

The impact of HIV/AIDS on children in Swaziland: opportunities for, and constraints on, scaling up interventions

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Contents

| | |
|-----------------------|---|
| Abstract | 3 |
| Acknowledgements | 4 |
| List of Abbreviations | 5 |
| List of Figures | 7 |
| Contents | 8 |

Abstract

This research focuses on vulnerable children in Swaziland, the country with the highest level of adult HIV prevalence in the world, where nearly 25 percent of children will be orphaned by 2010. It investigates the experiences of relatively poor urban children growing up in the epidemic and the coping strategies the children and their adult carers adopt.

Through the lens of both children and adult carers, it explores the ways sexual knowledge is gained and used by older children in the context of HIV/AIDS as well as the experience of coping with widespread bereavement. In this way, it adds to the literature on childhoods in the 'South' and the increasing recognition of the heterogeneity of children's lived experiences.

Rather than being seen as passive, the agency of both vulnerable children and their adult carers emerges as they seek to improve their livelihoods. The way this agency connects with government, NGO and community structures is revealed by showing the opportunities for and constraints on gaining access to education and health-care.

The interwoven roles of government, international donors, NGOs and civil society is explored by assessing the relative merits of supporting vulnerable children by either welfare assistance to poor families or new forms of 'community' care structures or institutionalised residential care. The critical importance of relationships and power relations between key actors in different organisations and the effect this has on implementation of interventions for children is discussed as well as the relevance of these findings to vulnerable children in other settings.

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I am familiar with domestic upheaval and there was yet another last year. Without the support and encouragement of family and friends I would never have made the final goal post. I sincerely thank many at St.Hilda's, my mother Mrs. Jean Garton, my brother Michael Garton and my children Emily, Ben and Sarah Jones. I thank Tom and Dorothy Jefferson, Ann Gray, Robin and Shirley Horne, Alistair and Sue Blaxley, Kerri Absalom, Huffy and Mike Massey. Whenever I doubted I could continue the courageous face of Xotsile Mhlanga always drifted into my mind and it is to the memory of Xotsile, who died in 2000, and children like her, that I dedicate this work.

List of Abbreviations used

| | |
|---------|--|
| AMICAAL | Alliance of Mayors and Municipal Leaders' initiative for community action on AIDS at the local level |
| ABC | Abstain, be faithful, use a condom |
| AIDS | Acquired immune deficiency syndrome |
| ANC | Antenatal clinic |
| ARV | Antiretroviral |
| BSS | Behavioural surveillance surveys |
| CBO | Community-based organisation |
| FBO | Faith-based organisation |
| FGD | Focus group discussion |
| FLAS | Family Life Association (Swaziland) |
| HIV | Human immune virus |
| MDG | Millennium Development Goals |
| MOHSW | Ministry of Health and Social Welfare |
| NERCHA | National Emergency Response Committee on HIV/AIDS |
| NCP | Neighbourhood care point |
| NGO | Non-government organisation |
| PEPFAR | (USA) President's Emergency Plan for AIDS Relief |
| PRSP | Poverty Reduction Strategy Papers |
| OVC | Orphaned and vulnerable children |
| RHM | Rural Health Motivators |
| SRHI | Swaziland Rural Health Initiative |
| UNAIDS | Joint United Nations programme of HIV/AIDS |

| | |
|--------|---|
| UNDP | United Nations Development Programme |
| UNICEF | United Nations Children's Emergency Fund |
| USAID | U.S. Agency for International Development |
| WHO | World Health Organisation |
| VCT | Voluntary counselling and testing |

SiSwati terms

| | |
|-------------|--|
| Ngwenyama | The king or 'father of the nation' |
| Ndlovukazi | The Queenmother or 'mother of the nation' |
| Tinkhundla | Swaziland is made up of 55 Tinkhundla administrative districts |
| Chiefdom | Swaziland is also divided into about 330 chiefdoms |
| Indlunkhulu | The chief's field tilled communally for the poor |
| Lutsango | A married woman appointed by the chieftaincy committee to be a carer for vulnerable children |
| Sigodzi | Each chiefdom is sub-divided into 6 to 10 sigodzi |
| Indvuna | Headman of a sigodzi, reports to the chief |
| Inyanga | A traditional healer |

