be noted here that Amy was told by her mother to maintain the secrecy of both their HIV positive status. On the other hand Amy felt she should tell but because of threats by the mother, had decided not to do so. Amy also wished that she could return to live at her mother's home (discussed in 5.2)

In my study two of the women had partners who were employed but that still left a gap in terms of effective provision of finances for the family as a unit. This was a theme that was also reflected in the literature. Other studies have shown that HIV-infected mothers are predominantly poor, have minority status, and are often single heads of household with dependent children (Scable et al., 1995; Sowell, Moneyham, & Aranda-Naranjo, 1999).

In addition to the possibility of losing their mothers, children of HIV-infected women may also face less than optimal mother-child relationships because of their mother's diminished physical and mental wellbeing, as well as the mother's fears that children may know, discover, or reveal their HIV status. HIV infected mothers with dependent children struggle with making and following through with plans for their children after their death, as well as their own death plans. They do not want to leave their children, believing no one can take care of them as well as they can (Ingram & Hutchinson, 1999a, 1999b). In my study, the mothers had made no plans for the future of their children in case they succumb to their illness, that is, no 'death plans'. It was not that women were not concerned about this; however, the lack of finances presented a stumbling block to make this possible. It must be noted that all the mothers went on to have at least one other child after giving birth to a child who had acquired the virus. Two mothers (Petra and Martha) stated that their partners wanted a child so they obliged. Rose & Clark-Alexander (1998) posit that in their study, having a HIV positive baby was a reality check for some of the women and was a critical factor in these women not having any more children as they did not want to risk having a next child with HIV. This was not so with the women in my study as all 4 mothers went on to have a child after the one that was HIV positive as mentioned before.

Levine and Neveloff-Dubler (1990) find that women with chronic diseases and those who may be dying choose to become pregnant knowing the risks involved, are more treasured by their families and admired by society for doing so. However, HIV positive women, in contrast are considered to be irresponsible for having babies who may face early death and who can be a burden on society in the future. Levine and Neveloff-Dubler (1990) argue that because reproductive decisions are crucial to biological and social life, HIV positive women must remain free to make reproductive choices that are consistent with their cultural, religious and personal values. It is interesting that they mentioned that having babies may not be a defensible moral choice but it may be the most reasonable choice available, something "natural", that is set apart from all other the other HIV issues in their lives in which avenues for self-definition and expression (other than mothering) are largely absent.



In this study it seemed as if the mothers were expressing gratitude for their partner's support and acceptance of an HIV positive child in the family. Thus, there may be a link between a desire to please someone who has accepted the presence of a child with HIV and producing another child. This appeared to be very important to the women as informal support from a partner ranked very high in their lives, higher than their socio-economic situation, since as having another child would certainly put a strain on already limited finances. This supports Levine and Neveloff-Dubler's (1990) contention that having babies may not be a moral choice but an avenue for self-definition and expression.

Nelms (2005) study consisted of women who were said to be untypical of HIV-positive mothers described in other literature. These women were not living in poverty and for the most part were working women supporting themselves financially or supported by working husbands.

These mothers wanted their children to be happy, wanted a future for themselves their children, wondered if they would be alive to watch their children grow up and wondered who would take care of their children in the future. These were some of the ambiguities of mothering found in his study which are similar concerns for women from lower socio-economic groups. Thus, mothering can be regarded as a valued role that transcends boundaries and circumstances. The value of motherhood was very important to the women in my study. It became part of their core being as individuals with HIV. The need to provide and protect their children was something they strove to accomplish against the odds of being HIV-positive. It appeared as if mothering within the context of HIV required greater effort in terms of the protection and care of children and from the viewpoint of the women this constituted 'good mothering' in the face of HIV-AIDS. It must be noted here that these mothers are responsible for parenting HIV-positive children as well as non-HIV-positive children. 3 out of 4 mothers also had children who were HIV-negative. This may place an additional burden on parenting as nurturing all children is important to these women but balancing the needs of children generally with the specific needs of HIV-positive children together with an additional perceived need to over-protect the child with HIV was clearly a challenge.

According to Nelms (2005), the phenomenon of mothering for HIV-positive women with dependent children was a constitutive pattern of burden which was both covered and infused by stigma.

Stigma casts a shadow over all experiences of HIV infected women and their children, making it different from and more complex than other experiences in which mothers have life-threatening illnesses and may die and leave their children (Bunting, 1996; Ingram & Hutchinson, 1999b; Herek *et al.*, 1998; Moneyham *et al.*, 1996). The effect of stigma on the women in the study thus far is discussed in the next section as it emerged as a major theme.

#### **4.5.4 Stigma and discrimination and secrecy**

The issue of stigma and discrimination (whether overt or secretly managed) was found in all the participants' lives. At some point in their lives, because of their HIV status, all the women had experienced some form of stigma and discrimination. This feeling had been internalised and passed on to their children, who in turn maintain the silence and secrecy. This seemed to be a family ritual that was passed down to the next generation for their self-preservation in the realm of HIV/AIDS.

One of the defining characteristics of the HIV epidemic has been its on-going association with stigma. Goffman (1963, pg. 3) defined stigma as "an attribute that is deeply discrediting, within a particular social interaction".

Two major aspects of HIV/AIDS create stigma: the fact that it is a progressive and infectious disease associated with death, and the view that it is transmitted by already stigmatised groups - gay men, drug users and sex workers (Herek & Capitanio 1993; Herek & Glunt 1988). Its association has shifted from private sexual behaviours to increased association with marginalised groups, for example, economically impoverished people of colour. Thus, stigma can be seen as the primary view of how the society sees HIV/AIDS. Hoffman (1996) states that stigma is often translated into discrimination, isolation and indifference towards those affected. This translation of stigma was seen in all the women in the study in the form of discrimination and isolation rather than indifference. Many experienced overt discrimination from health-care

personnel. As a result of this she has become even more isolated from people including the family around her.

*Mary- 'To be honest, I was never too friendly and now it worse. I was always a person to myself yuh know'.*

Aggleton *et al.* (2003) spoke about HIV/AIDS related stigma in the Caribbean. They contended that HIV/AIDS stigma is related to stereotyping, that is, what individuals do to others at times by putting them in certain categories. Link & Phelan (2001) added that stigma was seen as something that resided in the person who was stigmatized rather than a designation that others attached to that individual. Aggleton *et al.* (2003) stated that much research on stigma is methodologically weak since it fails to recognize stigmatization as a process with which individuals and their communities engage. Many studies have omitted to account for the social structures and cultural values that give HIV/AIDS related stigma its meaning. Aggleton *et al.* assert that within a culture, certain attributes are seized upon and defined as not worthy but that undesirable differences and “spoiled identities” do not naturally exist but are created by individuals and communities. In their view stigmatization describes a systematic process of devaluation rather than a concrete “thing” that can be measured. Individuals with HIV/AIDS are often seen as doing something wrong and therefore deserve their illness; that it is linked to a social wrong. In this study, the stigma experienced by the women was linked to stereotyping; however one must examine what Aggleton *et al.* purported with respect to stigma not being a mere “thing” but a systematic process of devaluation.

Aggleton *et al.* added that women with HIV/AIDS were seen as promiscuous despite clear evidence to suggest that in the majority of cases they had acquired the virus from their husbands or regular male partners. Women were unable to transcend this HIV/AIDS related stigma; it was likened as a cycle that keeps going around in circles no matter the circumstances.

Harek (1990) described stigma as representing the intersection of psychological processes with the cultural construction of HIV/AIDS. He looked at the multiple forces that converge to create HIV-related stigma such as biomedical, cultural, interpersonal and individual forces. There is the conflict that arises out of the rights of those with HIV

versus the protection of the public, that is, the dilemma of the rights of the individual with HIV and the role of the government in protection for the larger society. Participants struggle with the fact that there is so much information out there that educates the public on HIV, yet stigma still persists in the society. Pierret (1992) stated that some groups such as infants of HIV positive mothers and persons who had blood transfusions were seen as 'innocent' and thus treated less harshly by society. The women in this study all said that they had acquired HIV through a partner, however, they were unlikely to be seen as 'innocent' in the Caribbean context but may be seen as promiscuous in the eyes of society. The women perceived that they were likely to be judged unfairly based on this perception; the community at large being both judge and jury pronouncing them "guilty by reason of partner infection for HIV".

Mary experienced stigma and discrimination from health personnel. In a study of health personnel, some people believed that the risk of acquiring HIV through their work was considerable (Loring & Kelen 1990). This may help to explain the behaviour of the health professionals to which she was subjected.

*"They had on gloves and you know they reading meh file, they realise yuh HIV, everybody shoo shooing, everybody watching yuh know. [Mary]*

Given that health services are so crucial to survival, it is important that health personnel follow the international directives handling of blood and blood products. They should also be well aware of the stigma and discrimination involved in the overall picture of HIV/AIDS. Health professionals are most often than not the first point of call for persons diagnosed with HIV and if these persons experience stigma at this juncture this may create internalised stigma and fear of stigma elsewhere. Furthermore, this experience will certainly paint a gloomy picture for those infected by the virus and may further contribute to depression and isolation.

Poindexter and Linsk (1999) claim that while some women in their study did not experience overt HIV-related stigma, most had not disclosed their status to family members, thus did not expose themselves to be judged. The findings of my study also showed that stigma was internalised and disclosure was not an option for the mothers.

A secret has been defined by Bok (1989) as “anything, intentionally hidden, set apart in the mind of the keeper as requiring concealment” (p.6). He noted that secrets are kept intentionally to prevent others from possessing, using or revealing them. Thus, concealment is the defining characteristic of secrecy. Bok (1989) further discussed the impact of AIDS as a family secret which served as a divisive tool that excluded those members of the family system who were not aware that it existed.

It was found that HIV/AIDS related stigma contributed to the burden of care, forcing mothers to deal with tension between the secrecy surrounding the disease and the openness required in providing care and receiving social support. Mothers’ isolation was worsened by the lack of effective formal psychosocial support targeting children, a finding confirmed by Wong et al. (2006) in their analysis of international policies on voluntary counselling and universal access to ART for children.

There is some indication from my study that while secrecy was used to manage the potential negative impact of stigma, this approach may in the long run reduce possible social support from family members. Black (1993) is of the view that focusing on guarding the secret diverts energy that could be used for coping with the illness. Black further noted that one of the major issues when AIDS is a secret between a parent and a child is the concern of the parent that someone will reveal the diagnosis and this in turn creates a source of stress and anxiety for parents and children. This is reflected in the case of Mary when her daughter Amy told her teacher that she was HIV positive. Mary then had both to lie and to accuse Amy of lying in order to maintain the secret. This was a form of managed stigma.

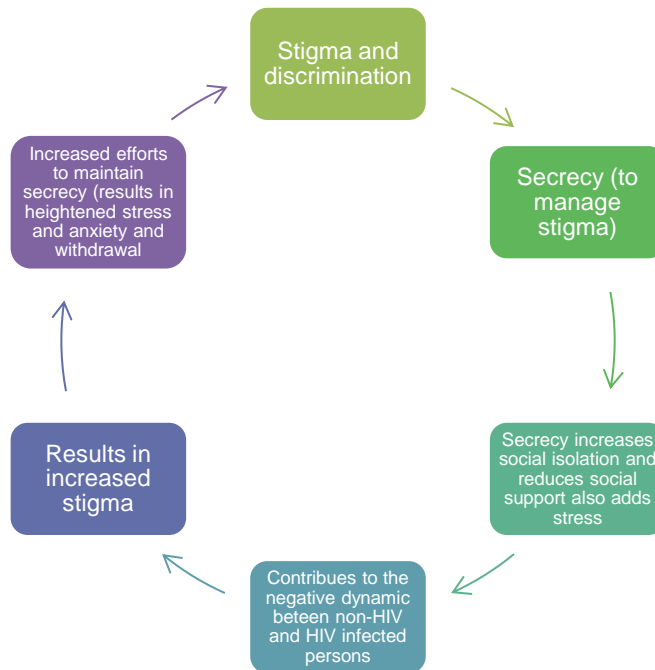
Within my study, there was evidence that women also use silence as a means of avoiding conflict in relationships. Demarco *et al.* (1998) find that silencing among the women in their study was used to avoid conflict and relationship issues. Crandall and Coleman (1992) assert that the negative consequences of stigmatization affect the social relations of the individual, resulting in withdrawal as a response to social situations. This was clearly the case for the women interviewed in my study who had become more withdrawn as a consequence of being HIV positive. Crandall and Coleman also suggested that those individuals who attempted interaction with the

stigmatized individual may feel awkward, tense, and embarrassed and that this dynamic contributes to HIV infected people losing their normal sources of social support. This stood out strongly in the case of Mary who said the following:

*“I doh mix, I doh socialise, I does just be work, home that’s right, that’s it. I doh really talk much only to Miss M. and we does have our group sessions so that is more or less my little past-time*

*Translation: I do not socialise, I just go to work and home. I do not talk much only to Miss M and we usually have our group sessions so that is more or less my past-time.*

The circularity of stigma can be summarised below:



Figure

#### 4.5: The circularity of stigma and discrimination

#### 4.5.6 Coping and resilience

The mothers all had a belief in God and prayer to help them cope on a daily basis with HIV. Two of the women sought the support of a professional as someone they trusted and who could listen to their concerns.

*Like I said for me coping is maintaining my children. More or less I does try to be normal. Try to ignore everybody and everything. Sometimes I does scream down the house when it quiet. Yeah but I ok. It hah days when I does cah function, I*

*doh know about anybody else but it has days I does be so depressed I cah even bathe. I refuse to bathe I refuse to get out of meh bed . I isolate, do not socialise, do not interact with people.[Mary].*

*(Coping means maintaining her children and trying to be normal as possible. I try to ignore everybody and everything. Sometimes I scream when it is quiet but I am ok. There are days when I cannot function, I don't know about anybody else but sometimes I get so depressed I cannot even bathe and I will refuse to get out of bed. I isolate myself and I do not socialise nor do I interact with people)*

*I does just pray. That's all I does do just pray. Well it might not help but sometimes it gives me a little ease. But if I have something really bothering me I will call Ms. James (nurse). I still have Ms. Smith (social worker) phone number so I will call her and talk. [Bertha]*

*(I pray, that is what I do. It might not help but it makes me feel better. If I need someone to talk to I will call Ms. James or Ms. Smith.)*

*Right about now I have a whole set of stories from the Bible. I have a Bible game, and all those on DVD so sometimes when I can't get my friends and them to talk to and I home alone I will put in the Bible. I will play the Bible game. This helps me feel better. [Petra]*

*I have two friends that I does go and lime with. Just to keep my mind off it because it have sometimes I will be home alone and I lie down on the bed and I does just get flashbacks. And I hate to be crying and thing because it breaks me down very much.[Petra]*

*(There are two friends with whom I socialise just to keep my mind clear. Sometimes I will be home alone and I will lie down on the bed and have flashbacks. I hate to be crying as it affects me very much).*

*Well I am in a church and sometimes the pastor speaks about HIV and Aids. Sometimes when they preaching, they talk about it. But you know I know to look onto Jesus and not look onto the people of the church because I know I am serving a true and living God and if he could bring me from so far, he could bring me to wherever he would like me to be. [Martha].*

It can be seen that the women had low moments and to cope they withdrew, cried, screamed and stayed in bed. Praying and reading the Bible helped to provide some measure of comfort, even socialising with friends or, in Mary's case,, interacting with the social worker who provided an effective formal support to help her cope with living with HIV-AIDS.

Coping is defined as a dynamic contextual process in which people use cognitions and behaviours to manage a situation they appraise as taxing or as exceeding their

resources (Lazarus & Folkman 1984). Chronic illness impinges on one's resources and HIV is a chronic illness accompanied by a host of other stressors ranging from stigma to uncertainty of illness progression (Ball *et al.* 2002). Lazarus & Folkman (1984) describe two types of coping, problem-solving and emotion-focused coping. Problem-focused coping comprises taking action-oriented steps to alter the cause of stress and develop a more satisfying situation. This helps when a person has a sense of personal control. Emotion focused strategies (prayer, positive reappraisal) however, are aimed at managing emotions aroused by stressors in order to maintain 'affective equilibrium'. Emotion-focused coping has been found to be more effective when control over outcome is limited and the stressor is considered unchanging and inescapable.

Problem-focused coping has been associated with better psychological functioning in chronically ill and HIV-positive individuals (Friedland *et al.* 1996). However, certain forms of emotion-focused coping, such as, seeking support, spirituality and optimism have also been related to improve psychological functioning in chronically ill and HIV-positive individuals (Moneyham *et al.* 1998). In fact, it has been suggested that persons with HIV often cope better when an emotion-focused strategy is used as there is no cure to the disease and thus a problem-focused approach may not be as effective (Nannis *et al.* 1997).

The women in this research project certainly used emotion-focused strategies, for example, spirituality, socialising, crying, and screaming. Although there was also evidence of both strategies being used together and it can be deduced that combined strategies strengthen overall psychological well-being.

Silva *et al.* (2008) stated that living everyday with children with HIV made mothers adapt to a new reality and developed coping strategies for managing stressors, for the physical, psychological and social welfare of children. Mothers had feelings of overprotection and fear when they dealt with their HIV positive children.

## **4.6 Conclusion**

The study shows that HIV/AIDS has a huge impact on mothering. Caribbean cultures contribute to a double-bind effect where society wants mothers to procreate but not if



they are HIV positive. The women in the study made a choice whether to reproduce based on cultural norms and not on their seropositive status. Emerging from being HIV positive is the concept of secrecy as a stigma-management tool in the family. Stigma and discrimination was seen as being part of the HIV tapestry with respect to women and children. Secrecy can prevent the individual from receiving social support as it served as a barrier or a shield to perceived stigma, more so if children were involved. Poverty can lead to direct as well as indirect costs to the household. The women were of low-economic status, thus poverty impacted on both their own and their children's ability to adhere to medication. Travelling expenses to the clinic and the ability to purchase nutritious foods proved to be a challenge. The psychosocial issues with respect to mothers were present in the economic, social and emotional realm and fear appeared to be the overarching factor for all three.

The themes discussed were somewhat distinct entities, however, in reality they manifested themselves as interrelated and the interconnection of psychosocial issues impacted and impinged on the lives of these HIV-positive mothers. Living with HIV-AIDS encompassed disclosure issues, poverty, mothering, stigma and discrimination and coping. The overarching theme that stood out was that of mothering with HIV. Mothering demanded a lot from the women but emerged as a role of fundamental importance to identity, self-image and maintaining partner relationships.

The core category that emerged was that of 'secrecy to protect'. According to Strauss & Corbin (1990) the core category is the central phenomenon around which all the other categories are integrated. In this research categories and sub-categories can be seen as main themes and sub-themes. Strauss & Corbin also defined a category (theme) as a classification of concepts as they are grouped together under a higher order. The mothers being aware of this felt that there was a need to protect their HIV-positive children from stigma and discrimination. Secrecy was the tool used to protect both parties as this was the common thread found throughout all the themes.

The second part of this chapter focuses on the findings from interviews with three mothers who had not told their children that they (mothers and children) were HIV-positive.

## Chapter : Findings Mothers Part 2

### 4.7 Introduction

This part of the chapter deals with the findings from interviews with three women who did not tell their children about their HIV-positive status. An interview protocol was developed to guide questions, in order to solicit the information needed. Discriminate sampling was used to choose the mothers who did not tell. This aspect of the research was carried out as a means of theoretical sampling (common in grounded theory research), to further investigate the core category that emerged from interviews with mothers who told, that of 'secrecy to protect', and also to help verify the core value of 'mothering with HIV-AIDS'. The core category of 'secrecy to protect' was the thread that ran through all the main themes that emerged through the analytic process. The mothers used this as a strategy to help sustain their children and to protect them from stigma and discrimination

In discriminate sampling, the researcher chooses the persons who will maximise opportunities for verifying the storyline and relationships between categories (Strauss & Corbin, 1990). Access to this sample took six months, as the mothers' trust in anyone whom they did not know was low, when speaking about HIV-AIDS. Sometimes appointments would be made with the women, or they would tell the researcher on the phone that they would meet, but then they would fail to turn up without calling to cancel. There were many wasted trips. I attempted to contact at least 8 participants; however, I only was able to get 3. When the women could not be contacted again, replacement participants were sought.

Table 4.8 Demographic table of women who did **not tell**

NO	AG E	M S	ET H	REL	EDLV L	CHLD	EMPS TAT	YR DIAG	WA	CD4	MED	AREA
Maxine	37	M	M	NR A	T	1	U	2001	NO		Yes	South
Anne	33	C	E	H	P	7	U	2000	NO	Not known	Yes	Central
Candy	33	C	A	NR	P	3	E	2006	NO	Not	Yes	East

				A						known		
--	--	--	--	---	--	--	--	--	--	-------	--	--

**Table Legend:**

**NAME** - Name of participant

**MS** - Marital status,

**M** - Married; **C** - Common-law;

**ETH** - Ethnicity

**A** - African; **E** - East Indian; **M** - Mixed

**REL** - Religion/Faith

**H** - Hindu; **NRA** - No Religious Affiliation;

**EDLVL** - Educational Level

**P** - Primary; **T** - Tertiary;

**CHLD** - Number of children

**EMP STAT** - Employment status

**E** - Employed; **U** - Unemployed;

**YRDIAG** - Year diagnosed

Four figures for the year, e.g. 1980

**WA** - Welfare assistance

**Participant A - Maxine**

Maxine is an Afro-Trinidadian who is 37 years old, married and has schooling up to tertiary level. Maxine was diagnosed HIV positive in 2001. She is on Anti-retroviral medication (her child also) and is not on welfare although she is unemployed (by choice). Maxine's husband did not initially know that she was HIV positive and found out after she had the baby. Maxine herself also found out after she had the baby. Her husband is HIV negative.

She has one child, a girl, who is nine years old and HIV positive. She has no religious affiliation and lives in the southern part of Trinidad.

### **Participant B - Anne**

Anne is an Indo-Trinidadian who is 33 years old, lives in a common-law relationship, and has schooling up to primary level. Anne was diagnosed HIV positive in 2000. She is on Anti-retroviral medication (her child also) and is not on welfare, even though she is currently unemployed. Anne has seven children, ranging in ages from two to eighteen years. The first five children are from a past relationship. The ten-year-old from the past relationship is HIV positive, and is the only child who is HIV positive. Her partner (common-law-husband) knew from the inception of the relationship that she is HIV positive. He is the biological father of her two last children who are HIV negative. He now however, has been diagnosed as HIV positive. She is of the Hindu faith and lives in the central area of Trinidad.

### **Participant C - Candy**

Candy is an Afro-Trinidadian who is 33 years old, lives in a common-law relationship and has schooling up to primary level. She was diagnosed HIV positive in 2006. She is on Anti-retroviral medication (her child also) and is currently employed and is not on welfare. Candy has three children, ranging in ages from sixteen to two years. The five-year-old is HIV positive. She has since had another child, who is HIV negative, by the same partner. Her partner is HIV positive. Partner found out about the virus after the child was born. Mother also found this out at the same time.

She has no religious affiliation and lives in the eastern area of Trinidad.

## **4.8 Themes**

The following table outlines the themes that emerged from interviews with the mothers who did not tell their children of their status.

Table 4.8 Themes of Mothers who did not tell

<b>Main Themes</b>	<b>Sub-themes</b>
1. Mothering with HIV-AIDS	<ul style="list-style-type: none"><li>• Non Disclosure</li></ul>
2. Adherence	<ul style="list-style-type: none"><li>• Reasons for taking medication</li></ul>

	<ul style="list-style-type: none"> <li>• Lies about medication</li> </ul>
3. Social support	<ul style="list-style-type: none"> <li>• Formal and informal support</li> </ul>

#### 4.8.1 Mothering with HIV-AIDS - Non-disclosure

All three mothers extolled the role of motherhood. They found fulfilment in this role and enjoyed having children and providing for them. This helped to corroborate similar feelings described by the first four women in Part 1 of the findings. These mothers felt that they had to protect their children and this was the primary reason they had decided not to tell of their status:

Maxine:

*“But you know when I look at it, as I said I don’t want to be insensitive, I could protect her for a little while but then when she grows up there is always the unguarded moment and if I protect her for 18 years or for 21 years, one day in her life she will grow up and she will want to experience life.”*

Anne:

*“To tell you the truth, I don’t feel comfortable. The reason why I don’t feel comfortable, knowing that the rest of children don’t have it and he is the onliest one. And when you hear he get big he go want to know how come he is the onliest one who have the virus and he go ask a setta questions*

*Translation: Anne does not feel comfortable knowing that her son is the only one of her seven children with HIV. She fears that when he gets older he will ask a lot of questions about why he was the only one of her children who had the virus.*

Candy:

- Q. Does your child know that you are HIV positive?  
A. No, because I find he ain’t reach the age to understand it.  
Q. And what else? He hasn’t reached the age to understand, and why else would you not tell him?  
A. I will tell him but when he reach older.  
Q. How old? Like what age do you think?  
A. Like around 10. He is 5 years; he is still a little child. He ain’t really know what is what yet.

*Translation: Candy felt that her son was not old enough to understand what being HIV positive means. He was only 5 years old and she considered him a little child. She felt that by age 10 he should be able to understand the*

*ramifications of what being HIV positive means, so in the interim she protects him.*

Non-disclosure to children was seen as 'secrecy to protect.' The mothers felt that the child was too young to keep a 'secret' and also that they may be too young to understand what having HIV means. These mothers were convinced that they were doing what was right for the child, and felt that the onus was on them as mothers to protect the child. The three mothers, however, said that they would tell the child of their status when the child got older. Thus, it was not a case of 'never tell' but of telling at a later stage. This is important, as it suggests the willingness of the mothers to disclose when they felt the child was ready, at a later date.

A further reason why the mothers may not have told their children may be related to whether the women had addressed their own HIV status and the feelings that they may have experienced, or were presently experiencing, as a result of being HIV positive. The women were all taking anti-retroviral medication, which formed part of managing their physical well-being; however the status of their psychological well-being was not known and this was not explored in the study. Nevertheless, Dane (2002) suggests that mothers must be able to manage their own feelings about their HIV status before telling their children. This is a point to note with respect to social workers interacting with mothers and children with HIV, and the issue of disclosure. There may be a need for dialogue as to how mothers are coping psychologically with the illness, as this seems to be a precursor for disclosure to children. It follows that if a mother is able to manage the illness both physically and psychologically, she may be in a better position to disclose to her child. She would have dealt with her feelings and issues surrounding HIV-AIDS, thus creating a platform for her to address issues of HIV-AIDS with her child from a better position.

Many studies support a developmental approach to disclosure, and suggest that parents who are HIV positive are most likely tell older children (Shaffer *et al.* 2001; Lee & Rotheram-Borus 2002; Schrimshaw & Siegal 2002). These authors all purport that the decision may be as a result of the mothers' perceptions that older children will be more likely to understand the implications of such information, and perhaps be better

equipped to keep that information confidential (Murphy 2008; Roberts *et al.* 2002). Rotheram-Borus *et al.* (1997) and Dematteo *et al.* (2002) suggest that, in the case of mothers, they worry about sharing their HIV status with their children for fear that the child would not be able to keep a secret. Consequently, as a result of these fears, mothers are found to have a 'relatively low' rate of disclosure to their children as compared to other family members (Schrimshaw & Siegel 2002).

In this study the three mothers felt that the children may disclose their status to others. According to Gibb *et al.* (1991), many parents do not want to burden their children with the knowledge of the child's HIV status at too young an age, as they fear that the child will reveal the diagnosis to others. Gibb *et al.* also state that it is the onset of adolescence and sexual development which prompts parents to tell children of their diagnosis. This is because parents were afraid that adolescents may pass on the infection to others, being aware at that stage children are attracted to the opposite sex and may even embark on intimate relations.

This in itself can create some challenges, as Gibb *et al.* (1991) state, as adolescence is already a difficult time and many of these youths may react by feelings of denial, resentment and, possibly anger that they have been deceived in the past. Gibb *et al.* claim that, more often than not, young people are unable to talk to their parents about intimate and emotional matters, and because of social stigma are also unable to speak to friends or other adults. In this study, there was non-discussion of HIV-AIDS in the home and non-disclosure. When these children become adolescents one wonders if they will be able to discuss issues that affect them with respect to HIV-AIDS and the ramifications of the illness.

Bor *et al.* (1993), in their study, also give reasons for mothers not disclosing, which include: fear of the child disclosing to others, which may threaten parental confidentiality; fear that disclosure may exacerbate the disease process, and concern about the effect of family instability. They also add that the stage at which parents choose to disclose the diagnosis to a child, and how they do this, is an important topic as it yields insights into family dynamics and how each member comes to terms with the diagnosis and illness. Armistead *et al.* (2001) report that the issue of whether to

disclose HIV status to a child is by no means a simple decision. Professionals working with HIV-infected families may be called on to assist in this decision-making process. They add that there are few empirical resources on which these professionals can rely in their attempts to help families with a decision.

Goffman (1963) writing about stigma, speaks about the significance of disclosure to discrediting information about oneself; he states that the situation of the stigmatized individual becomes more perilous as more people are informed.

Telling others of their status can also create a double bind for persons living with HIV (Ingram 1996). Going public can mean letting go of the energy it takes to keep secrets. However, this can come with a price, as telling more people can, on the one hand, expose both mother and child to negative reactions because of stigma, yet on the other hand it can create an environment of support for them and their children. These are decisions that proved to be challenging for the HIV positive mothers in this study.

Lack of open communication about HIV/AIDS created a context of confusion and mistrust and this was detrimental to the children's psychosocial development and coping. This compromised disease knowledge and increased vulnerability to risk behaviour (Abadia-Barrero & LaRusso 2006).

#### **4.8.2 Adherence**

Having the children take their medication was very important to the mothers. The mothers realized that, because they had not disclosed to their children, they did not want them to get sick under any circumstances, as that may mean telling them why they were ill and disclosing to them before the mothers thought that they (mother and child) were ready. The mothers had to lie to their children about the real reason why they were taking medication. Thus, adherence became a very important feature of these three families.

Maxine:

*Well, I am on medication. Right now everything is undetectable for quite a long while, like, in a short period. I take the medication like clockwork when I am supposed to. I ensure that my daughter does the same and I think I have more energy than most people that appear to ensure daughter take meds look normal*



*that I don't know anything about. I feel great and I think I will live very long and be very busy. Sometimes they ask me to calm down, I say, "No." It's the drugs and I love it.*

*She asked me about the medication once and I told her it is not medication, it is vitamins and vitamins keep people healthy and it is to ensure that you stay healthy, and you don't want to get sick like how you see children being sick and staying away from school with those bad colds and all those different things.*

*Fortunately she doesn't really get sick. Her CD4 is very high; it is 1200. So she is a remarkable child — anyway she was well fed — and she is doing fine.*

Anne:

*No he ent know. I does tell him, he ask me, he say, "Ma, what I taking the medication for?" So I tell him is because of the fits.*

*Translation: No my son does not know that he is HIV positive. When he asks me about the medication I tell him it is for the fits that he gets.*

*No, right now he healthy, that is from what the doctor say. The doctor say dey see no problem with him. He take he medication on time. He eat. He don't eat the best of things but he does eat. I make sure he get something to eat in the morning, he take he tablet. I give him something to eat in the night, he take he tablet.*

*Translation: No, he is not ill; presently he is healthy according to the doctor. The doctor said that they see no problem with him as he takes his medication on time. He eats, maybe not the best of meals, but he eats. I ensure that he eats in the morning when he has to take his tablet and also in the night.*

Candy:

*Well, boy, that is to keep you healthy and strong because if you don't drink it you will die, you won't see your friends and them so that is something you have to take. Yes, both morning and evening he have to take it. Look this morning I had was to beat him. It does have times he will take it with ease and then it does have times you does have to force him but he have to take it. Sometimes when he take it he does vomit and he have to take it over again.*

*Translation: I tell him that the medication is to keep him healthy, and if you do not take it you will die and you would not see your friends, and it is something that you must take. He has to take it both mornings and evenings. Look, this morning I had to hit him to take it; sometimes he takes it with ease and other times he vomits it up and then he has to take it all over again.*

**Muller et al. (1998)** say that stigma, and non-disclosure as a consequence, can influence children's motivation to take medication if they are unaware of the necessity of

the treatment. In this research the mothers lied about the use of the medication, but they emphasised to their children how important it was to take it. One even went as far as to hit her son and to tell him that if he did not take the medication he would die. Thus, the alternative reasons given for taking the medication motivated the children to take it anyway, as it was projected by the mothers as something very good to take. This helped to highlight the influence which the mothers had on their children, and the lengths that the mothers would go to, to ensure that their children were as healthy as possible. My findings contradict those of Muller *et al.* (1998), as the children were aware of the necessity of taking the medication even though they did not know the real reasons; this motivated them to comply, producing a somewhat similar effect to if they had been told the truth. In the mothers' views, the end justified the means since ensuring adherence was their goal.

Rogers (2009) suggests that lying to children destroys the trust relationship between child and caregiver. The choice by the latter is usually motivated by fear and denial. Rogers says, however, that when disclosure eventually occurs, the child will have to come to terms, not only with his/her status, but also with the fact of having been lied to by someone he/she trusted. An understanding of his or her HIV status may bring many benefits to a child. The social worker can foster emotional support, answer questions, make referrals for specialized support and provide access to peer support groups. The adolescent who chooses to engage in sexual activity is able to make informed sexual decisions, and also the ability of the sexual partners to make informed decisions provided the infected person informs them of their status, that is, with full knowledge of the risks to his or her partner. The caregiver can also benefit in many ways, through the opportunity to control disclosure to the child and to gain emotional relief from ending the secrecy about the illness. Another issue that Rogers speaks about is that children and adolescents tended to have a sense of their health status, even if they are not told of their health status (Rogers 2009). In Rogers' study, if children were unable to speak about their illness openly, they often blamed themselves for the illness and the effect on people around them. This self-blame was said to be likely to result in increased stress levels, which in turn can negatively impact upon the immune system.

Adherence seemed to be even more urgent with these mothers, as it helped with the overall health of the child and also it prevented the child from becoming ill. This appeared to be very important to the mothers as, if the child were to fall ill, they may ask questions about their health, or others may ask questions also. This may mean disclosing to the child before the mother thought that he or she was ready, or before the mother was ready to disclose. The 'secrecy to protect' theme, which emerged for the four women who did tell, seemed stronger with this cohort of women, as disclosure at this juncture was not an option. They felt that their children were not ready for this knowledge as they were too young, and feared that they may disclose the secret. The mothers who chose not to tell held the power to disclose in their hands, and even though the child had a father or step-father with whom they lived, this was not considered the father's role.

Hejoaka (2009) spoke about mothers' fear of disclosure to children and the lies that they tell to facilitate those lies. When mothers were confronted with questions from children about their illness, they came up with varying answers such as being underweight, having a sickly condition and weakness as reasons for their illness. Faced with the children's inquisitive questions about their illness or their "good state of health which does require taking medication everyday", the mothers expressed their helplessness by answering harshly and sometimes referring to fatality, that is, the use of death to get children to take their medication. This was also evident in my research as Candy told her son:

*"Well, boy, that is to keep you healthy and strong because if you don't drink it you will die, you won't see your friends and them so that is something you have to take"..*

Anne also alluded to another illness as a reason for her son to take his medication"

*"I does tell him, he ask me, he say, "Ma, what I taking the medication for?" So I tell him is because of the fits"..*

Maxine also found an excuse for her daughter to take her medication to maintain her good health:

*"She asked me about the medication once and I told her it is not medication, it is vitamins and vitamins keep people healthy and it is to ensure that you stay*

*healthy, and you don't want to get sick like how you see children being sick and staying away from school with those bad colds and all those different things".*

There seemed to be a link between non-disclosure to children and lying to maintain that secret.

The way a child will respond to the diagnosis and disclosure of being HIV positive in relation to his/her stage of development was examined by Abadia-Barrero & LaRusso (2006). They studied children aged one to 15 years. These children had no open communication about HIV/AIDS; instead there was the use of the disease symbol (medications) and children commented on the colours, schedules, tastes and names of the medication. Children younger than six learned to accept 'medication taking' and to silence 'illness-related questions' in their daily lives. They did not use the word "AIDS". Some four – five year olds would say they were "sick". This "sickness" however, was not related directly to AIDS but rather to a general feeling of "being sick" as when someone has a fever. However, the children displayed curiosity about their HIV/AIDS related experiences and would ask why they had to take medication. The adult's explanations usually were very vague. Eventually the children stopped asking. Consequently, children lacked proper explanations that matched their cognitive abilities and illness experience resulting in a lack of a supportive environment for developing trust, which was critical for the psychosocial development of the young child.

In my study the mothers seemed to have taken responsibility for that ultimate task of protecting their children. Also, in the whole scheme of things, one must look at the unconditional love that these HIV-positive mothers had for their children. In the midst of the fear of disclosure, stigma and keeping a secret, the mothers held on to this love and this was seen as something of intrinsic value that was acknowledged in these families. 'Secrecy to protect', the main issue that emerged in this research, seemed to have embedded in it the unconditional love which the mothers had for their children.

### **4.8.3 Social Support**

The social support structure of the mothers was limited because they did not trust or have confidence that others would keep the secret. They disclosed to only a few people,

much like the women who did tell. When the women *did* tell, they only disclosed to a few persons that fell in the category of informal support, that is, family and friends

Maxine:

*I am very close with my mom, so I didn't see anything was wrong about it and I thought that she had to know. We have a good relationship. Also, my sister-in-law. She has kids, she is experienced. Ever since, we had a good relationship but then I found like if I have a problem, she is somebody I could turn and talk to.*

Anne:

*To tell you the truth, nobody in my family don't know. I tell them I don't have it.. If I tell dem that I have the virus right, nobody wouldn't want to have nothing to do with me. I only tell my common-law husband.*

*Translation: To tell you the truth, nobody in my family knows. If I told them that I had the virus they would shun me.*

Candy:

*I will tell people but you have to be particular about who you will tell and how they will react to it, and then you have to study how to come out and tell them and how they will react to it.*

Candy did not tell her son's teacher that he was HIV positive.

*Because I don't know how, because besides this he went to another school and the school he went to, the teacher get to find out. Without I doing it, they went and spread a rumor. Well she did not want to keep him because she did not know nothing about that.*

*Translation: Because I don't know how to tell the teacher, as my son attended another school and at that school the teacher found out about his status. Then the rumour began. She did not want to keep him at the school as her knowledge of HIV was limited.*

Candy did not want to disclose to her son's new teacher because of her own past experiences. Keeping the secret of having HIV-AIDS to only a token few can be stressful, but the mothers tried to protect their families from the stigma and discrimination. This can mean that availability of support for both mother and child is restricted.

Rice *et al.* (2009) state that disclosure is inherently an activity engaged in within social relationships and research has shown that it matters to whom women disclose (Serovich *et al.* 2007 & Kalichman *et al.* 2003). Kalichman *et al.* (2003) look at stress,

social support and HIV-status disclosure to family and friends among HIV-positive men and women. They found patterns of selective disclosure, where most participants disclosed to some members of their circle of relationships and not to others. Disclosure was associated with social support. Friends were disclosed to most often and perceived as more supportive than family members, and mothers and sisters were disclosed to more often than fathers and brothers and perceived as more supportive than other family members. Disclosure and its associations with social support and depression varied for different relationships, and these differences have implications for mental health and coping interventions. HIV positive individuals rely on formal and informal social support systems for their HIV related concerns (Hays, Magee & Chauncey 1994; Ingram, Jones *et al.* 1999. With respect to informal networks, Ciambrone (2002) examines these among women with HIV/AIDS, as well as their present support and future prospects. She explored the composition of women's social networks and the extent to which these appeared to facilitate or mediate the disruption caused by HIV/AIDS. Women reported having at least one person, usually a family member, on whom they could depend for emotional support. Ciambrone states that although the women reported adequate levels of current support, the likelihood that their informal networks would provide support further along in the women's illness trajectories is questionable.

Gielen *et al.* (2001) describe the relationship between psychosocial factors and health-related quality of life among HIV-positive women. They found that women with larger social support networks reported better mental health and overall quality of life.

Considerable evidence suggests that positive social support helps people maintain their health and welfare under difficult circumstances (Hudson, Lee, Miramontes & Portillo 2001; Saunders & Burgoyne 2001).

Social support seemed to be important in the lives of these women and children, however they seemed to forego this to a certain extent in order to keep the secret and, in so doing, protect their children.

## **4.9 Similarities in findings for women in parts 1 and 2**

This discriminate sampling (Strauss & Corbin, 1990) of three women who did not tell their children of their status was a theoretical sample to further test the theme of 'secrecy to protect' that emerged from the analysis of the data from 'mothers who told their children.

### **Secrecy to Protect**

There was a link between both groups of mothers: they all showed unconditional love for their children, both groups thought that they were doing what was best for their children, and mothering with HIV-AIDS was the 'new normal' for these mothers. As discussed in 5.5.1, 'Disclosure for children', despite the evidence that social support helps, the mothers did not want to risk attracting discrimination into their homes as they felt that they may not be able to cope. The thought of being discriminated against outweighed some of the benefits of disclosure, such as informal social support. In 4.2.3, 'Parenting, mothers, mothering and HIV', the value of motherhood was described. The need for the mothers in both groups to protect their children was paramount and, from the viewpoint of the women, this constituted 'good mothering' in the face of HIV-AIDS.

### **4.10 Conclusion**

The interviews with the three women who did not tell of their HIV-AIDS status sought to discover more about the theme of 'secrecy to protect' which had emerged from analysis of the women who told their children of their status. The findings showed that the women who did not tell carried the 'secrecy to protect' even further by not telling their children, as they felt that they were too young, and they also felt that the children could compromise the secret by telling others. They lied to the child about why the child was taking medication to promote the child's compliance and to ensure that the child adhered to the medication. Adherence was linked to keeping healthy, so that the child actually kept healthy and no questions were asked about ill health by anyone, including the child. This was crucial, as disclosure was not an option in the lives of these mothers and, furthermore, they did not want their children to find out their status. The mothers were in total control of the disclosure issue, even though they had partners. This alludes to the importance the mothers played in the lives of their children and the importance

placed on mothering in the midst of HIV-AIDS, as well as how far the mothers would go to protect their children.



## Chapter 5: Findings Children

### 5.1 Introduction


This grounded theory approach focuses on 4 case studies inclusive of mother, child and a support person. In the previous chapter the findings of mothers were discussed, but in this chapter the children are the main focus. The children are introduced with the basic demographic information and economic, emotional, behavioural, social and health issues. All the children acquired HIV by vertical transmission. The interviews included asking a miracle question and voice to the participants was given in their feedback from the interviews, via answers to questions and the activities they completed. It was important that the lives of the child-participants were explored, as they were the principal participants of this research. As such, a portrait of the child's life with HIV was developed. As the pages turned, an insight into each child's life was revealed with his/her own issues and support needs. A miracle question was asked of each child, that is, if he/she went to sleep at night and awoke in the morning, what he/she would like to see change in his/her life. The interviews also included asking children to complete a small worksheet. Having a focus that was not about HIV but about 'normal' things is important in helping children to feel that they are not viewed only in relation to the virus. All identifying information was deleted on the worksheets.

### 5.2 Socio-demographic table of children

Table 5.2 Socio-demographic table of children

NO	AGE	SEX	ETH	REL	EDLVL	HIV STATUS	YR DIAG	WA	CD4	MED	AREA
1. Amy	13	F	A	B	P	POS	2006	NO	666	NO	WEST
2. Brian	11	M	M	RC	S	POS	1997	NO	<200	YES	SOUTH
3.	10	F	M	RC	P	POS	1999	NO	200	YES	SOUTH

Same mother



Cathy												
4. Dawn	9	F	A	B	P	POS	2000	Yes	NOT KNOWN	YES	EAST	
5. Evan	12	M	A	P	P	POS	1999	YES	NOT KNOWN	YES	NORTH	

**Table Legend:**

**NO.-** Number and name of Participants

**SEX-** M-Male F- Female

**ETH-** Ethnicity

**A-**African, **M-**Mixed

**REL-** Religion/Faith

**RC-**Roman Catholic, **B-**Baptist, **P-**Pentecostal, ,

**EDLVL-** Educational Level

**P-**Primary, **S-**Secondary

**HIV STATUS-** POS- Positive

**YRDIAG-** Year Diagnosed

Four figures for the year, e.g. 1980

**WA-** Welfare Assistance

**Y-**Yes, **N-**No

**CD4-** CD4 Cell Count

Three figures reflecting the Cell Count

**MED-** Medication-Yes, **N-**No

## 5.2 Child-Participant 1 – Amy 13 years

**Mother- Mary**

### Demographic information and economic issues

Amy was from the Mills family. She is Afro -Trinidadian and 13 years of age. She lived most of the time at her maternal grandmother's home. She had three siblings ranging in ages from 21years to 4 years. Amy was diagnosed positive in 2006. At the time of the study, she was not on ART medication because her health was good and Mary hoped

that it would remain that way. Mary hoped that Amy would be able to receive proper nutrition with her grandmother, as she (Mary) was unable to provide adequately for her at home, because of lack of finances; hence the reason why Amy spent most of her time at her grandmother's. However Amy claimed that she feels hungry periodically.

*Q. Do you think you get enough to eat or are you hungry at times?*

*A. Sometimes.*

*Q. What would you like to eat when you feel hungry?*

*A. Well, Mummy tell me KFC not good, but I does feel for KFC. Like today I feel for KFC but she say no. She don't have no money to buy no KFC. (Translation: Mummy tells me that Kentucky Fried Chicken (KFC) is not a good meal, but I generally prefer KFC. Today I desired it, but my mother refused. She does not have any money to buy KFC.)*

### **Emotional and Behavioural Issues: Thoughts on Being HIV Positive**

When asked about how she felt being HIV positive, she was quiet. Amy thought that HIV was a disease that can lead to death.

*Q. What do you think being HIV positive means?*

*A. That it is something in your blood and from HIV it could lead to AIDS.*

*Q. How do you feel about being HIV positive?*

*A. Sad.*

*A. I used to read the papers and thing that used to show you that; and also where people die from it. (translation: I read about HIV in the newspapers and it said that one can die from AIDS.)*

When her mother told her that she was HIV positive, Amy cried. She proceeded to ask her mother what HIV meant and was told it meant something that could kill her and it could turn into AIDS. She believed this. She thought that once she was able to 'eat properly' this would have a positive effect on her health. She however, would like to return to her mother's home as she wanted to be with the rest of her family. Amy was forbidden to disclose her status to anyone. Her mother threatened her and warned that if she tells anyone, she will get 'licks' (a beating).

*Q. All right. Would you tell anyone that you are HIV positive?*

*Q. Who would you tell?*

*A. My mummy don't want to tell my granny. My granny see when I went and take the blood test and she see this on my hand and I wanted to tell*

*her and I did not tell her.*

*(Her grandmother saw that she had a blood test and Amy wanted to tell her, but was forbidden to do so by her mother.)*

Q. *Why you can't tell her? Why you don't want to tell her?*

A. *Because Mummy might beat me. (Her mother might physically hit her)*

Her grandmother did not know about either Amy's or Mary's positive status and it was difficult for Amy to be by her 'granny' (grandmother) and not be able to tell her about being HIV positive. Amy said that she received counselling from a professional and it helped her to deal with some of her feelings with respect to being HIV positive.

### **Social Issues- School & Relationship with Peers**

Amy attended primary school and was due to sit the exam to attend secondary school Assessment (SEA) in the near future. She stated that she does not like school as she was teased all the time. Periodically she had an ear infection that oozed and the children laughed at her. This is linked to HIV. She stated that she was scorned by her peers and even physically abused at school.

*Tell me why you don't want to go to school. What happens at school?*

A. *People does scorn me and thing.*

Q. *How do you feel about that?*

A. *Bad.*

Q. *They know you are HIV positive?*

A. *No. My ears.*

Q. *Your ears hurt?*

A. *Yes.*

She does not like school because of this and claims she has no friends.

*And they scorn you because of your ears?*

A. *It does run yellow.*

*(Yellow liquid runs from her ears.)*

Q. *And they scorn you?*

A. *Yes.*

Q. *So when they scorn you, what do they do?*

A. *Stay away from me and they does beat me up and thing. (The children physically abuse her.)*

Q. *So you don't want to go to school?*

A. *No.*

She preferred to play with the smaller children as she felt more comfortable with them. She thought that she was no different from her peers as she was short and not “bright”, that is, not intelligent.

### **Relationship with Mother**

Mary and Amy had a positive relationship, although at times it was ambivalent as Amy is at times angry with her mother.. Amy is aware that her mother was HIV positive. She always enquires whether her mother was eating properly and was concerned about her well- being. She felt despondent and was worried about her mother having the virus and the possibility that she could die at any time. Amy also felt anger towards her mother for causing her to be HIV positive and felt violent towards her very often. However, she had no intentions of carrying out these negative thoughts.

*Q. Okay. And are you ever angry with her in any way that you have HIV too?*

*A. Yes.*

*Q You are angry with her at times?*

*A. Yes.*

*Q. So when you feel that way what do you want to do?*

*A. Fight.*

*Q. Fight her? Does it happen often?*

*A. I can't hit my Mummy.*

*Q. I know. But the feelings of anger, it happens often?*

*A. Yes.*

*Q. So you are sort of angry with her?*

*A. Yes.*

At times when Amy was at her mother's home she also helped to awaken her mother on mornings when she was at home, so that Mary could exercise. She then prepared a healthy breakfast for Mary. She also helped with the cooking and was very proud of her culinary accomplishments.

*A. I does cook. (I cook)*

*Q. Tell me what you cook?*

*A. Sometimes macaroni pie, callaloo, carrot rice,  
(popular local dishes)*

She boasted about her prowess in this area and beamed when the family spoke about their enjoyment of the meals.

*Q. So when you cook and you see everybody eating, how do you feel?*

*A. Happy. They does tell me the chicken season down to the bone. (This is a local saying which means the chicken was very tasty even the bones)*

*Q. So you feel good about that?*

*A. Yes.*

### **Health Issues**

Amy recalled that she suffered from headaches often and that her feet were swollen periodically. When this occurred, she had to stay away from school. She said her body felt normal and that she did not visit the doctor often. She only took an antibiotic called Septra. However, she was not on ART for HIV.

### **Miracle Question**

When asked, she replied that she would like to eat properly and also, that both herself and her mom would be free of HIV.

## **5.3 Activities**

### **Amy's "Drawing"**

Amy was asked to draw a picture of 'herself with HIV', along with the rest of her family. She drew herself bigger than the rest of the family; her actual heart was enclosed in the shape of a heart. The face of the drawing of her had a pleasant expression. She said she drew a heart because she had love inside of her. She labelled the picture with the words "This is me happy". She drew her oldest sibling, a brother, a little larger than the rest of the family, along with the rest of the family, her parrot and her dog. She added a male adult, about whose identity I enquired. She replied that she had a 'real' (i.e. biological) father and a step-father and this person was her step-father whom she did not like. She did not know who was her biological father. I asked her why she drew her step-father since she does not like him. She affirmed that she still cared about him. She told me not to let her mother see the picture as she would notice that she drew the picture of her step-father and she would not approve. It seems as if her mother does not

want anyone to know that an adult male is there at times in the home. Amy is aware of this, yet she risked this by drawing him in her family.

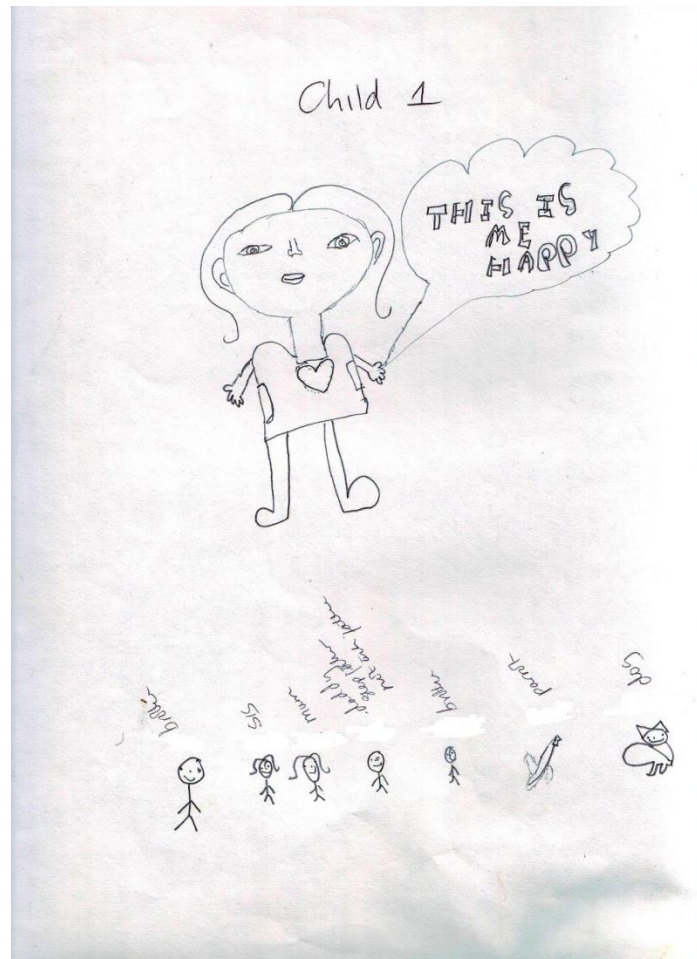


Figure 5.3a : Amy's Drawing

### Amy's "All About Me" Worksheet

This worksheet had 8 sentences to complete containing 8 variables: name, age, birthday, colour of hair, colour of eyes, height, teacher and lastly "I am special because". Amy was able to finish all sentences except the one that asked about her height. She answered "I am special because I am living still". This answer denotes how Amy's

thoughts were focused on having HIV and her fixation with 'living with the virus'. This was also shown via the 'miracle question' asked in the interview where Amy hoped that having HIV would just disappear. This showed that addressing fears on having HIV is crucial for this child and she viewed it as a big negative in her life. She did fill in her name and her teacher's name but both have been removed in keeping with confidentiality.

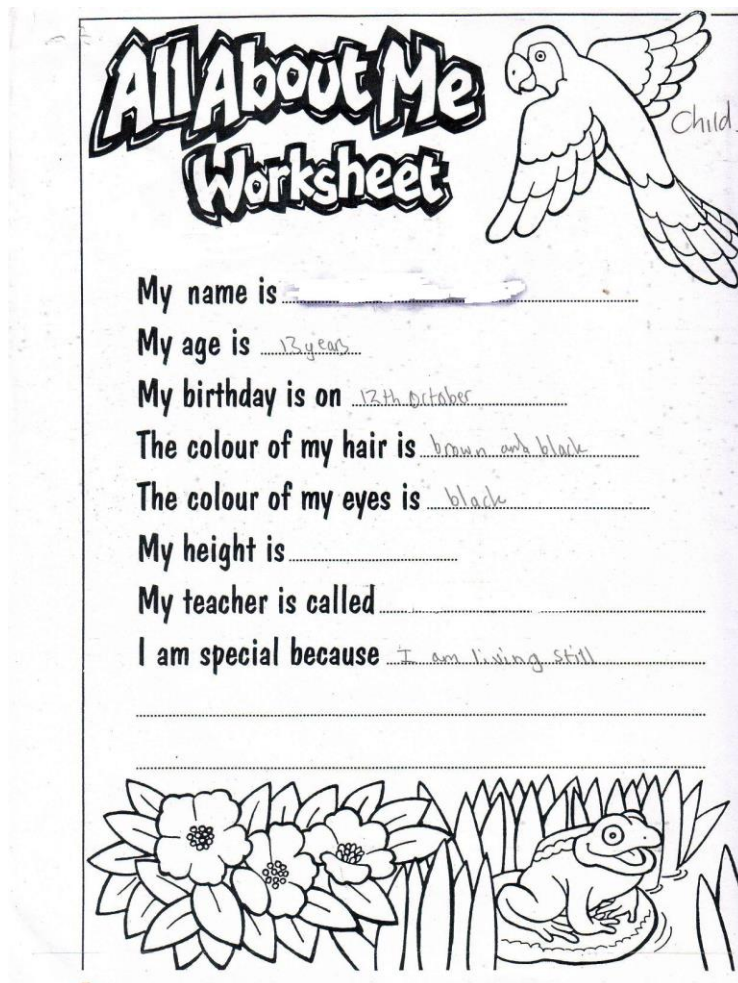


Figure 5.3b: Amy's Worksheet

### Amy's "Picture of Different Faces of Expressions and Action"

Amy was asked to circle the one that best represents her. She circled the picture at the top and stated, "This is me on top, smiling". I asked her what made her choose that picture and she said in the picture she chose, "no one is fighting or falling down". In the interview Amy had mentioned that she was angry at times with her mother and also had



violent thoughts towards her, because of her positive status. She seemed to be unable to reconcile these ambivalent feelings.

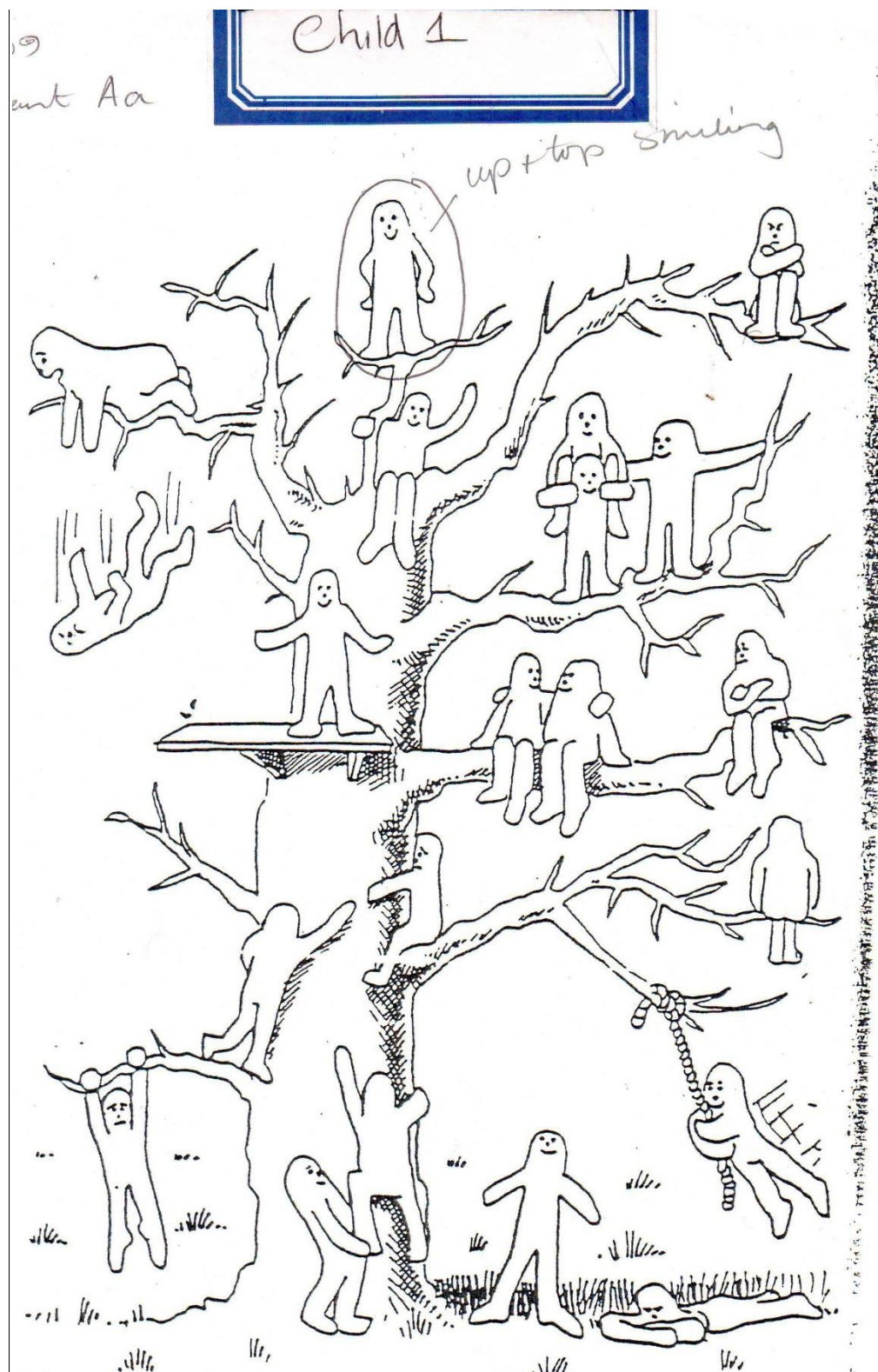


Figure 5.3c: Amy's Picture of Different Faces of Expressions and Action

### **5.3.1 Summary of Case**

Amy expressed her despondency when she spoke about having HIV and its links to death and dying. It was apparent that her knowledge of HIV was deficient because she had internalised whatever her mother had told her. She was dependent on her mother for emotional and instrumental support, thus she believed what she was told. She could not discuss HIV with anyone outside the home as this was an overt rule that had been established. The covert rule of non-discussion of HIV prevailed in the home. She had no other avenue of gaining a balanced view of "living with HIV" and her world had been constricted to her mother and siblings. Sometimes she was tempted to disclose the truth, but because of the threats from her mother, she was prevented from doing so.

## **5.4 Participant 2 – Brian 11 years**

### **Mother- Bertha**

#### **Demographic Information & Economic Issues**

Brian was from the Briggs family. He was of mixed descent and 11 years old. Brian lived with his parents and his younger sister who were all HIV positive. He had an older sibling who lived at a residential home for children with HIV. The family lived in the southern part of the country, where he attended secondary school nearby. Brian acquired HIV through vertical transmission. The Briggs family was from the lower socio-economic stratum of society. The family rented a small two bedroom apartment. Both Brian's parents had jobs but the income was insufficient at times to provide adequately for the family.

#### **Emotional and Behavioural Issues- Thoughts on HIV**

When asked what he feels being HIV positive means, Brian was silent at first. When he responded, he said he did not know. When asked how he feels about having HIV, he responded that he felt sad.

*Q. I know that you are HIV positive. How do you feel?*

*A. Sad.*

He did not have the knowledge of what it meant, but he felt depressed having it. He also commented that he felt despondent about his mom having HIV. When asked about the stigma and discrimination of this disease, Brian could not identify with it. He is on ART for HIV and he did not have a problem taking the medication, as he took it together with his mom and sister in the morning and at night. Brian said he would not tell anyone about his status as his mother had forbidden him to do so.

*Q. Did you tell anyone that you have HIV?*

*A. No, I can't, my mother say not to  
(His mother warned him not to tell anyone).*

### **Social Issues- School and relationship with peers**

Brian attended secondary school and is in Form 1. He enjoyed school and playing with his friends. His favourite subject was English language and he looks forward to being at school. Brian appeared to be very quiet and shy. He did not think that he was different from other children because he had HIV. Brian said that he does not like going to church and he had not been for a while. He could go only if his mother attended.

Brian loved his mother and helped with domestic chores. He was satisfied with the things she did for him.

*Q. You think she can help you in any way more than she is helping you now?*

*A. No, she does all she can for me.*

### **Health Issues**

Brian said he generally felt fine and did not visit the doctor regularly. On observation, there was a rash all over the exposed parts of his body. His mother said his CD4 cell

was less than 200. His mother confirmed that there were adherence issues in the past, however, they were trying as a family to take the medication regularly.

### **Miracle Question**

When asked the miracle question he replied that he wished that he could stop taking medication for HIV.

## **5.5 Activities**

### **Brian's "Drawing"**

Brian was asked to draw how he views himself with HIV and also to draw his family. He drew his dad first, bigger than all the other members of his family, then he drew himself, his sister and then his mother. All had smiling faces. However, he drew his mother without arms and last in order.

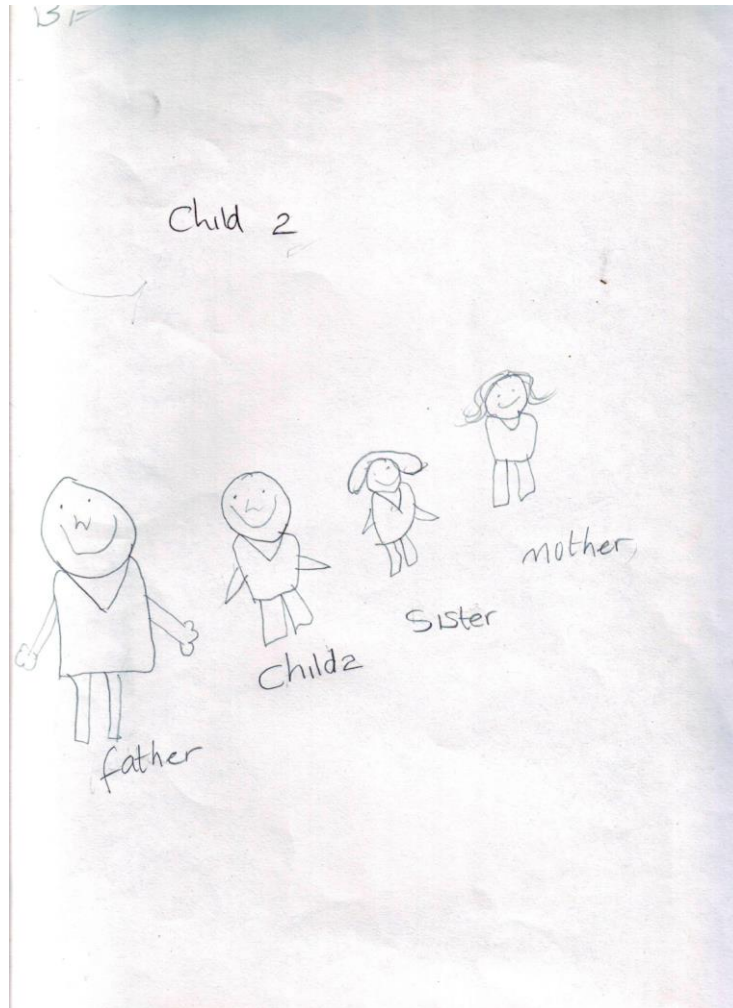


Figure 5.5a: Brian's Drawing

**Brian's "All About Me" Worksheet**

Brian was able to finish all the sentences of the worksheet. He wrote that he was special because he played football. Brian did mention that he enjoyed playing football.

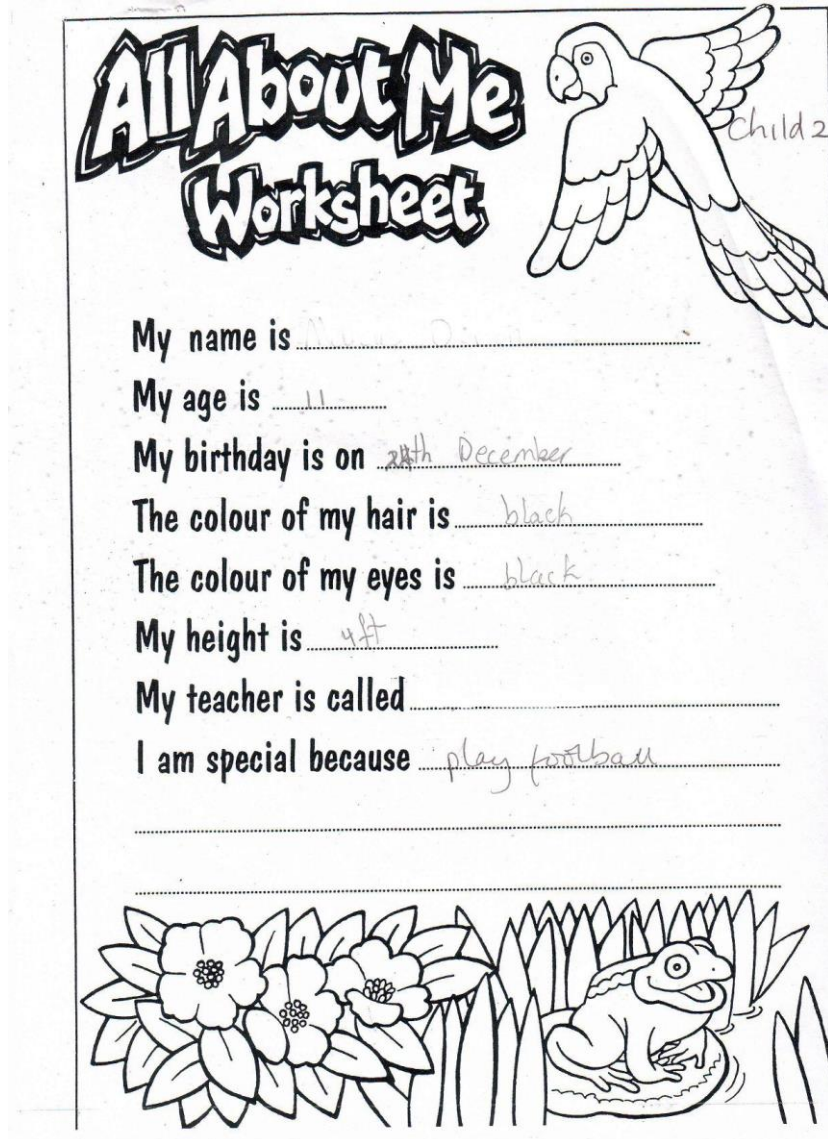


Figure 5.5 b: Brian's "All about me worksheet"

**Brian's "Picture of Different Faces of Expressions and Action"**

Brian was asked to circle the one that best represents him. He circled the picture of a person swinging on a rope and having fun. He said he loved to swing and play.



Child 2

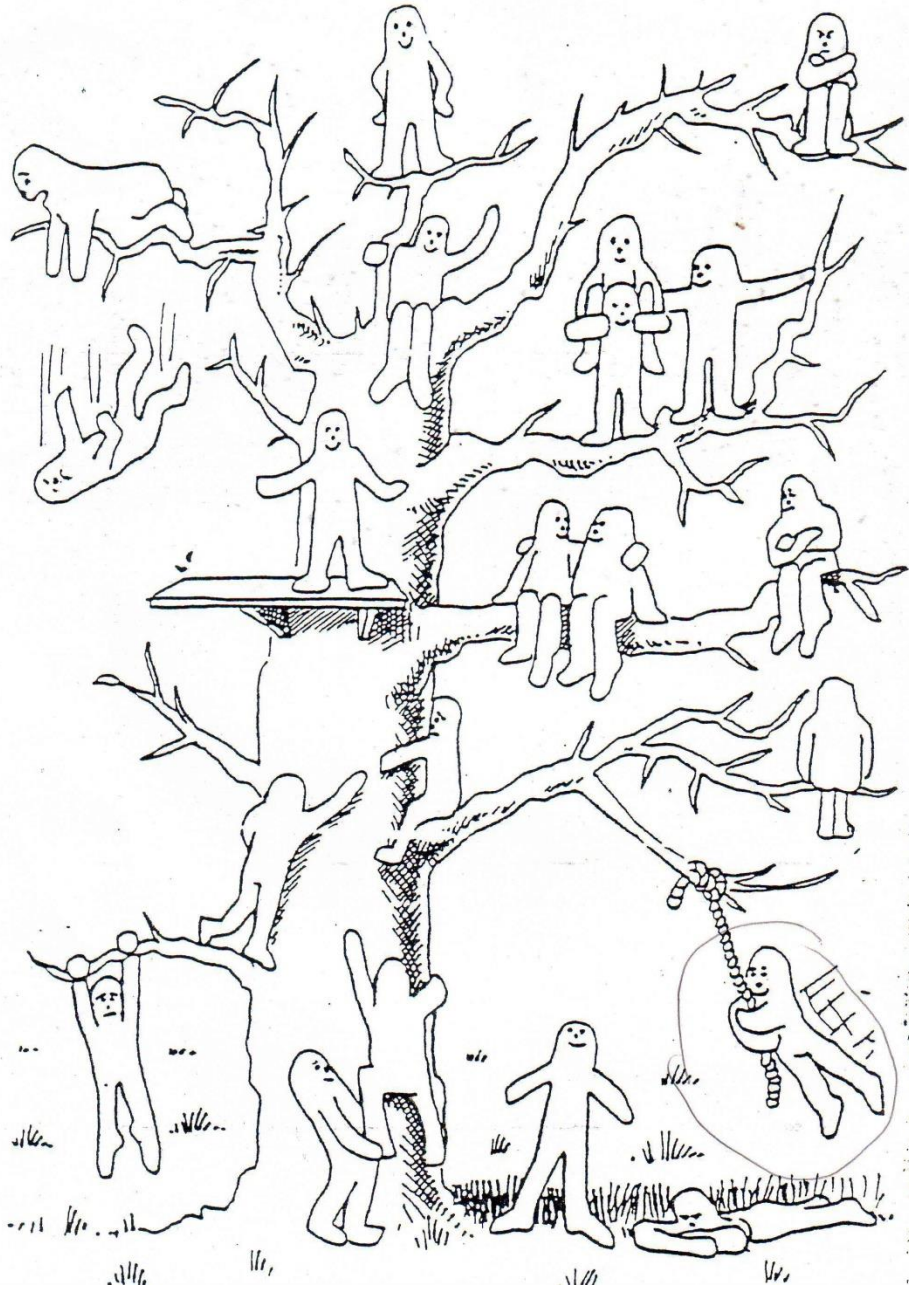


Figure 5.5c: Brian's Picture of Different Faces of Expressions and Action

### **5.5.1 Summary of Case**

Brian expressed sadness whenever he thought about HIV/AIDS. He also felt this way about his mother having HIV. He did not understand what having HIV means. He was reticent and had to be asked questions, sometimes twice, in order to solicit a response. He loved school and liked to play with his friends. He took ART in the morning and at night. It seemed as if there was an adherence issue as even though Brian was taking antiretroviral medication, his CD4 cell count was less than 200. The rash on his skin did indicate an opportunistic infection (OI). The activities indicated that even though he was sad, this may primarily be with respect to HIV, otherwise he was a happy child. He could not tell anyone about HIV and it was not spoken about in the home. His knowledge of the virus was limited or non-existent and this might have been a contributing factor to his sadness.

## **5.6 Participant 3 – Cathy 10 years**

### **Mother- Bertha**

#### **Demographic Information & Economic Issues**

Cathy is also from the Briggs family. She lives with her parents and older brother who are all HIV positive. At present all family members are HIV positive. She is 10 years old and attends a primary school nearby. She acquired HIV via vertical transmission in 1999. The socio-economic constraints are the same as that of her brother, Brian. The family is now living with inadequate finances to meet their daily needs. Cathy is on HIV medication and her CD4 cell count is 200. This meant that she with any opportunistic infection could be seen as having AIDS instead of just being HIV positive. Cathy states that she is hungry at times, mainly at school. When this occurs, she usually buys something to eat.



### **Emotional and Behavioural Issues: Thoughts on HIV**

Cathy said that when she thought about HIV she felt depressed. When asked if she knows what having HIV means, she said that it was a disease. She said that she would not disclose to anyone that she had the virus, as she may experience stigma and discrimination.

*Q. What do you think it is?*

*A. A disease.*

*Q. How do you feel about that?*

*A. Sad.*

*Q. Okay. Would you tell anybody that you are HIV positive?*

*A. No.*

*Q. Why? What do you think will happen?*

*A. They will go and tell people about me.*

She seemed to have a bit more knowledge of the virus compared to her brother, Brian. She was more open in the discussion and answered readily. She did not have any problems taking the medication. She knows her mother also had the virus and she felt helpless about that too, so HIV was not discussed in the home and she does not tell anyone about it as she feared discrimination. She had a pessimistic view of the disease as the feeling connected to the topic was that of helplessness. She could not offer more information on what HIV was apart from it being a disease, because her knowledge of the virus was limited.

### **Social Issues- School and relationship with peers**

Cathy is in Standard 5 and will be taking the Secondary School Assessment (SEA) exam soon. She had friends at school that she said were kind and helpful, which she reciprocated and that the best thing about school is her friends. Her favourite subject was English language, (writing essays). She did not like going to church as she found it boring. She is of the opinion that her HIV-positive status did not make her any different from other children. Her status is a secret, therefore, HIV does not enter her world when she is outside the home.

Cathy loved her mother and smiled with delight when she spoke about her. She claimed to be very helpful to her with domestic chores: washing clothes, wares and picking up the wash from the line.

*Q. So what do you do to help your mom?*

*A. I help her wash. Wash the wares  
I help her to pick up clothes.*

*Q. And you enjoy doing those things with your mom?*

*A. Yes.*

Cathy coped by using the defence mechanism of denial: she does not think of her mother as having HIV.

### **Health Issues**

Cathy felt energetic. She said she goes to the doctor for checkups. On observation, she had a rash on her skin. Her CD4 cell count was 200 and she might have an (OI). Her mother confirmed that there were adherence issues and the family is really trying to overcome them by taking the medication on time.

### **Miracle Question**

Cathy was asked if she went to sleep at night and awoke in the morning, what she would like to see changed in her life. She replied that she would like to have a happy life.

## **5.7 Activities**

### **Cathy's "Drawing"**

Cathy was asked to draw how she views herself with HIV and also to draw her family. She drew her mother first, her father, herself and then her brother. All her drawings were the same body size, unlike her brother who drew their father first as the largest figure, followed by him, his sister and his mother last (the smallest drawing). All her family members had smiling faces, including herself.

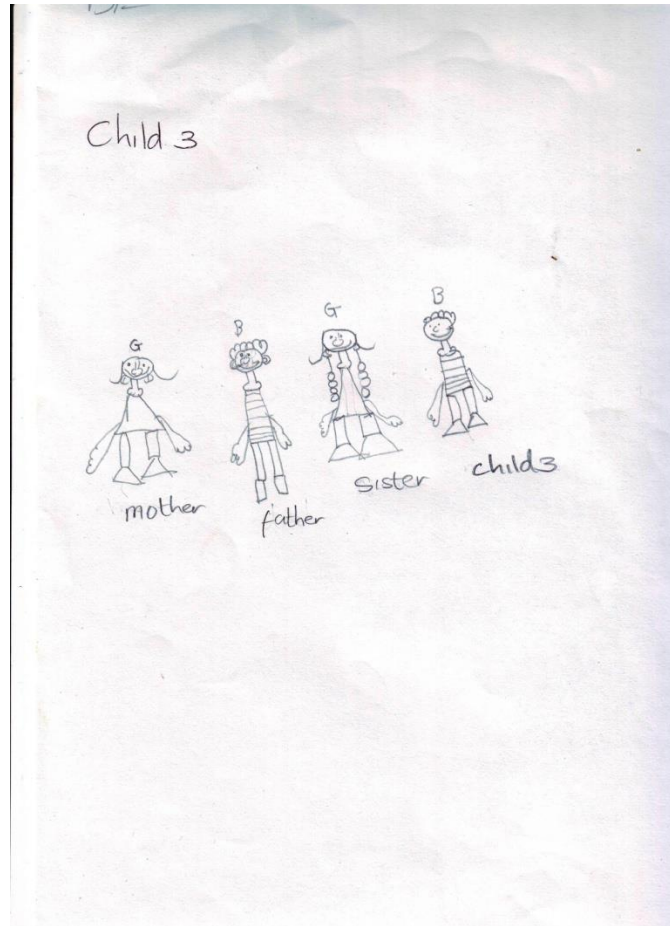


Figure 5.7a: Cathy's drawing

### **Cathy's "All About Me" Worksheet**

Cathy answered all the questions in the worksheet. She wrote that she was special because she "helps people to be kind to people".

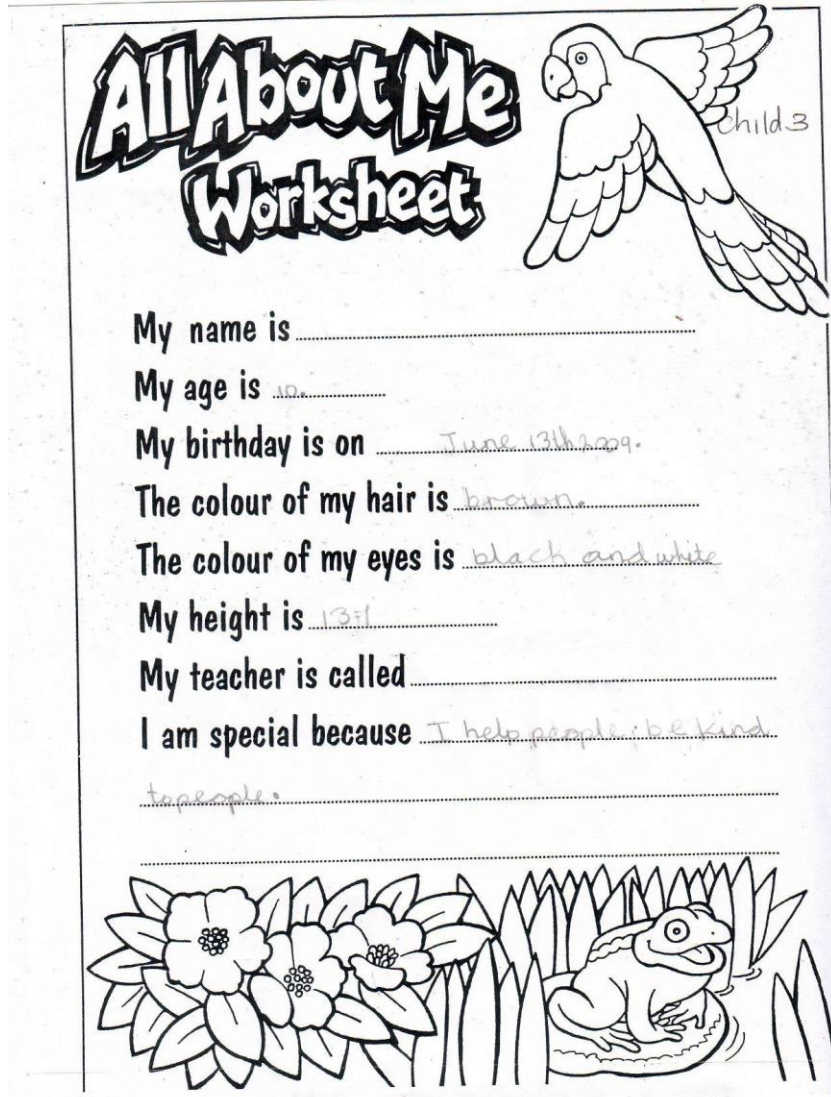


Figure 5.7b: Cathy's "All About Me" Worksheet

**Cathy's "Picture of Different Faces of Expressions and Action"**

Cathy was asked to circle the picture that best represents her. She circled the picture of someone helping another to climb up a tree. This reiterates her special stated character trait of being helpful to others.

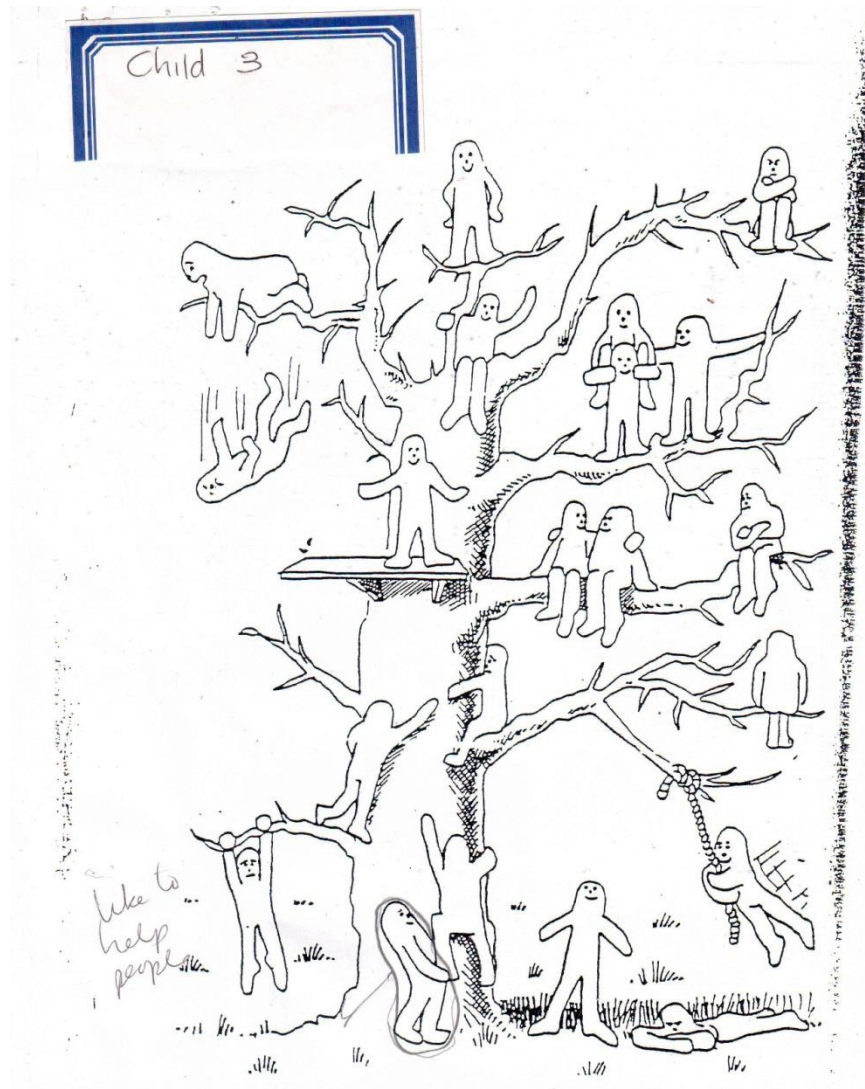


Figure 5.7c: Cathy's "Picture of Different Faces of Expressions and Action"

## 5.8 Summary of Case

Cathy is 10 years old, of mixed descent and the younger of two children of the Briggs family. She was HIV positive and felt sad about this. She thought that HIV was a disease, which is the sum total of her knowledge about it. She also felt sorrowful about her mother having the virus but she did not dwell on that. It seemed as if Cathy could not describe her emotions beyond sadness. This feeling was mentioned only in reference to HIV, otherwise, she was generally happy and did not regard herself as being different from other children. She was delighted when she spoke about helping her mother with the chores and would like to have a happy life.

## 5.9 Participant 4 – Dawn 9 years

### Mother – Petra

#### Demographic Information & Economic Issues

Dawn was 9 years old, Afro -Trinidadian and lives in the east with her mother and step-father. She was the penultimate child of her mother and had 4 siblings: three sisters and a brother. She was HIV positive and contracted the virus via vertical transmission in 2000. Dawn and her family lived in abject poverty in a one-room home, which served as a bedroom and kitchen. There was no running water and they normally rely on a water-delivery truck. Sleeping arrangements were cramped as there is one bed and a double bunk. Two of the older female siblings slept on the top bed, Dawn below with another sister, and her mother, step-father and young brother slept on the single bed. Their home is attached to another and is separate from that unit by galvanised sheets that do not extend all the way up to the roof, thus these units were not at all soundproof. Dawn was the only child who was HIV positive. Her mother was unemployed and was receipt of social welfare, which was the only source of income for that family, apart from her stepfather's contribution.

#### Emotional and Behavioural Issues- Thoughts on HIV

Dawn expressed the emotion of sadness at having HIV. She also said it was a disease and did not offer any other explanation.

*Q. Do you know what being HIV positive means?*

*A. It is a disease..that is all I know.*

*Q. How do you feel about being HIV positive?*

*A. Long pause...I feel sad*

*Q. Is that all you feel? Don't you feel anything else?*

*A. No, I doh feel anything else...*

*(I do not feel anything else.)*

She had limited knowledge of the disease, yet she was wise enough not to disclose her status, as she may attract a negative reaction.

*Q. Would you tell anyone that you are HIV positive?*

*A. No ...because they will tell everybody and then nobody will like me*

*Q. Being liked is important to you?*

*A. Yes, I want my friends to like me.*

Dawn had a heavy cough and her mother said that it would not disappear even with medication. The mother did not know Dawn's CD4 cell count. There were adherence issues as her mother disclosed that sometimes she did not have the ART to give Dawn. Dawn revealed that the medication made her feel better. She felt badly that her mother was HIV positive as she has had to be admitted often into the hospital. She loved her mother and has a good relationship with her.

*Q. How do you feel about your mother being HIV positive?*

*A. I feel bad ....she goes to the hospital plenty.*

*(She feels unhappy about it as her mother is admitted to hospital a lot of times.)*

*Q. What type of relationship do you have with your mother?*

*A. A good one...I love my mummy.*

### **Social Issues- School and relationship with peers**

Dawn did not feel any different from other children. This might have been so, as she does not disclose her status, so no one at school knows that she was HIV positive. She interacts a lot with her siblings, because she did not go anywhere. However, she said she would like to go to Barbados one day by plane.

### **Health Issues**

Dawn said her body felt good and that she did not visit the doctor often. She went to the clinic because she had a cough and was given medication for it.



## Miracle Question

When asked what she would like to see changed when she slept and awoke in the morning. Dawn replied that she would not like to be sick anymore.

## 5.9 Activities

### Dawn's "Drawing"

Dawn drew a picture of her family and how she saw herself with HIV. She drew all starting with her step-father, the smallest drawing of them all, then her mother and other siblings. She drew herself the largest in all and then her brother bigger than her step-father. All the characters had smiling faces. She enjoyed this activity.

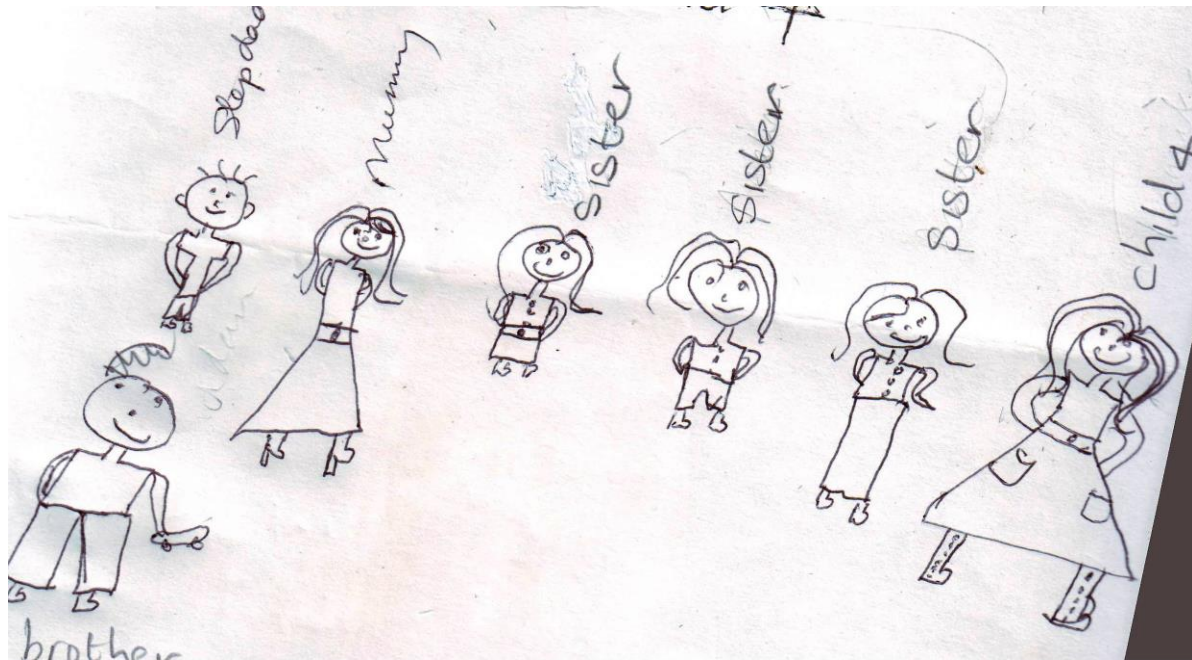


Figure 5.9a: Dawn's Drawing

### Dawn's "All About Me" Worksheet

Dawn answered all except two of the eight sentences of the worksheet. She did not know her height and she did not complete the sentence "I am special because".



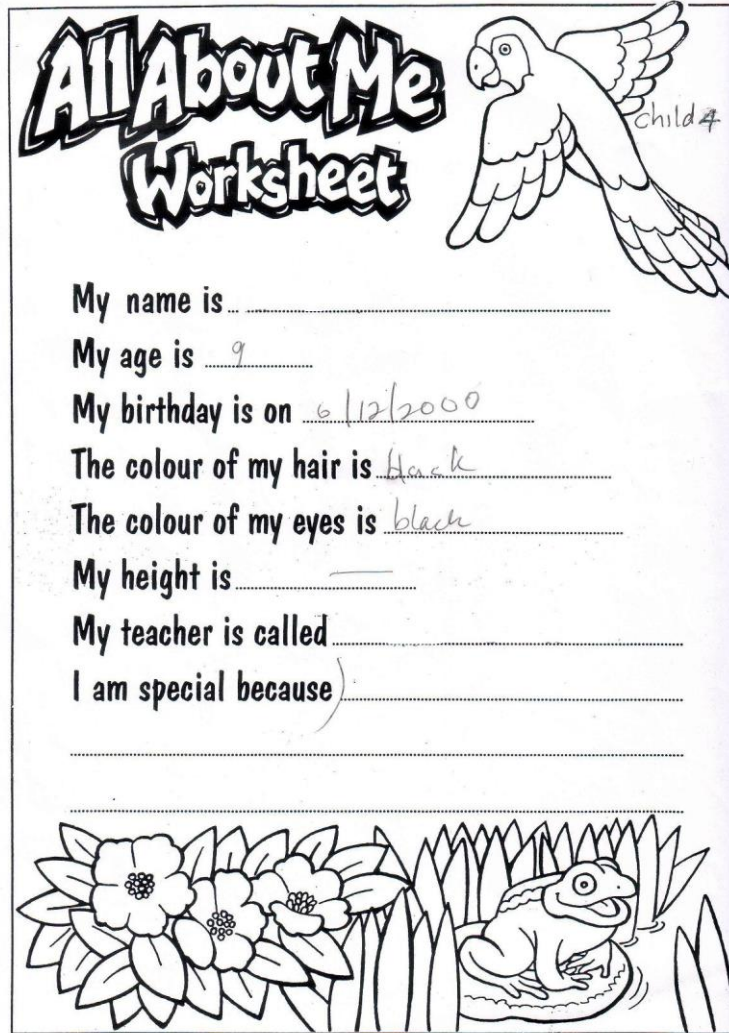


Figure 5.9b: Dawn's "All About Me" Worksheet

**Dawn's "Picture of Different Faces of Expressions and Action"**

Dawn was asked to circle which picture best represented her. She chose the one in which the subject was holding on to a rope and swinging, which affirmed that she liked to play a lot.

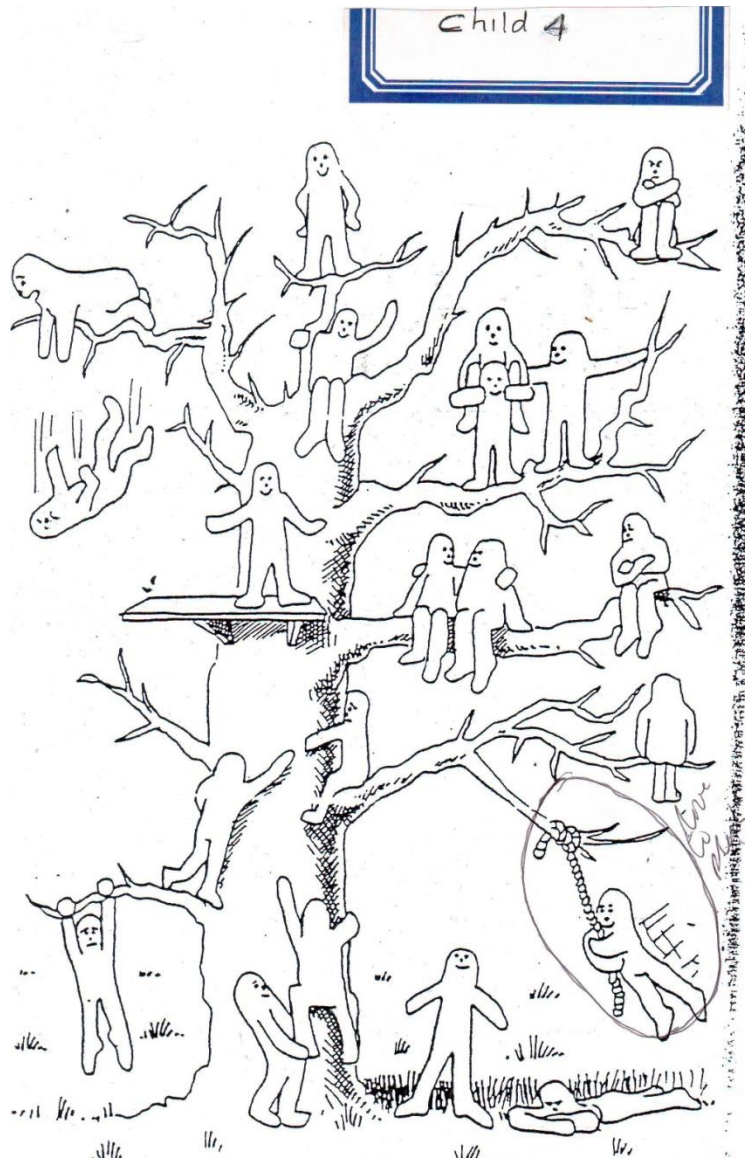


Figure 5.9c: Dawn's "Picture of Different Faces of Expressions and Action"

### 5.10 Summary of Case

Dawn was at present living in abject poverty but seemed happy and contented with her life. She loved her mother and was grieved when she had to be hospitalised. She had a persistent cough and was given medication from the clinic. She did not disclose her status to anyone and felt sorrowful about having HIV. She knew only that HIV was a disease. She considered herself to be just like other children and no different even though she had HIV. HIV was not a topic discussed in the home. There was no privacy

and all the 7 members of the family lived in one room that served also as a kitchen. Her mother was unemployed and on welfare.

## **5.11 Participant 5 – Evan 12 years**

### **Mother- Martha**

#### **Demographic Information and Economic Issues**

Evan was 12 years old, of Afro-Trinidadian descent and lives with his mother, younger brother and stepfather in the West. He attended primary school nearby. They lived in a one-bedroom apartment with a small kitchen at the side. The room had only one bed and at nights a mattress was placed on the floor to accommodate both boys. Evan's mother was on welfare. Evan acquired HIV via vertical transmission and was diagnosed HIV positive in the year 1999. His mother did not know his CD4 cell count. However, he is on ART.

#### **Emotional and Behavioural Issues- Thoughts on HIV**

Evan stated that no one explained to him what HIV meant. He said it was a 'sickness'.

- Q. *What does it mean to be HIV positive, do you know?*  
A. *Sickness.*  
Q. *It means sickness. Anything else? What do you think it means?*  
A. *You can't tell anybody about it.*  
Q. *Why you can't tell anybody about it?*  
A. *They would not want to be around you again.*

He felt depressed at times about his status as he thought he could die from HIV. Evan does not understand what having HIV meant, yet he cannot tell anyone about it. He said that once people knew they would not like him or want to be in his company. This alluded to stigma and discrimination. His knowledge of HIV was limited, yet he felt that if he spoke about it or disclosed this he would not be liked. This was the message being conveyed to him. This was what he understood. He did not think about HIV. He said he would not disclose his status, as his mother told him not to do so.

- Q. *So would you tell anybody about your status?*  
A. *No.*  
Q. *Tell me why you would not tell anybody?*

- A. Mummy tell me not to tell anybody.  
Q. Would you like to tell anybody?  
A. I don't know.

The only frame of reference with respect to HIV that Evan had was what was conveyed to him by his mother.

- Q. *And what gives you that feeling that they would not want to be around you?*  
A. *Because Mummy tell me not to tell nobody.*  
Q. *And if you tell anybody, how do you feel they will react?*  
A. *They would not want to be around me.*  
Q. *So you have not disclosed it to anybody? You haven't told anybody?*  
A. *No.*

It seemed as if ensuring that 'there is no disclosure' was more important than the understanding and meaning of being HIV positive. Evan wanted to disclose the truth, but he did not dare to do so as his mother would be displeased.

Evan took the ART as it made him feel better; this was taken in the morning before school and in the evening after school. He felt comfortable taking the medication and is of the opinion that if he didn't, he will get sick. He thought it is dreadful that his mother had HIV as some time in the future she would get sick because of it.

### **Social Issues- School and relationship with peers**

Evan liked school and interacting with his friends. He did not think that he was different from other children because he was HIV positive. The children and teachers knew nothing of his HIV status and as such, it did not come into the picture. He had a strong relationship with his mother, who supported him by providing for him and by showing him affection.

- Q. *What type of relationship do you have with your mum?*  
A. *A strong relationship.*  
Q. *Tell me about it. What do you all do together, tell me.*  
A. *We share things; we go out together.*

He attended church with his mother. He prayed and thought that this activity provided support in his situation. His body felt fine and he attended clinic on a regular basis. He experienced no side effects from the medication. He did not have much to eat and felt hungry while at home. Evan would like to live in a big house someday.

### **Health Issues**

Evan felt that once he took the ART he would be fine. He attended clinic every month and experienced no side effects from the antiretroviral medication.

### **Miracle Question**

Evan said that if he were to go to sleep and awoke in the morning, the change he would like to see is a move to live in a bigger house.

## **5.12 Activities**

### **Evan's "Drawing"**

Evan enjoyed this activity of drawing his family, his mother and brother. He did not put his stepfather in the picture. He placed his mother in the middle with hands outstretched on either side holding him and his brother. He wrote 'love' above his mother's two hands. He included clouds and a rainbow in the sky and flowers at their feet. All had smiling faces. He said the picture was that of his happy family in the park.

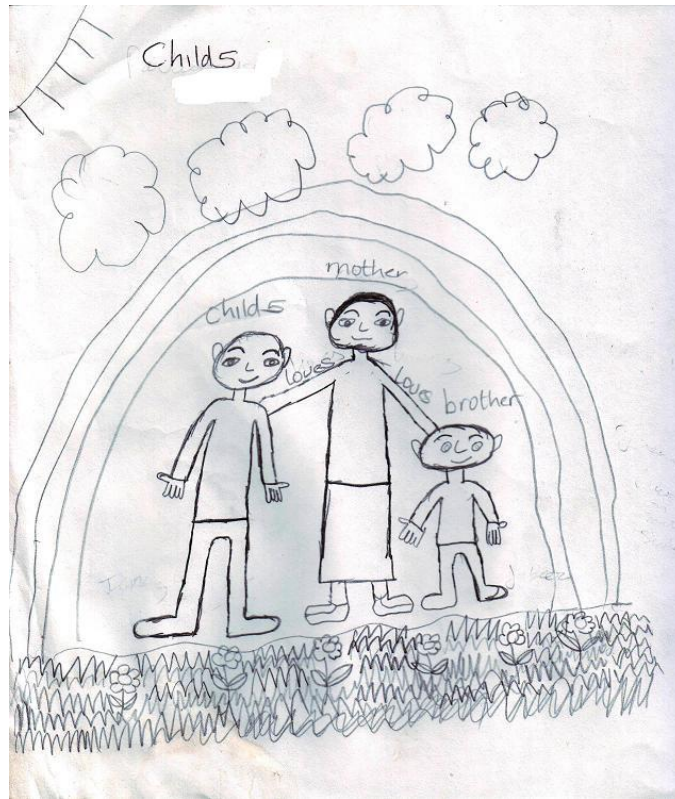


Figure 5.12a: Evan's drawing

### **Evan's "All About Me Worksheet"**

Evan answered all except the question on height. He wrote that he was special because "God made me".