List of Figures

| | | |
|-------------------|---|-----|
| Figure 1: | Map of Swaziland | 20 |
| Figure 2: | Informal settlement, Mbabane | 63 |
| Figure 3: | Swazis gathering at the King's Kraal | 86 |
| Figure 4: | A tradition of gendered lives: King's Kraal | 87 |
| Figure 5: | Long-established informal housing with vegetable plot | 107 |
| Figure 6: | Heterogeneous housing in informal settlements | 107 |
| Figure 7: | Girl weaving a mat from dried grass | 115 |
| Figure 8: | Table of family forms | 117 |
| Figure 9: | Typical sanitation in an informal settlement, Mbabane | 154 |
| Figure 10: | Water supply for some families in informal settlements | 155 |
| Figure 11: | Food preserves marketed to help fund Manzini Youth Care | 270 |
| Figure 12: | Eswatini food preserving factory | 270 |

Contents

| | |
|--|------------|
| CHAPTER 1: Introduction to the Thesis | 18 |
| CHAPTER 2: Methodology | 53 |
| CHAPTER 3: Child-Care in Poor Urban Settlements in Swaziland in an Era of HIV/AIDS | 89 |
| CHAPTER 4: Relationships, Partnerships and Politics in the Lives of the Urban Poor in AIDS-Afflicted Swaziland. | 123 |
| CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youth in AIDS-Afflicted Swaziland | 164 |
| CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland | 205 |
| CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy | 238 |
| CHAPTER 8: Conclusion | 277 |
| Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints. | |
| Bibliography | 311 |
| Appendix | 338 |

| | | |
|---------------|---|-----------|
| 1. | CHAPTER1: Introduction to the Thesis | 18 |
| 1.1 | <u>Introduction</u> | 18 |
| 1.1.1 | The key gaps in knowledge | 18 |
| 1.1.2 | The location of the research | 20 |
| 1.1.3 | Introduction to Swaziland | 20 |
| 1.1.4 | The rationale for researching child-care in Swaziland | 21 |
| 1.2 | <u>The significance of the problem</u> | 26 |
| 1.2.1 | Changes in traditional family care network | 26 |
| 1.2.2 | Evidence from Zimbabwe | 30 |
| 1.2.3 | Evidence from Kenya | 31 |
| 1.2.4 | Evidence from Uganda | 31 |
| 1.2.5 | Evidence from Malawi | 32 |
| 1.2.6 | The special pressures of fostering children in an AIDS epidemic | 33 |
| 1.3 | <u>Children’s Geographies</u> | 36 |
| 1.3.1. | From human becomings to human beings | 36 |
| 1.3.2 | Global space and local space: webs of connectivity in children’s lives | 41 |
| 1.4 | <u>The child’s perspective</u> | 44 |
| 1.4.1 | Children as social actors | 44 |
| 1.4.2 | Children embedded within social relationships | 45 |
| 1.5 | <u>Thesis structure</u> | 47 |
| 2. | CHAPTER 2: Methodology | 53 |
| 2.1 | <u>Introduction</u> | 53 |