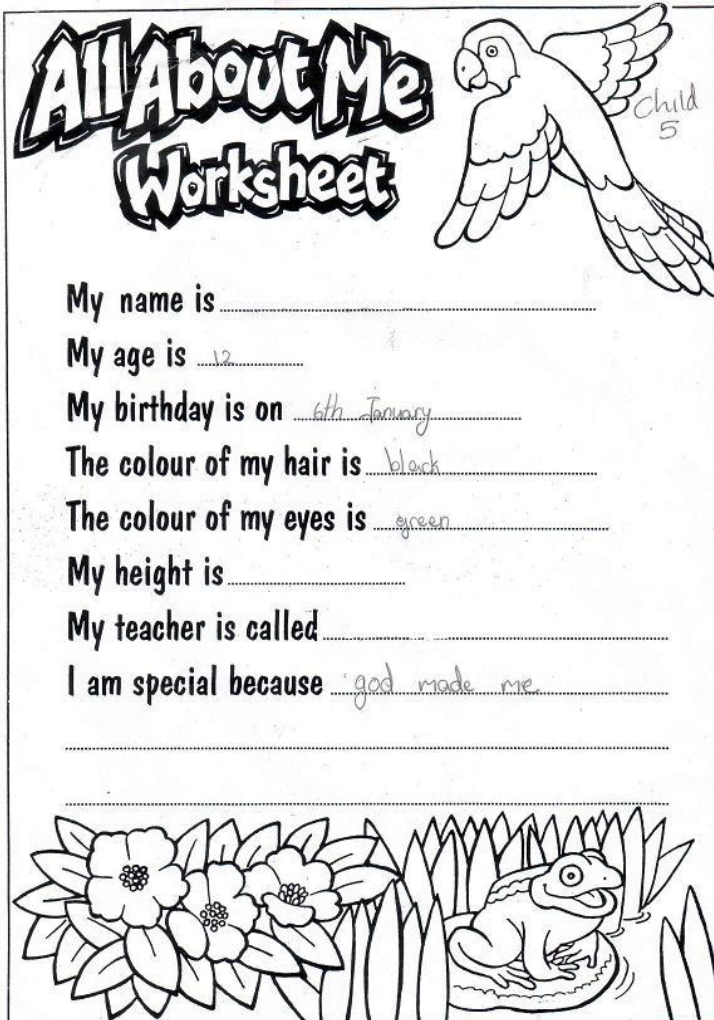


Figure 5.12b: "All About Me Worksheet"

**Evan's "Picture of Different Faces of Expressions and Action"**

Evan was asked to circle what picture best represented him. He circled one of the figures sitting on top of a tree waving and smiling. All Evan's activities were positive.

child 5

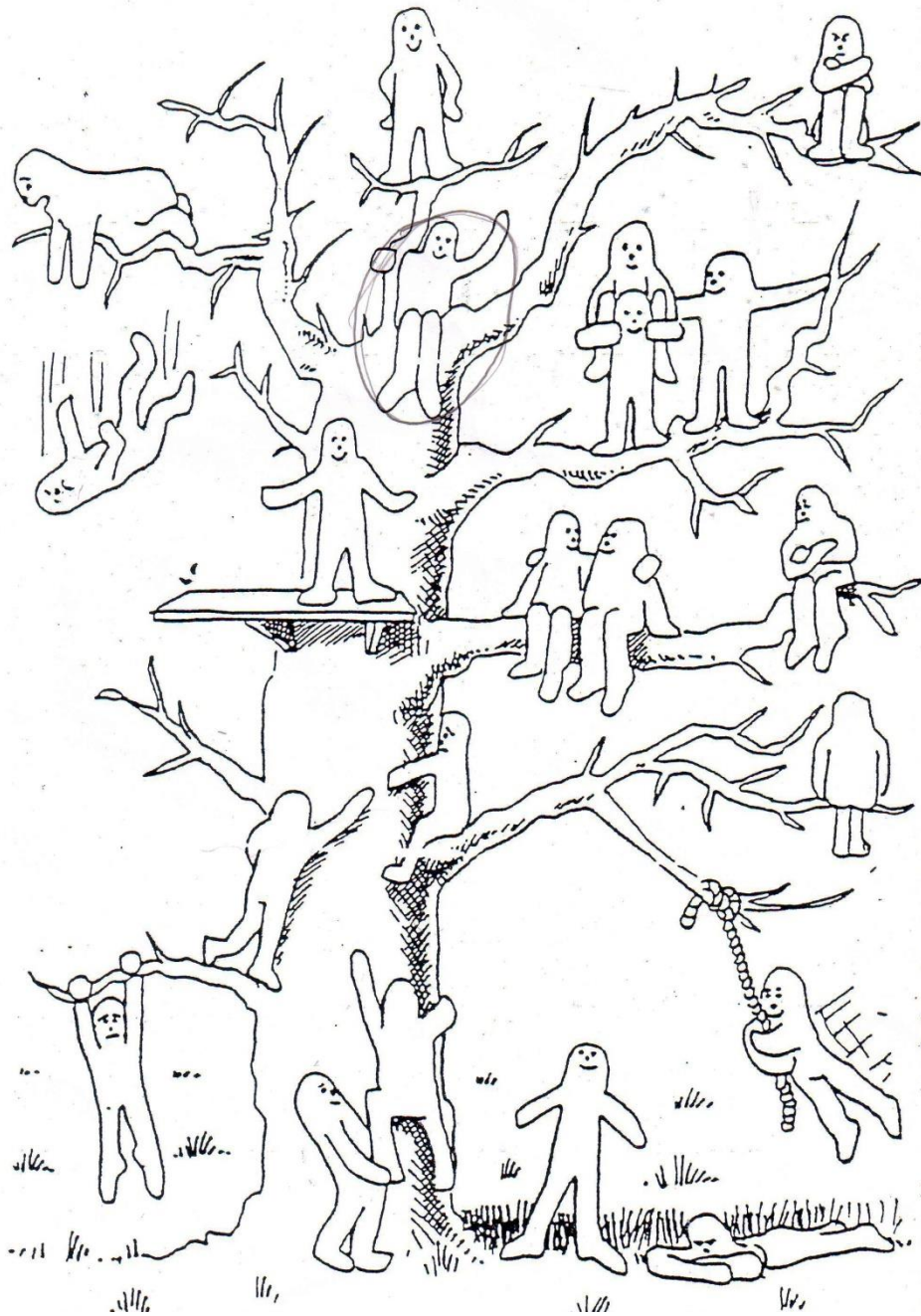


Figure 5.12c: Evan's "Picture of Different Faces of Expressions and Action"



### 5.13 Summary of Case

Evan was 12 years old and lived with his mother, younger brother and step-father, the latter of whom were both HIV negative. He is on ARVs and took them both mornings and evenings, which allowed him to feel better. He thought that HIV was a sickness and had limited knowledge of what it actually meant. He would not disclose his status to anyone, as his mother would be displeased, so no one at school knew that he was HIV positive. Evan said that if they knew, they would not like him. He was therefore voicing that there may be stigma and discrimination as a result of disclosure.

### 5.14 Themes

Theoretical sampling was undertaken simultaneously with data analysis utilising the grounded theory approach and through open, axial and selective coding the following main themes and sub themes emerged.

Table 5.14 Themes for Children

Main Themes	Sub-Themes
1. Living with HIV	<ul style="list-style-type: none"><li>• Social and emotional issues: (below)</li><li>• Illness and medication</li> <li>• Limited knowledge of HIV</li><li>• Feelings of sadness</li> <li>• Feels no different from other children because of HIV</li> <li>• Coping</li> <li>• Appears happy despite having HIV</li></ul>
2. Children as carers	Concern about mothers
3. Mother/Child Bond of	Stigma and Discrimination

### **Three main themes emerged:**

1. Living with HIV
2. Children as carers
3. Child carers

#### **5.14.1 Living with HIV**

##### **Social and emotional issues**

According to Gosling *et al.* (2004), HIV is one of the few chronic illnesses that affect both mother and child simultaneously. It can be seen as a true family illness with everyone being affected (Melvin & Sherr 1993). Owing to the introduction of antiretroviral treatment, HIV has now become a chronic condition, even though the threat of mortality is still present (Brown & Lourie 2000). They add that children have to contend with myriad effects of having a chronic illness with no cure, as well as having a parent with the same illness.

The children in this research ranged from 9 to 13 years and were from the lower economic stratum of the society and lived in living conditions that were cramped and the amenities inadequate. They were therefore often hungry. Two mothers were on welfare, while two others were not. The earning capacity of two households may eventually be compromised as two of the mothers may not be able to work in the near future. Hunger and malnutrition are intrinsically linked to children's security and nutritional deficiencies significantly compromise a child's ability to fight off disease. These negatives severely undermine the conditions necessary for children to survive, attain maximum development and succeed in many areas of social and personal growth, inclusive of their cognitive maturation (Shonkoff & Phillips 2000).

The effects on children's development, survival and psychological well-being are long-term and their experiences with HIV are impacted by the following critical issues: psychological distress; low economic status; educational opportunities (withdrawal

from school); health and nutritional status (malnutrition and illness); treatment and care; and stigma and discrimination (fear and isolation) (UNICEF 2002). Poverty can be viewed as a risk factor in HIV that can affect medication compliance, proper nutrition and proper growth and development in children. This can have an impact on the normative developmental processes such as puberty, growth and peer relationships.

HIV-AIDS in the home was not discussed; reference was made only to the taking of medication. The following made up the social and emotional issues.

### **Illness and Medication**

All the children except one were on ART. Amy who was not on ART had to take an antibiotic called Septra most of the time. Each child except one had some form of illness such as ear infection, swollen feet, constant coughing and skin rashes. Only Evan showed no outward signs of illness. Amy's CD4 cell count (666) was the highest. She occasionally had ear infections and swollen feet. The CD4 cell count of Brian and Cathy (from the same family), was less than 200 and 200 respectively and there were manifestations of OIs. This reflected adherence issues in the past. They were both trying very hard to maintain the taking of their antiretroviral medication. Both had a rash on their skin. The CD4 cell count of Dawn and Evan was not known by the mothers, even though these children attended clinic on a regular basis.

Medication adherence is very important. Cheever (2000) suggests that adherence to medication involves complex behaviour supported by a variety of factors. These involve the patient, the medication regimen, the doctor-patient relationship and the medical system where the individual receives care. Adherence encompasses more than the commitment of patients to treatment. It involves taking a complex combination of pills with specific dosage (Chesney 2000). Chesney adds that non-adherence to treatment includes any deviation from the prescribed dose, skipping days, incorrect dose-spacing and temporary periods of cessation. Non-adherence to ART can have serious consequences as it often results in increased viral replication and the continued destruction of CD4 cells. This can lead to viral resistance to the ART (Cheever 2000). This can impact negatively on their already compromised quality of life. Jones (2009) in

her study from Trinidad identifies inadequate finances as a major barrier to adherence. These children came from a low economic status, thus at times finances are an issue and this can negatively impact their adherence to medication. Cyrus (2009) in her study in Trinidad notes that insufficient finances caused mothers to miss their clinic appointments, since other basic needs took precedence over medical needs. It follows that if this happens, non-adherence can adversely affect both mother and child and in a situation with already limited resources, becoming ill is not an option. Illness in the family would put added stress on the already limited resources such as finances for medication and/or for transportation.

### **Limited Knowledge of HIV**

In this research the children knew they had HIV, but did not know what it meant, as their concerns and understanding of the illness were not explored. They viewed it as a disease that can lead to death. Some clinicians experienced in HIV generally agree that disclosure of HIV status to school-age children, if treated as a process that explores the children's concerns and understanding of the illness, is beneficial to their well-being (Lipson 1994).

Bacha *et al.*(1998) report that children who knew their HIV status had higher self-esteem and were less depressed than children who did not know their diagnosis. Blasini *et al.* (1998) report positive psychosocial adjustment in children who were informed of their diagnosis in the context of a supportive environment. The key words here are 'supportive environment'. It is important that when children know their positive status, that the support is present to help them understand what having the virus means, the importance of adherence to medication and other pertinent knowledge of the disease. This will auger well for their mental health.

### **Feelings of Sadness**

One common theme in this study is the child's "feelings of sadness" with respect to being HIV positive. They felt it yet they could not explain it. They were of the view that being HIV positive had negative connotations in their lives. This was based on what was

told to them by their mothers. The children were forbidden to disclose their status to anyone, thus limiting their interaction with the outside world. The only information filtering into their lives and space was from their mothers. They knew nothing else.

Loving and supportive relationships with caregivers sustain life in early childhood and provide the foundations for social, emotional and moral development (Ainsworth 1978). Caregivers facing competing economic and social pressures can experience impaired ability to attend to the emotional needs of children who may also be under stress (Betancourt *et al.* 2010). In this research, mothers were also HIV positive and they had to take care of children who were HIV positive. This is health care multiplied by two, or in one case by three, for these individuals, and this can have an emotional toll on all involved, as mothers are concerned for children and vice versa. There is a demand on the mothers to ensure that the many needs (physical, emotional and social) of their HIV-positive children are met.

As families struggle to address economic issues regarding HIV infected children, mental health concerns get little attention (Betancourt *et al.* 2010). A few studies to date have documented increased risks of emotional and behavioural problems in HIV/AIDS-infected children including depression, anxiety and social withdrawal (Atwine *et al.* 2005). These “feelings of sadness” could be depressive symptoms with respect to HIV in these children and point to the mental well-being of the children in this study. The findings indicate that there is likely a large gap of unmet needs for mental health services among HIV/AIDS-infected children.

### **Feeling no different from others**

The children in this study felt no different from their peers. Their main interaction with children their age was at school. Mothers did not disclose their children’s status to school personnel, thus, no one knew that these children were HIV positive. Their teachers and peers look at them as being as any other child. Nothing has been introduced to change that landscape. Thus, non-disclosure in this setting has helped the children to maintain some form of normalcy in their lives. One may ask “is this good or bad?” In this situation, it seemed beneficial, as the threat of being on the receiving end

of stigma and discrimination from peers and teachers was non-existent and it helped the children to exhale. Contrastively, it may be detrimental, as these children had limited knowledge and understanding of the virus. They said that if they reveal their status, the other students would not want to play with them. Therefore, limited knowledge put them at a disadvantage, as they would not know fact from fiction about HIV. They could be placed in a defenceless position and could be harmed emotionally. This can lead to isolation, as children may not want to go to school anymore, for fear of what their friends may say.

The mothers may be right in insisting on non-disclosure at school, as in Trinidad and Tobago it has been found that schools have a general unwillingness to accept children who are HIV positive. McKay (2002) identifies a case in Trinidad and Tobago where infected children were made the subject of protest demonstrations and complaints and they were eventually denied entry into the school. Discrimination continues to occur while children are at school as they report that they are teased, laughed at and made the subject of gossip and are excluded from recreational activities (McClellan *et al.* 2009). McClellan *et al.* report that parents have resorted to withholding information on the status of the child in order that he or she may have an equal chance at an education. Non-disclosure implying normalcy at school means that children have a better chance of an education without having to deal with discrimination, which can be debilitating.

### **Coping with HIV**

Coping is defined as a dynamic contextual process in which people use cognitions and behaviours to manage a situation that they appraise as taxing or as exceeding their resources (Lazarus & Folkman 1984). Chronic illness is a condition that taxes an individual's resources and HIV is a chronic illness accompanied by a host of stressors, ranging from social stigma to uncertainty of illness progression (Ball *et al.* 2002). Children in the research seem to cope by totally relying on their mothers for all forms of support. Their mothers had absolute power over their lives. Both child and parent being ill indicate that there may be a symbiotic relationship in existence. Each supports the

other; each can identify with each other. An inextricable bond is formed. Children's limited knowledge of HIV creates an even greater dependency on their mothers, as this is where any word on HIV emanates. The impact of non-disclosure coupled with limited knowledge of HIV/AIDS creates a platform for the child to cope, albeit in a dysfunctional way. This defence mechanism has therefore been created in the home to foster some semblance of normalcy.

### **Children generally happy despite HIV**

An assessment was undertaken of the visual images produced by the children: drawings, "All about me" and "Picture of expression and action". All provided an inside view of how the child felt with HIV. The importance of family emerged strongly, as did how the children viewed themselves. Happy dispositions and positive actions were evident in their feedback. All members of the family had smiles on their faces. Evan did not draw his step-father in his picture. He considered his family to be his mother and brother only. Amy drew her step-dad in her picture even though her mother did not consider him part of the family. However, he seemed to be providing some form of support. The children were asked to describe what they drew.

Veale (2005) speaks about the use of drawings as a tool that can offer insight into children's individual experiences. A number of researchers have recognised the potential contribution of drawing as a research process that offers a representation of a child's world view (Golomb 1992). Vygotsky (1935, 1978) posits that from about 7 years, children begin to master the symbolic meaning of drawing and that drawing can serve as a cultural tool, in the same way as signs and language, for the mediation and transmission of messages. Drawings can be a communicative tool and in their production, pictures are "discovered" (Andersson 1994). This was the case with the children in this research. Their world view was not that of only sadness; there were positive elements in their lives. This can be a strong point from which to begin work. Gaining important knowledge and understanding of HIV coupled with the positive outlook of children can have an affirmative effect in their lives and help with their

“feelings of sadness” in the short or long term, depending on the child. Without these activities, the realistic picture of a child’s life with HIV would not have surfaced.

### **5.14.2 Children as Carers**

In the Caribbean it is normal for children to help in the home. However, the children in this study found themselves in a unique situation whereby they and their mothers were both HIV positive. Amy helped to ensure that her mother ate properly and took her medication; Brian and Cathy did chores around the home. The children were also concerned about their mothers’ well-being. In the Caribbean the term ‘young carers’ is generally not used in reference to children assisting ill parents in the home. Young carers are defined as those under the age of 18 who are primary caregivers in their family due to parental illness, disability or addiction (Aldridge & Becker 1993). The young person in these circumstances is forced to take on full or partial adult roles to support the survival of the family.

Charles *et al.* (2009) mention that in Europe such young persons are called ‘young carers’ and are seen as needing support in coping with such unique circumstances in the family. They said that in North America if they are noticed at all, they are viewed and labelled as ‘parentified children’. Rather than support them, their situation is pathologised and they are sometimes removed from the home or sent for therapy. Parents are viewed as unconsciously abdicating their roles in the family with needs of the adult coming before the developmental needs of the young person (Chase 1999).

There is some overlap in the definition in that, in both cases, young persons are found in situations where they have adult responsibilities as minors and they all may be in parentified roles. However, according to Charles *et al.* (2009) the definition of young carer does not mean an automatic judgement about the parent-child relationship and the emotional boundaries. They continued by saying that parentification assumes a narcissistic demand being placed on the young person by the adult. The young carer definition assumes only that circumstances in the family require that young people take on the responsibility. The role reversal is one of necessity.



In this research these children are seen as young carers in line with the discussion above rather than parentified children. Their mothers do care and they do what they have to assist. Periodically as seen, a mother may have physical problems as a result of being HIV positive and children at times provide that informal support in terms of helping in the home. Thus, in this research the 'young carer with HIV' represents a child who at times assists in the home because of necessity and concern for their mothers. This term coined for this research suggests that the spotlight be turned on the children. This should attract awareness of their circumstances and the necessary support from interventionists. The intent is not to pathologise these children but to instil awareness of their situation among those who interact with them whether they are family or professionals.

In context, Afro-Caribbean families are characterised as 'matrifocal', that is, they possess the enduring bond between mother and child, coalitions centred on the grand-mother-child stem, single parenting by women and a high proportion of female-headed households (Leo Rhynie 1997; Massiah 1983). Child-bearing continues to be perceived as a natural part of the life course for Caribbean women and motherhood the pivotal signifier of womanhood. Mothering in the Caribbean has always been defined to include economic support for children and increasingly, women have to deal with the dilemma of balancing career goals and self-interest against strong social pressure to be a 'good mother' (Mohammed & Perkins, 1999).

Thus, the role of motherhood is very important in families and pressure is there for mothers to ensure that they live up to the expectation of society by being a 'good mother'. If the mother with HIV and a child with HIV are placed within this context, then one can see that there may be additional stress within that family. The mother may see herself as being deficient in her role as the child picks up household or parental roles because of HIV related physical and psychological issues on her part. Awareness of these circumstances is important for all those persons who interact and intervene with these children on a personal or professional level.

### 5.14.3 Mother/Child Bond of Secrecy

This theme of secrecy continued from the findings of the mothers. Their fear of stigma and discrimination appeared to have a debilitating effect on their children. The mothers experienced “felt stigma” which is the fear of being discriminated against (Scambler 1998) at some point in their lives. They did not like the experience and thought that this would adversely affect the child. They were trying to prevent the children experiencing “felt stigma” as well as “courtesy stigma”. “Courtesy stigma” is the least studied of the three types of stigmas and it refers to prejudice and discrimination against individuals, who are associated with others who are stigmatised. (Goffman 1963; Hebl & Mannix 2003). This can directly affect family members (including children) and friends. It can even extend to those who are merely seen in the presence of the stigmatised person (Hebl & Mannix 2003). Many young children, as young as 7-14 years of age, are aware of courtesy stigma related to parental HIV, and as such, this affects their decision to disclose their parents’ status to friends (Murphy, Roberts & Hoffman 2002). This phenomenon was not so in the study. Children were not aware of “courtesy stigma”.

The children had been told by their mothers not to disclose their status to anyone, and even if they wanted to, they could not, as they did not want to disobey their mothers. The lives of these children were severely constricted in terms of their interaction with the outside world, as the fear of persons discovering their status reflected the fear of their mothers. This was passed on to the children who voiced that if anyone found out, they would not be liked and no one would want to be in their proximity. They did not label “revealing their status and not being liked” as stigma and discrimination, because of their limited knowledge of the virus. They seemed to believe and repeat what was being conveyed to them by their mothers.

Thus, secrecy was seen as a way of coping with this fear. The mothers perpetuated the secrecy as a way of protecting themselves and their children from the outside world, thus eroding the process of helping the children gain a better understanding of the disease. The topic of HIV was not discussed in the home, limiting even further whatever desire the children may have had to gain insight into the virus. The only outlet they had

was that of ‘feeling sad’ when the topic of HIV is broached. What impacted their minds most of all was the fact that HIV was a disease that can lead to death. The child in this research lived under a shroud of secrecy with a chronic illness called HIV.

This does not paint an encouraging picture for that child in terms of healthy development psychologically. The child is completely dependent on the mother for social support, and yet that very social support is inimical to the child. This seems to be a veritable dilemma. These mothers think that they are in fact doing what is best for their children; however the findings of this study and of other literature on the topic suggests that this shroud of secrecy may do more harm than good.

Most research on HIV stigma and families has been done from the stand- point of parents with HIV, with primary focus on mothers (Ingram & Hutchinson 1999, 2000). Some studies have also collected data from children with HIV-infected parents (Vallerand *et al.* 2005) or caregivers, including mothers, grandmothers, partners, other family members and friends (DeMatteo *et al.* 2002). However, there seems to be little research on HIV-stigma issues from the perspective of all family members, including HIV-infected fathers and mothers and their children and caregivers. A recurrent theme in the realm of “felt stigma” has been parental worry about children experiencing discrimination (Corona *et al.* 2006; Vallerand *et al.* 2005). In this research HIV-stigma issues from the perspective of children who are HIV positive were explored and the core findings were that of secrecy- to- protect. They may not have understood that being shunned by others because of their HIV status actually translates into stigma and discrimination as they had never experienced it because they had disclosed to no one, hence the felt-stigma on the part of the mothers.

## **5.15 The Development of the Storyline**

Strauss and Corbin (1990) spoke about identifying the story and in my study the writing up of memos helped to flush out the storyline. Thus far, the main story emerging is that this research seems to be about how mothers manage the fear of stigma and discrimination with respect to HIV. They do this by protecting their children and themselves

## CASE STUDIES

**Mothers and HIV**



**Who to tell?**



**Selective few**



**Why?**



**Fear of Stigma & Discrimination (S&D)**



**Ultimate goal**



**To protect child**

**& Self**



**Method**



**SECRECY**

Figure 5.15a: Mothers and HIV case

As the second part of the triad “Children with HIV” was added this is what is seen:

Figure 5.15b: Case studies



Mothers protected children (as seen in the findings of this chapter) from “felt stigma” by creating a shroud of secrecy in their homes. The categories developed were like pieces of the puzzle that continue to come together, leading up to the core category

of “Secrecy-to-protect”. It must be noted here that stigma and discrimination is real in the lives of the mothers however, from the children’s perspective, stigma was not the core issue since they had little awareness of stigma. For them the secret had taken on a life of its own and was a key defining characteristic of their interpersonal relationships, their communication patters, their need for self-expression and exploration of emerging identity. This is what they knew and embraced as part of living with HIV-AIDS. The ‘secrecy to protect’ phenomenon is one of the key psychosocial issues that emerged with respect to the children and mothers as a response to stigma and discrimination. It carries it one step further in this research for children living with HIV-AIDS.

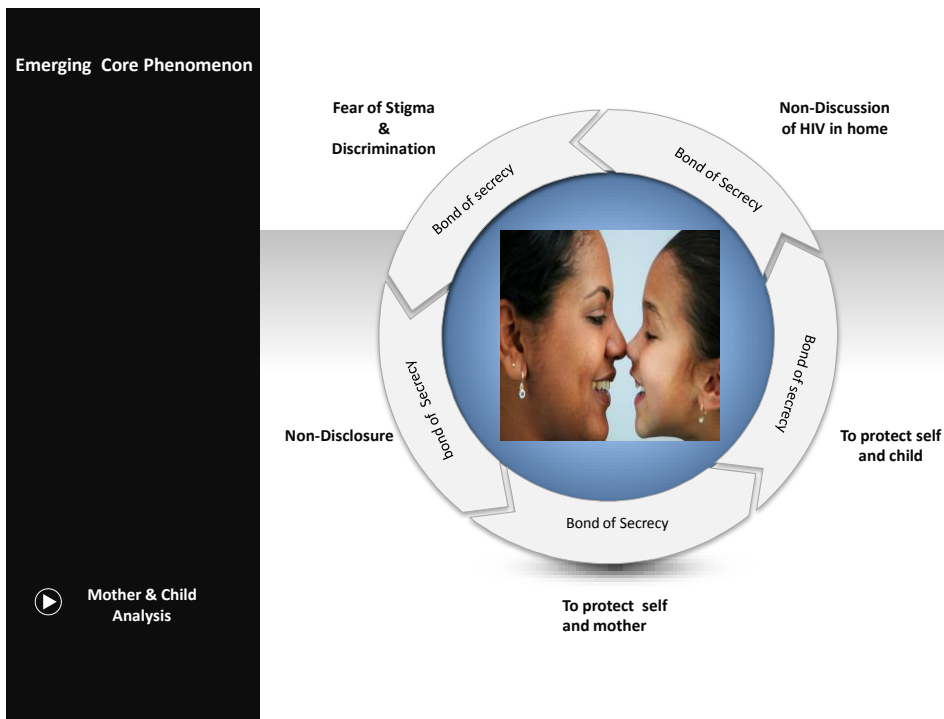


Figure 5.16b: Emerging core phenomenon

## 5.16 Conclusion

Five children were interviewed using theoretical sampling and analysis of data took place simultaneously which is synonymous with the grounded theory approach. Open, axial and selective coding were used to develop main themes, sub themes

and sub-sub themes. Interview methods included several tools to help children tell the story of their lives with HIV. It was found that children thought that HIV was a disease that can lead to death. They had limited knowledge and understanding of what HIV is and they had 'feelings of sadness' whenever the subject was discussed. However, the activities revealed that the children appear to be happy apart from the 'feelings of sadness' that they expressed while talking about HIV.

The children were told never to disclose their status to anyone, as no one would like them. They believed this wholeheartedly and complied, even though they wanted to disobey. The children were all from the lower economic stratum of the society and consequently, their families had financial constraints and the children experienced of hunger at times. All except one had some form of illness and there were medication adherence issues. The children were also seen as 'young carers with HIV' - a term unique to this research and which I use to suggest that the spotlight must now be turned on their situation so that others will be aware of their circumstances and differentiate these children who care for mothers with HIV from children just helping in the home.

The storyline is one of mothers maintaining secrecy to protect 'self and child' and children maintaining secrecy to protect 'self and mother' creating a mother/child bond of secrecy. The core category emerges as "secrecy-to-protect".

## **Chapter 6 – HIV Friends**

### **6.1 Introduction**

This chapter on personal support (HIV friends) forms the concluding part of the case triad that consisted of four HIV positive mothers (first part of triad) and their five HIV positive children (second part of triad). The same format of analysis using the grounded theory approach of simultaneously interviewing participants and analysing their responses to generate themes, sub-themes and sub-sub-themes was used as for the mothers and children. In the two previous findings chapters, it was reported that the mothers considered their HIV status to be a secret and this secret was perpetuated by the children via threats by the mothers and by the children's loyalty towards their mothers. A storyline of 'secrecy-to-protect' and protection of secrecy emerged that related to the mother's protection of the child and the child's protection of the mother, resulting in a symbiotic relationship of secrecy. As the HIV friends were interviewed, it was found that they were part of this secrecy-protection cycle and indeed it is likely that they had been identified as confidantes because of the belief that they would support and help to maintain secrecy. This secrecy was initiated by the mothers; the children upheld it and the HIV friends supported it. This was a common thread throughout the case triad analysis. While this chapter focuses on support it is important to stress that this was provided in the context of the 'secrecy cycle'. Furthermore, although I draw primarily on interviews with HIV friends, I also refer to findings that emerged in interviews with mothers and children and make reference to other chapters in which similar themes emerged.

### **6.2 Definition of Social Support**

Owens (2003) provides the following definition of informal social support.



## **Informal support**

Informal support is seen as emanating from an individual's family and friends and consists of the following four aspects:

- a) Affective support: Love, care, empathy, concern and compassion;
- b) Family commitment: Family availability and the ability to take part in family gatherings;
- c) Family acceptance: Sharing HIV status with family members and receiving positive feelings of acceptance.
- d) Concrete support: Help with parental responsibilities and household activities by family members, as well as help with financial assistance.

Other types of social support include, formal support and informational support, as follows:

## **Formal Support**

The term "formal support" refers to activities such as welfare grants and other help from governmental agencies inclusive of social work intervention, concrete support such as help with housing and financial assistance and NGOs. In the case of my study this refers specifically to social work support, health care and public welfare assistance.

## **Informational Support**

A further type of support is informational support (Owens 2003) and in this case refers to information on how to cope with HIV/AIDS. I found this a useful definition as the basis for exploring support because it explained the meaning of support that I wanted to convey in this study.

## **Theoretical Reflection of Social Support**

Social support has been defined as information that prompts the individual to believe that he or she is cared for, loved, esteemed and valued and is a member of a network of common and mutual obligation (Cobb 1976). It can also include a) what exists, that is the amount of support available (Sarason & Sarason 1982), b) quality of support, that is, a person's satisfaction with what is received (Vaux & Aphanassopoulou 1987) and c) support that is deemed to be encouraging and discouraging. (Schilling 1987).

Considerable evidence suggests that positive social support helps people maintain their health and welfare under difficult circumstances (Hudson, Lee, Miramontes & Portillo 2001; Burgoyne & Saunders 2001). Researchers have suggested that positive social support networks may be linked to avoidance of high-risk sexual behaviour among HIV positive individuals (Kimberly & Serovich 1999).

Social support may either reduce an individual's stress levels or improve one's standard of living, regardless of what level of stress experienced (Cohen & Wills 1985). It has been suggested that absence of social support makes a person more vulnerable to the effects of adverse life events and thus indirectly to the reduction in immune function (Kaplan 1991). Solomon (1987) hypothesises that stress and psychosocial factors can influence the replication of HIV and the onset of AIDS. Generally, social support is more associated with the psychological well-being of the person affected (Turner 1981; Sarason *et al.* 1983; Cohen & Wills 1985). The social services literature supports the view that social support increases the physical and mental health and stress coping abilities of HIV+ individuals (Vaux 1988). Another researcher (Gielen *et al.* 2001) describes the relationship between psychosocial factors and health related quality of life among HIV-positive women. They found that women with larger social support networks reported better mental health and overall quality of life. Women who practiced more self-care behaviours (healthy diet and vitamins, adequate sleep and exercise and stress management) reported better physical and mental health and overall quality of life. The high prevalence of physical abuse and child sexual abuse reported by this sample underscores the importance of screening for domestic violence when providing services to HIV-positive women. That such potential modifiable factors such as social support and self-care behaviours are strongly associated with health-related quality of life suggests a new opportunity to improve the lives of women living with HIV. Sources of support can be extrinsic and intrinsic (Walsh 2002) and provided informally by acquaintances and kin and by formal services systems (Streeter & Franklin 1992).

The social unacceptability of being HIV positive is reported to be one of the major concerns of people with HIV (Longo *et al.* 1990) and may lead to family separation, decreased social interaction and withdrawal (Longo *et al.* 1990). An HIV diagnosis is

commonly associated with depression, suicidal tendencies, guilt and fears of social seclusion (Platt 1992). Being HIV positive represents changes in attitudes and personal relations (Miller1987) and may involve the creation of a new self (Sandstrom 1990). It is therefore noted that social support was identified by a group of HIV positive individuals as being vital for survival (Mandel 1986).

Based on the above, people with HIV/AIDS need a complex array of social support systems. It is important that social workers working with this population be aware of the different kinds of support that may be most effective in helping women with HIV/AIDS maintain their health and sustain or improve their quality of life.

Few studies show how women cope with living with HIV/AIDS, (Kaplan, Marks, & Mertens 1997; Dunbar *et al.* 1998), however, Schulte *et al.* (2000) in examining social support with women, who are HIV positive, investigate the economic, social and psychological situation with regard to the special situation of a group of women in Germany. While there was no difference in clinical parameters, they found that HIV-positive women were in a worse economic situation. Concerning psychosocial situations, there were a few differences, but HIV-infected women sought help by voluntary workers more often. Schulte *et al.*, (2000) show a link that supports the fact that specific education and socio-economic support of HIV-infected women are conditions for the success of antiretroviral therapy of HIV-infection, which has recently become more demanding and complex.

Hudson *et al.* (2001) focus on social interactions, perceived support and level of distress in HIV-positive women. He stated that although powerful pharmacological therapies are helping women with HIV infection live longer, women continue to experience the stressors of chronic illness. The study used a person-environment systems framework to describe social interactions, perceived social support and psychological distress in HIV positive women. Women reported limited social interactions with family and friends and a low level of perceived social support. Social support and level of distress did not differ by ethnicity. Limited perceived social support was a significant predictor of distress in this sample of women. Supportive interactions from health care providers can be useful in mediating the relationship between the stressor of HIV disease and distress in

HIV-positive women. Community-based nurses can enhance HIV-positive women's support network by providing positive and supportive interactions as they intervene with women in symptom management, case management and other health care services.

Research has shown a link between disclosure and social support. Kalichman et al. (2003) look at stress, social support and HIV-status disclosure to family and friends among HIV-positive men and women. This showed patterns of selective disclosure, where most participants disclosed to some relationship members and not to others. Rates of disclosure were associated with social support. Friends were disclosed to most often and perceived as more supportive than family members, and mothers and sisters were disclosed to more often than fathers and brothers and perceived as more supportive than other family members. Disclosure and its association to social support and depression varied for different relationships and these differences have implications for mental health and coping interventions.

Lichtenstein (2002) explores chronic sorrow in HIV-positive patients with respect to issues of race, gender and social support with men and women. This research indicated that chronic sorrow in HIV-positive persons is related to illness, fear of death, poverty and social isolation especially for women with children. More than half the subjects scored as depressed, with African American women scoring significantly higher than Caucasian men or women. Social isolation often resulted from the stigma, as framed in Erving Goffman's theory (1959) of discredited identity. The women were likely to be stigmatised because of their association with "dirty sex," contagion and moral threat in heterosexual communities. Based on these preliminary findings, stigma should be considered a marker of chronic depression in the HIV-positive person, and support services should take account of the stigmatising contexts in which PLWHA have to live..

HIV positive individuals rely on formal and informal social support systems for their HIV related concerns (Hays, Magee & Chauncey 1994; Ingram, Jones, Pass, Neidig & Song 1999). With respect to informal networks, Ciambone (2002) examines the informal networks among women with HIV/AIDS, their present support and future prospects. The author explored women's social network composition and the extent to which these networks appear to facilitate or mediate the disruption caused by HIV/AIDS. Women

reported having at least one person, usually a family member on whom they could depend for emotional support. Although women report adequate levels of current support, the author questions the likelihood that their informal networks will provide support further along in women's illness trajectories.

It has been found however that sources of support differ by social group, for example, gender, ethnicity and sexual orientation. Women have been found to benefit more than men from social support (Metcalf, Langstaff, Evans, Paterson & Reid 1998). They rely more heavily on informal support networks (Florence. Lutzen & Birgitta 1994) and report using religion to cope with their HIV related issues (Biggar *et al.* 1999). However, women also report approaching formal systems such as social services agencies with considerable anxiety: they felt more isolated and unsupported, distrust medical providers and are less satisfied with managed care programs (Cherin *et al.* 2001; Ingram *et al.*; Land 1994). Walsh (2000) finds that women experienced greater stress with larger social networks because they tended to view themselves as caregivers rather than receivers of support. Lea (1994) posits that women are expected to support others and receive fulfilment by this role, notwithstanding the self-sacrifice involved. The social construction of gender stipulates caring as a natural part of the nature of women (Altschuler 1993). Thus, women who are HIV positive are no exception to this finding, as they are expected to care for others while caring for themselves (Dowling 1995).

## **Summary**

Information gathered in the review of literature suggests the importance of social support both formal and especially informal in HIV/AIDS. Social support is also important to the mental wellbeing of women as it forms a buffer between strenuous life events and escalating stress levels. Women have been found to benefit more than men from social support, which impacts on their quality of life. Primary research on HIV/AIDS has focused mainly on men, rendering more knowledge about men than women. There is the need to bridge the gap and increase our knowledge about the role of social support among women who are HIV positive. This study provides important information about this population, particularly with respect to Trinidad and Tobago and women who are HIV positive. It is the first study to provide qualitative information on the

psychosocial support needs of children (and to some extent, their mothers) and will inform practice and policies that are mutually relevant and appropriate.

### 6.3 Interviews

Each interview was conducted and then analysed. Questions were derived from the issues that emerged in the interviews with mothers and children and the focus on support achieved by drawing on Owens’s definition. The interview questions covered disclosure, exploration of emotions, health issues, stigma and discrimination, the coping mechanisms used by mothers and children and the opinions of support persons in terms of what further support they felt the families needed to assist them in their daily lives. Below is the list of persons identified by the mothers as their main support. It should be noted that two of the women identified professionals (formal support) as their main form of support instead of family (informal support). This suggests that their informal support networks were weak. The other two identified other family members inclusive of a partner and sister.

Table 6.3 Mothers and HIV Friends

No.	Participant	Person Identified
1.	Mary	Medical Social Worker
2.	Bertha	Sister
3	Petra	Common-law husband
4	Martha	Adherent Nurse/Officer

### 6.4 Themes

As noted in the chart below, the following four main themes emerged: social support (types), coping (mothers and children), how HIV friends viewed mothers and children and intervention needed at all levels. This suggests that in relation to HIV, Owens’ definition is incomplete; for example, for people living with HIV, support requires an acknowledgement of resilience and coping, that is, not ‘deficit-based’ but ‘strengths-based’ suggesting that people need to feel that they are not perceived as ‘passive victims’ of a disease but agents with some measure of control over their lives. Also, interviews with HIV-friends clearly highlighted an ability to maintain the secrecy cycle as

an important form of support and planning for the future. Owens' definition 'fixes' support as something tangible; however, in this research a different definition seemed to be developed, one that sees support as what might be available in the future as well as what is present..

Table 6.4 Themes of HIV friends

No.	Main Themes	Sub-Themes
1	Social support	<ul style="list-style-type: none"> <li>• Social support</li> <li>• Support role</li> </ul>
2	Coping (children and mothers) Adults minimised the impact of HIV/AIDS on children	Adults thought children were coping well
3	How HIV friends view mothers and children	Circumstances with respect to mothers and children
4	Intervention needed at all levels	<ul style="list-style-type: none"> <li>• Health issues</li> <li>• Overall future support</li> </ul>

### 6.4.1 Social support

The four mothers in the study accessed **formal support** in the form of clinic services that included free anti-retroviral therapy (ART), doctors' examinations, and access to social workers and counselling services. The mothers were accepting of these services as the women may have felt that they had no one else to go to for support. Two of the women, Mary and Martha identified a social worker and a nurse as their main support (HIV friend). The mothers, in an expression of their own agency, may have identified these individual professionals as people they can trust or because a relationship of trust had developed over time. When asked about their choice of HIV friend trust seemed to be the determining factor for the relationship. These professionals worked in government agencies that were responsible for providing support for HIV positive

individuals. When necessary, they provided counselling, informational support (intangible support) and food-stuff (tangible support); however, only Martha and Petra received welfare benefits on a monthly basis. All the services were provided free of charge. Apart from these services the women also received effective support in the form of empathy and compassion from these formal sources of support.

All the women received and accepted these services as part of their HIV/AIDS management. Mary and Martha trusted these professionals as based on their relationship; they knew that they could depend on them to maintain their secret of being HIV positive. Mary also received concrete support from an ex-partner as the father of her last child (who did not live with the family) came to help her with parental responsibilities. However, he does not know that Mary and her daughter are both HIV positive. If he found out that information he would need to be tested as she has never confided her status with him. This is an issue that could create additional stress in that family.

The other two women, Bertha and Petra, identified their HIV friend in the informal support category as a family member (sister) and a partner (common-law husband), respectively. These individuals provided the women with primarily (a) emotional support, which was affective support, such as love, empathy, compassion and concern; and (b) family acceptance. In both cases, these support people also provided concrete support in the form of financial assistance and help with household activities. Petra also received parental assistance from her support person (common-law-husband). The mothers trusted these individuals in keeping the secret. The common thread among the four women is the trust they placed in their HIV friends to keep the secret and not disclose their HIV status to anyone.

## **Support role**

### **Responses to what role the HIV friends played in the lives of the mothers.**

#### **HIV Friend 1**

*“This was the response to the question on what role does the HIV friend play in Mary’s life. HIV Friend 1 (social worker): She comes to the support groups. I see*



*her every last Thursday of the month; I would see her there. However, she has my cell number so she can call me at anytime. That's a rare thing, I don't usually give out my cell number but given the nature of this case, the need, she can call me when she has concerns, immediate concerns and emerge. Within the group, she can call other members for support. So my support is really letting her know that she has the resilience, she has the capacity to bounce back in spite of. Because many times, especially now where her health is being compromised, she will feel depressed.*

*I have recommended her for the TT Card, (a card where she can access money to buy basic food items) the credit card, the food card and she is still awaiting that. I have recommended her to also get social welfare. So my support will let her know that this is the process, you just have to be patient, letting her be encouraged that, yes, she is trying to help herself.*

*She is very, very creative. If her sister sends things from the States (United States of America) like clothes and towels and so on she will sell it so that she can make money to buy food and clothes for her kids.*

*She is very, very creative, very, very resourceful. My support will be to praise her. I say, "Look at that strength you have, you will be able to use this money." And I keep giving her the encouragement that there is hope.*

*So basically my support is providing counselling, letting her know that she is not alone on the journey, developing her skills, tapping into her strengths. I will use the 'strength' perspective and let her know, "Yes, you have what it takes".*

As can be seen from HIV Friend 1's responses, Mary received formal support in the terms of counselling from the social worker and the group support. The social worker also tried to secure tangible support for Mary in the form of finances for food items via a government agency. Mary did not have any informal support from family members as she had not disclosed her HIV status to them; however, she received material support from her sister in the U.S.A. The confidentiality that the social worker upheld assisted Mary in keeping the secret of her HIV status from her family and from others. The social worker also went out of her way to help as she gave Mary her cell phone number to call her whenever she had concerns. This may have helped cement the trust that Mary later developed with the social worker.

## **HIV Friend 2**

*HIV Friend 2 (sister): "I said I try to support her in everything she does, emotionally too, and help with finances if she needs it I try to help her. I cannot help her much with the kids and stuff because I have two kids too to take care of and plus she lives in south and I live in Port-of-Spain (west)."*

As HIV Friend 2's response notes, Bertha received informal support in the form of affective support and family acceptance as her sister has accepted her HIV positive status. Her sister also provided financial support at times so she received some tangible support as well. However, because of the distance between their homes it was not possible for her sister to provide that support for Bertha's children. Her sister has maintained Bertha's secrecy with respect to her HIV-positive status.

### **HIV Friend 3**

*HIV Friend 3 (common-law husband): "I play everything, father, counsellor, I try my best to calm her down, talk to her and all this type of thing. This helps her in an emotional way. I also provide help in terms of finances".*

HIV Friend 3's responses showed that Petra received informal support in the form of affective support and family acceptance from her partner. She also received tangible support in terms of finances to help in the home. His role as an HIV friend was interlinked to his role as her partner and step-father to her children, except the last child who was his biological son. As a partner he felt obligated to give her that support even for his step-children as he was accepted in the home as that father-figure by both Petra and her children. He had totally accepted Petra's status and was committed to the relationship. Her secret was safe as she trusted her partner with this information.

### **HIV Friend 4**

*HIV Friend 4 (nurse): "Well, I am a nurse, That is, going home, making sure that she is taking the medication in the right way, making sure that he is always supplied with medication because she is not always, as I mentioned before, financially equipped to come to get the medication. So I will always like, if I am able, drop it for her or make sure that she has enough supply that would tide (keep) her over a period of time. This is not for the mother this medication is for the child to ensure that there is the availability of medication for use. Also, when Christmas comes around and our department has hampers we give to her to help with foodstuff".*

From the interview with HIV Friend 4, it is clear that Martha received formal support and tangible support from her HIV friend in terms of receiving medication supplies and (periodically) hampers. She also received intangible support such as advice. All this support was given as part of the nurse's professional duties. What the HIV friend did

that was not in line with her normal duties was to deliver medication personally to Martha's home when she had no finances to pay for transportation to the treatment centre to collect it. This nurse went out of her way to help Martha. This may have been the difference between that particular professional and another and may have contributed to the development of trust within that relationship for Martha. This HIV friend showed care and concern for Martha's situation as a professional and as an individual. This suggested an interpersonal relationship that has gone beyond professional boundaries. This HIV friend was an adherent nurse and as such, she wanted to ensure that adherence was a priority in the lives of Petra's children as non-adherence can lead to AIDS. Cyrus (2009) found that there were many psychosocial issues that affect non-adherence; one of them being lack of finances. This happened to Martha as at times she did not have finances to pay for transportation to the treatment centre to collect the medication for her children.

During the literature search, it was found that most of the research on social support was conducted in the 1990s. It has been shown that sufficient social support improves the physical and mental health and the stress coping ability for a variety of populations of concern to health services providers (Vaux 1988). Social support can be material or emotional (Walsh 2000) and it can be provided informally by friends and family and by formal social services systems (Streeter & Franklin 1992). Women have been shown to benefit more than men from social support (Metcalf *et al.* 1998; Turner *et al.* 1998) and women rely more heavily on informal support networks (Florence *et al.* 1994).

In Trinidad, Joseph (2009) finds that women with HIV were more inclined to seek formal support structures rather than informal ones. In this study, mothers were evenly divided between informal and formal support. In the research conducted by Florence *et al.* (1994), which found that HIV positive women in their study relied more on informal support structures, it was reported that the HIV positive women who had strong social and family support were coping better with their situation than were women with little support.

Non-disclosure by the mothers to other family and friends was because of their fear of stigma and discrimination. Aggleton *et al.* (2003) state that, with respect to HIV/AIDS all

over the world and especially in Latin America and the Caribbean, stigma related to HIV/AIDS is not based on personal prejudice but is a social product with deep societal origins. Women with HIV/AIDS are viewed as having been promiscuous, despite clear evidence to suggest that, in the majority of cases, they have acquired the infection from husbands and regular male partners. This could be one reason behind why women did not disclose to more family members

The mothers were aware of the consequences of stigma and discrimination, thus, as a means of protection of themselves and their children they made a decision to keep their HIV status a secret. This could help explain why women tend to access formal social support more often than informal social support.

#### **6.4.2 Coping: mothers and children**

##### **Mary and her daughter Amy**

###### **Mary**

The women's' HIV friends related how the mothers and children coped with HIV/AIDS.

Mary's HIV friend (social worker) said the following:

**HIV Friend 1 (social Worker):** *Honestly, in counselling, she expressed that she sleeps.*

*She would ignore them and just go and sleep. That is what she does. And that's something that the group — because of the dynamics of group support, the other members are telling her that 'sometimes she would neglect them if she just goes and sleeps'. So this daughter is actually a child who parents the others. When she goes into this mode and she sleeps she uses that as an escape and also as a coping strategy.*

*Her other coping strategy is every last Thursday of the month to come to the support group and just share. She has met a friend within the group and sometimes they would go out. And they know about retail therapy; they would go and buy some little thing in the \$10 store, sit down on the promenade and just chat a little bit.*

Mary withdrew and slept as a coping strategy according to her HIV friend, leaving Amy to take care of the other children. Group support members saw this as a negative and potential neglect as they most likely viewed this scenario from a mother's viewpoint.

However, the HIV friend was a social worker and based on her training and assessment saw this from a more professional point of view as a coping mechanism even though it

may have been perceived as a negative by other mothers. This may need some intervention by the social worker eventually as leaving a young child to look after her siblings in a situation like this may not be best for that child. The responsibilities during the time that Mary slept and ignored her children shifted to Amy and this can place Amy in a role she was not ready for because of her age and developmental stage. This was noted in the findings for children and reiterated the role of the 'young carer with HIV' in the family (see section 5.14.2). It appears as if Amy took on the role of a parent on the occasions that her mother was not able to perform that role. Mary also shared in her group meetings and periodically ventured out with a member from the group. Their activities included shopping and chatting.

## **Amy**

HIV Friend 1 reported that Mary's daughter Amy coped in the following way:

*HIV Friend 1 (social worker): "From my little intervention, she copes by mothering the other children, the two other siblings, by taking care of them and letting her mother not be too active with them because she sees the mother daily being frustrated by quarrelling and arguing and stuff like that. So if she usurps the mother's role and takes over she would feel like she is in control and that gives her some degree of comfort. Also, she would talk to the teacher. She told the teacher that she is sick".*

*"A coping strategy which is a negative one for her was to fight. You wouldn't believe it. She used to feel powerful when she fought, on top of the world. It is a negative one but she used to want to fight, and she used to be the instigator, she would want to be fighting all the time".*

Amy's coping style was corroborated earlier when she said she helped her mother, Mary, in the home and she was concerned about her mother's well-being. This was discussed in the findings chapter for children 5.14.2. . Amy is seen as a "young carer with HIV" who at times assists in the home because of necessity and concern for her mother. This comment also reflected that Amy wanted to talk to someone about her status. She wanted to break the secret; however, doing so was not allowed. The fighting also seemed to be a result of Amy being angry at times with her mother. Amy in her interview said that she was angry at times with her mother because of having HIV as mentioned in 5.1.4. and wanted to fight her occasionally. This may have been a way for her to vent those angry feelings.

## **Bertha and her children Brian and Cathy**

### **Bertha**

HIV Friend 2 reported that Bertha and her children coped in the following way:

*HIV Friend 2 (sister): She would like to go shopping. This is her way of coping. She likes to go grocery shopping.*

Like Mary, Bertha does some form of shopping to cope with the stress of HIV/AIDS. Shopping is a required act in the scheme of things and is part of 'normal' life. Thus, it seems as if Bertha was maintaining a sense of normalcy through shopping as a coping strategy.

### **Brian and Cathy**

*HIV Friend 2: I said they have it hard because they can't talk to their friends at school about it.*

- Q. *You know that is what they said?*
- A. *Yes, they can't talk to their friends at school about it and they have to keep it buckled up inside.*
- Q. *So there is a need for them to tell?*
- A. *Yes, they need to talk. They don't really have anyone to talk to more than mummy and daddy. A counsellor that might help them with it because they need to talk*

This HIV friend (the mother's sister) felt that the children needed to speak to someone as their way of coping was to suppress all their feelings. This presented as psychologically unhealthy for the children. In the home, the children did not talk about HIV, thus there was no outlet for them to share how they felt. Although they went to clinic, they did not share there either. It was as if no one noticed that HIV/AIDS could have a psychological affect on their lives and that they needed some form of intervention tailored to their needs.

### **Petra and her daughter Dawn**

Petra's HIV friend (partner) reported that she was coping, as follows:

*HIV Friend 3 (partner): She tries. Sometimes she all right and then again she does just break down (sometimes she is fine but at times she breaks down emotionally). There were things that happen to make her break down, like, stress, things, especially sometimes like family and the kids and them with the problems. Sometimes I might give trouble too once in a while, so all that does pertain too.*

*(The children and her family have problems at times and sometimes I give trouble as well so it all adds up).*

Apparently, Petra was sometimes overcome by stress, while, most times, she was able to cope. Her partner added that he also posed some problems at times apart from the children and this contributed to increased stress for Petra. He seemed to be attuned to her needs and is aware of what is happening in the home. There may be need in the future to engage in research that looks at “HIV positive men with HIV positive women”. Jones (2009) said that HIV-AIDS affects families who may be experiencing other challenges such as poverty, substance abuse, illness or disability. These issues can actually be exacerbated because of HIV-AIDS. Jones also added that HIV is a health issue that intersects with social, cultural and psychological factors to create complex, multi-layered challenges for people affected by the disease and their families. In Petra’s case there was poverty and illness due to HIV which impacted on her family.

## **Dawn**

Dawn’s HIV friend reported on Dawn’s coping abilities, as follows:

*HIV Friend 3: To me Dawn is stronger than the mom. Dawn, from baby she growing up with it so right now she coping with it and she going fine. (He felt as if Dawn was stronger than her mother as she had HIV from birth so she is doing fine.)*

He was convinced that Dawn was fine as she had been HIV positive since the time she was a baby. This was how he viewed her coping. In his way of thinking, having HIV from birth and growing up with it equated to being fine. Again, there was non-discussion of HIV/AIDS in Dawn’s home. He never asked how Dawn felt about having HIV, yet he stated that she was coping so well. Again, here is an adult who spoke on behalf of the child who was not aware how the child really felt.

## **Martha and her son Evan**

Martha's HIV friend (nurse) stated the following regarding Martha's ability to cope:

*HIV Friend 4 (nurse): "I think she is coping well because like if the child gets sick or anything she would get up and bring him to the hospital. I think she is coping well. She is doing well for more than one reason. She is trying to look for a job but then she has a smaller child and there is no one to leave him with and I believe she doesn't want to get too many people involved because of the status because when people see you taking medication they would want to know why you are taking medication and she would have to do a lot of explaining. So I think that is her main reason for not working; getting someone to baby-sit".*

Martha's HIV friend said that Martha was coping well and she equated this to Martha's ability to help her child when he was ill and the lack of her attempts to find employment. Martha was afraid that others may find out about her status and she had fears about taking her medication in the presence of a babysitter. Martha preferred not to work rather than let the secret of her HIV status be discovered. She had dire financial needs but chose to stay at home to keep the secret. This indicated the depth to which Martha would go to protect the secret, there were already financial constraints, and poverty and it would have been expected that acquiring a job would help alleviate these issues. However, she chose to stay at home to keep that secret. Protection of herself and child was paramount.

## **Evan**

Martha's HIV friend reported on Martha's son's coping abilities, as follows:

*HIV Friend 4: "Very good. He is doing very good. I sat and talked with him on more than one occasion and he is handling it very well. He does not have complaints or anything and he does not express much as he does not talk much. He appears to be coping".*

Martha's HIV friend indicated that Evan was coping well. This was contradictory because although she said that she spoke to him on more than one occasion, he did not talk or express much. She seemed to have formed an opinion about his coping based on his quiet nature and not on his feelings about the issue of being HIV positive. This was one instance where the HIV friend actually spoke to a child to ascertain whether they were coping.



According to Pittiglio and Hough (2009), when experiencing a chronic and stressful illness such as HIV, coping behaviour becomes an important aspect of illness management. Some of the self-preservation techniques used by the women included sleeping, isolating themselves, shopping and chatting with a friend. These techniques helped the mothers gain some semblance of self-control in their lives and could be akin to emotion-focused coping. Emotion-focused strategies are aimed at managing the emotions aroused by stressors in order to maintain “affective equilibrium” (Moos & Billings, 1982). Emotion-focused coping has been found to be most effective when control over the outcome is limited and the stressor is considered unchanging and inescapable (Schussler, 1992). In this study, emotion-focused coping was the strategy that HIV friends most often found in their assessments of the mother’s behaviours.

The HIV friends were aware of the coping strategies of the mothers and actually stated what the mothers did to cope. However, with respect to the children, their reports on coping were based on observation of the child’s behaviour. Assumptions were then made based on that behaviour. The children did not share how they felt or how they coped and so the HIV friend’s observations and assumptions about the children’s coping strategies were not based on contributions from the children.

Hough et al. (2003) note that the psychosocial adjustments of a child of an HIV-positive mother appears to be related to the mother’s emotional distress, which itself is affected by the mother’s level of social support, HIV-related stress and coping behaviour. It is to pay attention to the coping strategies HIV-positive mothers use and how these strategies impact their children. According to Herman and McHale (1993), children seek social support from parents and peers in order to cope with stressful situations. Social support and coping appear to be linked; one is a result of the other. Thus, social support is also important in the management of HIV/AIDS as it encourages positive coping strategies.

Using a case triad method that incorporated both mothers and children was important as based on the interviews and data analysis it was seen that, to a great extent, addressing the psychosocial issues and social support of children depended upon the

mothers. Management, treatment and care of children with HIV/AIDS greatly impacted the mothers' coping strategies and their social support structures.

### **6.4.3 How the HIV Friend viewed the mother and the child**

The HIV friends viewed the mothers and the children in varying ways based on their observations of the interactions between the mother and her child, as follows:

*HIV Friend 1 (social worker): 'I see a mother struggling to cope in terms of disclosure. To date the school is not aware. A lot of key personnel who should have known by now, they are not aware in terms of establishing support for the child. The grandmother is not aware. The other siblings are not aware. So she is very much sheltering her daughter by just keeping it between both of them'.*

*'Right now, because the daughter is now 13, the daughter is aware for the past two years and the daughter is exhibiting some strange behaviour. There is actually role reversal. She actually wants to mother her mother. She is making sure that her mother takes the medication. However, she of herself is not being aware that she needs to take her medication'.*

*'So she is denying herself, but making sure Mummy gets hers. That is a kind of strange kind of behaviour'.*

In this case, disclosure seemed to be a significant issue with the mother and keeping the secret was a priority in Mary's life. Amy has become increasingly aware of her HIV status, she is also aware that her mother should be taking her medication, however, she does not focus on herself with respect to her medication ( Amy was taking antibiotics, not ART).. The role reversal here seems to be one of necessity emphasising again that these were 'young carers with HIV'.

*HIV Friend 2 (sister): "Well, she blames herself all the time. On the other hand, the children act like there is nothing wrong with them. They act normal. Although they know they are sick, they act normal. Emotionally the mother is vulnerable".*

In this scenario, there appeared to be a lot of self-blame by the mother and emotional vulnerability. This friend thought that the children should not be seen as normal because they were sick. The friend thought that, maybe, the children should have exhibited some form of sickly behaviour. The HIV friend was questioning what was normal; however mothers created a 'new normal' with respect to parenting with HIV-AIDS.

*HIV Friend 3 (partner): "It is, how to put it, they are hurting a lot in many ways. Petra right now she is sorry about her position, (being HIV-positive) what it is, and certain times she does regret that she is (HIV-positive) you know. Yes, it is hard for them.*

*The main issue is that they are sick, and people out here, society out here, when they do find out, they are just going to watch them and scorn them and treat them like they is nothing. I learn about HIV what it is about. I went and learn about it and get information. I went to the seminars with Petra and find out exactly what it is about although I had ideas before. I am comfortable with it".*

In this response, this friend saw the mother and child as hurting. He saw Petra as being hard on herself with respect to contracting the virus and regretted being HIV-positive. He also viewed Petra and her child as sick. He alluded to the possibility that Petra and her daughter would experience stigma and discrimination if their status was disclosed. Thus, he decided to keep their secret.

*HIV Friend 4 (nurse): "I think she views herself as a normal person. She doesn't see it as a handicap in any way. Her main issue is poverty; poverty is the main issue. On more than one occasion she has called and asked for some financial assistance and I try to help her as best as I could".*

In this situation, Martha most likely may have been experiencing social hardships before which were exacerbated by living with HIV. Lesar and Maldonado (1997) report that the impact of HIV can be overwhelming for a family. Families of children with HIV are burdened by social and economic disadvantages, face additional issues related to social isolation and the fear of rejection, as well as feelings of guilt and care-burden demands that may threaten the equilibrium both of the individuals in the family unit and the family unit itself (Lesar *et al.* 1995). In this research, in addition to the information mothers shared about the ways in which HIV affects them, the HIV friends noted the presence of these issues in the mothers' lives. These issues include self-blame, guilt, regret, isolation and poverty.

In the children's findings of this research, the children said that they felt normal among their peers; however, their peers did not know that they were HIV positive. One of the HIV friends said Bertha's two children 'acted normal' even though they were sick. In their study, Cree *et al.* (2006) speak about how children stressed that their experience was 'normal' and that they had 'normal parents'. These children did not want to be

treated differently from other children. However, in an earlier study, Cree *et al.* (2004) state that the lives the children described were evidently outside of 'normal' experience for most children mainly because of the stigma attached to HIV/AIDS. The children in this study tended to normalise their experience as a coping strategy in order to live with HIV/AIDS in the home. Unlike the Cree *et al.* (2006) study, the children in this study had limited contact with extended family members and did not receive much support.

According to McLean *et al.* (2009) vulnerable children affected by HIV/AIDS in Trinidad face a broad range of problems often related to the illness and death of parents. Many of the critical issues, including psychological distress and economic hardship, have negatively impacted their health and nutritional status as well as their social development. Stigma and discrimination are major challenges faced by vulnerable children and their families, resulting in problems with educational facilities. This is often reflected in the children feeling the need to conceal their own HIV status or the HIV status of their parents in order to have access to the educational system. This concealment results in fear and isolation, negatively impacting the children in the long-term.

#### **6.4.4 Health issues**

When the mothers' HIV friends were asked about future health needs they responded as follows:

*HIV Friend 1 (social worker): "I think some of the services are, like at Medical Research Foundation (MRF), they need to have a separate unit. It is too much happening there. They are taking the blood; they are doing the general check-ups. And the staff in terms of ratio of patients to the care givers or the medical team, it is ridiculous. It is something like 40 to 1, and on an average there is a team of about three doctors and the capacity can be over 300 on a daily basis or sometimes, let me see, the most it could be is 350 or so on a daily basis, which is kind of like impossible.*

*So they need to have a proper approach to care. Like polyclinics, that is what I would suggest, polyclinics within the areas like - okay, the pilot was for Woodbrook and a few other areas to have polyclinics where they would do the x rays, home deliveries and things like that.*

*They could also have a separate unit — because of the sensitivity of HIV, people fear being identified because of the fear of stigma and discrimination. Therein lies*

*the problem. So it has to be properly couched within, like a skin clinic or within a diabetic clinic or something to that effect where they would not be vulnerable to any kind of discrimination.*

*So I would say they could try the polyclinic approach and use that because the overload at MRF is ridiculous. The service is good but it is too much. Because of that, sometimes one doctor would take too long or they might have to rush. You could get two sides of it”.*

In this situation, HIV Friend 1 identified several issues that were problems specifically found within the health sector. She felt that the burden of delivery of services from the MRF (main provider of ARVs) was too much and health care could be compromised. She suggested the help of polyclinics (clinics that provide a multiplicity of services) to reduce the burden placed on the MRF. She is also mindful of the stigma and discrimination that mothers and children can encounter when they try to access health care.

*HIV Friend 2 (sister): “As I said, they need more information on HIV, everything about it. This information will help young people from getting into that situation.*

This HIV friend felt that a need exists for greater dissemination of HIV-related information to foster more awareness and increase the public’s knowledge about HIV.

*HIV Friend 3 (partner): “Well so far — probably if they could help her, I presume yes, she could do with some more health services if it is possible”.*

*HIV Friend 4: Well, as I mentioned before, the only thing that she would need now and then is a little financial help, or if not financial help, foodstuff when we can afford it, when we can give her. I don’t know about support from family members as I have never met any of her family members”.*

#### **6.4.5 Overall future support**

The HIV friends provided their views on what should be done for HIV families in the future:

***HIV Friend 1 (social worker): “We need to put a structure in place, a built-in structure where mothers and children could get quality support. We need to take it away from the main hospitals too, try to incorporate it within the districts, polyclinics or something like that.***

*We need a much more formal structured support base for them. Many times our HIV clients and children have to just struggle with the informal systems, within*

*that they have to be so careful of who they choose to disclose to. So if they would be more receptive to a structured support base, then they would not have to go fishing to get an informal support, if there is something within the system that speaks to that.*

*So we have to work as a team: The coordinator of the Prevention of Mother to Child Transmission Unit; the medical social workers, the nurses, the doctors, the people at MRF and also too there is a support in terms of Mercy House if the person is on end stage”.*

**HIV Friend 2 (sister):** *“Mothers should not blame themselves because they did not know that they got it so they should not blame themselves and they shouldn't blame the children for having it”. (Mothers should not blame themselves as they do not know how they got the virus).*

**HIV Friend 3 (partner):** *“Most I can say is that everybody have to look at it beyond the HIV point. They have to look beyond that. They can't study that. The person still alive, they still human. So even self they sick or what, they still human. Just act as normal, it shouldn't have no difference. Yes. And people have to learn. That is the whole point. Nobody want to learn about it. They just say, like, because this person have this, they just ignore the person and lock them out. That shouldn't be”.*

*(Everybody has to look beyond the person with HIV and see that the person has life and is no different from everybody else. People just have to learn more about HIV, otherwise they will ignore the infected person and shut them out and this should not be).*

**HIV Friend 4 (nurse):** *“There are those who are really in need. I think the government is doing a good job as I see it now but then there are those like her who are really in need of let's say housing and I don't know if the government can help them in that area. If they can help them in that area it would be good, it would be very good.*

*I think that some of them (HIV infected individuals) do not have access to treatment because some of them live in very remote areas. And if the government could at least, either decentralise treatment areas, that's one, or provide transportation. We don't have to provide transportation that people would know where they are going; unmarked buses or something, some sort of transportation for them. Because as a result of not being able to go to the treatment centres or go for treatment, the children and the mothers too are not totally adherent to medication and this is what causes the children to become ill and some die in the interim”.*

As can be seen in these responses, the HIV friends felt that there should be polyclinics (clinics in every area of Trinidad and Tobago that address the issue of HIV with mothers and children) as part of the provision of health care for the whole population or at least

transportation should be provided for individuals so they can visit the centralised clinics. The respondents also noted that the persons involved in the care should be mindful of the issue of stigma and discrimination when introducing new services. They must also be mindful that PLWHA who are unable to easily access services might be noncompliant with respect to taking their medication. Consequently, this can lead to illness and even death. Traditional medical models of care seemed to be insufficient for catering for the unique needs of mothers and children infected by HIV/AIDS.

It was also suggested that more public education on the topic of HIV should be conducted. This can help increase awareness of the disease and reduce the stigma and discrimination experienced by the people who have HIV. Housing was another area that required attention as the homes of some of the HIV infected individuals lacked some measure of comfort.

### **Social services needs of women and children with HIV/AIDS**

The feedback from HIV friends included responses from professionals, a sister and a partner. How can this feedback be heard? How can these responses be linked so as to ensure that all the identified issues related to HIV-infected mothers and children are heard collectively and addressed effectively in an intervention? This research exposed these notable gaps

Research responses revealed that any intervention must arise from an ecological frame of reference and be conducted at all levels of society. This is to ensure that the government of the day is aware of the gaps in addressing the concerns of mothers and children and it must begin with them and trickle down to the other levels of society. This type of multifaceted response will address the needs of HIV mothers and children by involving individuals who support HIV-infected people at the macrosystem level, the exosystem (community) level, the mesosystem (family) level and the microsystem level.

Stein *et al.* (2005) note that a significant amount of funds are required to provide for the basic material needs of children and families affected by HIV. Additionally, intervention programmes that are sustainable, culturally appropriate and cost effective are urgently needed to support mothers and children with HIV. According to Hudson *et al.* (2001)

health care providers have opportunities to enhance the social network of HIV-infected women. Nurses, physicians and therapists can be important members of HIV-infected women's support networks by providing information and by affirming support.

Hackl *et al.* (1997) state gender-specific treatment models that help disadvantaged women of colour address their stress-management, support building, self-efficacy and self-esteem enhancement needs are generally important. They also noted that while intervention focuses on the women's needs, it must also provide supportive services to their family systems as the women define them to be. Group or individual interventions directed at affected HIV-positive or negative children, spouses or partners and extended family members can more effectively augment a woman's support network, facilitate increased HIV/AIDS knowledge and enhance social contact. Family education is important and this can help de-stigmatise HIV within the family unit. Individuals, such as children, can benefit from family-focused therapies in a safe environment where it is acceptable to express fears, anger and grief. It appears that garnering expanded and diverse systems of support will help HIV-infected women develop better primary coping methods than denial, concealment or isolation.

Hackl *et al.* (1997) find that medical care was insufficient in meeting the psycho-social needs of women living with HIV/AIDS. Hackl *et al.* argue for an integrated health care system that targets the women's overall health; however, on the basis of the findings of this study, this integrated system must also include services unique to children with HIV/AIDS.

## **6.5 Summary**

Four main themes were found in this study namely coping by children and mothers, social support, how HIV friends viewed mothers and child and the intervention needed at all levels.

Mothers identified their HIV friend based on the following criteria: trust, support and the ability of the person to keep the mother's secret. Additionally, two professionals, the social worker and the nurse, did more than they would typically do for a client in their capacity as care service providers; for example, the social worker gave Mary her phone

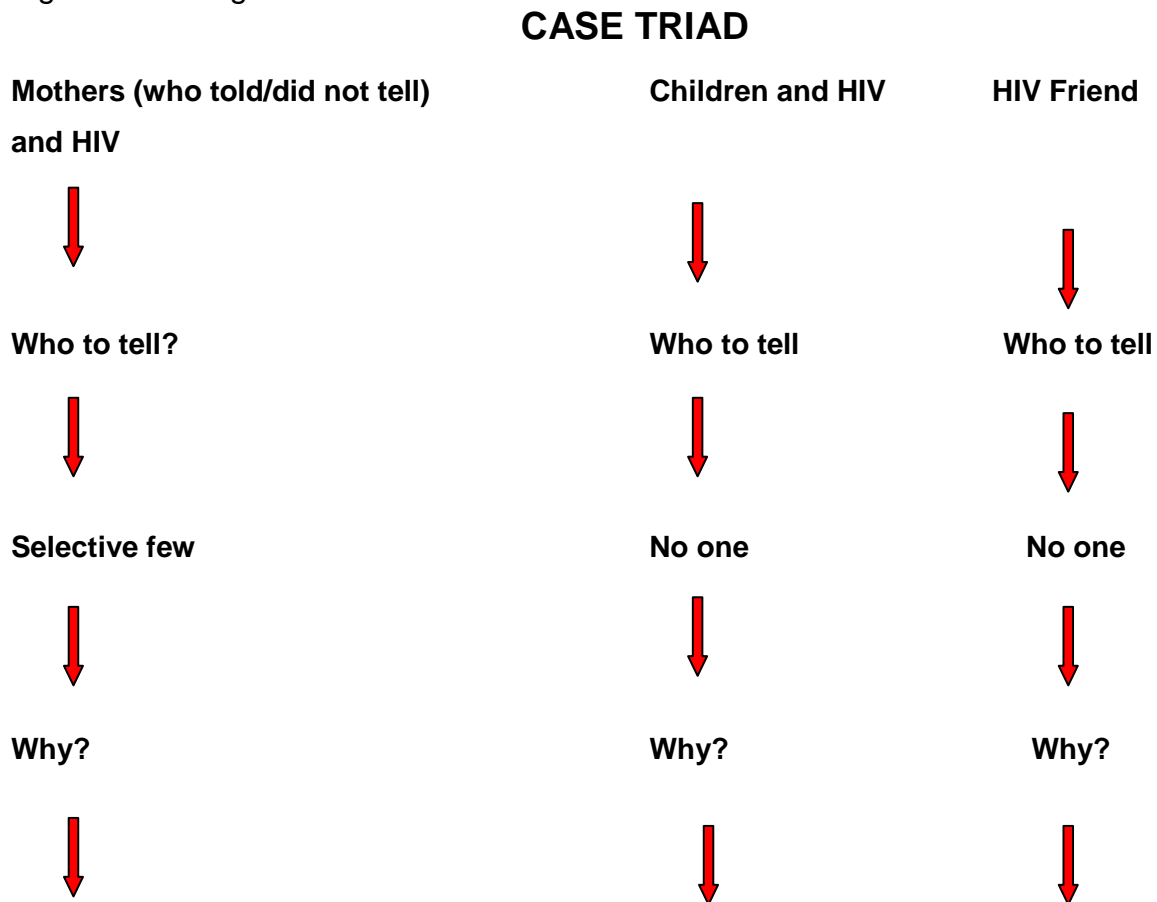


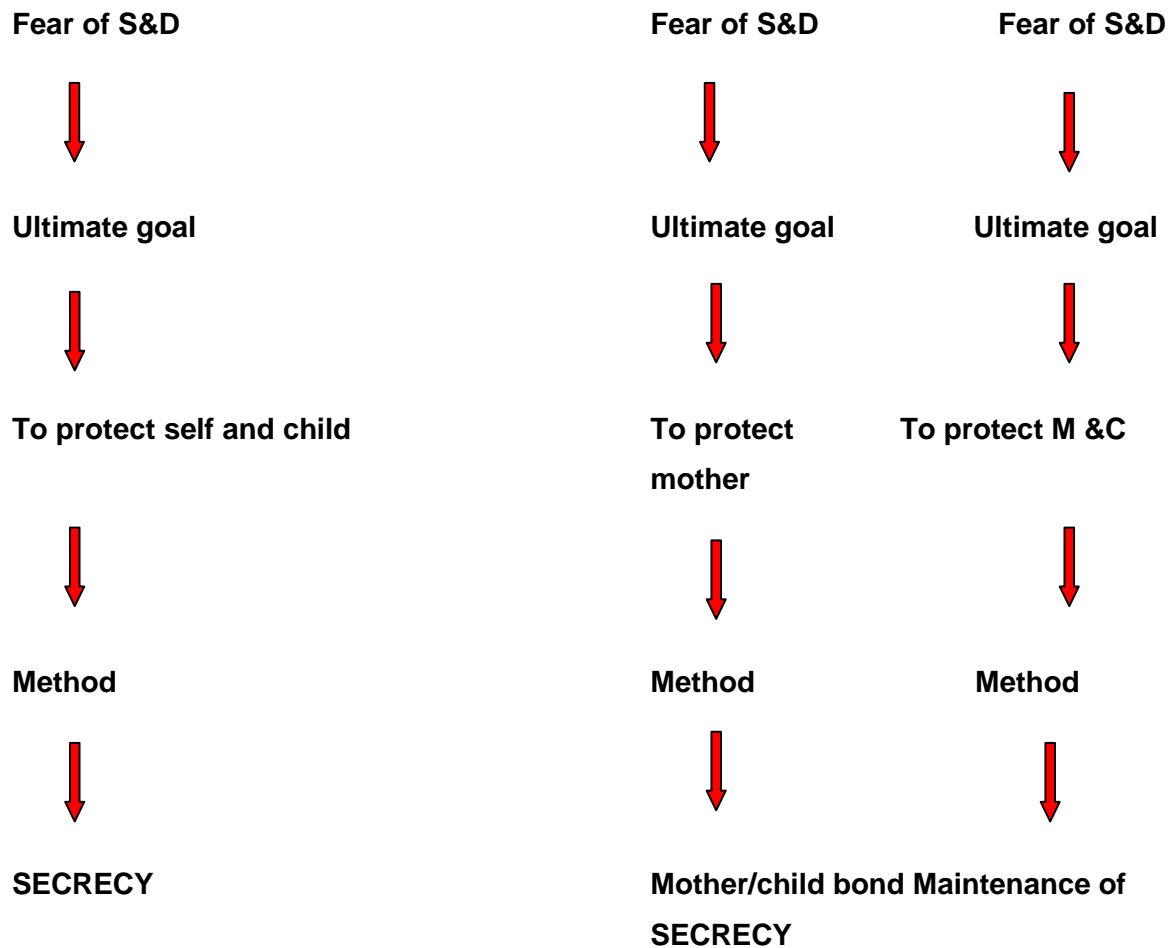
number and helped her with finances, when necessary. The nurse brought medication to Martha when she could not keep her clinic appointment as a result of limited finances for transportation. These personal support gestures helped to build trust between the women and these professionals.

The mothers and the children used coping strategies to help minimise the psychological effects of living with HIV/AIDS. Social support was more likely to be formal than informal as the informal networks of mothers and children were very limited. When exploring how someone with HIV was viewed, the term 'sick' was used to describe mothers and children and negative connotations were attached to this label. Some of the HIV friends made suggestions with respect to what was needed in the future to better assist mothers and children with HIV/AIDS. These suggestions included the institutionalising of polyclinics in various parts of the country to provide services for both mothers and children and to cater to their unique needs and concerns.

The following illustration shows the complete triad of secrecy:

Figure 6.5: Diagram of case triad





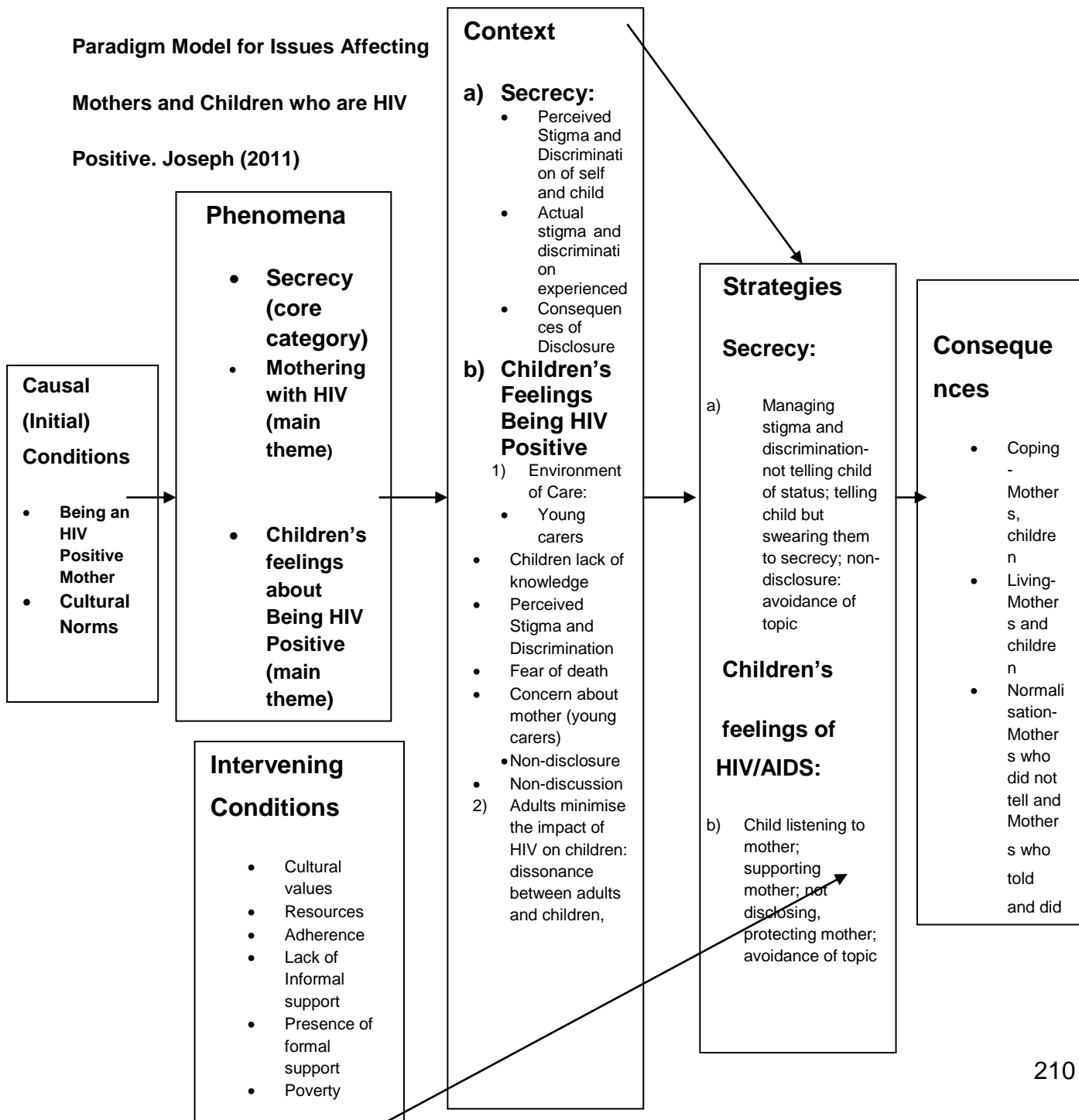
The story line has been completed. The grounded theory approach generated data that helped to put together a theory that suggests that mothers who told their children of their HIV status, mothers who did not tell, children and HIV friends all had one aim: to keep and maintain the secrecy of HIV-AIDS. However, the HIV friend of Bertha did say that Cathy and Brian should talk about their situation with someone. Having case triads helped to uncover the main underlying issues and to reveal how children survive in families with HIV-AIDS. It is important to note that the psychosocial issues impacted significantly on the family and especially children however a gap was uncovered in the way children were viewed. Children were not viewed as persons with their own feelings

about HIV but as the recipients of the projected views of the adults involved in their lives. This research provides heightened awareness of the needs of children born with HIV and the issues that impact their lives and emphasises the importance of children's voices being heard and addressed amidst the issues related to HIV-AIDS.

# Chapter 7

The purpose of this research was to understand the psychological issues and support for children with acquired HIV. The theoretical model framework suggested by Strauss & Corbin (1990) (3.6) was followed to help to fulfil that purpose. Fig 7.0 illustrates what evolved from the present investigation.

Figure 7.0: Paradigm Model- Culmination of themes and sub-themes for the case triad



## 7.1 Introduction

Thus far this thesis has explored the psychosocial issues and support for children with acquired HIV. Chapter four looked at the issues that affected mothers, chapter five in particular showed the issues that impacted the children and chapter 6 focused on the findings of interviews with the HIV friend. Main themes were discussed in relation to existing literature in keeping with the tenets of the grounded theory approach, to ascertain what information supports, explains, and refutes the findings. The main phenomenon, 'secrecy to protect' was discovered in the process.

It is important now to bring the themes of chapters four, five and six together to explain the emergence of the main phenomenon and also to highlight the themes that stood out in all the three chapters. Examples of these are 'mothers, mothering and HIV' and 'feelings of children living with HIV. The purpose of this chapter is to provide a framework for the understanding of the psychosocial issues and support among children with acquired HIV and to see theoretically how the themes played an integral part of the process. The chapter utilises the paradigm model by Strauss and Corbin (1990) to help draw the themes together in 'oneness' to delineate the issues that affected children and the family as a whole. This coming together can be likened to coastal redwood trees that grow so close together that they merge to form a canopy. Each of the components of the paradigm model will be explained with the canopy of themes to elicit the understanding of the complexity of the findings.

## 7.2 The Paradigm Model

The Paradigm Model (Strauss & Corbin, 1990, p. 99) was used to link the core categories or core phenomena with the overall themes of the three findings chapters with respect to the mothers, children, and support providers. The model consisted of six parts: a) causal conditions b) phenomenon, c) context, d) intervening conditions e) action/interaction strategies and f) consequences.

a) **Causal (Initial) Conditions-** This term refers to the events or incidents that lead to the occurrence or development of a phenomenon. They are mainly antecedent conditions which are often located in the data by terms such as "when," "while," "since,"

“because,” “due to,” “on account of”. One can focus on the phenomenon and look back into the data for events or happenings that seem to precede it (Strauss & Corbin, 1990).

b) **Phenomenon (core category and main themes categories)** - This is the central idea, event or happening, which a set of actions/interactions is directed at managing or handling (Strauss & Corbin, 1990).

c) **Context**- This represents the specific set of properties that pertain to a phenomenon. It is also the particular set of conditions within which the action/interaction strategies are taken to manage, handle, carry out and respond to a specific phenomenon (Strauss & Corbin, 1990).

d) **Intervening Conditions**- These are conditions that relate to the phenomenon. These conditions act to either facilitate or constrain the action/interactional strategies taken within the specific context. These conditions include: time, space, culture, economic status, career and individual biography (Strauss & Corbin, 1990).

e) **Action/Interaction Strategies**- Grounded theory is an action/interactional method of theory building. In studying individuals, groups or collectives there is action/interaction, which is directed at managing, handling, carrying out, and responding to a phenomenon as it exists in context. The action/interaction is purposeful and goal-oriented with its main purpose being to manage a phenomenon. Thus, it involves strategies and tactics.

f) **Consequences**- Action and interaction strategies taken in response to or to manage a phenomenon have certain outcomes or consequences. These may not always be predictable or what was intended. The failure to take action/interaction also has outcomes or consequences. There may be consequences to people, places or things. Consequences may be events or happenings.

### **How The Paradigm Model was Used**

The paradigm model in Chapter 7, Fig. 7 is a model that represents a visual strategy for presentation of the grounded theory that emerged from the study. This is a representation of the grounded theory that was developed from this research. The use of illustrative models is a relatively new strategy for the presentation of grounded theory

findings with the first and second-generation grounded theorists focusing instead of diagramming as a method of analysis (Birks & Mills 2011). The main parts were explained in Section 7.2. and expanded upon in the following Sections of the chapter based on Fig.7.

The model helps to make sense of the findings by illustrating the analytic methods used. Core categories and main themes that emerged from the interviews with the children, mothers and HIV friends are presented in relation to the framework suggested by Strauss and Corbin (1990) in Fig. 7.2. This highlights 'causal conditions', 'phenomenon', 'context' and 'intervening conditions' as the main elements for investigation. The different elements are linked in the following ways:

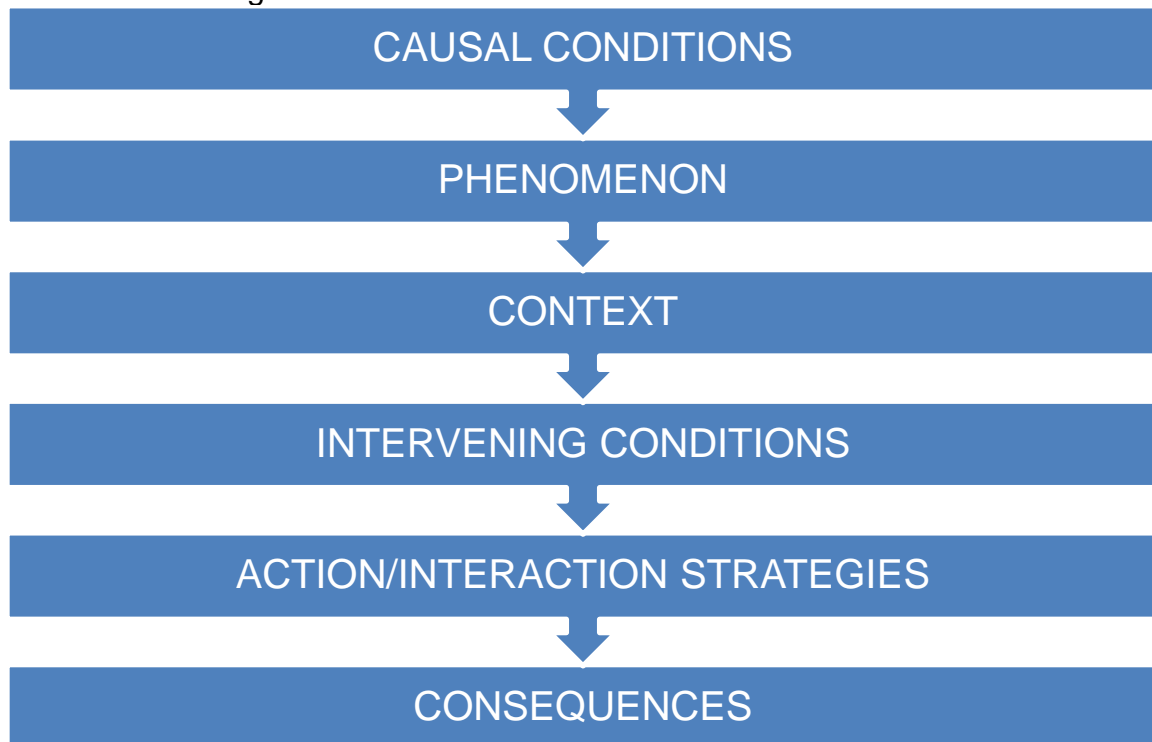
- Section 7.3 to Section 7.3.2 explores the causal conditions related to being an HIV positive mother and Caribbean cultural norms on mothering.
- Section 7.4 and its sub-sub headings addresses the phenomenon (lived experiences) resulting from a) being an HIV positive mother and b) Caribbean cultural norms (causal conditions). Additionally, the core category of secrecy; children's feelings about being HIV positive and mothers, mothering and HIV are discussed in this section.
- Section 7.5 and its sub-sub headings describe the context in which the phenomenon occurred and explore issues of secrecy; stigma and discrimination; concern for future of children; children's feelings about HIV-AIDS; environment of care; young carers; non-disclosure and non-discussion and, adults minimisation of the impact of HIV-AIDS on children.
- Section 7.6 and its sub-sub headings examines the intervening conditions in relation to the phenomenon which are identified as cultural values and gender relations; poverty; adherence; and, informal and formal support.
- Section 7.7 and its sub-sub headings describe the strategies used by mothers and children. This section focuses on the different strategies for managing stigma and discrimination by mothers 'who did not tell' as compared to mothers 'who told their children' about their HIV status. This section also discusses the strategies children used.

- Section 7.8 discusses the consequences of the strategies used by mothers and children: living and coping mothers, living and coping children, normalisation, self-blame, resiliency (mothers), resiliency (children).
- Section 7.9- Conclusion – this section pulls together the main themes

This model represents the final storyline (Strauss & Corbin 1990) giving the theoretical constructs (categories and their relationships) precedence. Birks & Mills (2011) posited that storyline has a dual function in grounded theory in that it provides a means by which the theory can be conveyed to the reader. Birks & Mills added that as a tool of integration, storyline aids in the constructing and formulating of the final theory and as a mechanism for presenting findings, it enables the researcher to bring to life a theory that may be otherwise dry and unpalatable. It is both a means and an end in itself. I chose to use the storyline to help formulate the final theory and illustrate it through the paradigm model in Fig. 7. The main theoretical positions presented in the thesis thus contribute new knowledge on the psychosocial issues and support for children with acquired HIV-AIDS in Trinidad and Tobago.



Figure 7.2: How Paradigm model was used



The use of this model assisted in putting the main themes together and organised them in such a way that the theoretical model for 'psychosocial issues', the support for children who acquired HIV from their mothers, and the phenomena that developed could be traced.

### **7.3 Causal Condition of Phenomena**

The causal situation refers to factors that influenced the central phenomenon or core categories - the events, incidences, and or happenings (Strauss & Corbin, 1990 p. 100). Two types of causal situations emerged from the analysis of data when the qualifying statements "due to", "because of" and "on account of" were explored with the data: a) Being an HIV Positive mother and b) Caribbean cultural norms.

#### **7.3.1 Being an HIV positive mother**

The seven mothers in this study expressed apprehension about being present and actively involved in their children's lives as the children grew up. The four mothers who revealed their status to their children were all from the lower socioeconomic level of

society, two of these women were employed in low salaried positions whilst the other two barely existed on the government's welfare.

Of the additional three mothers in the study who did not tell their status to their children, two were unemployed, (one of whom had chosen to be at home for the sake of her child and was in the best situation financially) and the third worked in a low paying job. Six mothers were all confronted with the reality that their financial situation clearly meant that they were frequently unable to meet the basic requirements for their children.

Abraham Maslow (1954) in building his "Hierarchy of Needs" model emphasis the foundational requirement for all humans to prosper and find happiness and contentment in their lives by denoting distinct areas, which include financial freedom. This is said to instil a sense of security, good health and high energy which is the productive outcome of a healthy body achieved through proper diet, exercise and adequate sleep. These mothers were mostly economically unable to supply their children with these basic needs and this reflected in the general decrease in their quality of life.

Even of greater concern, was these seven HIV positive mothers' state of general health, since at any given time they could be beset by HIV influenced illnesses that might diminish their life expectancy. They were troubled by the thought that their own lives may terminate prematurely and their children would be left, at young ages, unable to fend for themselves.

Additionally, the two working mothers expressed concern that their own deteriorating and indeterminate health condition could inevitably lead to the loss of their jobs and thus their means of livelihood. The implications of the latter for their children's and their own futures exacerbated their concerns. One of the four women revealed that it was challenging to remember to take her medication on a consistent basis, and suffered from general weariness and the absence of energy in the workplace. Another of the four had also contracted diabetes.

Jenkins and Coons (1996) note that when HIV enters women's lives it enters lives that most typically already contain other stressors such as, lack of health care, poverty and employment difficulties. Murphy *et al.* (2010) assert that mothers living with HIV-AIDS

report that their greatest source of stress is combining the maternal with the psychological and medical demands of coping with a chronic, life-threatening condition. Parenting stress has been defined as the difficulty that arises from the demands of being a parent and as a construct it consists of multiple components, including characteristics of the child, the parent and the context of the family (Reitman *et al.* (2002). Rodgers (1998) posits that parenting stress both directly and indirectly affected parenting behaviour. Moreover, Anderson (2008) asserts that parents in poor health reported significantly higher levels of parenting stress than healthier parents.

Mothers living with HIV report compromised parenting skills across a variety of parenting domains, for example, in a study by Kotchick *et al.*, HIV-infected African-American mothers are less likely to have a positive parent-child relationship and reported less parental supervision than a comparison group of non-infected mothers (Kotchick *et al.* 1997).

### **7.3.2 Caribbean Cultural Norms**

The second causal condition consisted of Caribbean cultural norms. Women have a greater vulnerability to HIV infection through heterosexual contact when compared to men and this is related to a number of biological, social, and economic factors, such as their physiological make-up, cultural norms and poverty (Jarrett *et al.* 2007). Bombereau & Allen (2008) explain that some of these social factors include Caribbean cultural constructions of masculinity and femininity. These cultural constructions impose obligations and restrictions leading to risky sexual practices, for example, early age at first sexual intercourse and multiple partnerships by men. Complying with gender expectations creates vulnerabilities for acquiring HIV. The authors added that the economic environment and associated gender inequalities affect sexual practices, for example, men and to greater extent women, put themselves at risk by accepting multiple partnerships and not negotiating condom use. Gender scripts represent culturally shared norms and beliefs about gender and sexuality that influence sexual behaviour in relationships and operate in three forms: a) cultural scenarios, b) interpersonal scripts, and c) intrapsychic scripts (Gagnon 1990; Simon & Gagnon 1999). Jarrett *et al.* (2007) state that cultural scenarios operate on the societal level and

provide relatively abstract guidelines for acceptable gender role behaviours, appropriate relationship partners, and sexual activities. Interpersonal scripts are constructed within the constraints of societal situations; they take into account the relevant standards of behaviour and comportment. Intrapsychic scripts are relatively free of the constraints of the other two, and represent the private fantasies or desires of the individual. These desires are not always in interpersonal scripts; instead, they constitute the person's inner world that may be considered inappropriate for interpersonal scripts.

The women in this research clearly had intrapsychic scripts, as they did not follow the prescribed gender cultural scripts on acceptable gender role behaviours, appropriate relationship partners and sexual activities. The women changed the script in part by making their own choices with respect to reproduction.

In Trinidad and Tobago it seemed as if these written scripts conveyed to women, that it was acceptable to have children but not when you are HIV positive. Thus there is the expectation that there should be a deviation from the norm (having children) to not having children once a woman is HIV positive. This deviation can be regarded as an exception to the rule of the normative script. On the one hand, this Caribbean society frowns upon women for not having children, but on the other, society is not in agreement with them having children while being HIV positive. Notably however, six out of the seven mothers went on to have children after giving birth to a child with acquired HIV. These women had re-written the prescribed gender scripts and had opted to write intrapsychic scripts that were relatively free of constraints and which represented the desires of the mothers to have more children knowing that they were HIV positive. This alludes to the self-determination and resiliency of the mothers. Childbearing was seen as a value in the mothers' lives even though it meant doing so with HIV with the attendant implications that this involved. Resiliency was a strength that pervaded the lives of the mothers. The mothers made their own choices in the presence of the following conditions: health concerns, concern for the future of their children, financial constraints, and the possibility of dying.

The notion of choice is problematic – it suggest the free expression of agency, however in reality women's choices are influenced and often determined by a range of social,

cultural and environmental factors. So in this instance, women's choices to become mothers were linked to expectations that for them to be viewed as whole, functional and valued women in society, they also needed to be mothers.

Amaro & Raj (2000) state that the social status and roles assigned to groups based on gender, race/ethnicity, and class are profoundly relevant to the understanding of the nature and dynamics of women's risks of HIV infection, and eventually, to the reduction of these risks. The authors added that in Freire's (1970) terms, poor women and women of colour most affected by the HIV epidemic have been "acted upon" or turned into objects. Freire refers to this as the disempowerment of individuals according to social status which results in the lack of ability or power to play an active role in decision about things that have direct impact on their lives. Reid (1993, p.143) also observes that "being silenced means having no access to dialogue and decision making. It means that others will set policies and define rules. In psychological research, poor women have been shut out and also shut up, that is, effectively silenced. Freire concedes that those who our society regards as the ones who are the experts are the voices that have guided public health programmes that are applied to poor women and women of colour. In this study the mothers can be said to fit the category of poor women of colour and it is important that what they had to say is heard and acted upon rather than there being sole reliance on the experts in the field.

Sexual behaviour is shaped by prescribed gender roles, which in all societies are defined largely by the lower status ascribed to women (Ehrhardt & Wasserheit 1991; Lips 1999). The AIDS pandemic takes place within a social context and it is intrinsically embedded in how gender, race/ethnicity, and class are defined, how resources are allocated, and how scientific activities are carried out (Haraway 1991).

Mothering with HIV has become the 'new normal' for these mothers because of their unique situation of being both a mother, being HIV positive themselves and, having a child who is HIV positive. The psychosocial issues present contributed to this and these included living with a chronic illness, financial constraints, disclosure issues, concern about the future of their children and the possibility of dying. In their own way they seemed to set a 'singular standard' among themselves as they extracted the capacity to

cope from within themselves and having limited social support, were able to translate this into resiliency in living with the disease. This new knowledge can help in the way intervention is conducted with women with HIV in that knowing that a woman may be self-determined to have another child, the social worker can give the necessary information needed with respect to ARVs and adherence to ensure that if the woman did become pregnant the child will be protected. This information cannot be taken for granted and it must be stressed in any intervention with women.

### **Theoretical Ideas and Concepts**

Research indicates that biological factors, prevalence of STDs, particularly among adolescents, socio-economic factors and economic reliance on older men who often have multiple partners contribute to women's greater vulnerability to HIV-AIDS in the Caribbean (Scott 1997). Scott stated that older women are not spared from these infections, as they are equally sexually active, either with their unfaithful husbands or other sexual partners. Research also shows that an increasing number of older married women are becoming infected with HIV. Scott points out that these women 'are vulnerable to STDs not so much because of their own sexual behaviour but because of their own partners; male promiscuity is commonly accepted as the norm by Caribbean women at all socio-economic strata' (p.248).

In the Caribbean as akin to the developing world, gender imbalance that dictates the female status, complex socio-economic norms, religion, ruling on sex, levels of poverty and a variety of factors negatively affect the ability of girls and young women to make decisions regarding their sexual and reproductive health, including the decision to protect themselves from HIV-AIDS (Collins & Toure 2004). The youth have become a vulnerable subpopulation for sexually transmitted diseases, including HIV. Young people are now the group at the highest risk of acquiring the virus, with 50% of the new infections occurring in young people between 15-24 years old and 70% of all HIV cases falling within the age group 15-44 (Camara *et al.* 2003). Douglas, Reid and Reddock (2009) posit that to date there has been no true explanation or understanding of the complex interplay between the social, cultural and economic forces that influence the gender differences in sexuality and therefore individual sexual behaviours in the

Caribbean. They added that it is clear that these factors have implications for the acquisition and transmission of the HIV virus and therefore the perpetuation of the HIV epidemic.

### **Patriarchy**

Gender has been found to predict adolescent sexual behaviour and gender-specific risk factors for sexual activity have been identified (Stallworth *et al.* 2004). In Trinidad and Tobago cultural contexts, multiple sexual partners are common and socially accepted and alongside this women experience difficulty in negotiating sexual practices and the use of condoms. These challenges arise because of power imbalances related to gender inequality and patriarchal values. According to Moore & Rosenthal (1992) individuals who subscribe to a traditional sexual gender role script allow for unequal power sharing within the intimate relationship between men and women. Women become submissive participants, whereas men become dominant participants within the intimate relationship. Also, sexual relationships between men and women are largely determined by acting out expected gender roles, place women in particularly precarious circumstances. This in turn may lead to undesirable circumstances from sexual risk behaviours, that is, the practice of unprotected sexual intercourse and of multiple sexual partners. Such behaviours may lead to sexually transmitted infections, HIV and unwanted pregnancy.

While patriarchy is not a fixed concept and there are many Caribbean women who are able to express and exert control over their sexual lives, nevertheless the factors I refer have been identified as a major reason for the growth of HIV prevalence among women.

The patriarchal power relations that operate within this context include:

- a. Gender inequalities - often related to men's greater economic power
- b. Masculine and feminine Caribbean identities (which include identities of motherhood)
- c. Historical and colonial legacies which have traditionally positioned women and children as objects who are possessed and controlled
- d. Patriarchal values

## **7.4 Phenomenon Resulting from a) Being an HIV positive mother and b) Caribbean cultural norms**

The two causal conditions, 1) Being an HIV positive mother and 2) Caribbean cultural norms, led to the development of one core category and two main themes as the phenomena found in the analysis of the finding.: **a) Core category- secrecy b) Main theme 1- Children's feelings about being HIV-positive and c) Main theme 2- Mothers, mothering and HIV.** Codes and categories were compared among the mothers, children, and HIV friends (Case triad) and from the three additional women.

### **7.4.1 Core Category- Secrecy- Mothers who told and Mothers who did not tell their Children**

The research showed that some mothers did not tell their children, keeping the secret while mothers who did tell their children ensured that those children told no one. The secret was kept at two levels within the homes: between mother and child, and mother from child (even more closed).

In the triad of mothers, children and HIV friend apart from the main themes that emerged there was the phenomenon of 'secrecy to protect' that linked the triad together. In the case of mothers who told and mothers who did not tell of their HIV positive status, the reason was because of fear of stigma and discrimination and their ultimate goal was to protect self and child. The method used to do this was that of secrecy in the home. The mothers however, told a few persons to obtain services and also a few family members for support. The children, who knew of their status, were told never to disclose because of the same fear of stigma and discrimination. They did not fully understand but realised that it was a request from their mothers that they must adhere to. Their goal was to protect their mothers. There emerged the mother/child secrecy bond. The HIV friends were the trusted few whom the mothers told, however they too decided not to tell because they wanted to protect the mother and child, so they kept the secret.



In looking at the findings the only persons who had the autonomy to reveal their status to a selective few were the mothers. The children were silenced in this regard, they did not have a say in their lives with HIV. The children in this study could discuss HIV in the home, have limited knowledge of what having HIV means and were told never to reveal their status. This rendered the child even more powerless as they did not know what their mothers were protecting them against. Secrecy was the method used by mothers to be in control of their situation and they genuinely felt that they were doing what was best for the child. Consequently, this brought attention to the nature of the social support system available to the children. The children viewed their mothers as their main support system and even if they wanted to disclose, they were afraid to do so when they considered the repercussions from their mothers.