| | | |
|--------------|--|-----------|
| 2.2 | <u>Ethics of researching with children</u> | 58 |
| 2.2.1 | Informed consent and confidentiality issues | 58 |
| 2.2.2 | Minimising harm | 59 |
| 2.2.3 | Appropriate methodologies | 63 |
| 2.2.4 | Beneficial outcomes for children | 65 |
| 2.3 | <u>Research identity and the role of research assistants</u> | 66 |
| 2.3.1 | Situated identity | 66 |
| 2.3.2 | Fluid identities | 67 |
| 2.3.3 | The cultural lens of research assistants | 72 |
| 2.4 | <u>Research field sites, methodologies and data analysis</u> | 73 |
| 2.4.1 | Introduction and specific research questions | 73 |
| 2.5 | <u>Field site one: families living in informal settlements in Mbabane</u> | 74 |
| 2.5.1 | Entry points to the community | 75 |
| 2.5.2 | Semi-structured interviews with families and other conversations | 77 |
| 2.5.3 | Analysing community data | 78 |
| 2.6 | <u>Field site two: Children in ‘private spaces’ away from adult carers</u> | 80 |
| 2.6.1 | Choice of field sites and the challenge of ‘gatekeepers’ | 80 |
| 2.6.2 | Limitations of the data | 82 |
| 2.7 | <u>Field site three: key informants in the community and in organisations</u> | 83 |
| 2.7.1 | The space between words and actions | 83 |
| 2.7.2 | Accessing key informants | 83 |
| 2.7.3 | On the record and off the record data collection | 83 |
| 2.7.4 | Participant observation, compromised identity? | 84 |
| 2.7.5 | Situated learner | 85 |

| | | |
|-------|---|------------|
| 2.7.6 | Textual methodologies | 87 |
| 2.8 | <u>Conclusion</u> | 88 |
| 3. | CHAPTER 3: Child-Care in Poor Urban Settlements in Swaziland in An Era Of HIV/AIDS | 89 |
| 3.1 | <u>Introduction</u> | 89 |
| 3.1.1 | Ambiguity of terms used in the AIDS literature | 91 |
| 3.1.2 | Inclusion or exclusion of 'other' children | 94 |
| 3.1.3 | Identifying stress in extended family care-giving | 95 |
| 3.2 | <u>Research setting</u> | 98 |
| 3.3 | <u>Methodology</u> | 101 |
| 3.4 | <u>Research findings</u> | 104 |
| 3.4.1 | Cultural constructions of orphanhood | 104 |
| 3.4.2 | Perceptions of the extended family, urban-rural linkages and constructions of 'home' | 106 |
| 3.4.3 | Changes in the Swazi extended family and the gendered nature of child-care | 110 |
| 3.4.4 | Kinship care of orphaned children | 116 |
| 3.4.5 | Reasons for 'crisis' fostering of orphaned children | 118 |
| 3.4.6 | Kinship care of non-orphaned children | 119 |
| 3.5 | <u>Conclusion</u> | 121 |
| 4. | CHAPTER 4: Relationships, Partnerships and Politics in the Lives of the Urban Poor in AIDS-Afflicted Swaziland | 123 |

| | | |
|--------------|---|------------|
| 4.1 | <u>Introduction</u> | 123 |
| 4.1.1 | Governance issues and the response to HIV/AIDS | 123 |
| 4.1.2 | Understanding relationships at the local level | 125 |
| 4.1.3 | The descent into persistent poverty in the context of HIV/AIDS | 129 |
| 4.2 | <u>Research setting</u> | 131 |
| 4.3 | <u>Research methodology</u> | 134 |
| 4.4 | <u>Multiple deprivations and vulnerability to shocks</u> | 135 |
| 4.5 | <u>Support from beyond the family</u> | 138 |
| 4.5.1 | Negotiating neighbours | 138 |
| 4.5.2 | Church communities | 138 |
| 4.5.3 | Productive work-based relationships | 140 |
| 4.6 | <u>Children’s access to schooling</u> | 141 |
| 4.6.1 | Swaziland’s progress towards free, universal, basic education | 141 |
| 4.6.2 | Negotiating relationships: power, agency and leverage | 144 |
| 4.6.3 | Lack of vertical linkages | 145 |
| 4.6.4 | ‘Top down’ and ‘bottom up’ leverage | 145 |
| 4.7 | <u>The role of relationships in accessing healthcare</u> | 150 |
| 4.7.1 | The contextual background of healthcare in urban Swaziland | 150 |
| 4.7.2 | The lived reality of home-based care and access to healthcare in informal settlements | 152 |
| 4.8 | <u>Conclusion</u> | 160 |
| 5. | CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youth in AIDS-Afflicted Swaziland | 164 |