The picture with respect to the children that emerged highlighted the limited informal support available as a result of the secrecy. That informal system of the child was the informal system of the mother. The needs of the child with respect to HIV were fulfilled physically in terms of visits to the clinic, medication and ART. However, psychologically there seemed to be a gap as the feelings and issues of the HIV positive child. This gives a new meaning to the term vulnerable as not only were the children vulnerable by having HIV and the psychosocial issues that ensued but they were also silenced by their mother's actions.

Secrecy in families involves the intentional concealment of information by one or more family members from others who may be impacted by it (Bok 1982). It is also important to distinguish between privacy and secrecy. The distinction lies in the relevance of the information concealed for those who are unaware of it (Karpel 1980). As Imber-Black (1998, p. 21) says "What is truly private doesn't impact our physical or emotional health" whereas secrets may have negative effects on, for example, the ability to maximise preventative health care. Imber-Coppersmith (1985) adds that even secrets made with the best intentions (to protect young children) might affect family relationships and interactions.

Theoretical, empirical, and clinical knowledge has focused on the motivation and mechanisms for keeping secrets and has identified three categories: a) relationship-based motivation, b) individual-based motivation, and c) information-based motivation. Relationship-based motivation is intended to maintain relational harmony and intimacy or to shield a family member. Individual-based motivation serves to maintain one's autonomy, ego boundaries, individual identity, and self-esteem. Information-based motivation is guided by a desire to convey information in a clear and relevant way (Afifi & Guerrero 2000; Golish & Caughlin 2002). The findings in my study suggested that the motivation to keep a secret was both relationship-based and individual-based at both levels of secrecy, more so with mothers who did not tell. Relationship-based in that the mothers in this study felt that it was necessary to shield their children from the outside world with respect to stigma and discrimination.. Individual-based in this regard meant that the mothers in the research wanted to maintain their autonomy and control over what occurred in their lives.

Nagler *et al.* (1995) state that many people affected by AIDS take on the associated stigma as a part of their own identity; in part, this explains the level of secrecy where mothers did not tell. Their resulting self-concept as unwanted and unloved contributes to the fear of disclosing the secret of their HIV status and their response may become one of further secrecy and denial. The internalising of stigma occurs when individuals incorporate standards from the wider society, making them more vulnerable to feelings of self-hatred (Lee *et al.* 2002). Cree *et al.* (2004) add that another reason for parents' reluctance to disclose their HIV status to their children is their fear that their children cannot keep secrets, while other parents do not disclose because they consider the children are too young (Faithfull 1997). This was confirmed in my study however, all the mothers stated that they intended to tell their children when they felt that they were old enough to understand and to be able to keep a secret.

Disclosure of maternal HIV to the child may be beneficial to the child (Amistead & Forehand 1995). It may provide the opportunity for anticipatory grieving and facilitate open communication between mother and children about the mother's illness (Doll & Dillon 1997). This is important because a child may be aware of the mother's illness and

may be unable to discuss his or her concerns and fears about the mother's illness (Zay & Roma 1994). In my study even when children had been told of their status, the topic of being HIV-positive was not discussed in the household. It must be noted that, because of the stigma and the discrimination that continue to be associated with HIV, a child who is told about his or her mother's illness must typically hide this information from others and if the child is unable to do so, he or she may confront cruel treatment from others (Armistead *et al.* 1997). This was one of the greatest fears of mothers on both levels in this study.

Secrets may have both positive and negative consequences. The aim of protecting others from adverse consequences may be viewed as a positive motivation. On the other hand, secrets in families may reveal dysfunctional relationships and may be physically or physiologically damaging (Bor *et al.* 1989). The destructive sequelae of secrets clearly outweigh any positive consequences. It remains to be seen whether secrecy-related problems in HIV/AIDS diminish as the social stigma towards those affected decreases (Bor *et al.* 1993).

It became clear that at every level of the analysis, secrecy was used as a means of protecting the family from stigma and discrimination. A cycle of the fear of stigma and discrimination had developed and in the perception of the participants what prevented discrimination from happening thus far was the fear of exposure, which fuelled the secrecy. Secrecy became a protective shroud over the family. Research has also shown how stigma may prevent access to and provision of care (Turan *et al.* 2008). Turan *et al.* purport that HIV/AIDS-related stigma contributed to the burden of care, forcing mothers to deal with tensions between the secrecy surrounding the disease and the openness required in providing care and receiving social support. The isolation of the mothers was exacerbated by the lack of effective formal psychosocial support targeting children, a finding confirmed by Wong *et al.* (2006) in their analysis of international policies on voluntary counselling. Dane (2002) speak about women and the enormous effort they exert to buffer their children from discrimination.

Secrecy with respect to HIV/AIDS is sometimes necessary to protect infected women and their children from discrimination; however, it can also lead to increased conflict and

disruption in the family (Walker 1991). The energy and resources that could otherwise be channelled toward coping with illness are spent on guarding the secret, leading to a distancing between family members (Black 1993).

#### **7.4.2 Children's feelings about being HIV Positive**

In the analysis of findings from the children, children considered themselves to be sick and they linked being HIV-positive to death. They had limited knowledge of the disease. They were quite willing to draw themselves and their families and they took part in other activities. However, they felt sad about having the disease. Some activities showed a more positive aspect of the children indicating hope for the future.

Many studies have only examined caregivers' perceptions of caring for an HIV-infected child (Hamra *et al.* 2005; Mawn 1999) and for those with other chronic illnesses (Dixon, 2003; Trzepacz *et al.* 2003). Few have actually studied children's perceptions of their illnesses (Instone 2000). Waweru *et al.* (2008) talk about the importance of studying children's perceptions of themselves, general well-being, psychological functioning, and social functioning as this can help assess and determine a child's quality of life. They added that HIV has become a chronic illness and that the effects of chronic illnesses on self-concept can increase as life with a chronic illness is prolonged. Thus, it is important to increase knowledge of the effects that living with HIV has on a child's self-concept as treatment outcomes and overall quality of life are affected by how children feel about themselves.

Nagler *et al.* (1995) speak about mothers' reluctance to disclose and said that the physical effects of AIDS-illness are undeniable; therefore, the results of these protective attempts is "to render the disease unnamed, unspoken, and often unspeakable to children who then have no name for what they know is happening to their loved ones and to themselves" (Nagler *et al.* 1995, p. 75). They concluded that the issue of secrecy is more about naming than about knowing; even when children have not been told, it would be inaccurate to say that they do not know. They know that something is wrong but it is something for which they cannot use the name (HIV); it becomes the 'nameless dread'. Without the name, children are unable to use language and words to help them understand and cope with frightening fantasies and painful realities. This can be likened

to children in this study who were not told. However, knowing the name but not having permission to use it puts children in a situation where they feel that they are defying their parents and being disloyal every time they have a clear thought about their position. In the experience of Nagler *et al.* (1995), once children have the name, they do not necessarily use it much as most children will keep the secret as their parents and society have taught them to do. They continued that although this protects the family from stigma, it also prevents the child or adolescent from receiving clarification, validation, and support. In the long term, this may threaten their psychological growth, impede their developmental progress, and interfere with their ability to cope in all the important areas of their lives.

It was also found that a significant mechanism for keeping secrets is topic avoidance, withdrawing from a conversation or omitting certain content (Christensen & Heavey 1993). This is typically used to avoid disclosure of failures, negative past experiences, and content that carries social stigma or taboo (Cain 2006; Dailey & Polomares 2004; Khadushin 2000). In this study, topic avoidance was used by all mothers to omit content that carries social stigma or taboo pertaining to HIV/AIDS. The mothers who told their children of their status imparted to them that HIV meant that they were sick. There was no discussion of the topic in the home. This led to limited understanding of the virus on the part on the children. In this regard the topic of HIV was avoided in the home as it seemed as if mothers themselves had unresolved issues about the topic and did not feel comfortable discussing it with their children..

Daniel *et al.* (2007) add that in the era of AIDS, silence and secrecy about death and illness might increase the physical and psychosocial vulnerability of affected and bereaved children. Vulnerability is associated with risk factors and cultural silence may be seen as an additional risk factor. Hence, breaching cultural silence may be seen as a protective factor enhancing a child's resilience. Resilience has been defined by Luthar, Cicchetti & Becker (2000, p. 543) as "a dynamic process encompassing positive adaptation within the context of significant adversity". The emphasis on resilience represents a shift in thinking about childhood away from focusing on vulnerability to give a more contextualised understanding of children's responses to adversity (Evans 2005).

Cultural silence is frequently the outcome of deep-seated taboos regarding adults talking to children about sex and death partly due to rules of respect that underlie family and kinship structures which may limit communication across generation and gender divides (Caldwell 2001; Allen & Heald 2004). Evans's study with children in HIV families looked at a model of resilience, centred on the concept of closeness and competence as conditions for coping. The results showed that cultural silence emerged as a risk factor that increases children's vulnerability through undermining both closeness and competence, while disclosure and openness- the breaching of cultural silence- are revealed as protective factors that may enhance resilience among children. Hence, breaching cultural silence could be a protective factor enhancing a child's resilience. Rutter (1990) state that vulnerability and resiliency are two poles of the same concept. Resiliency is not a fixed attribute of the individual; rather, it is enhanced by one or two protective factors, such as, close relations with competent and caring adults in the family.

#### **7.4.3 Mothers, Mothering and HIV**

Their main concern was the welfare of their children. In the mix was self-blame from two mothers and regret from a third, according to their "HIV Friend". With respect to children, mothers expressed a certain amount of guilt over either unintentionally transmitting the disease to their children or the stigma that their children might have experienced because of their mother's disease (Kneisl 1993).

The mothers felt that they had to protect their children as much as possible from the stigma that was directed to persons with HIV in society and they were convinced that they were doing what was best for them. Consequently they ensured that their children did not disclose to anyone and they themselves disclosed to only a trusted few. In disclosing to family and friends, women must be prepared to confront ignorance, anxiety, fear, sadness, guilt, blame and anger (Dane 2002).

Due to their financial situation, concerns for their health and future of their children, and the unique situation of having a chronic illness that is both shared by mother and child

created mothering with HIV as the 'new normal' in the lives of the mothers. This translated into resiliency with that situation.

Women with HIV infection are often faced with socio-economic stressors that exacerbate the negative consequences of HIV for their physical and mental well-being (Sobo 1993). The stressors of HIV-positive women with few financial resources are often compounded by the multidimensional responsibilities of being the family's primary caregiver (Hackl *et al.* 1997). Women reported that in spite of their HIV infection, family members expected them to remain in the role of primary caregiver (Florence *et al.* 1994). The decision to disclose their status places a complex burden on mothers. Parents often have difficulty discussing their status with children and in the instance where a child is also positive, discussing the child's illness (Nagler *et al.* 1995).

## **7.5 Context**

The context represents the specific set of properties that pertain to the phenomena; that is, the location of events or incidents pertaining to the phenomena (Strauss & Corbin, 1990). Strategies for living and coping were developed in response to **a) secrecy b) children's feelings about HIV/AIDS and c) Mothers, mothering and HIV**. These strategies were influenced by the causal factors: **a) Being an HIV positive mother b) Cultural norms**. The context in essence included the culture and socio-economic circumstances as discussed in the causal factors a and b.

### **7.5.1 Context with respect to secrecy**

The context in which secrecy operated included the perceived stigma and discrimination of self and child, the actual stigma and discrimination experienced, the consequences of disclosure and a general concern for the children's future. Mothers functioned within this context. The fear of stigma and discrimination from society played a large part in the way these mothers functioned at both levels (those who told and those who did not tell their children). This created the 'secrecy to protect' phenomenon that emerged. Some of the mothers experienced stigma and discrimination directly while the others knew that it existed. The reason they did not want their children disclosing to anyone, was that they perceived negative consequences of that disclosure with respect to their children

### 7.5.2. Stigma and Discrimination

Aggleton *et al.* (2003), in their work entitled “Stigma, Discrimination and HIV/AIDS in Latin America and the Caribbean”, acknowledge stigma and discrimination as playing a big role in the way people view HIV/AIDS. They said that HIV/AIDS plays to deep-seated fears and anxieties. All around the world, and especially in Latin America and the Caribbean, it has systematically played to, and reinforced, existing prejudices and anxieties. Aggleton *et al.* view stigma as existing beyond the minds of individuals, and as a social product with deep societal origins. In Trinidad and Tobago, children with HIV/AIDS have been denied access to primary school because of the fears and anxieties of parents of other children (Aggleton *et al.* 2003). All of the women in the study stated that they would not tell the school of their children’s status. They were very firm in this decision and ensured that their children did not disclose. One child tried to disclose her status but the mother interjected and told the teacher that this was not true. A recurring theme in the realm of felt-stigma (fear of being discriminated against) across both qualitative and quantitative research has been parental worry about children experiencing discrimination (Corona *et al.* 2006; DeMatteo *et al.* 2002; Ingram & Hutchinson 1999; Sandelowski & Borroso 2003; Scrimshaw & Siegal 2002; Semple *et al.* 1993; Vallerand *et al.* 2005). This study reflected these findings and led to the phenomenon of ‘secrecy to protect’. The thought of their children experiencing discrimination from society was a great concern for parents and they ensured that their children did not reveal their status to anyone. Hejoaka (2009) opines that understanding the daily HIV/AIDS care provided by women to HIV-positive children also requires consideration of the stigmatisation surrounding HIV/AIDS. She added that HIV/AIDS-related stigma adds an additional layer to the burden of care, compelling mothers to deal with tension between the secrecy surrounding the disease and the openness required in providing care and receiving social support. This dilemma was found in this study.

The mothers in this study also experienced this burden of care in mothering their children with HIV. They however, decided to deal with the tension between the secrecy and disclosure by choosing the path of secrecy even though disclosure might mean that they could access more social support. Goffman’s (1963) work on social stigma



provides a way to explore care interactions shaped by secrecy. He distinguished the discredited (those whose stigma is known) from the discreditable (those whose stigma can be hidden), which would include the mothers in this study. Goffman highlighted how the problem of the discreditable is to manage information (not saying anything about being HIV-positive) rather than the tensions generated during social contacts (interaction with people who know your HIV status). The care given by mothers to their HIV-positive children must therefore be understood as embedded in the context of the daily management of the secret (Hejoaka 2009).

### **7.5.3 Concern for Future of Children**

The mothers were all concerned about the future of their children. They expressed this in the clustering tool entitled “Me Myself and HIV”. They related that they did not put any concrete plans in place for their children’s care, as they did not have the finances to do so. Dane (2002) says that 25 out of 26 women made plans for their children’s future and these plans were to be absorbed into the family network, including, aunts, uncles, grandparents, and older siblings. The women in her study felt comfortable discussing plans for their children and the coping strategies they depended on throughout the disclosure process to the family were the same resources they used to plan for the future care of their children. The women did this based on the support they received when they disclosed their illness and their resulting sense of safety from discrimination.

Disclosure with support is very important. It may help women to better plan for their children’s future. In this study the mothers disclosed to a few persons thus minimising the informal social support available to the family. The mothers in this study did not trust those around them with respect to disclosure. They did not try to find out whether disclosure would have increased their circle of social support. It may have increased the number of persons who knew but they were not sure if it would have actually increased their social support. They did not want to take that risk and never discovered if there were indeed benefits of disclosing to more individuals. Thus, disclosure, when to disclose and to whom was an issue in this research.

#### **7.5.4 Context- Children's Feelings about HIV/AIDS**

The context that influenced children's feelings about HIV/AIDS was the environment of care which consisted of a) being a young carer, their lack of knowledge of HIV/AIDS, fear of death, being young carers with HIV (concern for mother), non-disclosure, topic avoidance, and lack of discussion about the topic of HIV/AIDS, and b) the minimising of the impact of HIV on children by adults, which created dissonance between adults and children.

#### **7.5.5 Environment of Care**

The children's environment consisted of a mother who was HIV-positive, other siblings, and a father or stepfather. Armistead *et al.* (1999) state that some work has occurred in the investigation of children's understanding of and knowledge about HIV/AIDS; however, such studies do not appear to have been conducted with children who have a parent infected with HIV/AIDS. Armistead *et al.* feel that a mother who is infected with HIV/AIDS should be best able to educate her children on the aetiology, transmission, and prevention of HIV/AIDS as her sense of vulnerability should help. However, it may be that mothers lack an adequate level of understanding of HIV/AIDS and are less knowledgeable than assumed. In this situation, the discrimination and stigma that occur around HIV may, in many cases, result in infected parents feeling too uncomfortable or ashamed to discuss their illness with their children (Armistead & Forehand 1995). Such mothers might not be inclined to initiate discussion of the topic, resulting in the loss of a potentially rich educational resource for these children. In my study, discussion of HIV/AIDS did not occur in the homes. The children were told not to disclose and they obeyed. Thus, there was no in-depth explanation of what the disease entailed. The children equated HIV/AIDS with death and dying and felt sad about that. Their only frame of reference was their mothers and the information given to them with respect to HIV/AIDS. They had no one with whom to discuss their feelings. It could have been that because of their situation and the way society reacts to people living with HIV (with discrimination) that they had difficulty resolving the issue of HIV within themselves and even more so with their children. More attention should be placed on mothers talking about their feelings of living with HIV and also having discussions with their children. The increased and improved knowledge and understanding that the children could gain

in this regard could help reduce the sadness that they feel whenever the topic or name HIV is broached.

Even though children were told about HIV, they were not told enough to extract an understanding or in depth knowledge of the disease. This placed the children at a disadvantage. Consequently they equated HIV-AIDS with sadness, a feeling they could not explain in words. However, when children's minds were diverted from the topic their demeanour changed to a more positive outlook and this was reflected in the given activities. This contradiction gives hope for future intervention with children. It shows that children infected and affected by HIV-AIDS can have a more balanced and improved quality of life once educated on the disease. Waweru *et al.* (2008) related that a number of distinctive psychological implications might be present in children living with HIV/AIDS and they need additional support. HIV/AIDS is surrounded by a code of silence and secrecy.

According to Waweru *et al.* (2008), art is one of the few expressive modalities when used with children leaves a tangible product, a visual legacy, and proof of a child's existence. They added that this is even more apparent during a life-threatening illness. Art is an unspoken, visual language and a valid and expressive form of communication. The activities given to the children included drawing their families and how they saw themselves with HIV. The drawings were positive representations of family and it was a visual representation of how they felt and what was happening in their lives. This was a tangible product that the children could actually see and acknowledge. It also seems as if this was the first exercise that allowed the children to express themselves with HIV-AIDS. The role of art and other forms of expression may be an important tool in interventions with children especially in situations in which children have little opportunity to express their feelings.

Letting the children draw and do other activities apart from the interviews provided me with a broader sense of what was happening in the children's lives. It gave a snapshot of how they viewed themselves and their families around them.

### 7.5.6 Young Carers

The children who participated in the study all helped their mothers in the home. Tisdall *et al.* (2004) posit that children and young people are even more likely (than what) to be affected by parental HIV as parents are living longer and are able to have more children. In the Tisdall *et al.* study, children and young people tended to be very involved in the health care of their parents but none received direct support from statutory social workers.

A growing body of research is dedicated to the impact of HIV/AIDS on children, but there is little that acknowledges the role of children in providing care and support for ailing parents or ageing guardians. There has been a tendency to downplay the active role and agency of young carers (Skovdal *et al.* 2009). In the research of Skovdal *et al.* the children in families with HIV (11-17) coped by mobilising social support, engaging in income generating activities, and constructing positive social identities around caring roles. They were able to participate in the community and negotiate support from it.

In my study, the children were between 5 and 13 years old and they were told not to disclose. They had limited knowledge of HIV/AIDS and could not mobilise social support. The only support they knew was in their immediate homes and in the clinic that they visited for their check-ups. However, one cannot dismiss the important fact that the children in this research mobilised internal resources in trying to maintain the secret and thus from their perspective could be seen as making their own contribution to the safety and protection of the family. The term 'young carers with HIV' may be an important way of giving recognition to the valuable role children play in families living with HIV. In Trinidad and Tobago, the term 'young carer' is not usually used to describe children who help ill parents in the home, thus by ascribing them this name it brings to awareness the important physical and especially psychological role they play in the protection of their families.

Amy helped her mother, Mary, to remember to take her medication and to take care of her younger siblings. She also cooked at times for the family. Brian and Cathy said that they helped their mother with the washing and with jobs around the home. Dawn and Evan also assisted in the home. They knew their mothers had HIV and they were

concerned. In their minds, they linked HIV with sadness and death; thus, they felt obligated to help. These children were told to keep their HIV status a secret. They could not reach out to anyone; they were told not to tell. The tasks, however, did not appear burdensome beyond the usual familial and societal expectations of children's contributions to the households via household chores. The main issue here was the concern for their mothers. This was the impetus for helping in the home.

Parents with HIV are living longer since the advent of ART and the concern is that children and young people are more likely than ever before to be affected by parental HIV (Kay et al. 2004). One does not want parents to die with HIV/AIDS; however, in this study, its extended duration meant a longer period for children to carry this psychological burden without some form of professional intervention.

#### **7.5.7 Non-Disclosure & Non-Discussion (Double Negative)**

The mothers of Amy, Brian, Cathy, Dawn, and Evan told them not to disclose to anyone for fear of attracting stigma and discrimination. Amy tried to disclose to her teacher but her mother went to the school and spoke to the teacher. She claimed that it was a lie. Non-discussion was a covert rule in the home. Non-disclosure and non-discussion served to compound the secret of HIV/AIDS. Those parental dictates muted the children's voices. Kay et al. (2004) state that in their research although all the children they interviewed expressed their concern about their parents, only a few were able to talk to parents about their fears or to ask questions about the illness.

#### **7.5.8 Adults minimise the impact of HIV/AIDS on Children**

Whether mothers told, or did not tell, their children, all believed that keeping the secret by neither disclosing or discussing the disease, protected their children from harm and the negative effects of stigma and discrimination, . However, the social support of the child's world was constricted. The mothers were determined to protect their children, and in that commitment, lost sight of the actual feelings of the children with respect to HIV/AIDS. The mothers were not aware of their narrow views of their children, of how they were coping with HIV/AIDS, and of how the situation affected emotionally. Their focus was on the effects of stigma and discrimination, which might have been one issue of many psychosocial issues affecting the child.

Two of the four HIV Friends said that Dawn and Evan were coping well. One said that Dawn was stronger than her mother, she was growing with HIV, and so she was coping with it fine. The other friend said that Evan was coping fine as he never had any complaints. She said that he did not talk much. It seemed as if adults were making assumptions about the children. They equated coping “fine” with growing with HIV and having no complaints about HIV/AIDS when they had never actually had a conversation with either child about their positive HIV status. The friend of Brian and Cathy said that the children were fragile and that they needed to speak to someone, maybe a counsellor. The friend of Amy said that Amy coped by mothering her siblings and ensuring that stress was reduced in her mother’s life. It is important that adults try to listen to children and to be aware of their needs. Children do need to have some input in their lives especially when living with a chronic illness.

## **7.6 Intervening Conditions- Cultural Values & gender relations**

In addition to context there were intervening conditions that led to the phenomena. Intervening conditions include a) cultural values, b) resources, c) lack of adequate informal support, d) presence of formal support and e) poverty.

Cultural values that impacted on the mothers were the high status of “the mother role” in the Caribbean, linking of child-bearing to a strong self-image and a sense of motherhood that serves as a “rite of passage” for women.

Bombereau & Allen (2008, p. 2) examine the social and cultural factors driving the HIV epidemic and came up with the following. They posited that Caribbean cultural constructions of masculinity and femininity impose obligations and restrictions leading to risky practices (early age at first sexual intercourse and multiple partnerships by men. Complying with gender expectations creates vulnerabilities for HIV in the general population and not just among people often thought to be at high risk such as sex workers and men who have sex with men. They added that the economic environment and associated gender inequalities affect sexual practices. To access economic resources, men and to a greater extent women put themselves at risk by accepting multiple partnerships, not negotiating condom use and or trading sex for money and goods.. These practices are supported by the cultural norm that men should provide

financially for their sexual partners. Bombereau & Allen discovered numerous studies documenting social and cultural factors driving risky sexual practices in the Caribbean but only a handful which documented social and cultural factors that may have a protective effect in reducing the risk of HIV transmission. Among these were a sense of “connectedness” with school (for young people) and strong and supportive family relationships appear to be important protective factors.

Stuart (2000) states that in Caribbean society, the gender-power relations are such that men make the decisions in sexual relationships. Women may have some power as a result of the important roles that she has in the family, however, men usually make decisions of a sexual nature. Caribbean women who are economically dependent on their male partner, power and decision-making is further impaired. Campbell (2006) states that gender inequality and the subsequent effect on negotiating safer sexual behaviours is at the heart of gender-related HIV-AIDS risk for girls and women in the Caribbean. These are a vast number of manifestations of gender inequality and have implications for risk.

The cultural construction of masculinity and femininity in the Caribbean played a major part in male/female relationships. And do contribute to risky sexual practices. These cultural values and factors form the backdrop of the HIV positive mothers in this study

### **7.6.1 Poverty**

Barnette & Whiteside (2002) assert that AIDS deepens poverty and increases inequalities at every level, household, community, regional and sectoral. The epidemic undermines efforts at poverty reduction, income and asset distribution, productivity and economic growth. Stillwagon (2001) has recently convincingly argued that HIV prevalence is highly correlated with falling calorie consumption, falling protein consumption, unequal distribution of income and other variables conventionally associated with susceptibility to infectious disease, however transmitted. Stillwagon states that the causal chain runs from macro-factors that results in poverty: through the community, the household, the individual and into the resilience of the individual’s immune system. Protein energy malnutrition, iron deficiency anaemia, vitamin A

deficiency all of these poverty related conditions decrease resistance to disease in general and to HIV in particular.

Barnette & Whiteside (2002) posit that poverty is more than income and economics. There are many types of poverty: 1) service poverty where people are unable to access or are not provided with services such as health, and education and 2) resource poverty, where though they have sufficient incomes people are unable to access resources because they may be poor in terms of their rights, representation or governance..

The financial resources available for these mothers and children were limited as these families were from the lower economic stratus of the society. Although employed, Mary and Bertha were unsure of their jobs in the future because of ill health. Petra and Martha were unemployed and both depended on social welfare in the form of a disability grant and public assistance, respectively. Bertha, Petra and Martha depended on their spouse or partner for additional financial support. Mary depended on her last child's father for instrumental support, as he sometimes would come to her assistance in taking care of his child. The women did not experience service poverty nor resource poverty. Their household incomes were not enough for an adequate standard of living.

### **7.6.2 Adherence**

Adherence is crucial for both mothers and children to maintain a healthy lifestyle and to prevent the onset of AIDS. Bertha and Petra had adherence issues and were trying to have a regular medication schedule. ART is critical to the assessment of treatment success and there is need to maintain adherence levels at 95% to affect virologic suppression (Bartlett, 2002). Non-adherence allows the HIV to replicate rapidly and creates multi-drug resistant strains of HIV, thus compromising the person's health (Simon et al., 2002). Non-adherence by mothers spilled over to their children. Bertha's two children, Brian and Cathy, appeared to have symptoms of AIDS as their skin was covered in a rash and their CD4 cell count was less than 200. Their mother admitted that they too had adherence issues and that she was trying to correct this by taking the ART at regular times in the morning and evening. Petra's daughter had a persistent



cough and this may have been a result of her non-adherence as well. Petra could not remember her daughter's CD4 cell count.

Mary and Martha were able to maintain a strict adherence schedule. Mary's daughter Ann was not on ART but took the antibiotic Septra for other related infections. Martha ensured that her son Evan also maintained a strict ART regimen. It seemed to follow that if the mother was non-adherent, the child would have a similar experience, and this had negative influences on their health. One could also say that if the mothers were following a strict regimen and encouraging their children to do the same, then this could turn around the negative impact on their health. Thus far, the mothers in this study had a great influence on their children as they were all in the 'same boat' that is, infected with HIV, keeping it a secret, and to varying degrees, co-dependent on each other.

### **7.6.3 Informal and Formal Support**

Informal support was very limited for all the women as this was restricted by the secret of HIV/AIDS in the household. Both Mary and Martha identified a professional person as their main support, even though both had said that they disclosed to their sisters. They felt comfortable identifying professionals as supporters, suggesting that this group of persons able to provide them with some form of informal support was minimal. All the women entrusted this secret to at least one person. Murphy *et al.* (2009) posited that mothers with HIV were isolated as caregivers because they limited potential social support by keeping the disease secret. In this research, the mothers thought that they and their partners were quite capable of taking care of the infected child within the realm of secrecy. Yet mothers were both caregivers and clients of support services at the same time, which led to more stress on the part of the mother. They continued that further research was needed to integrate individual approaches in order to emphasise the experience of both caregivers and children in the context where care was shaped by secrecy.

## **7.7 Strategies**

The context, the intervening conditions, and the main themes that emerged created two major strategies for children living with acquired HIV/AIDS: a) managing stigma and

discrimination and b) managing children's obedience or compliance to non-disclosure of status and non-discussion of HIV/AIDS.

### **Managing Stigma and Discrimination**

The fear of stigma and discrimination was an issue in all families studied. The main response of mothers was secrecy. Some strategies used to maintain this goal included a) not telling the child of their status: secrecy maintained by the mothers, b) telling the child but swearing them to secrecy: non-disclosure to anyone, and c) non-discussion of the topic of HIV/AIDS in the home: topic-avoidance. Some strategies were common to mothers who told and to those that did not tell.

### **Mothers who did not tell**

The mothers who did not tell used the first strategy. They believed that they were protecting their children, that the children were too young to address living with HIV/AIDS, and that they would not be able to keep the secret. Faithfull (1997) state that women did wonder at what age they should disclose to their children. She granted that age might be a good reason for nondisclosure; however, she also noted that young children often sense the presence of serious illness and could probably benefit from age-appropriate explanations. Bor *et al.* (1993) state that the reasons mothers give for not disclosing the diagnosis to their children include fear of the child disclosing to others, which could threaten parental confidentiality, fear that disclosure may exacerbate the disease process, and concern about family stability. Armistead *et al.* (2001) added that given the lack of findings regarding the negative impacts of disclosure on child functioning, it might be safe for children (who were not HIV positive) as young as 10 or younger to bear the burden of knowing about a mother's HIV. However, the information must be relayed in a developmentally appropriate manner. This means that the child must be allowed to control the quantity and quality of information given by structuring the conversation around his or her questions.

Mothers in this study did not tell because they felt the children were not old enough and because they felt that the children might disclose the information about their status to others. Thus, the secret was kept firmly at one level - with the mothers. They felt

justified in not revealing the child's or their own status to their children as they believed that they were protecting them from stigma and discrimination.

### **Mothers who told their Children**

In some cases, the secret moved to the level of the child with HIV. The children were told not to disclose to anyone, even though they might want to do so. According to Green *et al.* (2003), disclosure entails shifting the burden to others who then become locked into another's private boundary, the disclosure is selective and accompanied by the knowledge of 'restricted circulation; from then on, these people become confidants, co-owners of the information and are obliged to assume certain responsibilities.

In the study, this is what happened. The children became co-owners of the secret and with it, they assumed the added responsibility of keeping the secret. They were told not to tell and they obeyed. The children did not understand fully what being HIV positive meant yet they knew they were HIV positive; they equated being HIV positive with death and dying, yet they could not discuss the topic of HIV/AIDS anywhere, including at home. They had feelings of sadness, and in addition, they had the stress of having to keep a secret. This might have been too much for a child to manage but it seemed as if the mothers thought they were protecting their children and that they genuinely believed this. However, they might have been doing more harm than good in the long term.

The children had no outlet for their feelings. This situation was an unhealthy one. It was as if the weights of these psychosocial issues were being added to one side of a scale making the child's life unbalanced. What would it take to even out both sides of the scale or even to reduce the heavily burdened side? From their exercises, these children showed that they had hope for the future. The question is however, how professionals and parents can tap into this hope (resilience-based interventions) and to use it to turn things around for the child.

### **Non-Discussion of HIV/AIDS- Topic Avoidance**

The topic of HIV/AIDS was not discussed. It seemed as if there was too much emotion attached to it as both mothers and children were HIV positive. They were supportive of each other but concern for their children's future, death and dying, adherence to

medication, illness, poverty, uncertainty, ignorance, and secrecy all acted as barriers to discussion of the topic within the family. This did not restrict the support required but further restricted the social support available to the children.

### **7.7.1 Children's Feelings on Having HIV/AIDS**

The strategies that children used to address HIV/AIDS were designed to protect themselves and their mothers by keeping the secret of HIV/AIDS. Although they were explicitly told not to tell anyone, one child told and another wanted to tell. However, they soon conformed to what was required by their mothers. In the world of children with HIV/AIDS, one wondered if there could be any allies for these children apart from their mothers. The mothers believed that they were doing what was best for them by engaging them in keeping a secret. The question for professionals becomes one of intervention – Is it appropriate? When? How? How extensively? What about children's rights? Betancourt *et al.* (2010) report that the security needs of children involved protecting their healthy and successful development. This means that for children with HIV/AIDS, human security strategies must not only protect the young from harm but must also create the conditions for children to develop, thrive, and reach their optimal potential. Betancourt *et al.* argue that realising the rights of children is about much more than ensuring their basic security needs. However, using the UN Convention on the Rights of the Child (CRC) as a guide, a human security approach to children affected by HIV/AIDS provides an important starting point for understanding the core threats to their life, survival, and development. Melvin & Sherr (1995 p. 411) state that “our understanding of issues for children are embryonic....the burdens of secrecy, bereavement, and illness may weigh heavy on young shoulders”. The children in this study did need much more support than they received, and maybe, if those with whom they interacted were aware of the issues that affected them, better services could be provided for their overall well-being.

### **7.8 Consequences of Strategies for Children Living with HIV/AIDS**

The strategies used by the mothers and children had consequences in their lives. The main consequences affected a) how they lived and coped, b) normalisation, and c) resilience.

## **Living and Coping with HIV/AIDS- Mothers**

HIV/AIDS infected women have to adjust their lives to survive the unique challenges and stressors of HIV, including disclosure, stigma and discrimination, poverty, and gender roles (Sandelowski *et al.* 2004). Stigma, discrimination, secrecy, and disclosure are unique and significant issues for parents living with HIV/AIDS (Hackl *et al.* 1997; Lesar & Maldonado 1997; Melvin & Sherr 1995). The women in the study experienced these issues and more in the face of HIV and used cognitions and actions to manage the stressors associated with living with their illness. Pittiglio & Hough, (2009) suggest that tension-reducing can be conceptualised as passive, decisive, or focused behaviours used to obtain physical or emotional relief from the multiple stressors associated with being a low-income, HIV-infected mother. The coping by the women in this research was more of a passive tension-reducing and emotion-focused nature. The women, even though they did not attend church regularly, depended on reading the bible and praying for emotional comfort and for strength to deal with the issues of living with HIV. This strategy was also found in the study by Pittiglio & Hough (2009)..

Social support is a coping resource that is external to the individual, which involves relationships with other individuals or groups (Smith *et al.* 2001). Social support includes supportive interactions (Turner 1981) and may include “instrumental, informational, and or emotional assistance” (Thoits 1995). Owens (2000) provides the following definition of informal and formal support. Informal support emanates from family and friends and consists of the following: emotional-affective support (love, care, empathy, concern, and compassion), family commitment, and family acceptance (intangible support). Formal support consists of assistance with parental responsibilities, household activities, and help from clinics.

In this research, all the mothers had access to formal support in the form of professional help: medication from clinics, visits to doctors, and social welfare. Children provided emotional and instrumental support. Other studies have also shown that children are an important source of social support for HIV-infected women (Andrews *et al.* 1993; Barroso 1997)

## **Aspects of Religion**

It was not religion per se that women used to help them to cope, but prayer and reading the bible – this suggests that there was value in finding spiritual meaning the experience of living with HIV as well as in garnering strength to manage their everyday lives. What I understand from this is that women were able to use prayer as a means of reframing the negative narratives of HIV victim and carrier of a deadly virus into positive narratives dominated by ideas such as the value of life, the need for thankfulness, the idea that there are others who are worse off, that life is given by God.

Despite the strong tendency towards secrecy, positive social support helps people maintain their health and welfare under difficult circumstances (Hudson *et al.* 2001). Supportive interactions for HIV positive women have addressed stressors such as isolation, stigma, and disclosure (Chung & Magraw 1992; Williams 1995). However, the mothers in this study preferred not to risk stigma even though sharing information about their status might have increased their informal social support network. They did not have the confidence to challenge stigma or to risk the loss of family relationships or friends; thus, they settled for isolation, secrecy, and minimal informal support.

## **Living and Coping with HIV/AIDS- Children**

Coping strategies that lead to successful adaptation to stress may be different for children than for adults. Whereas avoidance is associated with psychological distress in adults, stress and distress are often associated with increased social competence and the development of an internal locus of control in children (Kliewer 1991). It is widely recognised that children seek social support from parents and peers as a method of coping with stressful situations (Herman & McHale 1993; Rossman 1992). Garnezy (1983) identified support from family members and support from other adults and or agencies outside of the family as important protective factors that reduce the potentially harmful effects of chronic stressors on children. In a study where parents cared for HIV-positive children, the need for information on stress management, relaxation techniques, and coping came second only to the need for more information about HIV itself (Wiener *et al.* 1997).

Hough *et al.* (2003) mention that the psychological adjustment of a child of an HIV-positive mother appeared to be related to the mother's emotional distress, which itself was affected by the mother's level of social support, HIV-related stress, and coping behaviours.

### **Normalisation**

Children reported that they felt no different from their peers; they felt normal. There was no disclosure of their status. Consequently, there was no exposure to stigma and discrimination at school. The normalisation challenge for families living with HIV/AIDS is in maintaining a sense of well-being and hope while dealing with the unpredictable intrusion of health changes and treatment associated with HIV/AIDS (Antle 2001). In this study the children saw themselves as normal, and so did their peers because of the secret they held. The mothers felt that this was important, as they had no control as to what their peers might say or do if they knew their status. These children can feel falsely secure in this situation as if no one knows their status there can be no negative feedback with respect to HIV-AIDS. Also, if their peers found out and there was negative feedback, the ability to cope with this situation could be difficult. Non-disclosure was a form of protection that was used by mothers. The mothers who did not tell their children of their status kept the secret at their level. The children were not aware that they had HIV even though all took medication for the illness. Their mothers told them that the pills were vitamins and that they had to take them to maintain good health. The mothers felt they had to make their children's lives as normal as possible, again protecting them from stigma and discrimination. Mothers felt that they were doing what was best for their children.

### **Self-Blame**

Two of the HIV friends reported that the mothers felt responsible for giving their children HIV and experienced self-blame. This influenced the mothers to be even more protective of their children, and hence, the secret. Mothers were concerned about their children's health and felt that if it were not for them, they would not be in this predicament. There was also fear that the children may blame the mothers. They had to deal with their own health issues and their children's as well.

### **Resiliency - Mothers**

Henderson *et al.* (1999) define resiliency as the ability to spring back from and successfully adapt to adversity. The women in this study were diagnosed with HIV between 1994 and 2003; thus, they had been living with HIV from 8 to 10 years. During that time, they had children and a few had bouts of ill health. They had 2-4 children each, at least one of whom was HIV positive. Three of the women went to secondary school, where only one got 'Ordinary Levels' and 1 attended only primary school. Two were employed but considered ceasing work soon while the other 2 were unemployed and on welfare. All were on ART and attended the clinic. The children also attended the clinic. The women were from the lower economic strata of society and lived in inadequate housing.

The stress of keeping the secret of HIV/AIDS, the adherence to medication for both mother and child, periods of ill health, poverty, parenting children infected and affected by HIV, unemployment, tentative unemployment, facing issues on death and dying, not being able to provide for the future of their children and fear of stigma and discrimination all contributed to practical challenges in the daily lives of these mothers. The mothers demonstrated resiliency in the midst of it all as they continued to care for their children against the odds.

### **Resiliency - Children**

The children with limited knowledge of HIV and limited informal social support appeared to be happy despite their feelings of sadness. They were highly dependent on their mothers. They faced health issues daily. Ann had an on-going ear infection and was teased at school. Brian and Cathy both had low CD4 cell counts and had symptoms of AIDS (skin rash). Dawn had a persistent cough and Evan had to undergo an operation on his scrotum. All were on ART except Amy who was taking an anti-biotic for her ear infection. Among HIV-infected mothers with young children, Dura *et al.* (2000) posit that resiliency was associated with the parent-child relationship, parental monitoring, and parental structure. Research has shown that resilient children experiencing chronic adversity often benefit from a relationship with a supportive adult (Emery & Forehand 1996; Pedro-Carroll 2001). However, according to Murphy & Marelich (2008), younger



children depend on caregivers a great deal, and thus, they are vulnerable to declines in parenting quality. It follows that maternal HIV/AIDS may strongly influence children as a risk factor if they do not have other positive adult influences in their lives. In addition, it seems as if resilient children report better coping self-efficacy than non-resilient children, consistent with findings from Lin *et al.* (2004) showing that resilient children had greater efficacy in dealing with stress. Murphy & Marelich (2008) report that among resilient children, those who had a strong relationship with adult care-taking figures have learned from the coping skills by these adults.

The mothers of children in this study reinforced the resiliency of their children. This strength emerged in this study and is one that must be acknowledged. This can prepare children for future challenges with respect to HIV/AIDS and help them in encounters with stigma and discrimination that can test their resilience. However, it is important to ensure that acknowledgement of resiliency does not cause us to shift our gaze from the needs of children who are living with HIV/AIDS.

## **7.9 Conclusion**

This study with its grounded theory approach was distinctive in examining the psychosocial issues and support of children with acquired HIV/AIDS in Trinidad and Tobago within the context of Caribbean socio-cultural norms. It makes a significant contribution to knowledge in this area in the Caribbean. A theoretical model of the psychosocial issues and support of these children was constructed from the findings which were derived through qualitative methods, which engaged participants in the analytical process to reflect on their personal responses. The model illustrates the issues that impact children with acquired HIV within their particular social milieu. Banyard & Graham-Bermann (1993) emphasise the importance of researchers examining the social milieu in which the phenomena take place.

Data revealed the conditions that link to being an HIV-positive mother in a Caribbean country and led to the unearthing of the two-part phenomena: 'secrecy to protect' and children's feelings about being HIV positive. The intervening conditions and the context in turn, impact the strategies the women and children use to manage these phenomena.

Even though the children showed resilience in the midst of their challenges keeping the secret often seemed too much of a burden to carry.

## **Chapter 8- Essential Findings and Recommendations**

### **8.1 Introduction**

This chapter closes the journey of this research. The grounded theory study approach, using a case triad, formed the framework of this research design, which sought to identify “the psychosocial issues and support for children with acquired HIV-AIDS in Trinidad and Tobago”. The grounded theory approach utilised constant comparison, open coding, axial coding, selective coding as analytic methods and discriminate sampling to identify participants . The first four cases were chosen by purposive sampling to seek out the population of HIV-positive mothers who had a child with acquired HIV. These cases each formed a triad consisting of a mother with HIV-AIDS, a child with acquired HIV-AIDS from the mother, and an “HIV friend” (someone identified by the mothers as their main source of support). Theoretical sampling of a further three mothers with HIV-AIDS who did not tell their children about their HIV status was also undertaken in order to explore, at a deeper level, some of the themes that emerged from the initial analysis.

An initial literature review was undertaken to determine the extent of knowledge and any gaps in the field. Urquart (2007) argues that this is an effective means of orienting the grounded theorist to the field of study without necessarily prejudicing them towards existing theoretical concepts.

This chapter examines the overall main findings of the research, the methods and limitations of the study. This is followed by some recommendations for policy and practice and suggestions for areas of further research. The unique contribution to knowledge made by this study is also highlighted.

### **8.2 Situating the Study within a Caribbean Cultural and Social Context with Respect to HIV-AIDS**

Jones *et al.* (2009, p.126) report that culturally-sanctioned sexual gender roles are instrumental in defining human sexuality for both men and women in the Caribbean.

The social construction of masculinity and femininity shapes sexual expectations. Moreover, sexual relationships between men and women are determined by acting out expected sexual gender roles, which place women in particularly precarious circumstances. This can lead to undesirable consequences from sexually risky behaviours, i.e. unprotected intercourse and multiple sexual partners, that. Such behaviours may lead to sexually transmitted infections (STIs, HIV and unintended pregnancy).

Gender roles in the Caribbean encourage traditionally feminine expectations of women, and gender scripts are often characterised by unequal expectations (Jones *et al.* 2009). A script that endorses men having multiple sexual partners is pervasive throughout the Caribbean (Norman & Uche 2002 ; Kershaw 2006), whereas there are considerable constraints on women's expression of sexuality outside of a primary monogamous relationship with a man (Lewis 2003). It may be that men can indulge in sexual activity without guilt, whereas women are constrained by value systems that often associate guilt with their sexual activity. Cultural scenarios influence which partner will control sexual decision-making (Crosby *et al.* 2000), as well as gender differences in attitudes towards casual sex, sexual permissiveness, anxiety or guilt about sex and sexual behaviour (Oliver & Hyde 1993). Caribbean women are presented with conflicting definitions of femininity and womanhood. They are socialised to achieve academic and economic success, while being cautioned not to become too "self-sufficient", in order to meet expectations of women's deference to men in personal and sexual decision-making (Chevannes 2002). The term 'culture' describes the shared values, attitudes and traditions that are often long-standing or created over time within a group. Culture influences conceptualisations of sexuality, and shapes expectations about appropriate gender role behaviour and the social meaning of sexual behaviour (Simon & Gagnon 1999).

It is important to understand the gender dynamics that underlie sexual interactions in heterosexual relationships when exploring HIV-risk behaviour. Adherence to traditional gender scripts may account for women feeling unable to resist unwanted or unprotected sexual activity and for men feeling obliged to initiate sexual activity and engage in risky

sexual behaviour (Campbell 1995), thus increasing HIV risk for both men and women. These scholars highlight the importance of examining Caribbean gender scripts and gender roles within the context of Caribbean cultural values and norms.

Jones *et al.* (2009) conclude that, in the Caribbean, men are free to explore their sexuality. Lewis (2002 p.7) states that women “are expected to relate to it only defensively” and the prevailing gender script reflects male expectations, desires and needs. Jones *et al.* suggest that awareness of gender role expectations continues to influence behaviours in heterosexual relationships. This study is set within a specific social and cultural context that influences the way men and women interact with each other and forms the basis by which they interact sexually based on gender roles. While my focus is on HIV among mothers and their children, the problem is viewed as being impacted by the processes of gender socialisation, sexual behaviours and role expectations which in turn are mediated by cultural values and social conditions. In this study even though the women were impacted by gender socialisation and role expectations, the gender scripts were re-written in terms of their choice in having another child after having a child with acquired HIV. In the Caribbean being a mother is seen as a value and something to be proud of, however having children after having a child with acquired HIV is not something that is readily accepted by the general public.

### **8.3 Aims of the Research**

The research aimed to identify the following: 1) the psychosocial issues that affect children with acquired HIV-AIDS in Trinidad and Tobago; 2) the support that exists to improve their quality of life and any gaps in that support, and 3) the intervention strategies that could be gleaned from such research to assist, in the future, interdisciplinary teams which interact with this population. This study used a grounded study approach with a case triad which consisted of mothers (4), children (5) and HIV friends (4). Theoretical sampling of “women who did not tell their children of their status” (3) was further done to find out more about the emerging core category of “secrecy to protect”, the total number of interviews carried out were 16. Coding followed guidance outlined by Strauss & Corbin (1990) and open, axial and selective coding were used. This process helped to discover the sub-sub-themes, sub-themes and main themes for

the case triad and the “women who did not tell”. This process also guided me to the core category and the two main overarching themes that emerged.

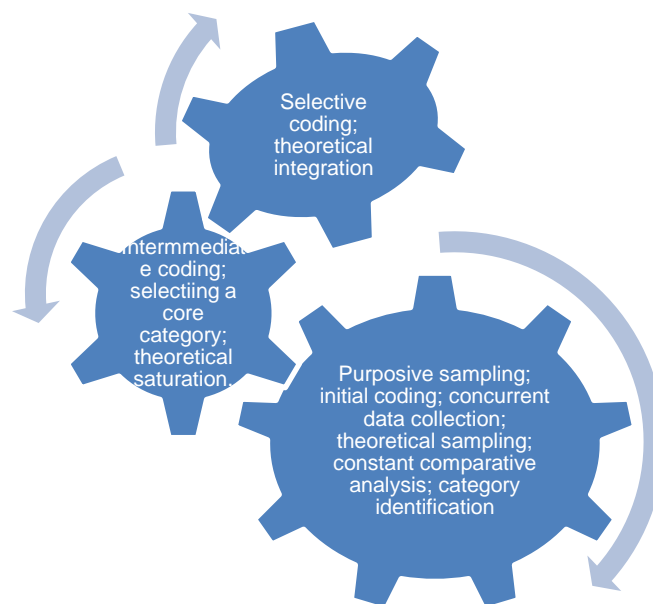
Chenitz & Swanson (1986, p.153) suggest that the best test of a grounded theory’s ‘fit’ is the reaction of individuals under study. The theory should explain clearly what the subjects (sometimes called actors) take for granted as true in their social world, and finally, any grounded theory study should lend new insight into the area under study.

#### **8.4 Grounded Theory - Appropriateness for Study**

Birks & Mills (2011, p.16) posit that, because of its unique nature, grounded theory is indicated when: 1) little is known about the area of study; 2) the generation of theory with explanatory power is a desired outcome, and 3) an inherent process that is likely to be explicated by grounded theory methods is embedded in the research situation. Birks & Mills add that grounded theory results in new knowledge.

This study’s intention was to examine a phenomenon of interest and to develop new knowledge in the process. This new knowledge can assist in improving intervention for children living with HIV-AIDS. The approach to this study was as follows:

Figure 8.4: Birks & Mills (2011) - Grounded Theory Approach



Evaluative criteria refer to the quality of the grounded research process via collection and analysis of data (Birks & Mills 2011). Strauss & Corbin (1990, p.253) note that evaluative criteria should not be read as hard and fast rules, but as guidelines. The authors add that new areas of research may require that the procedures and evaluative criteria be modified to fit the circumstances of the research. Imaginative researchers who are wrestling with unusual or creative use of materials will at times depart from the standard criteria. Straus & Corbin are referring to the adequacy of a study's research process and the grounding of its findings. In my study the research design was a grounded study approach using a case triad; thus cases were used, consisting of a triad: mothers who told their children of their (mother and child) HIV-positive status and mothers who did not tell; children of those mothers, and HIV friends of the mothers. The study utilised the facets of the grounded theory approach, namely, simultaneous data collection and analysis. A clustering tool was used as a precursor to the interviews with the mothers. This tool solicited information from the mothers on a sheet of paper that said in the middle 'Me, Myself and HIV'. They were asked what came to mind when they thought of themselves with HIV. The responses from this tool were followed up when questioning the mothers. The grounded study approach with case study method, the triad and the clustering tool were all part of the methodology that made this study unique in its approach to finding answers.

Charmaz (2006) asserts the importance of applying evaluation criteria in accordance with purpose and context. She looks at four criteria: credibility, which reflects conceptual grounding; originality, the significance of the study; resonance, that is, the need for the theory to have meaning; scope, for all those for whom it may be relevant, and usefulness, in relation to knowledge development and practical application.

### **Credibility**

Credibility is an evaluation of whether or not the research findings represent a "credible" conceptual interpretation of the data drawn from the participants' original data (Lincoln & Guba 1985 p.296).