| | | |
|--------------|---|------------|
| 5.1 | <u>Introduction</u> | 164 |
| 5.1.1 | Constructions of childhood | 166 |
| 5.2 | <u>HIV prevalence levels and Swazi youth</u> | 169 |
| 5.2.1 | Biological markers as indicators of sexual behaviours | 169 |
| 5.2.2 | Behaviour surveys as indicators of sexual behaviours | 171 |
| 5.3 | <u>Multi-method qualitative research</u> | 172 |
| 5.3.1 | Insights from family settings | 173 |
| 5.3.2 | The ethics of researching with children in the context of AIDS | 175 |
| 5.3.3 | Creating an ambience for researching sensitive issues | 177 |
| 5.4 | <u>Care-givers attitudes towards teenagers' sexual behaviour</u> | 179 |
| 5.4.1 | Communicating the link between sexual behaviour and AIDS | 179 |
| 5.4.2 | Key influences on teenage sexual behaviour according to - care givers | 182 |
| 5.5 | <u>The 'voice' of young respondents on gaining sexual knowledge</u> | 184 |
| 5.5.1 | Sexual discourse in the family setting | 184 |
| 5.5.2 | Sexual discourse with teachers | 186 |
| 5.5.3 | Gender issues at health clinics | 189 |
| 5.5.4 | The influence of mass media | 190 |
| 5.6 | <u>Making choices about sexual behaviour</u> | 192 |
| 5.6.1 | The range of options | 192 |
| 5.6.2 | The importance of gender in sexual negotiations | 194 |
| 5.6.3 | Social sub-cultures and economic drivers of sexual behaviours | 196 |
| 5.6.4 | Young respondents conclusions on what is needed to promote sexual behaviours | 198 |

| | | |
|--------------|--|------------|
| 5.7 | <u>Conclusion: linking the research findings to some practical solutions</u> | 199 |
| 5.7.1 | The main findings and their limitations | 199 |
| 5.7.2 | Recognising the vulnerability of adolescents | 200 |
| 5.7.3 | Youth and the elderly as part of the solution at community level | 201 |
| 5.7.4 | The importance of schools | 202 |
| 5.7.5 | The role of the international community | 203 |
| 6. | CHAPTER 6: Growing Up in An AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland | 205 |
| 6.1 | <u>Introduction</u> | 205 |
| 6.2 | <u>Methodology</u> | 210 |
| 6.3 | <u>Adult care-givers experiences of caring for bereaved children</u> | 213 |
| 6.4 | <u>Children's lived experience of parental loss</u> | 219 |
| 6.4.1 | Grief, loss and coping strategies | 219 |
| 6.4.2 | Orphaned children experiencing abuse and exclusion | 221 |
| 6.4.3 | The agency of orphaned children | 226 |
| 6.4.4 | From exclusion to inclusion: helping orphaned children return to school | 227 |
| 6.5 | <u>The 'voice' of children growing up in the epidemic but not (yet) orphaned</u> | 230 |
| 6.6 | <u>Conclusion</u> | 234 |

| | | |
|--------------|--|------------|
| 7. | CHAPTER 7: Considering Child-Care Options in Poor Countries | 238 |
| | Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy | |
| 7.1 | <u>Introduction</u> | 238 |
| 7.2 | <u>A critique of institutionalised care of children</u> | 239 |
| 7.2.1 | The link between poverty and children entering institutionalised care | 239 |
| 7.2.2 | Lack of statutory regulation and the dangers of child abuse in institutions | 240 |
| 7.2.3 | Totalitarian forms of care in institutions and segregation from society | 241 |
| 7.2.4 | The economic argument against institutionalised care | 243 |
| 7.2.5 | Is there a need for any institutionalised provision for vulnerable children? | 244 |
| 7.3 | <u>Minimising the need for institutionalised care of vulnerable children</u> | 247 |
| 7.3.1 | Cash transfers to poor families | 247 |
| 7.3.2 | Non-kin fostering of vulnerable children | 250 |
| 7.4 | <u>Fieldwork findings in Swaziland</u> | 251 |
| 7.5 | <u>Research methodology</u> | 252 |
| 7.5.1 | The difficulty of identifying vulnerable children in Swaziland | 253 |
| 7.5.2 | Child-headed households as an indicator of family breakdown | 255 |