In ensuring that the analysis reflected credibility, the triad of sources that formed the case studies, mothers, children and HIV friends, allowed for the

triangulation/confirmation of data. This helped to generate 4 levels of data for the case triad including the group of “mothers who did not tell” . This provided a richer and multi-layered credible data set than if the children alone were interviewed. This provided for data triangulation as data was collected from 4 sources. Activities were also given to the children to complete. As the interviews were being conducted, gaps were discovered, especially with respect to the children. The following gaps ensued. It was revealed that the children in this study had limited knowledge of HIV-AIDS and equated it with death and dying. There was a certain amount of sadness when the topic of HIV-AIDS was broached in the interviews. Even though the children expressed sadness on the topic of HIV-AIDS, the activities which they completed showed that they were generally in good spirits. If the activities had not been done by the children, I may not have seen a realistic picture of their lives. Thus, the activities the children did (apart from the interviews) inclusive of drawings, worksheets and describing their feelings assisted in building an overall picture of their lives with HIV. As each findings chapter was developed, the common themes began to emerge, along with the core category. Each findings chapter further developed the emerging core category of the phenomenon of secrecy; overarching themes of children living with HIV-AIDS and mothers, mothering with HIV-AIDS. The process of writing was itself a process of meaning construction. The case triad helped to gather information from the 3 parts of the triad, and supplementary information was generated from mothers with HIV-AIDS who had children with HIV-AIDS also, but who did not tell their children that they (the children) were HIV positive. The rationale for this is found in Chapter 6, part 2.

The themes emerged from the triad and revealed the phenomenon of ‘secrecy to protect’. The mothers kept the secret, they told the children to keep the secret and the HIV friends maintained the secret.

### **New Insights**

Categories offered new insights, especially with respect to children, where there was non-disclosure of their status to anyone and also where HIV was not discussed in the home. A double negative was seen as there was non-disclosure and non-discussion of HIV-AIDS from the families, as explained in section 7.5.7. It seemed as if the secrecy of



having HIV went a step further, to the non-discussion of the topic in the home, which could be akin to topic avoidance (section 7.7). There was no outlet for these children to express their feelings. They equated HIV-AIDS with death and dying, and had feelings of sadness, discussed in 7.3.2. This painted a picture of children with a debilitating disease not being able to disclose or discuss their unique situation of having acquired HIV. They were effectively silenced by the mothers, yet they persevered and demonstrated resilience (section 7.8). They had limited informal social support and appeared to be happy generally, despite having feelings of sadness.

The children faced relentless health issues and were highly dependent on their mothers. Dura *et al.* (2000) found that children's resilience was associated with the parent-child relationship, parental monitoring and parental structure. However, Murphy & Marelich (2008) suggest that younger children depend extensively on caregivers and are thus vulnerable to declines in parenting quality. It follows that maternal HIV-AIDS may strongly influence children as a risk factor if they do not have other positive adult influences in their lives. Among resilient children, those who had a strong relationship with adult caretaking figures had learned from, and been reinforced by, the coping skills of these adults. This appears to be the case in this research, as the children had learned from their mothers in this regard and resilience was reinforced by the mothers (section 7.7.1). Murphy & Marelich state that there has been little investigation to assess resilience among young children affected by HIV-AIDS. This is an area that can be explored by future research.

The study provided a new conceptual rendering of data. The main themes were developed for each triad and for the 'women who did not tell'; the paradigm model emerged from the themes and sub-themes. The application of existing literature and research in interrogating the themes that emerged served to ensure an even better understanding of the data generated.

### **Resonance**

The study provided a channel for all participants in the triad to talk about their lived experiences. The study used the actual expressions of the participants to develop themes and core categories, which led to a better understanding of the psychosocial

issues and support of children with acquired HIV in Trinidad and Tobago. This was discussed in 3.5.

### **Usefulness**

The analysis offered interpretations that multidisciplinary teams, inclusive of social workers, could use in their everyday work to enhance interventions with the population of children with acquired HIV-AIDS, and their mothers who mother in the whole lived experience of the virus. The mothers were aware that stigma and discrimination with respect to HIV-AIDS exists, and therefore, that protection of self and children via secrecy was important. This seemed to reflect the reality that, culturally, HIV-AIDS has a negative connotation.

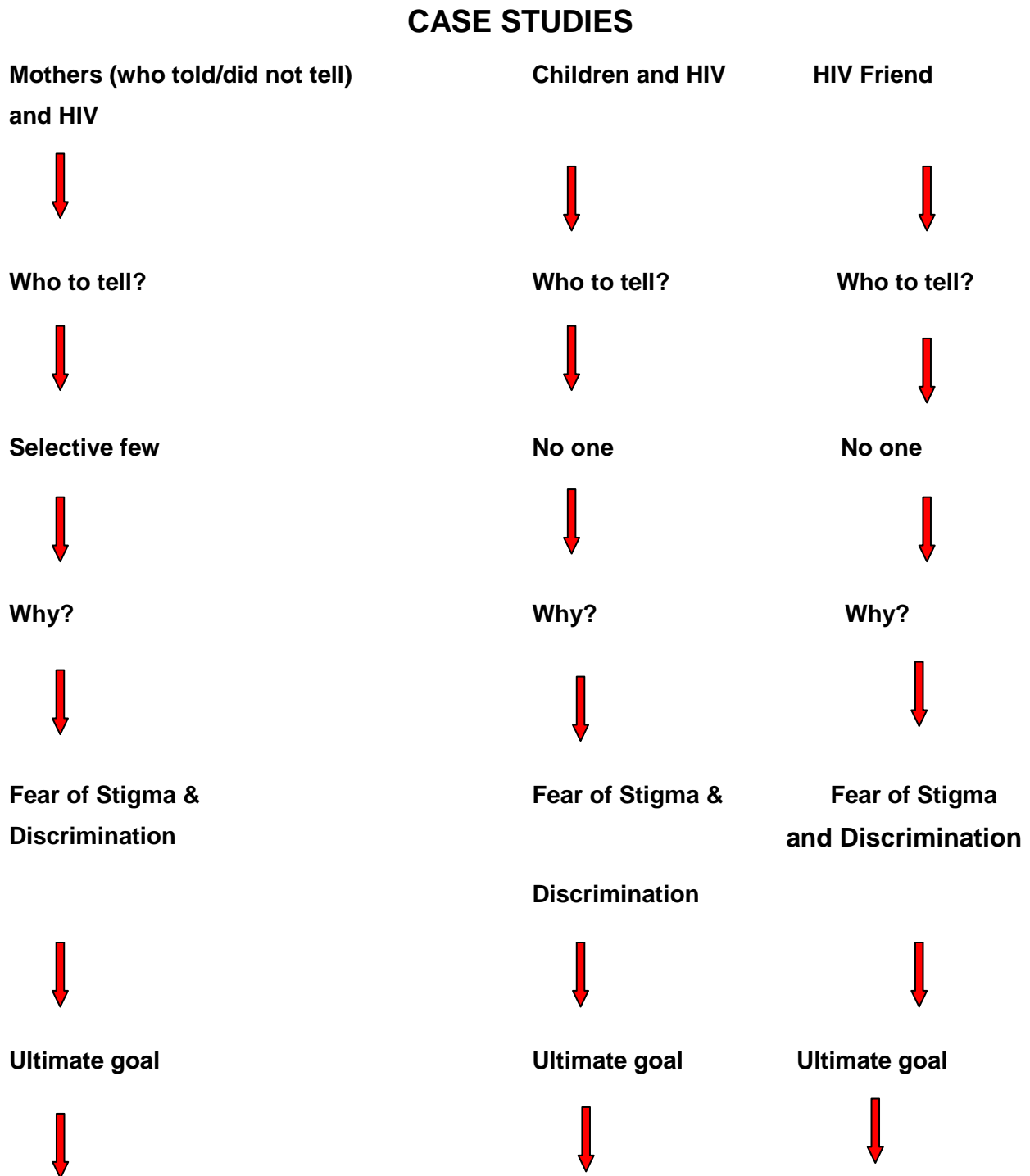
One may be able to identify with the core category of “secrecy to protect” following the data analysis. The main phenomenon of ‘secrecy to protect’ and the two other main themes: ‘Mothers mothering with HIV-AIDS - the new normal’ and ‘Young carers with HIV-AIDS in Trinidad and Tobago’, helped to explain the effects of HIV-AIDS on children via the psychosocial issues that affected them and the types of social support that were available. In its entirety, the main phenomenon and the two main overarching themes provided information on mothers and children affected by HIV-AIDS and its impact on their lives.

### **8.5 The Phenomenon of “Secrecy to Protect”**

The study revealed major themes and sub themes, with the overarching theoretical explanation being the phenomenon of “secrecy to protect”. In the sections that follow, I summarise this phenomenon and the two main themes. The phenomenon that emerged from the findings of the triad and “mothers who did not tell” their children of their status was “secrecy to protect”, while the other essential themes that stood out were ‘mothers mothering with HIV-AIDS - the new normal’, and children living with HIV-AIDS, that is, “young carers living with HIV-AIDS” in Trinidad and Tobago, a term I introduce to describe this cohort of children. These research findings may inform the development of intervention strategies to assist interdisciplinary teams in the future that would interact with mothers and children with HIV-AIDS. In the findings chapters and Chapter 7, the themes were examined against the literature, and similar or different aspects were

explored. The following diagram shows how the core phenomenon of "secrecy to protect" emerged from the triad:

Fig 8.4 Diagram of case triad



**To protect self and child**



**Method**



**Secrecy**

**To protect  
mother and child**



**Method**



**Mother/child bond  
of secrecy**

**To protect mother & child**



**Method**



**Maintenance of  
secrecy**

In examining the diagram one sees that, based on the findings, there are some similarities and some differences in the case triad. In terms of disclosure, the individuals in the triad decided who to tell: some mothers told their children of their status; other mothers did not tell their children; children did not tell as they were told not to by their mothers, and HIV friends did not tell as they were trusted not to do so. The question was then asked as to why they did not tell? The answer for all three was the fear of stigma and discrimination. On the children's part, they told no one, although 2 said that they would have liked to tell but both obeyed their mothers. The mothers felt that the children may experience stigma and discrimination because of their HIV positive status, so they made the decision on the children's part as to who to tell. It was the mothers solely who made the decision as to who to tell, and they told a selected few. The power of disclosure therefore rested in the hands of the mothers; they determined who the members of their support system would be and, by default, this became the support system of the children. The children had no say as to who would be involved in their informal support structure. The HIV friends also had no say as to the informal support structure of the mothers. They helped to maintain the secret. The ultimate goal of the individuals in the triad was, in the case of mothers, to protect themselves and their children. The children conformed to this and, in so doing, protected their mothers and themselves by their obedience. The HIV friends also did not tell anyone else, thereby keeping the trust of the mothers. The method used by all to ensure non-disclosure was

secrecy by the mothers, the mother/child bond of secrecy by mothers and children, and the maintenance of the secret by HIV friends, all geared towards the one goal of "secrecy to protect".

The children were unable to discuss HIV in the home, had limited knowledge of the meaning of having HIV, and were told not to reveal their status. This rendered the children especially powerless as they did not know what their mothers were protecting them against. Secrecy was the method used by mothers to have some semblance of control in their situation, and they genuinely believed that this was in their children's best interests. This, however, limited the availability of informal social support for these children since their mothers acted as gatekeepers to their children's social support structure.

Secrecy reduced the availability of social support; thus reducing the informal system of the mothers. The physical needs of the children were fulfilled by the formal support system, that is, visits to clinic, medication and anti-retroviral medication. However, with regard to the psychological needs of the children, there seemed to be a gap, as the feelings and issues of the child with respect to HIV were not addressed. This suggested a new meaning to the term 'vulnerable', as not only were the children vulnerable by having HIV, with the accompanying psychosocial issues, but they were inadvertently silenced by their mothers' actions, which rendered them unable to disclose their status to anyone.

In section 7.5.1, secrecy was discussed and a definition was given. The difference between privacy and secrecy was also explored. Privacy does not impact on our physical and emotional health, whereas secrets can have negative effects. Secrets that are kept with the best intentions (to protect young children) might adversely affect family relationships and interactions. There are motivations and mechanisms for keeping a secret. It was found that the motivation in this study was both relationship-based and individual-based. It was relationship-based in that mothers felt that they had to shield their children from stigma and discrimination, in particular the mothers who did not tell, while individual-based motivation was suggested in that the mothers wanted to maintain their autonomy and control over what happened in their lives.

As seen in section 7.5.1, the disclosure of maternal HIV may be beneficial to the child, as it may facilitate open communication between mother and child about the mother's illness. This is important, as a child may become aware of the mother's illness but be unable to discuss his or her concerns and fears. This may have been true for the children in my study. Whether mothers told or did not tell, in this study, the topic of HIV was not discussed. As a result of HIV and its association with stigma and discrimination, a child who is told of his and/or his mother's positive status must hide that information from others, as he or she could encounter cruel treatment from others.

Secrets can have both negative and positive consequences. In the positive sense, it can protect others from adverse conditions, but on the other hand, secrets in families may underline dysfunctional relationships and can be physically or psychologically damaging. It is important for children to understand HIV; even if the secret is kept, there must be some education and discussion in the home on the topic of HIV-AIDS. Better understanding may mean being better able to deal with the illness, and should give some insight to children as to living with the virus.

It was found that HIV-related stigma contributed to the burden of care, forcing mothers to deal with the tension between the secrecy surrounding the disease and the openness required in providing care and receiving social support. The UNAIDS 2012 Progress report for Trinidad and Tobago (Global AIDS Response Progress Report, January 2010-December 2011 (2012) found that in 2006 37.5% of women aged 15-49, who wanted the status of a family member be kept a secret compared to 42.7% in 2011. One would think that, with education and information being made readily available to the public, this would have improved.

## **8.6 Mothers Mothering with HIV - the New Normal**

Mothering stood out as a fundamental theme in the research. The mothers placed great value on mothering in the family. They wanted to be present in the lives of their children and to provide adequately for them and their future. They were the main form of informal social support for their offspring. The mothers maintained this traditional role of caregiver, while simultaneously living with HIV, being of lower socio-economic status, and having issues related to stigma and discrimination for self and child, which can be

overwhelming for mothers. Yet, in the midst of it all, they displayed a measure of resilience. This has become the 'new normal' for the women, which seems to validate their mothering with HIV-AIDS, and these women can be seen among themselves as a "singular standard" in the midst of the HIV-AIDS epidemic in Trinidad and Tobago. In the Caribbean, children are seen as valuable, and there is value in the "mother role". Hackl *et al.* (1997) and Faithfull (1997) also speak about mothers with HIV who continued their role as caregivers to their children. Antle *et al.* (2003) assert that many parents living with HIV experienced pressures that drained them of precious resources and affected their ability to parent effectively.

The mothers were concerned about the future of their children and wanted to ensure that they were present in their lives. Sandelowski & Barroso (2003) speak about worries related to the future of children. The issue of staying alive in order to take care of children is linked to other research, such as Cousar (2005), Shambley-Ebron (2003) and Shambley-Ebron & Boyle (2006). In addition, Pittiglio & Hough (2009) purport that mothers wanted to live in order to prolong their parenting role, as they believed that there would be no one willing to take care of their children.

As was discussed in section 7.3.2, the mothers, even though guided by cultural scenarios and interpersonal scripts, chose to re-write their intrapsychic scripts, which are scripts free from the constraints of others and which represent the private desires of the individual. Six of the seven HIV-positive mothers made their own reproductive choices, in that they had another child after having a child with HIV. These desires are not always manifested in interpersonal scripts

The mothers in the study set a "singular standard" among themselves as, having limited social support, they extracted the capacity to cope from within themselves, which translates into resilience in living with the disease. This is a strength that emerges in the lives of mothers living with HIV. It was noted, however, that one must be careful not to focus on resilience as strength alone, as this can result in overemphasising individual adaptation to negative circumstances, rather than addressing the environmental or social factors that have contributed to the situation. With respect to stigma and discrimination, the mothers displayed "felt stigma", as they thought that if anyone knew

of the children's HIV-positive status, there was the likelihood of the children experiencing stigma. Corona *et al.* (2006) and Vallerand *et al.* (2005) both allude to this in their studies.

Mothers disclosed to only a selected few as they feared stigma and discrimination. They felt that there were risks involved in doing so. Moore *et al.* (2008) state that persons who disclose may experience avoidance by others, be ridiculed or experience gossip. However, although disclosure can be challenging, social support decreases depressive symptoms among persons with HIV-AIDS and leads to better psychosocial functioning (Klein *et al.* 2002).

In section, 7.3.2, we saw that children are seen as desirable and highly valued, and that much status is placed on the 'mother role' in the Caribbean (Barrow 2008). Childbearing has long been linked to the emergence of a strong self-image and a sense of womanhood that serves as a 'rite of passage' within Caribbean societies (Durant-Gonzales 1982). Also, women in the Caribbean generally carry the primary responsibility for providing care to children and other dependent family members (Barrow 1996). The women had decided, of their own volition, to have another child; this, it seemed, was based on internalised perceptions of gender constraints and expectations, there being no external opposition, as no one really knew their status. This was related to self-determination, in that they made their own choices with respect to child-bearing, and resilience, and that they made that choice in the midst of other challenges such as poverty and illness.

The mothers in the case triad and the three "mothers who did not tell" all went on to have other children in addition to the child with HIV. They made that reproductive choice and were self-determined to have another. They had confidence in the ART that they were taking, and had hope that the child would most likely be HIV-negative. All were negative except for one child in the case triad, as the mother was not on ART at that time and the child was born within one year of the other. Ingram & Hutchinson (2000) speak about the double-bind of mothers with HIV. On the one hand, the predominant role of women in Caribbean society is to bear children, while on the other, society frowns upon the idea of an HIV-positive woman becoming pregnant. It is a situation



which suggests that if you do not have children, it is seen as a disgrace, but if you do so while being HIV-positive, it is also a disgrace. Two societal messages are being prescribed, but one appears to negate the other.

Other international research has shown that a woman's HIV status does not necessarily influence her reproductive decisions (da Silveira Rossi *et al.* 2005; Sowell *et al.* 2002). Women's decision to have children has been seen to be more influenced by the culturally constructed meaning of motherhood (Cooper *et al.*, 2007; Heard, Sitta, Lert & the VESPA Study Group 2007). Rose and Clark-Alexander (1998) posit that in their study, having an HIV-positive baby was a reality check for some of the women, and was a critical factor in these women not having any more children. Clearly in this research, this was not so. This study seems to be more in line with the international research that states a woman's HIV status does not necessarily influence her reproductive decisions.

## **8.7 Young Carers with HIV-AIDS in Trinidad and Tobago: Children Living with HIV-AIDS**

The report (<http://www.aids2012.org/youth.aspx>) states that almost half of new infections in the world are among people under 25. Estimates show that 7,400 people become infected daily, 3,300 of whom are young people. Young women under the age of 25 are at even greater risk of HIV and comprise 57.4% of infected youth. The article goes on to say that young people remain the group most vulnerable to HIV infection due to many factors, such as lack of information, education, societal influences and the inability to access health care services. There is need to link this opening paragraph with what comes next.

The research found that children in the triad were concerned about their mothers' well-being and would at times assist in the home. Helping in the home is seen as normal for Caribbean children; however, the children in the study also carried responsibilities and concerns for the well-being of their mothers which is over and above what would be considered normal. In 5.14.2 children as carers was discussed. Children in this study were viewed a "young carers with HIV" as opposed to "parentified children". This implied

that they were seen as needing support in coping with their unique circumstances of living with HIV-AIDS in the family and that only those circumstances require that the young person take on that responsibility. The role reversal was seen as a necessity in the family. They were "young carers with HIV-AIDS": a term that has been developed in this study to highlight awareness of their situation and to help tell their story.

The children had limited knowledge of HIV-AIDS and linked it to death and dying, and they described their feelings as sad. The children in this study, when they get older, could pass on the virus to others if there is a lack of information and education on HIV-AIDS in their lives.

They were told never to disclose to anyone and had to maintain that secret; even though two children may have wanted to disclose, they had to comply with their mother's request. The lives of the children with HIV-AIDS in this study were considerably restricted in relation to the outside world. This also led to restriction of informal social support, as the mothers only disclosed to a selected few. Awareness with respect to the children and their feelings on the issue of being HIV-positive was limited. The HIV friends thought that they were coping, but none spoke to them in depth to ascertain what their feelings were. The children in this study were voiceless. What made this worse was that the topic of HIV-AIDS was not discussed in the home, so there was no outlet for expression of feelings by the children in the study. They had no control within their living environment, yet they supported their mothers. It is important to note that when the children were asked to draw themselves and their families, there was a positive response, and they enjoyed doing the other activities which included a worksheet entitled "all about me" and another which helped to highlight their feelings. This was part of the interview plan, as it incorporated writing and drawing. Thus, they were not generally sad all the time, only when they spoke about their status and talk about having HIV-AIDS. This demonstrated that, if given the opportunity to address their feelings and gain enhanced knowledge of HIV-AIDS, this may change their outlook on having the virus and could, maybe, improve their quality of life. It is important to recognise that children do have feelings and that there is a need for them to express these feelings. They tend to appear as 'invisible' to service providers. They felt positive

about being part of their families and they valued the contribution that they made to the family unit. Bacha *et al.* (1999) report that children who knew their HIV status had higher self-esteem and were less depressed than children who did not know their diagnosis. Blasini *et al.* (2004) also report positive psychosocial adjustment in children who were informed of their diagnosis in the context of a supportive environment. It is important that children have the necessary knowledge about their HIV-positive status in a supportive environment, that is, at home, at the clinic where they attend for medical services and at school.

It is also important to ensure that children are taken into consideration as part of the HIV-AIDS prevention campaign. If children are not fully aware of their HIV positive status in terms of knowledge, then as they get older, this can influence the decisions they make with respect to relationships they build with others intimately. Prevention of the spread of HIV-AIDS plays an important part in the scheme for the reduction of cases of the virus, and effective education of young children on this issue can augur well in this whole process. The children in this study are going to become teenagers in the near future, having to grapple with adolescence and their own sexuality. They will most likely be seeking to form relationships, and this is where the knowledge of what being HIV-positive entails is important. There may be issues of disclosure in these budding relationships, and questions such as "do I disclose?", "When do I disclose?" and "To whom do I disclose?"

Two children in the study were willing to disclose but could not, because of their mothers' directions not to do so. As all the children get older, the issue of disclosure may become critical as they build new relationships, and if they choose not to disclose this can directly affect the spread of the virus. Understanding of the virus at this juncture in their lives could help them make informed decisions in future relationships. This is a crucial factor in the prevention of the spread of HIV-AIDS. Young carers with HIV-AIDS should be written into the contemporary sociology of childhood, which is, newly found information that affects the livelihood of children, as it would provide information on an aspect of childhood that affects children's quality of life in such a considerable way.

## 8.8 Practice and Policy Implications and Recommendations

The study suggests a need for interventions at various levels of society, and I make use of Bronfenbrenners's ecological theory to link the research findings with types of intervention. This theory consists of 5 environmental systems: microsystem, mesosystem, exosystem, macrosystem and chronosystem. The first 4 will be used in the recommendations. The chronosystem (refers to the patterning of environmental events and transitions over the life of an individual, as well as socio-historical circumstances) will not be used as it is felt that the first four should adequately assist in both short-term and long-term interventions. It is hoped that the recommendations in the short-term and long-term could directly impact the chronosystem in the future. That is, maybe change the way children are seen and lead to more awareness about how children feel living with HIV-AIDS.

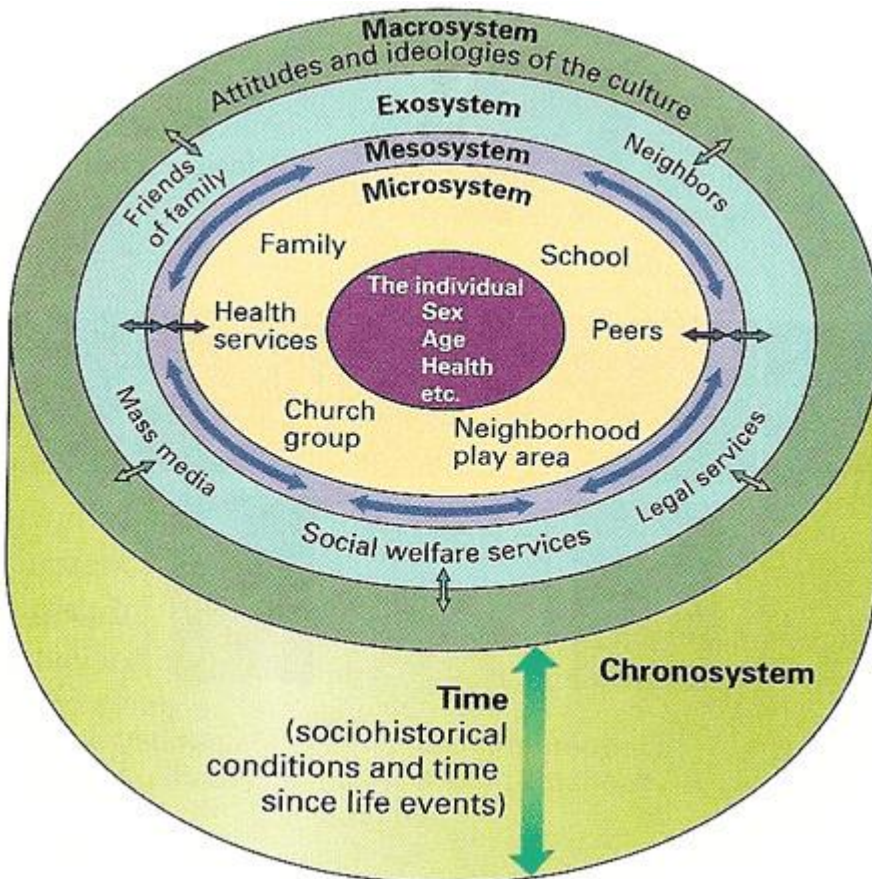


Figure 8.8: Bronfenbrenners's ecological theory

In the context of this study, the microsystem is made up of a child's family, peers, school and neighbourhood. The mesosystem forms the connections between the microsystem elements—for example, the connection between family experiences and school experiences via outreach programmes. The exosystem consists of legal services, welfare services and mass media. The macrosystem includes the roles of culture, customs, society's values and gender roles. There is interaction between and within all levels. The following will show how intervention could occur at varying levels of society, using Bronfenbrenner's ecological systems.

### **8.8.1 The Macrosystem**

This consists of cultural attitudes and ideologies, as highlighted in section 8.2. It is important that the government of the day be made aware of the findings of this research, as it provides knowledge of the secrecy element of children living with HIV-AIDS as a consequence of stigma and discrimination, and also of the gaps in support. A plan to enhance the education of the public on HIV-AIDS should be developed so that citizens are aware of what HIV-AIDS is and what it entails. This can help to bring about change in people's attitudes, behaviours and beliefs with respect to persons living with HIV-AIDS.

There is a need for a multi-sectoral response via government policies and programmes in the various ministries. These policies and programmes should reflect knowledge and understanding of the psychosocial issues, and support for children with acquired HIV-AIDS. The HIV-AIDS coordinator in each Ministry would have an active role in the planning and implementation of policies and programmes.

#### **Update on Policies in Trinidad and Tobago**

According to the Global AIDS Report, January 2010 - December 2011 Progress Report of the Government of Trinidad and Tobago (2012, p.4), several policies were formulated in 2010, including the Prevention of Mother to Child Transmission policy, the Post Exposure Prophylaxis policy and the Health Sector Workplace policy.

The reporting period saw a strengthening of programme areas, expansion of prevention services and improvements including Voluntary Counselling and Testing, the Prevention of Mother to Child Transmission, and treatment adherence. Prevention efforts were substantially scaled up in 2010 through increased access to, and geographic coverage of, VCT services. The number of sites providing HIV testing and counselling services increased from 28 in 2009 to 31 in 2010. There was a steady increase in the number of persons tested at same-day sites from 2007 to 2010, with 39,032 persons being tested in 2010.

Uptake of PMTCT, based on annual programme reports, showed a decline as 91% of new clinic attendees in 2010 consented to HIV testing and counselling, compared with 97% in the period 2007-2009 and a rebound to 95.1% in 2011. HIV prevalence among pregnant women increased from 1.2% in 2009 to 1.6% in 2010. It is important to note that in 2010, 85.9% of first clinic attendees adhered to all components of antiretroviral prophylaxis (83.2% in 2011), and that in 2010 all HIV-exposed infants received post-partum prophylaxis.

Vulnerable populations such as youth were targeted during the reporting period, with specific campaigns aimed at increasing HIV testing, promoting knowledge and awareness of HIV through initiatives such as the Barber Shop initiative, and 'youth linkers'.

2010 witnessed an increase of 13% in the proportion of patients on antiretroviral therapy compared to 2009. Diagnostic capacity was strengthened as viral load service was transferred from a regional agency to a major national hospital in 2010. A community-based home care project was successfully launched in one county in 2010, with 17 community health care workers being trained and 15 clients accepted into the pilot project. Adult in-hospital treatment in Tobago expanded to the Tobago Regional Health Authority in 2010.

Civil society organizations, including faith-based organizations, continued to play a critical role in advocacy for PLWH and at-risk groups, reducing stigma and discrimination and promoting HIV-AIDS awareness.

Even though new policies are in place, one needs to see how effective they are to date and if in fact there is a reduction of stigma amongst the population at large. One also wonders why, despite all the programmes being implemented to help reduce stigma and discrimination, this is not impacting on women and children as indicated in my study. Programmes need to be evaluated to ascertain how effective they are and, where gaps are found, something must be put in place. For example, there should be sensitisation of how children view HIV-AIDS and a concerted effort made to help them understand the illness in a “child friendly” manner. UNESCO (2008) has produced a booklet for schools entitled “Overview of Good Policy and Practice in HIV & AIDS and Education” (booklet series) that could help with respect to education on HIV-AIDS. These findings and examples of interventions can be referred to by programme and policy developers and implementers as they prepare education systems to respond to the needs of learners and educators.

This series of booklets take into consideration the understanding that the education system reaches beyond traditional classroom into homes, communities, religious centres and thus addresses educational practices in formal, non-formal and informal learning environments. Understanding that only local solutions will solve local challenges, this series aims to pull together a variety of programmatic and policy experiences from different regions that can be drawn upon when addressing community, district or national HIV and AIDS education needs (UNESCO 2008 p.6). This could help in schools in Trinidad and Tobago as it was found in this study that disclosure in schools was not encouraged by mothers for fear of the response. Hopefully education tailored for school personnel inclusive of children could help in this regard.

### **The Rights of the Child**

The United Nations Convention on the Rights of the Child is the first legally binding international instrument to incorporate the full range of human rights- civil, cultural,

political and social rights. In 1989 world leaders decided that children needed a special convention just for them because individuals under 18 years old need special care and protection. By agreeing to undertake the obligations of the Convention national governments have committed themselves to protecting and ensuring children's rights and they have agreed to hold themselves accountable for this commitment before the international community. Parties to the Convention are obliged to develop and undertake all actions and policies in the light of the best interests of the child (<http://www.unicef.org/crc/> ). The Trinidad and Tobago government has signed and ratified the Convention of the Rights of the Child on the 5<sup>th</sup> December 1991 and enforced it on 4<sup>th</sup> January 1992. This can assist in the development of programmes unique to children living with HIV-AIDS. The government of Trinidad and Tobago has developed numerous policies to assist with prevention, treatment and care and other areas of HIV-AIDS; however, these policies are not specific to children living with HIV-AIDS. They are more generalised for the whole population. In these policies the rights of the child should be visible to all, and be specific in addressing the needs of children. The following government ministries should be involved at the macro-level.

### **Education**

This should include the Ministry of Education, where teachers are made aware of the findings and understand the reasons why disclosure was not implemented at schools by mothers and children. HIV-AIDS should be part of the educative component for all teachers, and should also be included in the guidance counsellors' curriculum, tailored for delivery to parents, teachers and children at primary and secondary school levels.

Education on HIV-AIDS reinforces knowledge and, hopefully, understanding of the complex nature of HIV-AIDS and its impact on individuals, especially children. The world of a child with HIV-AIDS can be revealed, and awareness fostered by those with whom they interact, based on this research.

### **Health**

The Ministry of Health is another key stakeholder with respect to the delivery of care to children with HIV-AIDS. In the Ministry of Health there is the HIV-AIDS Coordinating Unit (HACU). HACU is responsible for policy formulation, standard setting, funding,



regulatory functions and coordination of the activities of the five Regional Health Authorities (RHAs). Regarding policy formulation, significant policies include the National HIV Testing and Counselling policy, Health Sector Workplace HIV and AIDS policy, the Prevention of Mother to Child Transmission policy and the Post Exposure Prophylaxis policy, the latter three approved in 2010. This unit coordinates, advises on policy direction, monitors and evaluates the implementation of the Ministry of Health's response to the HIV epidemic, and a Health Sector Plan covers the following priority areas :

- Priority Area I: Prevention
- Priority Area II: Treatment, Care and Support
- Priority Area III: Advocacy and Human Rights
- Priority Area IV: Strategic Information

This unit is responsible for health promotion using information, education and communication to focus on prevention. It is based on health promotion and events campaigns. So there are indeed policies and education campaigns, but there is nothing which specifically pertains to children with HIV-AIDS having their voices heard about what affects them. Thus there could be a joined-up policy in which children's rights are integrated and infused into other policy such as the Prevention of Mother to Child Transmission policy. This could develop awareness of children's needs in terms of educating them about HIV-AIDS, and awareness of their situation as young carers with HIV, so making them more visible. This could help improve their quality of life in the long term and prepare them to be more responsible teenagers and adults with respect to prevention of the spread of HIV-AIDS, according to the priority area I above. In addition, addressing children's concerns could help achieve priority areas I, II and III.

Policies should include delivery of care to these children at hospitals and health centres throughout the country. These policies should emphasise treatment as well as active listening to children's feelings on HIV-AIDS. This may present some challenges, as Barrow (2010, p.38) states that many persons, parents included, remain adamantly opposed to children's rights participation and interpret any move in this direction as

undermining adult rights and authority, regarding it as wrong to be doing so at the very time the children and youths appear to be increasingly disobedient and delinquent. UNICEF (1998, p.35) challenges this, suggesting that children of the Caribbean continue to be 'seen and not heard', that there is little allowance for their point of view and that they are simply expected to adhere to, and obey, directives from parents. Barrow (2010) adds that children's rights, as presented to parents, teachers and child care workers through social policies framed in accordance with UNCRC principles, are seen to encode Western notions of childhood autonomy and are deemed inappropriate to local Caribbean culture and family traditions. Brown *et al.* (1997, p.104) agree, and in their study found that the concept of children's rights (as opposed to children's obligations) was rarely discussed and seemed almost a "foreign" concept, particularly rights related to self-expression of independent ideas or feelings. Too often such independent speech is seen as "feisty" and "disrespectful", and thus socially unacceptable.

The absence of children's voices in this research may also lie in part in the ethical challenges of conducting studies with children and the reluctance of researchers to engage face-to-face with them, especially where painful episodes of neglect, abuse and abandonment may be uncovered (Christensen & James 2000; Fraser *et al.* 2004). Understanding their feelings and fears about HIV-AIDS is very important, as this means that the health professional can better intervene on their behalf. Children can play an active part in the administering of their health care, as opposed to being passive partakers. They can articulate their feelings and fears about their positive status and open a window into their world. A better understanding of the life of a child with HIV-AIDS makes for more effective intervention. There is a need to educate groups of persons that interact with children about the UNCRC. The UNCRC should be introduced to the populace at the macro level, and then filtered down to the other levels. Those in government at some of the populace may know what it means to ratify the UNCRC, while some of those that interact directly with children may not really understand what it means or how it has to be executed. There needs to be a paradigm shift as to what children are entitled to and what they receive with regards to HIV treatment and care.

Issues of disclosure should also be addressed. When to disclose to the child and how to disclose to the child are critical issues for mothers with HIV-positive children. Each child is unique, with unique circumstances; therefore disclosure, when desired, should be carried out accordingly. The benefits of disclosure should be shared with mothers. Mothers with HIV throughout the country should be made aware of the benefits of disclosure, and if they do decide to disclose, they should be guided accordingly by professionals taking into consideration the sensitive issues relating to stigma and discrimination. The 3 mothers that did not tell in this study stated that they would disclose to their children sometime in the future, thus, this could prove beneficial.

Mothers also need to be aware of the “secrecy to protect” core phenomenon that they could be exercising in their families as a buffer for their children. Increased knowledge can help in the decision-making process with respect to disclosure. They would be able to know what to disclose, when to disclose and why they should disclose. Mothers should also be made aware of how children may react to the virus and the concern they periodically feel for them. The mothers could be apprised of the term “young carers with HIV”, and also of what was discovered in the theme “mothers mothering with HIV-AIDS”, as this could make the children more visible and help their feelings to be acknowledged and understood. Increased knowledge could help with an increased understanding of how the issue affects children.

There should be the establishment of poly-clinics nationwide to provide specialised holistic intervention for children generally, inclusive of those who are HIV positive. These clinics should include a cadre of professionals, for example, nurses, doctors and medical social workers who are specifically trained in the field of HIV. In Trinidad the arrangement for treating persons with HIV-AIDS is centralised, although some clinics will do HIV testing. Treatment and care are services provided for adults at the Medical Research Foundation (MRF) in the capital (Port-of-Spain). Here clients receive medication, doctors’ check-ups and services from the social worker and a nurse counsellor. In the south, San-Fernando, these services are provided at Ward 2 at the San-Fernando General Hospital, and in Tobago, at the Tobago General Hospital. The children receive treatment and care at the children’s clinic at Mt. Hope Hospital and at

the residential facility of Cyril Ross Children's Home, which has a monthly clinic. The poly-clinics would de-centralise services and help eliminate some of the financial hardships experienced by some mothers in getting to the clinics from afar for treatment. In the long term this can help with adherence to medication, which is critical in the treatment of HIV-AIDS.

### **Social Development**

The reluctance on the part of the mothers to seek support because of fear of stigma and discrimination suggests the need for agencies such as The Family Services Unit of the Ministry of the People and Social Development to play an active role in the provision of services for families with HIV-positive members. The issues that young carers face, based on this research, should be acknowledged and addressed. Services that alleviate the burden of care and concern that children have for their mothers are necessary, as children taking on household and parenting roles is normalised within society and therefore the particular issues affecting children with HIV-positive parents are rendered invisible.

Poverty is another issue that impinges on the quality of life of mothers and children living with HIV. The inability to financially provide for the future of their children and purchase nutritional items is of great concern. The mothers in this study often had no finances for transport to collect medication. This raises serious issues for adherence to medication and the long-term consequences of inconsistent treatment, which includes resistance to the drugs as well as the hastening of the onset of AIDS. In addition, mothers may not be able to be employed in the near future because of HIV-related illnesses and fatigue. This population needs to be visible in the eyes of the government.

### **Community Development**

The findings of the research can be disseminated through town meetings in community centres throughout the country. Anyone in the community can be recipients of this knowledge. A clearer understanding of the psychosocial issues could follow, which would assist in influencing change in the reduction of stigma and discrimination directed towards persons with HIV-AIDS.

### **8.8.2 The Exosystem**

This consists of legal services, welfare services, mass media, friends of family and neighbours. The education of the populace would include all these groups, as it would be filtered from a top-down approach. The mass-media [should] be used in the re-education process, as this would be an effective means of reaching a wide cross section of individuals and groups at any given time. Snippets of data on HIV-AIDS used in culturally-made advertisements could be used for re-education purposes. The interplay between the macrosystem and the exosystem could be fluid in terms of how information is conveyed on HIV-AIDS.

Apart from the ordinary welfare services, there could be provision of additional services, such as housing, transportation and medication drop-off. These are suggestions; however, one must be aware that these very suggestions could contribute to increased stigma and discrimination. For example, if housing, transportation and medication drop-off were to be implemented, would there be a need to put the positive status of the person on application forms for housing? Would the transportation carry the logo of the Ministry of Health, so alerting neighbours or others that someone is ill and needs transport to clinics or even the medication drop-off? My research showed that stigma and discrimination is a reality, as such, the answers to the above questions posed would need to be considered. Whatever services are provided should be tailored carefully so as not to contribute to stigma and discrimination. These services must be sensitive to the issues of stigma and discrimination. However, it is important that the government acts to support families affected by the chronic illness of HIV-AIDS. The policies and practices at the macrosystem level may have a direct effect on elements in the exosystem.

The mothers in this research did not disclose to neighbours and friends, as trust was not present. Thus, it is important that education relating to HIV-AIDS reaches groups at the exosystem level.

### **8.8.3 The Mesosystem**

The mesosystem forms the connections between the microsystem elements, for example, the connection between family experiences and school experiences via outreach programmes. Here, there is the marrying of the two worlds of family and school. The mothers in this research did not want their children to disclose at school. The fear of stigma and discrimination was very real.

Outreach programmes—educative components developed in collaboration with the Ministry of Community Development and Ministry of Education at the macro-level—can filter to this level. These programmes can target family members and school personnel. Unique methods aimed at explaining HIV-AIDS to children at different levels of development could be used in these programmes. This would need some effort, as families with HIV-AIDS do not trust the school systems in Trinidad and Tobago with respect to their reaction to children with HIV-AIDS.

The Children's Research Centre (UWI-CRC) at the University of the West Indies (UWI), St. Augustine, can also utilise the findings from research to assist with the development of programmes for young children.

### **8.8.4 The Microsystem**

The microsystem is made up of a child's family, peers, health services, school, church and neighbourhood. It also includes the age, sex and health of a child. This is where the intervention is with the individual child.

The findings of this research can contribute to enhanced interventions with children who have acquired HIV-AIDS from their mothers. The knowledge gleaned on the core phenomenon and the two main important themes can assist multidisciplinary teams that interact with this cohort of children and their mothers on a regular basis; it can also provide information to the government of the day so that they can be guided in the making of policies and programmes that are child-based and which consider the needs of a child with HIV-AIDS.

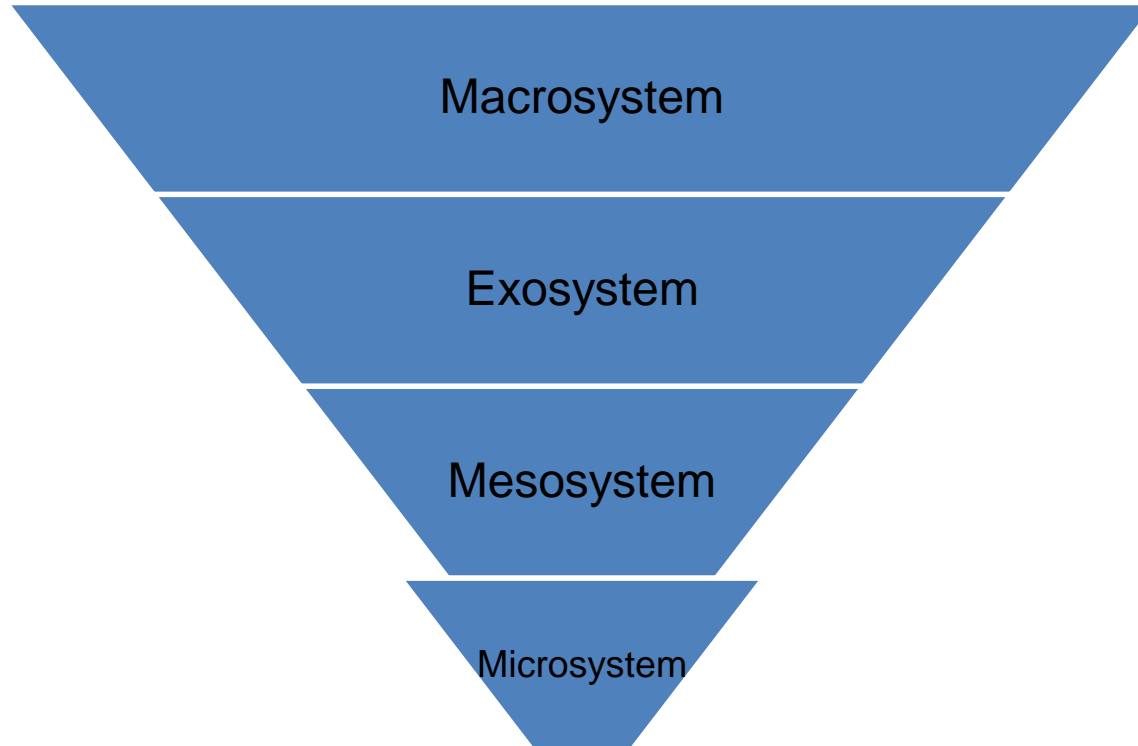
The education that has filtered down from the macro to the microsystem would play an important part at this level. Children attend clinics that cater for their needs. Personnel in these clinics include nurses, doctors and social workers. They must all be on the same page with respect to interventions in their field of work. Their knowledge of the virus, coupled with the findings from this research, should prepare them for individual interventions.

These professionals [should] make a concerted effort to find out from the child their feelings on being HIV- positive, and address the psychological aspects of death and dying. In this research, it was found that children generally look at life positively; however, the issue of HIV-AIDS creates a certain amount of sadness and fear among children. If this aspect of a child's life is addressed effectively with age-appropriate knowledge, then a better understanding of living with HIV-AIDS could be accomplished. This could contribute to an improved quality of life for that child. Making presumptions about a child's feelings with HIV-AIDS would be a thing of the past.

Mothers could also benefit from individual attention at this level, as a professional with whom they interact could impart the knowledge of how a child feels. This would help the mother to better understand the world of her child, and would also help them to recognise the burden these children carry as young carers in the family, especially in holding a secret.

The policies and programmes implemented by the government of the day for children and HIV-AIDS would help to make children more visible in the world of HIV-AIDS. In Trinidad and Tobago, children's feelings are presently not explored; the coping aspect of a child's life should be seen as "strength", and used accordingly in the intervention. When the child's feelings are validated, then they will be more able to share. When I interviewed the children, despite being a complete stranger, they responded with their feelings on the issue. This would help promote trust in the therapeutic relationship.

Figure 8.8.4: The Top-down Approach for Intervention for Mothers and Children with HIV-AIDS



### **Advocacy**

One of the roles a social worker adopts is that of an advocate for their clients.

Dissemination of findings from this research can be seen as advocacy for children living with HIV-AIDS. In order for the findings in this study to be effective, changes are needed at the macro-level with mechanisms in place to ensure these changes filter down to the micro-level, as shown in Fig 8.9.4

The policy responses of the government must be focused on change in the way HIV-AIDS is viewed among the populace. Stigma and discrimination towards persons with HIV-AIDS must be reduced considerably in order for mothers and children to foster the trust needed to disclose. The 'secrecy' that emerged as a core category in this research brought to the surface the reaction to the fear of stigma and discrimination that mothers felt. This created the impetus to protect their children at all costs, to the point of non-



disclosure in any circumstances. The research also revealed the passive and silent nature of children as they lived with HIV-AIDS.

## **8.9 Limitations of Study**

This study has offered a grounded study approach to the psychosocial issues and support needs of children with acquired HIV in Trinidad and Tobago. Trinidad and Tobago is a country that consists of 2 islands. Sampling was attempted in both islands, however, I was only able to obtain participants in Trinidad. I tried through professional contacts to source participants in Tobago to no avail. Thus, I was not able to sample anyone from Tobago. This was a limitation as to the content of the sample; however as this was a small qualitative study, the participants cannot be said to be representative of the population anyway while the findings are equally relevant to both islands of Trinidad and Tobago.

Also, because of the nature of the research, participants were difficult to access as they did not want their HIV-positive status to be known especially “mothers who did not tell”. It took about 1 year to access “mothers who did tell” of their status and about 6 months to access mothers “who did tell”. In both groups sometimes appointments would be made and mothers did not show-up without cancelling. I tried to call them via telephone without any success. Initially for “women who did tell” 10 participants were located as a group to facilitate theoretical sampling. At times some mothers would not be available as data collection and analysis were being done simultaneously and I had to move on to others. In the end, I was able to get enough mothers for the case triad and for further theoretical sampling. The time taken to source the participants was a concern as the study was time specific. The sample however, generated rich data and the limitations do not undermine the results of the research. Interviewing the children and HIV friends added to the richness of the data and added to the strength of the research.

The sample was small (20 participants in all) so caution was used with respect to any generalisations of the findings.

## **8.10 Further Research**

The examination of the psychosocial issues and support for children with acquired HIV could spark research with children and their significant others in so many areas.

Exploring the following as future research strategies can facilitate the attainment of this goal:

- 1) In this research, psychosocial issues and support were investigated. It would be interesting to find out more about the coping mechanisms of young children with HIV-AIDS, that is, how they manage in the home and at school. Another aspect that is considerably worthwhile to research is HIV-positive children's feelings living in a home with siblings who were HIV-negative and vice versa. How does this impact the HIV-positive child as well as the HIV-negative child who both share a parent that is HIV-positive. In addition to the above, research that looks at the partners (biological parents and non-biological parents) of these women and the psychosocial issues that affect their lives.
- 2) My study could be followed-up with the same methodological approach and the same cohort of children at 15-18 to ascertain the psychosocial issues and support that impact them at that stage in their lives. This study can also be used as a comparative study.
- 3) The issue of adherence to medication and its management in the midst of poverty for mothers and children with HIV-AIDS. This is important, as it alludes to morbidity and mortality of mothers and children living with HIV/AIDS.
- 4) The school environment and how this impacts on a child living with HIV-AIDS with respect to disclosure and non-disclosure.
- 5) Investigation into the ways disclosure of HIV-AIDS is carried out with children presently and their reactions.

## **8.11 Reflections**

Although I have worked on other research projects before, I would not think of myself as an experienced researcher. However, I think this aspect has been enhanced by my work and knowledge in the field of HIV-AIDS, and also my desire to help children and

mothers specifically in this field. This gave me the impetus to forge ahead. I have worked in the field of HIV-AIDS since 2002 as a clinical social worker and have acquired knowledge to date. I am also a mother. HIV-AIDS has also entered my family, as a close family member was infected with the virus. This created a great crisis in the family, as members did not have adequate knowledge of the virus and so did not know how to deal with it. I was able to intervene with my experience, even though it impacted me emotionally. I was thankful for the exposure of working in the field, knowledge of the virus and my training as a social worker, which enabled me to assist my family. This experience also contributed to the thirst for more knowledge via research in the field. I know that there is so much more to be done and revealed in the field of HIV-AIDS in relation to children. I am hoping that this research will have contributed somewhat to the enhancement of their livelihoods.

I had never interviewed children before in a research context, and this was quite new to me. I had to read a lot on conducting research with children, and familiarise myself with the tools that can help to elicit responses from them. Reading gave me the confidence that was needed to do these interviews. Also, being a trained social worker helped me to actively listen to participants. This training, coupled with the fact that I told them I worked in the field, also assisted in making the participants comfortable in the interview.

Acquiring participants for this research was quite challenging. I had colleagues and friends working as social workers in the area of HIV-AIDS, but even though this relationship assisted me immensely in reaching participants, it was still challenging. It seemed as if the mothers had to disclose their status to a stranger and they were not too comfortable with that prospect. Some mothers made arrangements to meet to be interviewed and they never turned up in more than one instance. They would not call to cancel, they just did not appear; when contacted, they gave numerous excuses as to why they did not come. This proved frustrating at times but I pressed on, depending on my colleagues to source more participants by telling them of the study and asking them if they would volunteer. These were the cohort of women who told their children of their status. When I tried to get mothers who did not tell their children of their status, acquiring participants became even more difficult. It took six months to gain access to

this population, as disclosure to a stranger was even more disconcerting to these mothers, a reflection of the stigma and discrimination of which the mothers were fearful in the society. In the end, I know that if it was not for my colleagues and friends in the field of HIV-AIDS, I would not have found these participants. Furthermore, the factors of being a trained social worker in the field of HIV-AIDS, and having colleagues and friends working in the field, were important in this research. The professionals accessed the participants, and they approached all the participants they knew who qualified for the research, so one would hope that this precluded any bias in the choice of participants. However, the research is unique in that it sought to listen to children with HIV-AIDS, listen to the mothers of these children and also to listen to an HIV friend that the mother identified.

## **8.12 Conclusion**

This study justifies the use of a grounded theory approach to the research topic and aims. It has provided insight into the psychosocial issues and support needs of children with acquired HIV-AIDS in Trinidad and Tobago, and the challenges faced by this population. It also places into the research equation mothers and HIV friends, which contributed to the depth of the understanding that emerged. It exposed gaps in support for these children and their mothers. The core category of “secrecy to protect” and the overarching main themes of “young carers living with HIV-AIDS” and “mothers, mothering with HIV-AIDS” emerged from the findings. Children were shown to be passive and silent participants in their interactions with the topic of HIV-AIDS.

It is hoped that this research can be recognised and acknowledged by the relevant stakeholders who care for children with HIV-AIDS. I sincerely hope that what I have discovered could be followed and understood by the readers of this research.

## References

- Abadía-Barrero C.E., Larusso M.D. (2006), The disclosure model versus a developmental illness experience model for children and adolescents living with HIV/AIDS in São Paulo, Brazil. *AIDS Patient Care STDS*, 20(1) pp. 36-43.
- Abebe, T., & Aase, A. (2007). Children, AIDS and the politics of orphan care in Ethiopia: The extended family revisited. *Social Science & Medicine*, 64(10), pp. 2058-2069.
- Adams, D. W., & Deveau, E. J. (1993). Coping with childhood cancer: Where do we go from here?: Needs and responses'. In C. A. M. Corr, J. N., (Ed.), *Adolescence and Death*, pp. 79-96. New York: Springer.
- Afifi, W. G., L. (2000). *Motivations underlying topic avoidance in close relationships*. In S. Petronio (Ed.), *Balancing the secrets of private disclosures*, pp.165-180. New Jersey: Lawrence Erlbaum Associates.
- Aggleton, P., Parker, R. G., Maluwa, M. (2003). *Stigma, discrimination and HIV/AIDS in Latin America and the Caribbean*: Inter-American Development Bank, Sustainable Development Dept.
- Ainsworth, M. D. S., Blehar, M. C., Waters, E., & Wall, S. (1978). *Patterns of Attachment: A Psychological Study of the Strange Situation*. Hillsdale, NJ: Erlbaum.
- Alderson, P. (2004). Ethics. In Fraser, S., Lewis, V., Ding, S., Kellett, M. & Robinson, C. (Eds.). *Doing research with children and young people*. pp. 97-112. London: Sage.
- Aldridge, J & Becker, S. (1994). *My child, my carer: The parents' perspectives, young carers research group*. Loughborough University.
- Allen, T., & Heald, S. (2004). HIV/AIDS Policy in Africa: What has worked in Uganda and what has failed in Botswana? *Journal of International Development*, 16(8), pp. 1141-1154.
- Altschuler, J. (1993). Gender and Illness: Implications for Family Therapy. *Journal of Family Therapy*, 15, pp. 381-401.
- Amaro, H., & Raj, A. (2000). On the margin: Power and women's HIV risk reduction strategies. *Sex roles*, 42(7), pp. 723-749.
- American Academy of Pediatrics (1999). 'Disclosure of illness status to children and adolescents with HIV infection'. *Pediatrics*,103, pp.164–166.
- Anastos, K. & Marte, C. (1989). 'Women the missing persons in the AIDS epidemic'. *Health/PAX Bulletin* 19 (4) pp. 6-13.
- Anderson, L. S. (2008). Predictors of parenting stress in a diverse sample of parents of early adolescents in high-risk communities. *Nursing research*, 57(5), pp. 340.

- Andersson, S. (1994). *Social scaling and children's graphic strategies: A comprehensive study of children's drawings in three cultures*. Linköping: Linköping Studies in Arts and Science.
- Andrews, S., Williams, A. B., & Neil, K. (1993). The mother-child relationship in the HIV-1 positive family. *IMAGE: Journal of Nursing Scholarship*, 25(3), pp.193-198.
- Antle, B. J., Wells, L. M., Goldie, R. S., DeMatteo, D., & King, S. M. (2001). Challenges of parenting for families living with HIV/AIDS. *Social Work*, 46(2), pp. 59-169.
- Attig, T. (1996). Beyond pain: The existential suffering of children. *Palliative Care* 12 (3) pp. 20-23.
- Armistead, L., & Forehand, R. (1995). For whom the bell tolls: parenting decisions and challenges faced by mothers who are HIV seropositive. *Clinical Psychology: Science and Practice*, 2(3), pp. 239-250.
- Armistead, L., Klein, K., Forehand, R., & Wierson, M. (1997). Disclosure of parental HIV infection to children in the families of men with haemophilia: Description, outcomes, and the role of family processes. *Journal of Abnormal Child Psychology*, 25, pp. 201-213.
- Armistead, L., Morse, E., Forehand, R., Morse, P., & Clark, L. (1999 (a)). African-American women and self-disclosure of HIV infection: Rates, predictors, and relationship to depressive symptomatology. *AIDS and Behavior*, 3(3), pp.195-204.
- Armistead, L., Summers, P., Forehand, R., Morse, P. S., Morse, E., & Clark, L. (1999 (b)). Understanding of HIV/AIDS Among Children of HIV-Infected Mothers: Implications for Prevention. *Children's Health Care*, 28(4), pp. 277-295.
- Armistead, L., Tannenbaum, L., Forehand, R., Morse, E., & Morse, P. (2001). Disclosing HIV status: are mothers telling their children? *Journal of Paediatric Psychology*, 26(1), pp. 11.
- Asander, A., Björkman, A., Belfrage, E., and Faxelid, E. (2009) HIV-Infected African Parents Living in Stockholm, Sweden: Disclosure and Planning for Their Children's Future. *Health & Social Work* 14 (2) pp.107-115.
- Australia Law Reform Commission/Human Rights and Equal Opportunity Commission (1997). *Seen and Heard: Priority for Children in the legal process*. Canberra: Australia Government Publishing Service.
- Bain, B. (2001). HIV/AIDS- Challenging a monster. In B. Dicks (Ed.), *HIV/AIDS and children in the English speaking Caribbean*, pp. 3-22. New York: Haworth Press.
- Bacha, T., Pomeroy, EC., & Gilbert, D. (1999). A psychoeducational group intervention for HIV-positive children: A pilot study. *Health and Social Work*. 24(4), pp. 303-306.
- Ball, J., Tannenbaum, L., Armistead, L., Maguen, S., & The Family Health Project Research, G. (2002). Coping and HIV Infection in African-American Women. *Women & Health*, 35(1), pp. 17-36.

- Barnett, T. & Whiteside, A. (2002). *AIDS in the Twenty-First Century: Disease and Globalization*. Palgrave Macmillan. New York.
- Banyard, V. L., & Graham Bermann, S. A. (1993). A gender analysis of theories of coping with stress. *Psychology of Women Quarterly*, 17(3), pp. 303-318.
- Barnes, D. B., & Murphy, S. (2009). Reproductive decisions for women with HIV: Motherhood's role in envisioning a future. *Qualitative Health Research*, 19(4), 481.
- Barnett, T. & Whiteside, A. (2002). *AIDS in the Twenty-First Century: Disease and Globalization*. Palgrave Macmillan. New York.
- Barroso, J., Buchanan, D., Tomlinson, P., & van Servellen, G. (1997). Social support and long-term survivors of AIDS. *Western Journal of Nursing Research*, 19(5), pp.554.
- Barrow, C. (2008). Early childhood in the Caribbean: Working Paper 47. The Hague, The Netherlands: Bernard van Leer Foundation This paper is a summary of a much fuller document by the author, *Childhoods and family culture: Growing up outside, shifted or left behind*.
- Barrow, C. (2010). *Caribbean Childhoods: 'outside', 'adopted' or 'left behind'*. Kinston: Ian Randall Publishers.
- Bartlett, J. A. (2002). Addressing the challenges of adherence. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 29(S2), pp. 502-510.
- Bauman, L. J., Silver, E. J., Draimin, B. H., & Hudis, J. (2007). Children of mothers with HIV/AIDS: unmet needs for mental health services. *Pediatrics*, 120(5), e1141.
- Beckford Jarret, S., O'Sullivan, L. & Hoffman, S. (2009). Gender Scripts Guiding the: Sexual Relationships of Caribbean Americans. In R. D. Roberts, Reddock, D. Douglas & S. Reid (Ed.), *Sex Power & Taboo: Gender and HIV in the Caribbean and Beyond* (pp. 110-125). Kingston: Ian Randle Publishers.
- Berger, R., & Paul, M. (2008). Family Secrets and Family Functioning: The Case of Donor Assistance. *Family process*, 47(4), pp. 553-566.
- Bernard, B. (1999). The foundations of resiliency paradigm. In N. In Henderson, Barnard, B. & Sharp-Light, N. (Ed.), *Resiliency in action: Pratical ideas for overcoming risks and building strengths in youth, families and communities* (pp. 5-9). Ojai: Resiliency in Action Inc.
- Bennetts, A. et al. (1999). 'Determinants of depression and HIV-related worry among HIV-positive women who have recently given birth, Bangkok, Thailand'. *Social Science and Medicine*, 49, pp. 737-749.
- Benton, D. (1996). *Grounded theory. In The Research Process in Nursing (Cormack D.F.S. Ed.)*. Blackwell Science: Oxford.

- Berg, B. (2004). *Qualitative research methods for the social sciences*. Boston: Pearson.
- Betancourt, T. S., Fawzi, M. K. S., Bruderlein, C., Desmond, C., & Kim, J. Y. (2010). Children affected by HIV/AIDS: SAFE, a model for promoting their security, health, and development. *Psychology, Health & Medicine*, 15(3), pp. 243-265.
- Bicego, G., Rutstein, S., & Johnson, K. (2003). Dimensions of the emerging orphan crisis in sub-Saharan Africa. *Social Science & Medicine*, 56(6), pp. 1235–1247.
- Biggar, R., Forehand, D., Devine, D., Brody, G., Armistead, L., Morse, E. & Simon, P. (1999). Women who are HIV infected: The Role of Religious Activity in Psychosocial Adjustment. *AIDS Care*, 11, pp. 195-199.
- Bikaako-Kajura, W., Luyirika, E., Purcell, D. W., Downing, J., Kaharuza, F., Mermin, J., et al. (2006). Disclosure of HIV status and adherence to daily drug regimens among HIV-infected children in Uganda, *AIDS and Behavior*, 10(4 Suppl.) pp. S85–S93.
- Black, L. (1993). AIDS and secrets. In E. Imber-Black (Ed.), *Secrets in families and family therapy* (pp. 359-360). New York: Norton.
- Blanche, S., Newell, M. L., Mayaux, M. J., Dunn, D. T., Teglas, J. P., Rouzioux, C., et al. (1997). Morbidity and mortality in European children vertically infected by HIV-1: the French Paediatric HIV Infection Study Group and European Collaborative Study. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 14(5), p. 442.
- Blasini I., Chantry C., Cruz C. et al. (2004). Disclosure model for pediatric patients living with HIV in Puerto Rico. *Journal of Developmental and Behavioral Pediatrics*. 25(3), pp.181–189.
- Bluebond-Langner, M., Lask, B., & Angst, D. B. (Eds.). (2001). *Psychosocial aspects of cystic fibrosis*. London: Arnold.
- Bogart, L. M., Cowgill, B. O., Kennedy, D., Ryan, G., Murphy, D. A., Elijah, J., et al. (2008). HIV-related stigma among people with HIV and their families: a qualitative analysis. *AIDS and Behavior*, 12(2), pp. 244-254.
- Bok, S. (1982). *Secrets: On the Ethics of Concealment and Revelation* (New York. Pantheon, 283. Bor, R., Miller, R. & Salt, H. (1989). Secrecy-related problems in AIDS management. *Journal of the Royal College of Physicians*, 23, pp. 264-267.
- Bok, S. (1989). *Secrets: On ethics of concealment and revelation*. New York: Vintage Books.
- Bombereau, Gaelle, and Caroline Allen. 2008. *Social and Cultural Factors Driving the HIV Epidemic in the Caribbean: A Literature Review*. Caribbean Health Research Council.



Bor, R., Miller, R., & Goldman, E. (1993). HIV/AIDS and the family: A review of research in the first decade. *Journal of Family Therapy*, 15(2), pp. 187-204.

Brown, et al. (1997). Caribbean fatherhood: Under-researched, misunderstood. In Caribbean Families: Diversity among ethnic groups. J. Roopnarine & Brown, J. *Caribbean Families: Diversity among Ethnic Groups*. Greenwich: Ablex Publishing.

Brouwer, C. N., Lok, C. L., Wolffers, I., & Sebagalls, S. (2000). Psychosocial and economic aspects of HIV/AIDS and counselling of caretakers of HIV-infected children in Uganda. *AIDS Care*, 12(5) pp. 535–540.

Brown, L.K. and Lourie, K.J. (2000) Children and Adolescents Living with HIV and AIDS: A Review, *Journal of Child Psychology & Psychiatry*, 41, pp. 81-96.

Brown, J. (1993). *Gender relations and conflicts in fathering*. Paper presented at research seminar, University of the West Indies, Kingston, Jamaica.

Bunting, S. (1996). Sources of stigma associated with women with HIV. *Advances in Nursing Science*, 19(2), pp. 64-73.

Birks, M. & Mills, J. (2011). *Grounded theory : a practical guide*. Los Angeles : SAGE.

Burns, D. N., & Mofenson, L. M. (1999). Paediatric HIV-1 infection. *The Lancet*, 354, pp. S111-S116.

Burgoyne, R.W, Saunders, D.S. (2001). Quality of life among urban Canadian HIV/AIDS clinic outpatients. *International Journal of STD AIDS*, 12(8) pp. 505-12.

Cain, A. C. (2006). Parent suicide: Pathways of effects into the third generation. *Psychiatry: Interpersonal and Biological Processes*, 69(3), pp. 204-227.

Caldwell, J. (2001). The globalization of fertility behavior. *Population and Development Review*, 27, pp. 93-115.

Campbell, C.A. (1995). Male gender roles and sexuality: Implications for women's AIDS risk and prevention. *Social Science and Medicine*, 41, pp. 197-210.

Campbell, C., Nair, Y., Maimane, S., & Sibiya, Z. (2008). Supporting people with AIDS and their carers in rural South Africa: possibilities and challenges. *Health and Place*, 14(3) pp. 507–518.

Carey, James W.; Wenzel, Patrick H.; Reilly, Cindy; Sheridan, John; Steinberg, Jill M.; and Harbison, Katherine G. (1998). *“CDC EZ-Text”: Software for Collection, Management and Analysis of Semi-structured Qualitative Databases (Version 3.06)*. Atlanta: Developed by Conwal Incorporated for the Centers for Disease Control and Prevention.

Caribbean Epidemiological Centre (2004). *Status and trends-Analysis of the Caribbean HIV-AIDS Epidemic 1982-2002*. Port-of-Spain, Trinidad and Tobago.

- Castro, A., & Farmer, P. (2005). Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti. *American Journal of Public Health*, 95, pp. 53–59.
- Central Statistics Office of Trinidad and Tobago (2000). *Census*, Port-of-Spain, Trinidad and Tobago: CAREC.
- Charles, G., Stainton, T. & Marshall, S. (2009). Young Carers: An Invisible Population. *Relational Child and Youth Care Practice*, 22(1).
- Chase, N. (Ed.). (1999). *Burdened children: Theory, research, and treatment of parentification*. Thousand Oaks, CA: Sage Publications.
- Charmaz, K. (2006). *Constructing Grounded Theory, a practical guide through qualitative analysis*. London: Sage.
- Chang, T. et al. (2003). Inhibition of HIV infectivity by a natural human isolate of *Lactobacillus jensenii* engineered to express functional two-domain CD4. *Proceedings of the National Academy of Sciences*, 100(20), 11672.
- Cheever, L. (2000). *AIDS adherence: Issues and strategies, Medscape HIV: Annual Update 2000*. Available at: <http://www.mwdscope.com/Medscape/HIV?AnnualUPdate/2000/mha.update05.08.cheever/mha05cheever.html>. Retrieved September 10<sup>th</sup> 2012.
- Chenitz, W.C. & Swanson, J. M. (1986). From practice to grounded theory: *Qualitative research in nursing*. Menlo Park, CA: Addison-Wesley.
- Cherin, D., Iluba, G., Steinberg, J, Reis, P., Melchiof, L., Marconi, K. & Panter, A. 2001. Satisfaction with services in innovative managed care programs for groups of additionally underserved individuals with HIV/AIDS. *Empirical Models, Home Health Care Services Quarterly*, 19, pp.103-125.
- Chesney, M. (2000). Factors affecting adherence to antiretroviral therapy. *Clinics of Infectious Disease*, 30(Supplement 2), pp. S171-176.
- Chevannes, B. (2002). Gender and adult sexuality. In P. Mohammed (ed.), *Gendered realities: Essays in Caribbean feminist thought*, pp. 485-494. Jamaica: University of the West Indies Press.
- Christensen, P. & James, A. (Eds.) (2000). *Research with Children: Perspectives and Practices*. London: Falmer Press.

- Christensen, A., & Heavey, C. L. (1993). Gender differences in marital conflict: The demand/withdraw interaction pattern. In S. C. Oskamp, S. (Ed.), *Gender Issues in Contemporary Society* (pp. 113-141). Newbury Park: Sage.
- Christensen, F. & Prout, A. (2002). Working with ethical symmetry in social research with children. *Childhood*, 9 (4), pp. 477-497.
- Chung, J. Y., & Magraw, M. M. (1992). A group approach to psychosocial issues faced by HIV-positive women. *Hospital & Community Psychiatry*, 43, 891-894.
- Ciambrone, D. (2002). Informal networks Among Women with HIV/AIDS: Present Support and Future Prospects. *Qualitative Health review*, Sep., 12, 7<sub>1</sub> pp. 876-896.
- Cobb, S. (1976). Social Support as a moderator of Life Stress. *Psychosomatic Medicine*, 38, pp. 300-314.
- Cohen, S. and Wills, T.A. (1985). Stress, Social Support and the Buffering Hypothesis, *Psychological Bulletin*, 98<sub>1</sub> pp. 310-357.
- Cooper, D., Harries, J., Myer, L., Orner, P., & Bracken, H. (2007). "Life is still going on": Reproductive intentions among HIV positive women and men in South Africa. *Social Science & Medicine*, 65(2), pp. 274-283.
- Corona, R., Beckett, M. K., Cowgill, B. O., Elliott, M. N., Murphy, D. A., Zhou, A. J.(2006). Do children know their parent's HIV status? Parental reports of child awareness in a nationally representative sample. *Ambulatory Pediatrics*, 6(3), 138-144.
- Cousar, R. L. (2005). *The lived experience of becoming and being HIV positive for African American women with children*. Doctoral dissertation, George Mason University, United States--Virginia. Retrieved August 12, 2007, from ProQuest Digital Dissertation database (Publication No. AAT 3194515).
- Coyne, T. (1997). Sampling in qualitative research: purposeful and theoretical sampling: Merging or clear boundaries? *Journal of Advance Nursing*, 26, pp. 623-630.
- Craft, S. M., Delaney, R. O., Bautista, D. T. & Serovich, J. M. (2007). Pregnancy decisions among women with HIV. *AIDS and Behavior*, 11(6), pp. 927-935.
- Crandall, C. & Coleman, R. (1992). AIDS-related stigmatization and the disruption of social relationships. *Journal of Social and Personal Relationships*, 9, pp. 163-175.
- Cree, D. V. E., Kay, H., Tisdall, E., & Wallace, J. (2006). Listening to children and young people affected by parental HIV: Findings from a Scottish study. *AIDS Care*, 18(1), pp. 73-76.
- Cree, V. E., Kay, H., Tisdall, K., & Wallace, J. (2004). Stigma and parental HIV. *Qualitative Social Work*, 3(1), pp. 7-25.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. London: Sage Publications, Inc.

- Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches*. London: Sage Publications, Inc.
- Crosby, R. A., Diclemente, R. J., Wingwood, G.M., Sionean, C., Cobb, B.K. & Harrington, K. (2000). Correlates of unprotected vaginal sex among African American female adolescents. Importance of relationship dynamics. *Archives of Pediatrics and Adolescent Medicine*, 154, pp. 893-899.
- Crotty, M., (1998). *The Foundations of Social Research*. Allen & Unwin: Australia.
- Cutcliffe, J. (2000). Methodological issues in grounded theory. *Journal of Advanced Nursing*, 31 (6), pp. 1476-1484.
- Cyrus, B. (2009). Women and adherence to antiretroviral therapy. In Jones. A., Padmore, J. & Maharaj, P., eds. *HIV-AIDS & Social Work Practice in the Caribbean*, Kingston: Ian Randle Publishers.
- da Silva, R., Neto, N. da Rocha, V. (2008). Emotional Experiences of HIV-Positive Mothers: Care Implications. *Neurobiologia*, 71(1-2).
- da Silveira Rossi, A., Fonsechi-Carvasan, G. A., Makuch, M. Y., Amaral, E., & Bahamondes, L. (2005). Factors associated with reproductive options in HIV-infected women. *Contraception*, 71(1), pp. 45-50.
- Dailey, R. M., & Palomares, N. A. (2004). Strategic topic avoidance: An investigation of topic avoidance frequency, strategies used, and relational correlates. *Communication Monographs*, 71(4), pp. 471-496.
- Dane, B. O. (1996). Children, HIV infection and AIDS. In Corr, C.A. & Corr, D. M. (Eds.), *Handbook of childhood death and bereavement* (pp. 51-70). New York: Springer.
- Dane, B. (2002). The voices of Thai women living with HIV/AIDS. *International Social Work*, 45(2), p. 185.
- Daniel, M., Apila, H. M., Bjørger, R., & Lie, G. T. (2007). Breaching cultural silence: enhancing resilience among Ugandan orphans. *African Journal of AIDS Research*, 6(2), pp. 109-120.
- Deacon, H., Stephney, I., & Prosalendis, S. (2005). *Understanding HIV/AIDS stigma: A theoretical and methodological analysis*. Cape Town: HSRC Press.
- DeMarco, R., Miller, K., Patsdaughter, C., Chilholm, M., & Grindel, C. (1998). From silencing the self to action: Experiences of women living with HIV/AIDS. *Health Care for Women International*, 19, pp. 539-553.
- DeMatteo, D., Wells, L., Goldie, R. S., & King, S. (2002). The 'Family' context of HIV: a need for comprehensive health and social policies. *AIDS Care*, 14(2), pp. 261-278.

Denzin, K. (1978). *The research act: A theoretical introduction to sociological methods*. New York: McGraw-Hill.

Denzin, N. K. & Lincoln, Y. S. (eds) (2003). *The Landscape of Qualitative Research*, 2nd Edition. Sage Publications: Thousand Oaks.

Dixon, L. (2003). A normal lifestyle? Challenges facing children with diabetes and their families. *Pediatric Nursing*, 15(8), p. 35.

Doka, K. J. (1996a). The cruel paradox: Children who are living with life-threatening illness. In Corr, C.A., & Corr, D.M. (Eds.), *Handbook of childhood death and bereavement* (pp. 89-105). New York: Springer.

Doll, L. & Dillon, B. (1997). Counseling persons seropositive for Human Immunodeficiency Virus and their families. In V. Devita, Hellman, S. & Rosenberg, S. (Ed.), *AIDS: Etiology, diagnosis, treatment and prevention* (pp. 533-540). Philadelphia: Lippincott-Raven.

Domek, G. J. (2006). 'Social consequences of antiretroviral therapy: preparing for the unexpected futures of HIV-positive children'. *The Lancet*, 367(9519), pp.1367–1369.

Dorsey, S., Klein, K., Forehand, R., & Family Health Project Research, G. (1999). Parenting self-efficacy of HIV-infected mothers: The role of social support. *Journal of Marriage and the Family*, pp. 295-305.

Dowling, S. (1995). Women have Feelings Too: Mental health Needs of Women living with HIV Infection. In L. Doyal, J. Naidoo and T. Wilton Eds. *AIDS Setting a Feminist Agenda* pp.113-121. London: Taylor and Francis.

Dunbar, H., Muellier, C., Medina, C. & Wolf, T. (1998). Psychological and spiritual growth in women living with HIV. *Social Work*, 43, 144-154.

Duran-Gonzales, V. (1982). The realm of female familial responsibility. In J. Massiah (Ed.), *Women in the Family* (pp. 1-27). Cave Hill: ISER, University of the West Indies.

Dutra, R., Forehand, R., Armistead, L., Brody, G., Morse, E., Simon Morse, P., et al. (2000). Child resiliency in inner-city families affected by HIV: the role of family variables. *Behaviour Research and Therapy*, 38(5), pp. 471-486.

Easterby-Smith, M., Thorpe, R., & Lowe, A. (1991). *Management research: An introduction*. London: Sage.

Ehrhardt, A., & Wasserheit, J. (1991). Age, gender, and sexual risk behaviors for sexually transmitted diseases in the United States. In J. Wasserheit, Aral S., and Holmes K. (Ed.), *Research issues in human behavior and sexually transmitted diseases in the AIDS era* (pp. 97-121). Washington DC: American Society for Microbiology.

Emery, R., & Forehand, R. (1996). Parental divorce and children's well-being: A focus on resilience. In R. Haggerty, Sherrod, L., Garmezy, N. & Rutter, M. (Ed.), *Stress, risk,*

*and resilience in children and adolescents: Processes, mechanisms, and interventions* (pp. 64–99). New York: Cambridge University Press.

Erving, G. (1963). *Stigma: Notes on the management of spoiled identity*. New York: Simon & Schuster. Faithfull, J. (1997). HIV positive and AIDS infected women: Challenges and Difficulties of Mothering. *American Journal of Orthopsychiatry*, 67(1), pp. 144-151.

Eisenhardt, K., (1989). Building theories from case study research. *Academy of Management Research Review*, 14 (4), pp. 532-550.

Evans, R. (2005). Social networks, migration, and care in Tanzania – Caregivers' and children's resilience to coping with HIV/AIDS. *Journal of Children and Poverty*, 11, pp. 111–129.

Evans & Davies (1997). Overview of issues of childhood socialisation in the Caribbean. In *Caribbean families: Diversity among ethnic groups*. pp. 1-24. Connecticut: Ablex Publishing Corporation.

Faithfull J. (1997). HIV-positive and AIDS-infected women: challenges and difficulties of mothering. *American Journal of Orthopsychiatry*, 67(1) pp. 144–51.

Flinders, D.J & Mills, G.E., (1993). *From practice to theory to practice: The roles of theory in research on standardized testing*. Teachers College Press: New York

Forsyth, B.W. (1995). Primary care of children with HIV infection. *Pediatrics*. 7, pp. 502-512.

Foster, G., Levine, C., & Williamson, J. (2005). *A generation at risk: The global impact of HIV/AIDS on orphans and vulnerable children*. MA. USA: Cambridge University Press.

Florence, M., Lutzen, K., Alexius, B. (1994). Adaptation of heterosexually infected HIV positive women: A Swedish pilot study. *Health Care for Women International*, 15(4), 265-273.

Franklin, B. (Ed.) (2002). *Revised handbook of children's rights*. London: Routledge/Falmer.

Fraser, S., et al. (2004). *Doing research with children and young people*. London: Sage.

Freire, P. (1970). *Pedagogy of the oppressed*. New York: Continuum.

Friedland, J., Renwick, R., & McColl, M. (1996). Coping and social support as determinants of quality of life in HIV/AIDS. *AIDS Care*, 8, pp. 15-31.

Gagnon, J. H. (1990). The explicit and implicit use of the scripting perspective in sex research. *Annual review of sex research*, 1, pp. 1-43.

- Garmezy, N. (1985). Stress resistant children: The search for protective factors. In J. E. Stevenson, ed., *Recent research in developmental psychopathology*, pp. 220-227. Oxford: Pergamon.
- Ganyaza-Twalo, T., & Seager, J. (2005). *Literature review on poverty and HIV/AIDS: measuring the social and economic impacts on households*. HSRC. Cape Town, South Africa.
- Gibb, D. M., Duggan, C., & Lwin, R. (1991). The family and HIV. *Genitourinary medicine*, 67(5), p. 363.
- Gilbert, D. J., & Wright, E. M. (2003). *African American women and HIV/AIDS critical responses*. Westport, CT: Praeger.
- Gielen, A.C., McDonnell, K.A., Wu, A.W., O'Campo, P. & Faden, R. (2001). Quality of Life Among Women Living with HIV: The Importance of Violence, Social Support, and Self Care Behaviours. *Social Sciences Medicine*, Jan, 522, pp. 315-322.
- Gillman, R. & Newman, B. (1996). Psychosocial concerns and strengths of women with HIV infection: An empirical study. *Families in Society*, 77 (3), pp. 131-141.
- Goffman, E. (1963). *Stigma; Notes on the management of spoiled identity*. Englewood Cliffs, NH: Prentice-Hall Inc.
- Golish, T. C., J. (2002). I'd rather not talk about it: Adolescents' and young adults' use of topic avoidance in stepfamilies. *Journal of Applied Communication Research*, 30, pp. 78-105.
- Golomb, C. (1992). *The child's creation of the pictorial world*. Los Angeles: University of California Press.
- Golafshani, N. (2004) Understanding Reliability and Validity in Qualitative Research. *The Qualitative Report* 8 (4) December pp. 597-607.
- Gosling S A, Burns J, Hirst F. (2004). Children with HIV in the UK: A longitudinal study of adaptive and cognitive Functioning. *Clinical Child Psychology and Psychiatry* 9(1), pp. 25-37.
- Greene, K., Derlega, V.J., Gust, A.Y. & Petronio, S. (2003). *Privacy and Disclosure of HIV in Interpersonal Relationships: A Sourcebook for Researchers and Practitioners*. Lawrence Erlbaum Associates, Inc. New Jersey.
- Hackl, K. L., Somlai, A. M., Kelly, J. A., & Kalichman, S. C. (1997). Women living with HIV/AIDS: the dual challenge of being a patient and caregiver. *Health and Social Work*, 22, pp. 53-62.
- Hall, J., McAllister, L., & Whiteford, G. (2009). The practice and praxis of professional decision making. In B. Green (Ed.) *Understanding and researching professional practice*, pp. 101-120, Rotterdam: Sense Publishers.

Hamra, M., Ross, M., Karuri, K., Orrs, M., & D Agostino, A. (2005). The relationship between expressed HIV/AIDS-related stigma and beliefs and knowledge about care and support of people living with AIDS in families caring for HIV-infected children in Kenya. *AIDS Care*, 17(7), pp. 911-922.

Hansen, B. & Kautz, K. (2005) Grounded theory applied-Studying information systems development methodologies in practice. *Proceedings of the 38<sup>th</sup> Hawaii International Conference on System Sciences*.

Harding, S. (1991). Strong Objectivity and socially situated knowledge. In S. Harding (Ed.), *Whose Science? whose knowledge? Thinking from women's lives* pp. 139-163. Ithaca NY: Cornell University Press.

Haraway D J, 1991 *Simians, Cyborgs, and Women: The Reinvention of Nature* Routledge: New York.

Hart, C. (1998). Doing a literature review : releasing the social science research imagination. London: Sage Publications.

Hays, R. B., Magee, R.H., & Chauncey, S. (1994). Identifying helpful and unhelpful behaviours of loved ones: The PWA perspective. *AIDS Care*, 6, pp. 379-392.

Heard, I., Sitta, R., Lert, F., & the VESPA Study Group. (2007). Reproductive choice in men and women living with HIV: Evidence from a large representative sample of outpatients attending French hospitals (ANRS-EN12-VESPA Study). *AIDS*, 21(Suppl. 1), S77-S82.

Health Economics Unit (2001). *Situational and response analysis of HIV-AIDS in Trinidad, St. Augustine, Trinidad and Tobago*: University of the West Indies.

Hebl, M.R., & Mannix, L.M. (2003). The weight of obesity in evaluating others: A mere proximity effect. *Personality and Social Psychology Bulletin*, 29, pp. 28-38.

Hejoaka, F. (2009). Care and secrecy: Being a mother of children living with HIV in Burkina Faso. *Social Science & Medicine*, 69(6), pp. 869-876.

Henderson, N., Benard, B. & Sharp-Light, N. (Eds.) (1999). *Resiliency in action: Practical ideas for overcoming risks and building strengths in youth, families and communities*. Resiliency In Action, Inc. U. S. A.

Herek, G. & Glunt, E. (1988). An epidemic of stigma. Public reactions to AIDS. *American Psychologists*, 43, pp. 886-891.

Herek, G. (1990). Illness, stigma, and AIDS. In P.T. Costa & G. R. VandenBos *Psychological aspects of serious illness*. Washington DC: American Psychological Association.



Herek, G., Mitnick, L., Burris, S., Chesney, M., Devine, P., Fullilove, M., et al. (1998). Workshop report: AIDS and stigma: A conceptual framework and research agenda. *AIDS & Public Policy Journal*, 13(1), pp. 6-47.

Herek, G. & Capitanio, J. (1993). Public reactions to AIDS in the United States: A second decade of stigma. *American Journal of Public Health*, 83, pp. 574-0577.

Herman, M. A., & McHale, S. M. (1993). Coping with parental negativity: Links with parental warmth and child adjustment. *Journal of Applied Developmental Psychology*, 14, pp. 121-145.

Hoffman, M. (1996). *Counselling clients with HIV disease*. Guilford Press: New York.

Heymann, J., Earle, A., Rajaraman, D., Miller, C., & Bogen, K. (2007). Extended family caring for children orphaned by AIDS: balancing essential work and caregiving in a high HIV prevalence nations. *AIDS Care*, 19(3), pp. 337–345.

Higgs, J. & Cherry, N. (2009) Doing qualitative research on Practice. In Higgs et al. (Eds.) *Writing qualitative research on practice* (p.10). Rotterdam: Sense Publishers.

Hough, E. S., Brumitt, G., Templin, T., Saltz, T., & Mood, D. (2003). A model of mother–child coping and adjustment to HIV. *Social Science and Medicine*, 56, pp. 643-655.

Holschneider, S. O., Alexander, C. S. (2003). Social and psychological influences on HIV preventative behaviours of youth in Haiti. *Journal of Adolescence Health*, 33 (1) pp. 31-40.

Hosegood, V., Floyd, S., Marston, M., Hill, C., McGrath, N., Isingo, R., et al. (2007). 'The effects of high HIV prevalence on orphanhood and living arrangements of children in Malawi, Tanzania, and South Africa'. *Population Studies – A Journal of Demography*, 61(3), pp. 327–336.

Hudson, A. L., Lee, K. A., Miramontes, H., & Portillo, C. J. (2001). Social interactions, perceived support, and level of distress in HIV-positive women. *Journal of the Association of Nurses in AIDS Care*, 12(4), pp. 68-76.

Hutchinson, A. (1993) Grounded theory: The method. In L. Munhall & A. Boyd (Eds.) (2<sup>nd</sup> ed.) *Nursing research: A qualitative perspective*, pp. 180-212. New York: National League for Nursing Press.

Hunter Susan and John Williamson, *Children on the Brink (2002): Strategies to support a generation isolated by HIV/AIDS*, Health Technical Services Project for United States Agency for International Development, Arlington, VA.

Hudson, A.L., Lee, K.A., Miramontes, H., Portillo, C.J. (2001). *J. Association Nurses. AIDS Care*, Jul – Aug: 124, pp. 68-76.

Imber-Black, E. (1993). *Secrets in families and family therapy*. New York: Norton.

Imber-Coppersmith, E. (1985). We've got a secret: A non-marital marital therapy. In A. Gurman (Ed.), *A casebook of marital therapy* (pp. 369-386). New York: Guilford Press.

Ingram D, Hutchinson SA. (1999a). Defensive mothering in HIV-positive mothers. *Quality in Health Research*, 9, pp.243–258.

Ingram, D. A. (1996). *HIV-positive women: Double binds and defensive mothering*. Doctoral dissertation, University of Florida, Gainesville, FL.

Ingram, K., Jones, D., Fass, R., Neidig, J. & Song, Y. (1999). Social Support and Unsupportive Social Interactions: Their Association with Depression among people living with HIV. *AIDS Care*, 11, pp. 313-329.

Ingram, D., & Hutchinson, S. (1999b). HIV-positive mothers and stigma. *Health Care for Women International*, 20, pp. 93-103.

Instone, S. L. (2000). Perceptions of children with HIV infection when not told for so long: Implications for diagnosis disclosure. *Journal of Pediatric Health Care*, 14(5), 235-243.

Jack, Noreen (2001). HIV/AIDS in Caribbean children and adolescents. In Dicks, Barbara A. (Ed.) *HIV/AIDS and children in the English-Speaking Caribbean*, Pennsylvania: The Haworth Press.

James, A., & Prout, A. (1997). *Constructing and reconstructing childhood: Contemporary issues in the sociological study of childhood*. New York: Falmer Press.

James, A., Jenks, C., & Prout, A. (1998). *Theorizing childhood*. Cambridge: Polity Press.

Jarrett E. M., Yee B. W. K., Banks M. E. (2007). Benefits of comprehensive health care for improving health outcomes in women. *Professional Psychology: Research and Practice*, 38, pp. 305–313.

Jenkins, S. R., & Coons, H. L. (2002). Psychosocial stress and adaptation processes for women coping with HIV/AIDS. *Women and AIDS*, pp. 33-86.

Jones, A. (2008). Involving children and young people as researchers. In Fraser, S., Lweis, V., Ding, S., Kellett, M. & Robinson, C. (Eds.). *Doing research with children and young people*. London: Sage.

Jones, A. (2009). Positive Women. In Jones. A., Padmore, J. & Maharaj, P., eds. *HIV-AIDS & Social Work Practice in the Caribbean*, Kingston: Ian Randle Publishers. pp. 157-184.

- Jones, A. & Rogers, T. (2008). *HIV Testing and Beyond: Exploring Perceptions, Behaviours and Experiences*. Forthcoming Publication.
- Joseph, D. (2009). Informal social support networks for HIV-positive women. In Jones. A., Padmore, J. & Maharaj, P., (Eds). *HIV-AIDS & Social Work Practice in the Caribbean*, Kingston: Ian Randle Publishers.
- Kadushin, G. (2000). Family secrets: Disclosure of HIV status among gay men with HIV/AIDS to the family of origin. *Social Work in Health Care*, 30, pp. 1-17.
- Kalichman, S.C., Di Marco, M., Austin, J., Luke, W., Di Fonzo, K. 2003. Stress, Social Support and HIV-status disclosure to family and friends among HIV-positive men and women. *Behavioural Medicine*, Aug, 264, pp. 315-332
- Kaplan, H.B. 1991. Social Psychology of the Immune System: A Conceptual Framework and Review of the Literature. *Social Sciences and Medicine*, 33, pp.909-923.
- Kaplan, M., Marks, C. & Mertens, S. (1997). Distress and Coping Among Women with HIV infection: Preliminary Findings from a multi-ethnic sample. *American Journal of Orthopsychiatry*, 6, 89-91.
- Karpel, M. A. (1980). Family secrets. *Family process*, 19(3), pp. 295-306.
- Kay, H., Cree, V., Tisdall, K., & Wallace, J. (2003). At the edge: Negotiating boundaries in research with children and young people. *Social Research*, 4(2), pp. 2-03.
- Kershaw T, Small M, Joseph G, Theodore M, Bateau R, Frederic R. (2006). The influence of power on HIV risk among pregnant women in rural Haiti. *AIDS Behaviour* 10.
- Kimberly, J.A. & Serovich, J.M. (1999). The role of family and friend social support in reducing risk behaviors among HIV-positive gay men. *AIDS Education and Prevention*, 11, pp. 465–475.
- Kliewer, W. (1991). Coping in middle childhood: Relations to competence, Type A behavior, monitoring, blunting, and locus of control. *Developmental Psychology*, 27(4), pp. 689-697.
- Klein, S., Karchner, W., O'Connell, D. (2002). Interventions to Prevent HIV-Related Stigma and Discrimination: Findings and Recommendations for Public Health Practice. *Journal of Public Health Management & Practice*, 8 (6) pp. 44-53
- Kneisl, C. R. (1993). Psychosocial and economic concerns of women affected by HIV infection. *Women, Children, and HIV/AIDS*, pp.241-250.
- Koocher, G. P. & O'Malley, J. E. (1981). *The Damocles syndrome: Psychosocial consequences of surviving childhood cancer*. New York: McGraw-Hill.

Kotchick, B. A., Forehand, R., Brody, G., Armistead, L., Simon, P., Morse, E., et al. (1997). The impact of maternal HIV infection on parenting in inner-city African American families. *Journal of Family Psychology*, 11(4), p. 447.

Land, H. (1994). AIDS and women of Color. *Families in Society*, 75, pp. 355-361.

Lazarus, R S and Folkman, S, (1984). *Stress, Appraisal, and Coping*. New York: Springer.

Lea, A. (1994). Women with HIV and Their Burden of Caring. *Health Care for Women International*, 15, pp. 489-501.

Lee CL, Johann-Liang R. (1999). Disclosure of the diagnosis of HIV/AIDS to children born of HIV-infected mothers. *AIDS Patient Care STDS*, 13 (1), p. 41.

Lee, R. S., Kochman, A., & Sikkema, K. J. (2002). Internalized stigma among people living with HIV-AIDS. *AIDS and Behavior*, 6(4), 309-319.

Lee, M. L., & Rotheram-Borus, M. J. (2002). Parents' disclosure of HIV to their children. *AIDS*, 16, pp. 2201-2207.

Leo-Rhynie, E. A. (1997). Class, race, and gender in child rearing. In J. Roopnarine & J. Brown (Eds.) *Caribbean Families: Diversity among ethnic groups* (pp. 25-55). London: Ablex.

Le Franc, E., Wyatt, G.E., Chambers, C., Eldemire, D., Bain, B., Ricketts, H. (1996). 'Working women's sexual risk taking in Jamaica'. *Social Science & Medicine* 42 (10), pp. 1411-1417

Lesar, S., & Maldonado, Y. A. (1997). The impact of children with HIV infection on the family system. *Families in Society*, 78, pp. 272-279.

Lewis, Sandra (2001). Coping over the long haul: Understanding and supporting children and families affected by HIV disease. *Journal of Paediatric Psychology* 26, (6), pp. 359-361.

Lewis, L. (2003). Exploring the intersection of gender, sexuality and culture in the Caribbean: An introduction. In L. Lewis (Ed.), *The culture of gender and sexuality in the Caribbean*. Florida: University Press of Florida.

Levine, C., & Neveloff Dubler, N. (1990). HIV and childbearing 1: Uncertain risks and bitter realities: The reproductive choices of HIV-infected women. *The Milbank Quarterly*, 68, pp. 321-351.

Lichtenstein, B., Laska, M.K. & Clair, J.M. (2002). Chronic Sorrow in the HIV-Positive Patient; Issues of Race, Gender and Social Support. *AIDS Patient Care STDS* Jan, 161, pp. 27-38.

- Lin, K. K., Sandler, I. N., Ayers, T. S., Wolchik, S. A., & Luecken, L. J. (2004). Resilience in parentally bereaved children and adolescents seeking preventive services. *Journal of Clinical Child and Adolescent Psychology*, 33, pp. 673-683.
- Lincoln, Y. & Guba, G. (1985). *Naturalistic enquiry*. London: Sage.
- Link, G., & Phelan, C. (2001). Conceptualising stigma. *Annual Review of Sociology*, 27, pp. 367-385.
- Lips, H. M. (1999). *A new psychology of women: Gender, culture, and ethnicity*. London: Mayfield Pub. Co.
- Lipson M. (1994). Disclosure of diagnosis to children with human immunodeficiency virus or acquired immunodeficiency syndrome. *Journal of Developmental Behavioural Pediatrics*, 15, pp. S61-S65.
- Longo, M.B., Spross, J.A. and Locke, A.M. (1990). Identifying Major Concerns of Persons with Acquired Immunodeficiency Syndrome: A Replication. *Clinical Nurse Specialist*, pp. 21-26.
- Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development*, 71, pp. 543 – 562.
- Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Sawires, S. R., Ortiz, D. J., et al. (2008). 'Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward'. *AIDS*, 22, p. S57.
- Massiah, J. (1983). *Women as heads of households in the Caribbean: Family structure and feminine status*. Essex: UNESCO.
- Mandel, J.S. (1956). Psychosocial Challenges of AIDS and ARC: Clinical and Research Observations in: L. McKusick ed. *What to Do About AIDS: Physicians and Mental Health Professionals Discuss the Issues*, 75-86. Berkeley: University of California Press.
- Masera, G. et al. (1999). Guidelines for assistance to terminally ill children with cancer: Areport of the SIOP working committee on psychology issues in pediatric oncology. *Medical and Pediatric Oncology*, 32 , pp. 44-48.
- Masten, A.S., & Coatsworth, J.D., (1998). The development of competence in favourable and unfavourable environments. Lessons from research on successful children. *American Psychologist*, 53 (2), pp. 205-220.
- Mawn, B. (199). Raising a child with HIV: An emerging phenomenon. *Families, Systems & Health*, 17 (2), pp. 197-215.
- Mayall, B. (2002). *Towards sociology for childhood: Thinking from children's lives*. Philadelphia, PA: Open University Press.

McLean, R. Sogren, S., Theodore, K (2009). The Impact of HIV-AIDS on Children at Risk-The Case of Trinidad and Tobago. In Jones, A., Padmore, J. & Maharaj, P., eds. *HIV-AIDS & Social Work Practice in the Caribbean*, Kingston: Ian Randle Publishers. pp. 71-99

Mc Kenzie, N. (1989). The changing face of the AIDS epidemic. *Health/PAC Bulletin*, 19 (4), pp. 3-5.

Meintjes, H., & Giese, S. (2006). Spinning the epidemic: the making of mythologies of orphanhood in the context of AIDS. *Childhood*, 13(3), pp. 407–430.

Mellins, C. A., & Ehrhardt, A. A. (1994). Families affected by pediatric AIDS: Sources of stress and coping. *Developmental and Behavioral Pediatrics*, 15, pp. S54-S60.

Mellins CA, Brackis-Cott E, Dolezal C, Abrams E. (2004). The role of psychosocial and family factors in adherence to antiretroviral treatment in human immunodeficiency virus-infected children. *Journal of Pediatric Infectious Disease*, 23 pp. 1035–1041.

Melvin, D., & Sherr, L. (1995). HIV infection in London children—psychosocial complexity and emotional burden. *Child: care, health and development*, 21(6), pp. 405-412.

Metcalf, K., Langstaff, J., Evans, S., Paterson, H. & Reid, J. (1998). Meeting the Needs of Women living with HIV. *Public Health Nursing*, 15, pp. 30-34.

Miles, B. & Huberman, M. (1994) *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks: Sage.

Miller, D. (1987). *Living with AIDS and HIV*. Basingstoke: McMillan.

Mohammed, P., Perkins, A., Gender, U. o. t. W. I. C. f., Studies, D., Activities, U. N. F. f. P., & Region, I. P. P. F. W. H. (1999). *Caribbean Women at the Crossroads: The Paradox of Motherhood Among Women of Barbados, St. Lucia and Dominica*: Canoe Press, University of the West Indies.

Moneyham, L., Seals, B., Demi, A., Sowell, R., Cohen, L., & Guillory, J. (1996). Experiences of disclosure in women infected with HIV. *Health Care for Women International*, 17, pp. 209-21.

Moore, Ami, Dorothy N. Kalanzi, and Foster K. Amey. (2008). “To disclose or not to disclose”: Lower class parents living with HIV/AIDS in Lomé, Togo. *International Journal of Sociology and Social Policy*. 28(9/10), pp. 351-364.

Morgan, R. & Murphy, S. B. (2000). Care of children who are dying of cancer. *New England Journal of Medicine*, 342, pp. 347-348.

- Morse, M. (1991). Strategies for sampling. In M. Morse (Ed.) *Qualitative nursing research: A contemporary dialogue*, pp. 126-145.
- Müller O., Corrah T., Katabira E., Plummer F., Mabey D. Antiretroviral therapy in sub-Saharan Africa. *The Lancet*. 1998;351, pp. 68–68.
- Murphy DA, Roberts KJ, Hoffman D. (2002). Stigma and ostracism associated with HIV/AIDS: Children carrying the secret of their mothers' HIV+ serostatus. *Journal of Child and Family Studies*, 11, pp.191–202.
- Murphy, D., Marelich, W., Armistead, L., Herbeck, D. and Payne, D. (2010). Anxiety/stress among mothers living with HIV: effects on parenting skills and child outcomes. *AIDS Care*, 22(12), pp. 1449-1458.
- Murphy, D. A. (2008). HIV-positive mothers' disclosure of their serostatus to their young children: a review. *Clinical Child Psychology and Psychiatry*, 13(1), p. 105.
- Murphy, D. A., & Marelich, W. D. (2008). Resiliency in young children whose mothers are living with HIV/AIDS. *AIDS Care*, 20(3), pp. 284-291.
- Nabyonga-Orem J, Bazeyo W, Okema A, Karamagi H & Walker O. (2008). Effect of HIV/AIDS on household welfare in Uganda rural communities: A Review. *East Africa Medical Journal*, 85, pp. 187–196.
- Nagler, S., Andropoz, J., & Forsyth, B. (1995). Uncertainty, stigma and secrecy: psychological aspects of AIDS for children and adolescents. In S. Geballe, Greundel, J. & Andiman, W. (Eds.), *Forgotten Children of the AIDS Epidemic*. New York: Yale University Press.
- Nannis ED, Patterson TL, Semple SJ. (1997) Coping with HIV disease among seropositive women: psychosocial correlates. *Women and Health*, 25(1), PP. 1–23.
- Nations, U. (2005). *Population, development and HIV/AIDS with particular emphasis on poverty*. New York: Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat.
- Nelms, T. P. (2005). Burden: the phenomenon of mothering with HIV. *Journal of the Association of Nurses in AIDS Care*, 16(4), PP. 3-13.
- Nkosi, T. M., Kipp, W., Laing, L., & Mill, J. (2006). 'Family caregiving for AIDS patients in the Democratic Republic of Congo'. *Healthcare Quarterly*, 9(3), pp. 94–101.
- Norman, L.R., and Uche, C. (2002). Prevalence and Determinants of Sexually Transmitted diseases: An analysis of young Jamaican males. *Sexually Transmitted Diseases*, 29(2) pp. 126-132.
- Nyamukapa, C., & Gregson, S. (2005). Extended families and women's roles in safeguarding orphans' education in AIDS-afflicted rural Zimbabwe. *Social Science & Medicine*, 60(10), pp. 2155–2167.

- O'Hare, B. A. M., Venables, J., Nalubeg, J. F., Nakakeeto, M., Kibirige, M. & Southall, D. P. (2005). Home-based care for orphaned children infected with HIV/AIDS in Uganda. *AIDS Care*, 17(4), pp. 443–450.
- Oliver, M.B. & Hyde, J.S. (1993). Gender differences in sexuality: A meta-analysis. *Psychological Bulletin*, 114, pp. 29-51.
- Ortiz-Torres, B., Serrano-Garcia, I., Torres-Burgos, N. (2000). Subverting culture: Promoting HIV/AIDS prevention among Puerto Rican and Dominican women. *American Journal of Community Psychology*, 28 (6), pp. 859-881.
- Ow, R., & Katz, D. (1999). Family secrets and the disclosure of distressful information in Chinese families. [Article]. *Families in Society-the Journal of Contemporary Human Services*, 80(6), PP. 620-628.
- Owens, S. (2003). African American Women Living with HIV/AIDS: Families as Sources of Support and of Stress. *Social Work*, 48(2), PP. 163-171.
- Pandit, N. (1996). The creation of theory: A recent application of the grounded theory method. *The qualitative report*, Vol. 2 (4) (<http://www.nova.edu/ssss/QR/QR2-4/pandit.html>).
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science & Medicine*, 57(1), pp. 13–24.
- Paul, M. B., B. (2007). Topic avoidance and family functioning in families conceived with donor insemination. *Human Reproduction*, 22(9), pp. 2566-2571.
- Pedro-Carroll, J. A. L., Sutton, S. E., & Wyman, P. A. (1999). A two-year follow-up evaluation of a preventive intervention for young children of divorce. *School Psychology Review*, 28, pp. 467-476.
- Pierret J. (1992). Coping with AIDS in everyday life. *Current Sociology*, 40(3), pp. 66-84.
- Pelton, J., & Forehand, R. (2005). Orphans of the AIDS epidemic: an examination of clinical level problems of children' *Journal of the American Academy of Childhood Adolescent Psychiatry*. 44(6), pp. 585-591.
- Phair, J., Jacobson, L., Detels, R., Rinaldo, C., Saah, A., Schragar, L., et al. (1992). Acquired immune deficiency syndrome occurring within 5 years of infection with human immunodeficiency virus type-1: the Multicenter AIDS Cohort Study. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 5(5), p. 490.
- Pittiglio, L., & Hough, E. (2009). Coping With HIV: Perspectives of Mothers. *Journal of the Association of Nurses in AIDS Care*, 20(3), pp. 184-192.
- Platt, S. (1992). Suicidal Ideation and behaviour in Human Immuno-Deficiency Virus HIV Disease. *Epidemiologia e Psichiatria Sociale*, 1, pp. 11-13.



- Poindexter, C., & Linsk, N. (1999). HIV-Related stigma in a sample of HIV-Affected older female African American caregivers. *Social Work*, 4, pp. 46-62.
- Ponton, L. E., & Lees, J. (1998). Psychological trauma of HIV in India. *International Review of Psychiatry*, 10(3), pp. 201-207.
- Powers, A. & Knapp, R. (1995) *A dictionary of nursing theory and research (2<sup>nd</sup> ed.)*. London: Sage.
- Qvortrup, J. (1994). Childhood matters: an introduction. *Childhood Matters: Social Theory, Practice and Politics* pp. 1–23.
- Rao, D. R., Sagar, R., Kabra, S., & Lodha, R. (2007). Psychiatric morbidity in HIV-infected children. *AIDS care*, 19(6), pp. 828-833.
- Reid, P. T. (1993). Poor women in psychological research. *Psychology of Women Quarterly*, 17(2), pp. 133-150.
- Reitman, D., Currier, R. O., & Stickle, T. R. (2002). A critical evaluation of the Parenting Stress Index-Short Form (PSI-SF) in a head start population. *Journal of Clinical Child and Adolescent Psychology*, 31(3), pp. 384-392.
- Rice, E., Comulada, S., Green, S., Mayfield- Arnold, E., Rotheram-Borus, MJ. (2009). *AIDS Behaviour*, 13(6), pp. 1253–1261.
- Richter, L. (2008). *No small issue: Children and families*. Universal Action Now. [Plenary Presentation at the XVII International AIDS Conference “Universal Action Now”, Mexico City, Mexico, 6 August 2008].
- Rico, L. (1983). *Writing the natural way*. Los Angeles: Tarcher.
- Rogers, T. (2009). Accepting to live: Disclosing the truth about HIV- The role of the social worker in disclosure. In Jones. A., Padmore, J. & Maharaj, P., (Eds.). *HIV-AIDS & Social Work Practice in the Caribbean*. Kingston: Ian Randle Publishers.
- Rodgers, A. Y. (1998). Multiple sources of stress and parenting behavior. *Children and Youth Services Review*, 20(6), pp. 525-546.
- Rodrigo, C., & Rajapakse, S. (2010). International Health. *International Health*, 2, pp. 9-16.
- Roopnarine, J. L., & Brown, J. (1997). *Caribbean families : diversity among ethnic groups*. Greenwich, Conn.: Ablex.
- Rose, M.A, Clark-Alexander B. (1998). Caregivers of children with HIV/AIDS: quality of life and coping styles. *Journal of the Association of Nurses AIDS Care*, 9(1) pp.58-65.

Rossmann, B. (1992). School-age children's perceptions of coping with distress: Strategies for emotion regulation and the moderation of adjustment. *Journal of Child Psychology and Psychiatry*, 33(8), pp. 1373-1397.

Rotheram-Borus MJ, Draimin BH, Reid HM, Murphy DA. (1997). The impact of illness disclosure and custody plans on adolescents whose parents live with AIDS. *AIDS*. 11 pp. 1159–1164.

Royce, R. et al. (1997). Sexual transmission of HIV. *New England Journal of Medicine*, 336(15), pp. 1072-1078.

Ruddick, S. (1989). *Maternal thinking: Toward a politics of peace*. Boston: Beacon Press.

Rutter M. Psychosocial resilience and protective mechanisms. (1990) In: Rolf J, Masten AS, Cicchetti D, Nuechterlein KH, Weintraub S, editors. *Risk and protective factors in the development of psychopathology*. pp. 181–214.. Cambridge; New York.

Rwemisisi, J., Wolff, B., Coutinho, A., Grosskurth, H., & Whitworth, J. (2008). What if they ask how I got it? Dilemmas of disclosing parental HIV status and testing children for HIV in Uganda. *Health Policy and Planning*, 23(1), pp. 36–42.

Salvi, V, Damania K. (2006). HIV, research, ethics, women. *Journal of Postgraduate Medicine*. Jul-Sep; 52(3), pp.161-2.

Sandelowski, M., & Barroso, J. (2003). Motherhood in the context of maternal HIV infection. *Research in Nursing & Health*, 26(6), pp. 470-482.

Sandelowski, M., Lambe, C., & Barroso, J. (2004). Stigma in HIV Positive Women. *Journal of Nursing Scholarship*, 36(2), pp. 122-128.

Sandelowski, M., Holditch-Davis, D. & Harris, G. (1992) 'Using qualitative and quantitative methods: The transition to parenthood of infertile couples'. In *Family Research* (GilgumJF, Daly K., Handel G. eds), Sage, London, pp. 301–323.

Sandstrom, K.L. (1990). Confronting Deadly Disease: The Drama of Identity construction Among Gay Men with AIDS. *Journal of Contemporary Ethnography*, 19, pp. 271-294.

Solomon, G.F. (1987). Psychoeuroimmunologic Approaches to Research on AIDS. *Annals of the New York Academy of Sciences* 496, pp. 628-636.

Daly and G. Handel (Eds.). *Qualitative Methods in Family Research*, pp. 301-323. London: Sage.

Sarason, I.G., Levin, H.M., Basham, R.B. and Sarason, B.R. (1983). Assessing Social Support: the Social Support questionnaire. *Journal of Personality and Social psychology*, 44, 127-139.

Sarason, I. & Sarason, B. 1982. Concomitants of Social Support: Attitudes, personality, Characteristics and Life Experiences. *Journal of Psychosomatic Research*, 22, pp. 205-208.

Selman RL. (2003). *The Promotion of Social Awareness: Powerful Lessons from the Partnership of Developmental Theory and Classroom Practice*. New York: Russell Sage Foundation.

Senior, O. (1991). *Working Miracles: Women's Lives in the English speaking Caribbean*. London: James Curry.

Serovich, J. M., Kimberly, J. A. and Greene, K. (1998). Perceived family member reaction to women's disclosure of HIV-positive information. *Family Relations*, 41, pp. 15-22.

Sherwen, L. N., & Boland, M. (1994). Overview of psychosocial research concerning pediatric human immunodeficiency virus infection. *Developmental and Behavioral Pediatrics*, 15, pp. S5-S11.

Scable, B., Diaz, T., Chu, S., Caldwell, B., Conti, L., Alston, O., et al. (1995). Who are the primary caretakers of children born to HIV-infected mothers? Results from a multi-state surveillance project. *Paediatrics*, 95(4), pp. 511-515.

Scambler, G. (1998). Stigma and disease: changing paradigms. *The Lancet*, 352(9133), pp. 1054-1055.

Scott, E., Simon, T., La Foucade, A., Theodore, K. and Gittens-Baynes, K. (2011). Poverty, employment and HIV/AIDS in Trinidad and Tobago. *International Journal of Business and Social Science*, 2(15), pp. 63-70.

Scrimshaw, E. S., K. (2002). HIV-infected mothers' disclosure to their uninfected children: Rates, reasons, and reactions. *Journal of Social and Personal Relationships*, 19, pp.19-43.

Semple, S. J., Patterson, T. L., Temoshok, L. R., McCutchan, J. A., Straits-Troster, K., Chandler, J. A., et al. (1993). Identification of psychobiological stressors among HIV-positive women. *Women & Health*, 20(4), pp. 15-36.

Senior, O. (1991). *Working Miracles: Women's Lives in the English speaking Caribbean*. London: James Curry.

Shaffer A, Jones DJ, Kotchick BA, Forehand R. (2001) The Family Health Project Research Group Telling the children: Disclosure of maternal HIV infection and its effects on child psychosocial adjustment. *Journal of Child and Family Studies*, 10, pp. 301-313.

Shambley-Ebron, D. (2003). *Self-care and cultural meanings of mothering in African American women with HIV/AIDS*. Doctoral dissertation, Medical College of Georgia,

United States--Georgia. Retrieved August 16, 2007, from ProQuest Digital Dissertation database (Publication No. AAT 3111965).

Shambley-Ebron, D. Z., & Boyle, J. S. (2006). Self-care and mothering in African American women with HIV/AIDS. *Western Journal of Nursing Research*, 28(1), p. 42.

Shonkoff, J., & Phillips (2000). *From neurons to neighbourhoods: The science of early childhood development*. Washington, DC: National Academy Press.

Schulte, E., Claes, C., Korner, T., Graf. Von Der, Schulenburg, J.M., Schmidt, R.E., Stoll, M. (2000). Deficits in Socioeconomic and Psychosocial Support of HIV positive Women. *Gesundheitswesen*, July, 627, pp. 391-399

Siegel, K., Schrimshaw, E., & Pretter, S. (2005). Stress-related growth among women living with HIV/AIDS: Examination of an explanatory model. *Journal of Behavioral Medicine*, 28, pp. 403-414.

Simon, W. G., J. (1999). Sexual Scripts. In R. P. a. P. Aggleton (Ed.), *Culture, society and sexuality: A reader*, (pp. 29-38). London: UCL. Press.

Simon, W. & Gagnon, J. (1999) Sexual scripts. In *Culture, society and sexuality. A reader*, (Eds.). R. Parker & P. Aggleton, (pp. 29-38). London: UCL Press.

Simoni, J. M., Frick, P. A., Lockhart, D., & Liebovitz, D. (2002). Mediators of social support and antiretroviral adherence among an indigent population in New York City. *AIDS Patient Care and STDs*, 16(9), pp. 431-439.

Singhal, A., & Howard, W. S. (2003). *The children of Africa confront AIDS : from vulnerability to possibility*. Athens: Ohio University Press.

Skovdal, M., Ogutu, V. O., Aoro, C., & Campbell, C. (2009). Young carers as social actors: Coping strategies of children caring for ailing or ageing guardians in Western Kenya. *Social Science & Medicine*, 69(4), pp. 587-595.

Smith, L., Feaster, D. J., Prado, G., Kamin, M., Blaney, N., & Szapocznik, J. (2001). The Psychosocial Functioning of HIV+ and HIV- African American Recent Mothers. *AIDS and Behavior*, 5(3), pp. 219-231.

Sobo, E. (1993). *One Blood: The Jamaican Body*. Albany: State University of New York Press.

Sourkes, B. M. (1995). *Armfuls of time: The psychological experience of the child with a life-threatening illness*. Pittsburgh: University of Pittsburg Press.

- Sowell, R., Murdaugh, C., Addy, C., Moneyham, L., & Tavokoli, A. (2002). Factors influencing intent to get pregnant in HIV-infected women living in the southern USA. *AIDS Care*, 14(2), pp. 181-191.
- Sowell, R., & Misener, T. (1997). Decisions to have a baby by HIV-infected women. *Western Journal of Nursing Research*, 19(1), pp. 56-70.
- Sowell, R., Moneyham, L., & Aranda-Naranjo, B. (1999). The care of women with AIDS. *Nursing Clinics of North America*, 34(1), pp. 179-197.
- Spinetta, J. J. & Deasy- Spinetta, P. (1981). *Living with childhood cancer*. St. Louis: Mosby.
- Spira, R., Lepage, P., Msellati, P., Van de Perre, P., Leroy, V., Simonon, A., et al. (1999). Natural history of human immunodeficiency virus type 1 infection in children: a five-year prospective study in Rwanda. *Pediatrics*, 104(5), p. e56.
- Sprenkle, D. (2002). *Effectiveness research in Marriage and Family Therapy*. Alexandria: American Association for Marriage and Family Therapy.
- Stein, J. (2003). HIV/AIDS stigma: the latest dirty secret. *African Journal of AIDS Research*, 2(2), pp. 95–101.
- Stein, A., Krebs, G., Richter, L., Tomkins, A., RoCHAT, T., & Bennish, M. L. (2005). Babies of a pandemic. *Archives of Disease in Childhood*, 90(2), p. 116.
- Stern, P., Allen, L. & Moxley, P. (1982) The nurse as a grounded theorist: History, process and uses. *Review Journal of Philosophy and Social Science*, 7, pp. 200-215.
- Stillwaggon, E. (2000). HIV transmission in Latin America: comparison with Africa and policy implications. *South African Journal of Economics*, 68(5), pp. 444-454.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. London: Sage Publications, Inc.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. London: Sage Publications, Inc.
- Street, C. & Franklyn, C. (1992). Defining and measuring social support: Guidelines for social work practitioners. *Research on Social Work Practice*, 2, pp. 81-89.
- Susan, H., & Williamson, J. (1997). *Children on the Brink 2002: Strategies to support a generation isolated by HIV/AIDS*. Health Technical Services Project for United States Agency for International Development, Arlington, VA.
- Tesch, R. (1991). Software for qualitative researchers: Analysis needs and program capabilities. In N. Fielding & R. Lee (Eds.). *Using computers in qualitative research*, pp. 16-37. London: Sage.

The Australian National Health and Research Council. (2007). National Statement on Ethical Conduct in Human Research (2007). *Chapter 4.2 Children and Young People*. [Accessed on February 12<sup>th</sup> 2013].

The Caribbean HIV/AIDS Epidemic and the Situation in Member Countries of the Caribbean Epidemiology Centre Prepared by: CAREC (2006). *Special Programme on Sexually Transmitted Infections*, November 30, [Accessed 20<sup>th</sup> September 2009].

The Millennium Development Goals Report (2011). New York: United Nations.

The National AIDS Coordinating Committee (NACC) (2010) *UNGASS Country Progress Report, Trinidad and Tobago*, Trinidad.

The President's Emergency Plan for AIDS Relief (PEPFAR) (2006). *Orphans and vulnerable children programme guidance for United States Government in-country staff and implementing partners*. PEPFAR.

The Society of St. Vincent and De Paul (2013). [http://www.svdptt.org/cr\\_nursery.htm](http://www.svdptt.org/cr_nursery.htm). [Accessed 9<sup>th</sup> May 2013].

The World Bank (2011). Country Income Groups. <http://chartsbin.com/view/2438>. [Accessed February 26<sup>th</sup> 2013].

Thoits, P. A. (1995). Stress, coping, and social support processes: Where are we? What next? *Journal of Health and Social Behavior*, 35, pp. 53-79.

Thomas, N. (2001). The importance of culture throughout all of life and beyond. *Holistic Nursing Practice* 15 (2) pp. 40-46.

Tisdall, K., Kay, H., Cree, V., & Wallace, J. (2004). Children in need? Listening to children whose parent or carer is HIV positive. *British Journal of Social Work*, 34(8), 1097-1113.

Tompkins, T. (2007). Disclosure of maternal HIV status to children: to tell or not to tell. That is the question. *Journal of Child and Family Studies*, 16(6), pp. 773-788.

Turner, R.J. (1981). Social Support as a Contingency in Psychological Well-Being, *Journal of Health and Social Behaviour*, 22, pp. 357-367.

Trad, P. V., Kentros, M., Solomon, G., & Greenblatt, E. R. (1994). 'Assessment and psychotherapeutic intervention for an HIV-infected preschool child'. *Journal of the American Academy of Child and Adolescent Psychiatry*, 33, pp. 1338-1345.

Trad, P. V., Kentros, M., Solomon, G., & Greenblatt, E. R. (1994). 'Assessment and psychotherapeutic intervention for an HIV-infected preschool child'. *Journal of the American Academy of Child and Adolescent Psychiatry*, 33, pp. 1338-1345.

Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care*.

Toronto: Oxford University Press.

Trzepacz, A. M., Vannatta, K., DAVIES, W., Stehbins, J. A., & Noll, R. B. (2003). Social, emotional, and behavioral functioning of children with haemophilia. *Journal of Developmental & Behavioral Pediatrics*, 24(4), pp. 225-233.

Turan, J., Miller, S., Bukusi, E., Sande, J., & Cohen, C. (2008). HIV/AIDS and maternity care in Kenya: how fears of stigma and discrimination affect uptake and provision of labor and delivery services. *AIDS Care*, 20(8), pp. 938-945.

Turner, H., Pearlin, L., & Mullan, J. (1998). Sources and determinants of social support for caregivers of persons with AIDS. *Journal of Health and Social Behaviour*, 39, pp. 137-151.

Turner, R. J. (1981). Social support as a contingency in psychological well-being. *Journal of health and social behavior*, 22(4), pp. 357-367.

UNAIDS, UNICEF and USAID, *Children on the Brink 2004: A Joint Report of New Orphan Estimates and a Framework for Action*, Population, Health and Nutrition Information Project for United States Agency for International Development, Washington, D.C., p. 8.

UNAIDS/WHO (2008). *Core Slides Global Summary of the HIV and AIDS Epidemic 2007*.

<http://www.unaids.org/en/KnowledgeCentre/HIVData/Epidemiology/epidemiologySlidesAuto.asp>. [Accessed on 9th September, 2009].

UNAIDS/WHO (2008) *Report on the Global AIDS Epidemic*.

[http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008\\_Global\\_report.asp](http://www.unaids.org/en/KnowledgeCentre/HIVData/GlobalReport/2008/2008_Global_report.asp). [Accessed on 9th September 2009].

UNICEF (2004). *The Convention of the Rights of the Child, Fifteen Years Later, The Caribbean*, Panama, UNICEF Regional Office for Latin America and the Caribbean [online], available at [http://www.unicef.org/lac/cdn\\_15\\_anos\\_ingles\\_full%282%29.pdf](http://www.unicef.org/lac/cdn_15_anos_ingles_full%282%29.pdf). [Accessed November 10<sup>th</sup> 2011].

UNICEF (2005). *Situational analysis on children and HIV-AIDS in Trinidad and Tobago*, Georgetown, Guyana: UNICEF.

UNICEF, UNAIDS, & WHO. (2007). *Children and AIDS: A stocktaking report. Actions and progress during the first year of Unite for Children, Unite against AIDS*. UNICEF. [http://data.unaids.org/pub/Report/2007/20060116\\_stocktaking\\_report.pdf](http://data.unaids.org/pub/Report/2007/20060116_stocktaking_report.pdf). [Accessed 9th September 2009].

UNAIDS & UNICEF (2005). *A call to action: Children, the missing face of AIDS*. UNICEF.

UNAIDS (2006). *Report on the global AIDS epidemic*. Geneva: UNAIDS.

UNAIDS (2009). Global report : Fact sheet Caribbean. Geneva: UNAIDS.

UNAIDS & WHO (2010). Global report. *UNAIDS report on the global AIDS epidemic*. [online] [http://www.unaids.org/documents/20101123\\_globalreport\\_em.pdf](http://www.unaids.org/documents/20101123_globalreport_em.pdf) [Accessed November 10th 2011].

United Nations (2005). *Population, development and HIV/AIDS with particular emphasis on Poverty: The Concise Report*. Department of Economic and Social Affairs Population Division. New York. [online] <http://www.un.org/esa/population/publications/concise2005/PopdevHIVAIDS.pdf> [Accessed on November 10<sup>th</sup> 2011].

UNGASS (2007). *Country Progress report, Trinidad and Tobago*. Reporting period January 2006- December 2007. [http://data.unaids.org/pub/Report/2008/trinidad\\_and\\_tobago\\_2008\\_country\\_progress\\_report\\_en.pdf](http://data.unaids.org/pub/Report/2008/trinidad_and_tobago_2008_country_progress_report_en.pdf). [Accessed 9th September, 2009].

UNICEF, UNAIDS, & WHO. (2007). *Children and AIDS: A stocktaking report. Actions and progress during the first year of Unite for Children, Unite against AIDS*. UNICEF. [http://data.unaids.org/pub/Report/2007/20060116\\_stocktaking\\_report.pdf](http://data.unaids.org/pub/Report/2007/20060116_stocktaking_report.pdf). [Accessed 9th September 2009].

UNDP/UNFPA/WHO/World Bank (2003). *Special Programme of Research, Development and Research Training in Human Reproduction*. WHO/HIV/2003.07. HIV-infected women and their families: psychosocial support and related issues. A literature review.

United Nations (1989) *Convention on the rights of the child*. New York: United Nations.

United Nations Population Fund (2002). State of the world population 2002: HIV/AIDS and poverty. Retrieved April 8 2013, from <http://www.unfpa.org/swp/2002/english/ch6>.

Urquhart, C. (2007). The evolving nature of grounded theory method: The case of the information systems discipline. . In C. C. Bryant, C. (Ed.), *The Sage handbook of grounded theory* (pp. 339-359). London: Sage.

Vallerand, A. H., Hough, E., Pittiglio, L., & Marvicsin, D. (2005). The process of disclosing HIV serostatus between HIV-positive mothers and their HIV-negative children. *AIDS Patient Care & STDs*, 19(2), pp. 100-109.

Vallerand, A. H., Hough, E., Pittiglio, L., & Marvicsin, D. (2005). The process of disclosing HIV serostatus between HIV-positive mothers and their HIV-negative children. *AIDS Patient Care & STDs*, 19(2), 100-109.

Van Graan, A., Van der Walt, E., & Watson, M. (2007). 'Community-based care of children with HIV in Potchefstroom, South Africa'. *African Journal of AIDS Research*, 6(3), pp. 305–313.

Van Hollen, C. (2010). HIV/AIDS and the Gendering of Stigma in Tamil Nadu, South India. *Culture, Medicine and Psychiatry*, pp. 1-25.



Vaux, A. & Ahanassopoulou, M. (1987). Social Support Appraisal and network resources. *American Journal of Community Psychology*, 15, pp. 153-166.

Vaux, A. (1988). *Social Support: Theory, Research and Intervention*. New York: Praeger

Vaz, L., Corneli, A., Dulyx, J., Rennie, S., Omba, S., Kitetele, F., et al. (2008). The process of HIV status disclosure to HIV-positive youth in Kinshasa, Democratic Republic of the Congo. *AIDS Care*, 20(7), pp. 842–852.

Veale, A. (2005). Creative methodologies in participatory research with children. In S. Greene & D. Hogan (Eds.), *Researching children's experiences: methods and approaches* (pp. 252–272). London: Sage.

Vygotsky, L. (1935/1978). *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.

Waechter, E. H. (1984). Dying children: Patterns of coping. In Wass, H. & Corr, C.A. (Eds.) *Childhood and death* (pp. 51-68). Washington, DC: Hemisphere.

Walker, G. (1991). *In the midst of winter: systemic therapy with families, couples, and individuals with AIDS infection*. New York: WW Norton & Company, Inc.

Walsh, J. (2000). *Clinical case management with persons having mental illness*. Ontario: Brooks/Cole.

Walsh, F. (2002). A Family Resilience Framework: Innovative Practice Applications. *Family Relations*; Apr.2002, 51(2) pp.130- 8.

Waweru, S. M., Reynolds, A., & Buckner, E. B. (2008). *Perceptions of children with HIV/AIDS from the USA and Kenya: self-concept and emotional indicators*. *Pediatric Nursing*, 34(2), pp. 117-124.

Wisner, B. 2001. Vulnerability in Disaster Theory and Practice: From Soup to Taxonomy to Analysis and finally Tool. Unpublished paper International Work Conference, Disaster Studies of Wageningen University and Research Centre

WHO [World Health Organisation] (2004). *Gender Dimensions of HIV Status Disclosure to Sexual Partners: Rates, Barriers and Outcomes*, a Review Paper. Switzerland: WHO.

Wiener, L. S. (1991). Women and human immunodeficiency virus: a historical and personal psychosocial perspective. *Social Work*, 36(5), pp. 375-378.

Wilcher, R., & Cates, W. (2009). Reproductive choices for women with HIV. *Bulletin of the World Health Organization*, 87(11), pp. 833-839.

Williams, A. B. (1995). Women and HIV/AIDS. *Imprint*, 42(4), 62-83.

Williams, S. E. (2003). HIV-positive African American women and their families: Barriers to effective family coping. In D. J. Gilbert & M. Wright (Eds.), *African American Women and HIV/AIDS: Critical responses* (pp. 77-84). Westport, CT: Praeger.

Winter, P. (2004). Respectful relationships: Listening to the voices of infants and toddlers in care. *Every Child*, 10(2), pp. 24-25.

Witte, S. S., & de Ridder, N. F. (1999). "Positive Feelings": Group Support for Children of HIV-Infected Mothers. *Child and Adolescent Social Work Journal*, 16(1), pp. 5-21.

Woodhead, J. & Faulkner, D. (2000). Subjects, objects or participants? Dilemmas of psychology research with children, in P. Christensen and A. Janes (Eds.) *Research with Children: Perspectives and Practices*. London: Routledge Falmer.

Wofsky, C. B. (1987). Intravenous drug abuse and women's medical issues. In *Report of the Surgeon's General's Workshop on children with HIV infection and their families* (pp. 32-33). Washington DC: Us Department of Health.

Wong, V., Macleod, I., Gilks, C., Higgins, D., & Crowley, S. (2006). The lost children of universal access—issues in scaling-up HIV testing and counselling. *Vulnerable Children and Youth Studies*, 1(1), pp. 44-55.

Working Group on Antiretroviral Therapy and Medical Management of HIV-infected Children. (2009). *Guidelines for the use of Antiretroviral Agents in Paediatric HIV infection*. February 23, pp. 1-139. Available at <http://aidsinfo.nih.gov/ContentFiles/pediatricGuidelines.pdf>. [Accessed 3<sup>rd</sup> April 2009]

Wrubel, J., Tedlie Moskowitz, J., Anne Richards, T., Prakke, H., Acree, M., & Folkman, S. (2005). Pediatric adherence: Perspectives of mothers of children with HIV. *Social Science & Medicine*, 61(11), pp. 2423-2433.

Yin, K. (1989) *Case study research: Design and methods*. London: Sage.

Yin, K. (1994) *Case study research: Design and methods* (2<sup>nd</sup> ed.). London: Sage.

Zay, I., & Roma, K. (1994) (1994). Adolescents and parental deaths from AIDS. In C. Levine (Ed.), *AIDS and the new orphans* (pp. 59-76). Westport: Auburn House.

# Appendix 1

## DEMOGRAPHIC FORM- MOTHERS

**Psychosocial Issues and Support for Children who Contracted HIV/AIDS Perinatally in Trinidad and Tobago.**

### DEMOGRAPHICS

**Age:** \_\_\_\_\_

**Marital Status:** Married ( ) Single ( ) Widowed ( ) Divorced ( ) Separated ( ) Common-law ( ) Visiting ( )

**Ethnicity:** African ( ) E/Indian ( ) Asian ( ) Caucasian ( ) Mixed ( )

Other: \_\_\_\_\_

**Religion/Faith:** Roman Catholic( ) Anglican( ) Methodist( ) Jehovah Witness( ) Seventh Day Adventist( ) Muslim( ) Hindu( ) Baptist( ) Pentecostal( ) Christian ( ) No religious affiliation( )

Other: \_\_\_\_\_

**Education Level:** Primary( ) Secondary( ) Olives( ) A 'Levels( ) Tertiary( ) Tech./Vocational( )

**Children:** No. of children: \_\_\_\_\_

Age						
Sex						

Ref #
DATE:

**Which of the children is HIV POSITIVE.....**

**Employment Status:** Employed( ) Unemployed( ) Self-employed( ) Student( )

**In which County do you reside?**

St. George East St. George West St. Patrick Tobago

St. Andrew/St. David Nariva/Mayaro Victoria Caroni Other

**Month and Year Diagnosed.....**

**Do you receive Public Assistance .....**

**CD4 Cell Count (if known) .....**

**Are you on Antiretroviral Therapy .....**

# Appendix 2

## DEMOGRAPHIC FORM- CHILDREN

Ref #
DATE:

Psychosocial Issues and Support for Children who acquired HIV/AIDS  
Perinatally in Trinidad and Tobago

### DEMOGRAPHICS

Age: \_\_\_\_\_

Ethnicity: African ( ) E/Indian( ) Asian( ) Caucasian( ) Mixed( )

Other: \_\_\_\_\_

Religion/Faith: Roman Catholic( ) Anglican( ) Methodist( ) Jehovah Witness( ) Seventh  
Day Adventist( ) Muslim( ) Hindu( ) Baptist( ) Pentecostal( ) Christian ( ) No  
religious affiliation( )

Other: \_\_\_\_\_

Education Level: Pre-School ( ) Primary( ) Secondary( )

In which County do you reside?

St. George East ( ) St. George West ( ) St. Patrick ( ) Tobago ( )

St. Andrew/St. David ( ) Nariva/Mayaro ( ) Victoria ( ) Caroni ( )

Other .....

With whom do you Reside? .....

Year Child Confirmed HIV+ .....

Child CD4 Cell Count (if known) .....

Is the child on Antiretroviral Therapy .....

# Appendix 3

## DEMOGRAPHIC FORM- Family Member (s)

Ref #
DATE:

**Psychosocial Issues and Support for Children who Acquired HIV/AIDS Perinatally in Trinidad and Tobago.**

### DEMOGRAPHICS

Age: \_\_\_\_\_

Relationship to Participant (mother): .....

Marital Status: Married( ) Single( ) Widowed( ) Divorced( ) Separated( ) Common-law( )  
Visiting( )

Ethnicity: African ( ) E/Indian ( ) Asian ( ) Caucasian ( ) Mixed ( )  
Other: \_\_\_\_\_

Religion/Faith: Roman Catholic ( ) Anglican ( ) Methodist ( ) Jehovah Witness ( )  
Seventh Day Adventist ( ) Muslim ( ) Hindu ( ) Baptist ( ) Pentecostal ( )  
Christian ( ) No religious affiliation ( ) Other:\_\_\_\_\_

Education Level: Primary( ) Secondary( ) Olives( ) A 'Levels( ) Tertiary( )  
Tech./Vocational( )

Employment Status: Employed( ) Unemployed( ) Self-employed( ) Student( )

In which County do you reside?

St. George East; St. George West;. St. Patrick; Tobago; St. Andrew; St. David; Nariva/Mayaro; Victoria Caroni ; Other

# Appendix 4

## INTERVIEW GUIDE FOR MOTHERS

**Topic:** *Psychosocial Issues and Support for Children who Acquired HIV/AIDS Perinatally in Trinidad and Tobago*

**Introduction:** Introduction of self and some background information on my work in the field of HIV.

### Purpose of Research

I will explain the purpose of the research which is, exploring the knowledge of an HIV positive diagnosis and the impact of that on the parenting of a child with HIV. I will then ask the mothers if they will like to read the information sheet and consent form or if they will like me to read it for them. I will explain the use of the clustering tool. I will then give the mothers the clustering tool that will help to elicit information from them.

**Interview Begins:** (Probes & Prompts will be used throughout the interview exercise).

The topics I will explore in conjunction with the Clustering Tool are as follows:

### Diagnosis

- When diagnosed HIV positive (before pregnancy, during pregnancy or after giving birth).
- Initial response

### Exploration of emotions

- How/whether status was discussed with partner
- Impact of diagnosis on pregnancy (e.g. thoughts of termination)
- Whether baby was breastfed – implications of doing so/not doing so
- Fears about being HIV positive
- Diagnosis of child (e.g. waiting for results for child's HIV test after giving birth)
- Parenting issues faced
- Future planning for children

### Treatment & Services

- Whether on medication
- Experience of taking medication
- Effects of medical treatment
- Experiences with respect to Social Services Agencies (services received or not received, services that helped/did not help).

### Disclosure

- Reasons for disclosure/non-disclosure
- Who disclosed to
- Experience of stigma and discrimination

### Strengths & resources

- How person copes on a daily basis with HIV
- Person's views on parenting/care of a child who is HIV positive
- Availability of financial resources
- Who provides help (family, friends, other)
- Type of help received
- Ideas for improving systems that can help

**Miracle Question:** If you are to go to bed tonight, what will you like to see improve in your life by tomorrow?

# Appendix 5

## INTERVIEW GUIDE FOR CHILDREN

**Topic: Psychosocial Issues and Support for Children who Acquired HIV/AIDS Perinatally in Trinidad and Tobago**

**Introduction:** Introduction of self and some background information on my work in the field of HIV.

### Purpose of Research

I will explain the purpose of the research which is, exploring the knowledge of an HIV positive diagnosis and the impact of that on the different aspect of the child's life. I will then ask the child if they will like to read the information sheet and consent form or if they will like me to read it for them. I will explain the use of the clustering tool and drawings. I will then give the child the clustering tool that will help to elicit information from them. The child will be allowed to draw also on the topic of 'Me Myself & HIV'.

**Interview Begins:** (Probes & Prompts will be used throughout the interview exercise).

The topics I will explore in conjunction with the Clustering Tool are as follows:

### Emotional & Behavioral Issues:

- What being HIV positive means
- Feelings about being HIV positive -Children will be given a sheet of faces with different expressions and intensity of expressions from which to choose.
- Issues of stigma & discrimination, isolation, adherence issues, disclosure will be pursued.
- Who children disclose to and reasons for choosing particular people
- What medication is taken for HIV
- Feelings about medication
- Feelings about mother being HIV positive

### Social Issues

- Feelings of difference/commonality with other children
- Friendships
- Education
- Relationship with mother
- Understanding of the implications of mother being HIV positive
- Mother's role in supporting the child with HIV
- Role of religion in child's life

### Health Issues

- How child feels about his/her body
- How often child attends clinic/doctor
- The effects of the medication

### Economic Issues

- Whether the child has enough to eat
- Form of transport used

Miracle Question: *If you go to sleep tonight and you had one wish for tomorrow what will that wish be?*

# Appendix 6

## INTERVIEW GUIDE

*Topic: Psychosocial Issues and Support for Children who Acquired HIV/AIDS Perinatally in Trinidad and Tobago*

Interview Guide for Family Member

**Introduction:** Introduction of self and some background information on my work in the field of HIV.

### **Purpose of Research**

I will explain the purpose of the research, which is, exploring the knowledge of an HIV positive diagnosis on the mother and the impact of that on a child with HIV. I will then ask the family member if they will like to read the information sheet and consent form or if they will like me to read it for them.

**Interview Begins:** (Probes & Prompts will be used throughout the interview exercise).

These are the sought of questions I will ask

### **Disclosure**

- When did mother disclose her HIV+ status.
- Initial response

### **Exploration of Emotions**

- Impact of knowing
- View of mother and child with HIV
- Thoughts on how they view themselves
- Main issues affecting mother and child
- Mother coping mechanism
- Child coping mechanism

### **Support**

- Role played
- Type of help given (concrete/non-concrete)
- Additional help needed (Formal & non-formal)

### **Stigma & Discrimination**

- Observation re: mother and child

### **Health Issues**

- Services received
- Services needed



# Appendix 7

## Information Sheet for Mothers

**Research Topic:** Psychosocial Issues and Support for Children who Acquired HIV/AIDS Perinatally in Trinidad and Tobago.

### Introduction and Study Purpose

My name is Debra Joseph and I am conducting a research study that examines Psychosocial Issues and Support for Children who Acquired HIV/AIDS Perinatally in Trinidad and Tobago.

As part of the study you will be participating in an audio taped interview lasting approximately one (1) hour. You will be asked some questions about psychosocial issues and social support with respect to HIV. By participating in this study, you may be able to assist in developing improved services for mothers and children who are HIV positive. There are no right or wrong answers.

### Support for Study Participants

If you become agitated, or emotionally upset as a result of the interview, the Principal Researcher, Ms. Debra Joseph, will deal with your initial concerns and refer you for follow-up counselling at The Medical Research Foundation.

### Risks and Benefits

You may feel embarrassed or anxious when you answer sensitive questions. However, by participating in this study you may be able to assist in developing better ways of helping mothers and children who are HIV positive with respect to psychosocial issues and social support.

### Research Standards and Rights of Participants

Your participation in this study is voluntary. If you feel uncomfortable with any of the questions asked, you do not have to answer and you will not be penalised. If you choose to withdraw from the study at any time during the interview, it will have no impact on you receiving services.

### Confidentiality

The information you give will be used only by The University of Huddersfield, and only for research purposes. No one except the Principal researcher and her supervisors, Professor Adele Jones and Professor Eric Blyth will be allowed to see the information that you provide in this study without your written permission. I understand that all data will be maintained in a locked file cabinet at the University of Huddersfield for a minimum of three years after the termination date of the study, after which time they will be destroyed.

The Principal Investigator will not release any information to anyone unless there is a possibility of imminent harm to yourself or others. In such cases, the Principal Researcher will notify the relevant authorities.

### Anonymity

Your name will be removed during transcription of the interview and a number substituted in its place. The only person who will have access to a single list linking my name to the assigned number is the Principal Researcher, Ms. Debra Joseph.

## Appendix 7 (cont'd)

### **Dissemination of Research Findings**

The research findings will be shared with you the participants, government, policy makers and other agencies that have an interest in this area. A copy of this thesis will be filed at the library at the University of Huddersfield. The information and findings will be used for presentation at conferences and for writing of scholarly peer-reviewed articles.

If you have further questions or concerns about your rights as a research participant, you may contact Dr. Linda Hadeed at the University of the West Indies, St. Augustine.

Telephone number 663-6810

### **Contact the Researcher**

Debra Joseph

The Centre for Applied Childhood Studies

School of Human and Health Sciences

University of Huddersfield

Tel: 762-8481

Email: [d.joseph@hud.ac.uk](mailto:d.joseph@hud.ac.uk)

# Appendix 8

## INFORMATION SHEET

### Children

(printed on coloured paper)

**INTRODUCTION:** Hello. My name is Debra Joseph. I am a research student at the University of Huddersfield. This university is a 'big' school that you can attend when you grow up.

**PURPOSE:** I am here to find out from you about how you view being HIV positive and how does it affect you.

**PROCEDURES INVOLVED:** I am going to give you a piece of paper with the word HIV in the centre and you are going to write and draw about how you feel about it. I will even ask you some questions on your writings and drawings. This will take about 1 hour.

I would like to talk to you alone, but if you like you can ask for your mother to be present at any time.

**IDENTITY AND INVOLVEMENT:** I have already been talking to your mother about these things and now I would like to try to understand what you think. So I would like to know if your name is \_\_\_\_\_?

**RISK:** Some of what we talk about may be about things that are quite personal and that you may not say to anyone. It may be difficult to answer. If anything we discuss makes you feel uncomfortable or gives you a funny feeling inside or you don't want to answer then you do not have to.

**ABILITY TO SAY NO:** Remember you do not have to talk about anything you do not want to. If you want to stop, this will be fine. However, I would really appreciate it if you would answer the questions based on your writings and drawings honestly and openly. This will help me to find out about what young children in Trinidad and Tobago really think about HIV. Your answers will be very important to us. Do you have any questions about any of the things I have just said?

**WHAT WILL HAPPEN WITH THE INFORMATION:** I will be asking children from different places all over the country the same questions on the writings and drawings. When the research is over, I will collect all the responses I have received and keep them safe. You will be able to find out about the results by contacting me.

**WHO WILL HAVE ACCESS TO THE RESEARCH:** The researcher and my two supervisors, Professor Adele Jones and Professor Eric Blyth.

**CONFIDENTIALITY:** If you agree to take part in this interview, the things you tell me would be confidential, that is, only shared with my supervisors and no one else. I am not going to write down your name. If you agree you can show your agreement by making a mark here. Also, I can sign here to say that I have witnessed your agreement. If I think you are in any harm, I will have to tell someone about it. Do you understand?

**SEEKING COMPREHENSION:** Do you have any questions about any of the things I have just said?

**SEEKING VOLUNTARY AGREEMENT:** Do you want your mother to stay with us while we are talking?

In case of any queries contact the researcher DEBRA JOSEPH, Tel. 762-8481.

# Appendix 9

## Information Sheet for Participants Family Member (s)

**Research Topic:** Psychosocial Issues and Support for Children who Acquired HIV/AIDS Perinatally in Trinidad and Tobago.

### Introduction and Study Purpose

My name is Debra Joseph and I am conducting a research study that examines Psychosocial Issues and Support for Children who Acquired HIV/AIDS Perinatally in Trinidad and Tobago.

As part of the study you will be participating in an audio taped interview lasting approximately one (1) hour. As a family member, you will be asked some questions about psychosocial issues and social support with respect to HIV. By participating in this study, you may be able to assist in developing improved services for mothers and children who are HIV positive. There are no right or wrong answers.

### Support for Study Participants

If you become agitated, or emotionally upset as a result of the interview, the Principal Researcher, Ms. Debra Joseph, will deal with your initial concerns and refer you for follow-up counselling at The Medical Research Foundation.

### Risks and Benefits

You may feel embarrassed or anxious when you answer sensitive questions. However, by participating in this study you may be able to assist in developing better ways of helping mothers and children who are HIV positive with respect to psychosocial issues and social support.

### Research Standards and Rights of Participants

Your participation in this study is voluntary. If you feel uncomfortable with any of the questions asked, you do not have to answer and you will not be penalised. If you choose to withdraw from the study at any time during the interview, it will have no impact on you receiving services.

### Confidentiality

The information you give will be used only by The University of Huddersfield, and only for research purposes. No one except the Principal researcher and her supervisors, Professor Adele Jones and Professor Eric Blyth will be allowed to see the information that you provide in this study without your written permission. I understand that all data will be maintained in a locked file cabinet at the University of Huddersfield for a minimum of three years after the termination date of the study, after which time they will be destroyed.

The Principal Investigator will not release any information to anyone unless there is a possibility of imminent harm to yourself or others. In such cases, the Principal Researcher will notify the relevant authorities.

### Anonymity

Your name will be removed during transcription of the interview and a number substituted in its place. The only person who will have access to a single list linking my name to the assigned number is the Principal Researcher, Ms. Debra Joseph.

## Appendix 9 (cont'd)

### **Dissemination of Research Findings**

The research findings will be shared with you the participants, government, policy makers and other agencies that have an interest in this area. A copy of this thesis will be filed at the library at the University of Huddersfield. The information and findings will be used for presentation at conferences and for writing of scholarly peer-reviewed articles.

If you have further questions or concerns about your rights as a research participant, you may contact Dr. Linda Hadeed at the University of the West Indies, St. Augustine.

Telephone number 663-6810

### **Contact the Researcher**

Debra Joseph

The Centre for Applied Childhood Studies

School of Human and Health Sciences

University of Huddersfield

Tel: 762-8481

Email: [d.joseph@hud.ac.uk](mailto:d.joseph@hud.ac.uk)

# Appendix 10

**TITLE OF PROJECT: *Psychosocial Issues and Support for Children who Acquired HIV/AIDS Perinatally in Trinidad and Tobago.***

**NAME OF RESEARCHER: Debra Joseph  
Interview Consent Form**

## Mothers

I have been fully informed of the nature and aims of this research and consent to taking part in it.

I understand that I have the right to withdraw from the interview at any time without giving any reason, and a right to withdraw my data if I wish.

I give my permission/do not give my permission for my interview to be tape recorded.

I give permission to be quoted (by use of pseudonym).

I understand that the tape will be kept in secure conditions at the University of Huddersfield.

I understand that no person other than the interviewer will have access to the recording.

I understand that my identity will be protected by the use of pseudonym in the research report and that no information that could lead to my being identified will be included in any report or publication resulting from this research.


Name of participant

Signature

Date

Name of researcher

Signature

Date

# Appendix 11

**CONSENT FORM-** (To be administered to children 5-13)

**INTRODUCTION:** Hello. My name is Debra Joseph. I am a research student at the University of Huddersfield in England. This university is a 'big' school that you can attend when you grow up.

**PURPOSE:** I am here to find out from you about how you view being HIV positive and how does it affect you.

**PROCEDURES INVOLVED:** I am going to give you a piece of paper with the word HIV in the centre and you are going to write and draw about how you feel about it. I will even ask you some questions on your writings and drawings. This will take about 1 hour.  
I would like to talk to you alone, but if you like you can ask for your mother to be present at any time.

**IDENTITY AND INVOLVEMENT:** I have already been talking to your mother about these things and now I would like to try to understand what you think. So I would like to know if your name is \_\_\_\_\_?

**RISK:** Some of what we talk about may be about things that are quite personal and that you may not say to anyone. It may be difficult to answer. If anything we discuss makes you feel uncomfortable or gives you a funny feeling inside or you don't want to answer then you do not have to.

**ABILITY TO SAY NO:** Remember you do not have to talk about anything you do not want to. If you want to stop, this will be fine. However, I would really appreciate it if you would answer the questions based on your writings and drawings honestly and openly. This will help me to find out about what young children in Trinidad and Tobago really think about HIV. Your answers will be very important to us. Do you have any questions about any of the things I have just said?

**WHAT WILL HAPPEN WITH THE INFORMATION:** I will be asking children from different places all over the country the same questions on the writings and drawings. When the research is over, I will collect all the responses I have received and keep them safe. You will be able to find out about the results by contacting me.

**WHO WILL HAVE ACCESS TO THE RESEARCH:** The researcher and my two supervisors, Professor Adele Jones and Professor Eric Blyth.

**CONFIDENTIALITY:** If you agree to take part in this interview, the things you tell me would be confidential, that is, only shared with my supervisors and no one else. I am not going to write down your name. If you agree you can show your agreement by making a mark here. Also, I can sign here to say that I have witnessed your agreement. If I think you are in any harm, I will have to tell someone about it. Do you understand this?

**SEEKING COMPREHENSION:** Do you have any questions about any of the things I have just said?

**SEEKING VOLUNTARY AGREEMENT:** Do you want your mother to stay with us while we are talking?

In case of any queries contact the researcher DEBRA JOSEPH, Tel. 762-8481.

\_\_\_\_\_  
Youth/Child Agreement                      Adult Person?                      Witness                      Date

District \_\_\_\_\_ Area Name \_\_\_\_\_

# Appendix 12

**TITLE OF PROJECT:** Psychosocial Issues and Support for Children who Acquired HIV/AIDS Perinatally in Trinidad and Tobago.

**NAME OF RESEARCHER:** Debra Joseph

Interview Consent Form  
Family Member (s)

I have been fully informed of the nature and aims of this research and consent to taking part in it.

I understand that I have the right to withdraw from the interview at any time without giving any reason, and a right to withdraw my data if I wish.

I give my permission/do not give my permission for my interview to be tape recorded.

I give permission to be quoted (by use of pseudonym).

I understand that the tape will be kept in secure conditions at the University of Huddersfield.

I understand that no person other than the interviewer will have access to the recording.

I understand that my identity will be protected by the use of pseudonym in the research report and that no information that could lead to my being identified will be included in any report or publication resulting from this research.


Signature

Date

Name of researcher

Signature

Date



# Appendix 13

Clustering Tool

**ME, MYSELF AND HIV**



## Appendix 14



5, Third Street West  
Cazabon Avenue  
Trincity  
**30<sup>th</sup> April 2009**

Dr. Raymond Noel  
Manager  
Tobago Health Promotion Clinic  
Corner Calderhall Rd & Sargeant Cain Roads  
Scarborough  
Tobago

Dear Sir

I am a PhD student in social work at the University of Huddersfield, Centre for Applied Childhood Studies. I am conducting research on children in Trinidad and Tobago who are living with HIV-AIDS and as one of the foremost professionals working in this field, I am writing to you to request your cooperation and support for the study.

This research project is the first study on psychosocial issues and social support among this population and will contribute to the understanding of the issues encountered by children and their mothers. It will also provide vital information for the Government, Non-Governmental Organisations and other significant stakeholders involved in the fight against HIV-AIDS and will assist social workers in developing practice strategies with this population.

I should be grateful if you would give your permission for me to contact women involved with the Tobago Health Promotion Clinic in order identify mothers and children who may be willing to be interviewed. Participation will be totally voluntary and information obtained will be summarised in a way that will maintain the confidentiality and anonymity of the individual.

The study will be carried out with regard to strict ethical principles and approval from the University Ethics Panel which is required before the commencement of data collection. Participants will be fully informed of their rights as research volunteers. Thank you in anticipation of your support for this study.

Yours sincerely  
Debra Joseph MSW  
PhD. Student: Tel. No. 762-8481

Appendix 15

# All About Me Worksheet



My name is .....

My age is .....

My birthday is on .....

The colour of my hair is .....

The colour of my eyes is .....

My height is .....

My teacher is called .....

I am special because .....

.....

.....



(Author unknown)

# Appendix 16



(Author unknown)



## Appendix 17

06/29/12

Codebook Summary Report

Page 1

BLAME	Mothers blame themselves
CHLDCOP	Child Coping mechanisms
CHLDCTE	Child cannot tell anyone
CHLDFRA	Coping child fragile
CHLDHLP	Children need help
CHLDI.AC	Children lack knowledge of HIV
CHLDPAR	Child parenting of mother
CHLNEG	Child neglects to take meds
CONCHLD	Mother Concern for children
COPDISC	Disclosre issues
COPLIME	Coping by liming
COPSHOP	Coping by shopping
COPSTMO	Child coping is stronger than the mother
COPTALK	Coping by talking
COPWELL	Coping well
COUNSM	Role of counsellor for mother
EMOTVUL	Emotional vulnerable
ENCRMNT	Provides encouragement for mother
FCSRES	Focus on resiliency of mother
FIGHTIN	Child coping behaviour
FINANC	Futher support finances
FRSUPFI	Further support finances
FRSUPST	Further support reduction in stigma and disc
HOUSING	Further support housing
HURTRES	Initial response to hearing
IRANGER	Initial response anger
MANISPO	Main issue lack of finances poverty
MEDSIDE	Medication side effects
MTHANGR	Mother Angry with her HIV situation
MTHRCOP	Mother coping mechanism
NONINFO	Not enough information
NOSTIG	No Experience of Stigma and Discrimination
NOTBLAM	Mothers should not blame themselves
PATOCOP	Patterns of coping
PRAYER	patterns of coping prayer
ROLADOF	Role played adherent officer
ROL.COUN	Plays the role of a counsellor
ROLEREV	Child Role reversal
ROLFATH	Role of a father
SLEEP	Patterns of coping sleep
SUGHTFS	Person sought to get formal support for mother
SUPCONC	Concrete Support-financas or help with child
SUPEMOT	Emotional support
SUPFOR	Formal Support
SUPNED	What further support is needed
SUPPGRP	Patterns of coping support group
SUPPREC	Support received formal and infromal
VIEWCON	View concern for the child
VIFWMC	View of mother and child with HIV
VIEWNOR	Children/mother view themselves as normal
IEWSAD	View of mother child sad
VIEWSEL	How mother and child view themselves with HIV.
VIHURT	View mother and child as hurting
VIREGRT	Mother view herself with regret
VISTIG	Feel that they will be stigmatised if others knew
VSICK	View them as sick
YESSTIG	Experienced Stigma and Discrimination

# Appendix 18

06/29/12

Cocobook Summary Report

Page 1

Code:	BLAME
Short Desc.:	Mothers blame themselves
Code:	CHLDCOP
Short Desc.:	Child Coping mechanisms
Code:	CHLDCTE
Short Desc.:	Child cannot tell anyone
Code:	CHLDFRA
Short Desc.:	Coping child fragile
Code:	CHLDHLP
Short Desc.:	Children need help
Code:	CHLDLAC
Short Desc.:	Children lack knowledge of HIV
Code:	CHLDPAR
Short Desc.:	Child parenting of mother
Code:	CHLNEG
Short Desc.:	Child neglects to take meds
Full Desc.:	Child neglects to take meds but sees that mother does
Code:	CONCHLD
Short Desc.:	Mother Concern for children
Code:	COPDISC
Short Desc.:	Disclosre issues
Code:	COPLIME
Short Desc.:	Coping by liming
Code:	COPSHOP
Short Desc.:	Coping by shopping
Code:	COPSTMO
Short Desc.:	Child coping is stronger than the mother
Code:	COPTALK
Short Desc.:	Coping by talking
Code:	COPWFI1
Short Desc.:	Coping well
Code:	COUNSM
Short Desc.:	Role of counsellor for mother
Code:	EMOTVUL
Short Desc.:	Emotional vulnerable
Code:	ENCRMNT
Short Desc.:	Provides encouragement for mother
Code:	FCSRES