| | | |
|--------------------|--|------------|
| 7.6 | <u>The case for cash transfers to Swazi families</u> | 258 |
| 7.7 | <u>Key actors and stages</u> | 259 |
| 7.7.1 | The emergence of a National Policy on Children | 259 |
| 7.7.2 | Community based approaches to support vulnerable children | 261 |
| 7.7.3 | Issues of piecemeal coverage, confusion and sustainability | 265 |
| 7.7.4 | Children in residential care | 267 |
| 7.7.5 | Agendas, power, personalities and accountability | 273 |
| 7.8 | <u>Conclusion</u> | 275 |
| 8. | CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints | 277 |
| 8.1 | <u>Introduction</u> | 277 |
| 8.2 | <u>Revisiting the research questions</u> | 277 |
| 8.3 | <u>Further reflections</u> | 290 |
| 8.3.1. | Reflecting on Methodologies | 290 |
| 8.3.2 | Research Assistants/Interpreters and ‘whiteness’. | 296 |
| 8.3.3 | Children’s Geographies revisited | 299 |
| 8.4 | <u>Some suggestions for further research</u> | 306 |
| 8.5 | <u>Some final comments on the development debate</u> | 307 |
| | Bibliography | 311 |
| Appendix 1: | Community interview guide | 338 |
| Appendix 2: | Example of a completed family interview | 342 |
| Appendix 3: | Sample of all responses to one part of a question | 349 |

| | | |
|---------------------|---|-----|
| Appendix 4: | Environment index sample sheet | 353 |
| Appendix 5: | Sample of demographic sheet for adults in the household | 354 |
| Appendix 6: | Demographic sheet for children in the household | 355 |
| Appendix 7a: | Informed consent: letter given to children in school | 356 |
| Appendix 7b: | HIV/AIDS stimulus material used with children in formal school | 357 |
| Appendix 7c: | Care of vulnerable children stimulus material used with children in school | 358 |
| Appendix 7d: | Focus group guide used with children in formal school | 359 |
| Appendix 7e: | Focus group guide used with children not in formal school | 361 |
| Appendix 8a: | List of key informants | 363 |
| Appendix 8b: | Sample from fieldwork diary | 366 |
| Appendix 9a: | Family forms of children with parents alive | 370 |
| Appendix 9b: | Family forms, employment and vulnerability | 371 |
| Appendix 9c: | Family data and environment summary | 372 |
| Appendix 10: | Major NGO's involved in HIV/AIDS in Swaziland | 373 |

1. CHAPTER 1: Introduction to the Thesis

1.1 Introduction

The number of orphaned children, in sub-Saharan Africa, continues to climb and has not yet reached its peak. The death of parents because of AIDS is one of the main causes of these increasing numbers. This thesis searches for a deeper understanding of the effect of the AIDS epidemic on children, and the implications this has at family, community and national levels.

In 2003, 12% of sub-Saharan African children under 18 years old were orphans, compared with 7% in Asia and 6% in Latin America and the Caribbean. It is not possible to determine the number of orphans due to AIDS, even if it were desirable, since in many countries, given the stigma surrounding AIDS, death certificates do not state HIV/AIDS as the cause of parental death, and information on deaths is not accurately recorded. However, United Nations agencies do attempt to estimate numbers using demographic indicators, and of the 43.4 million orphans in sub-Saharan Africa, 12.3 million are thought to result from AIDS. By 2010, orphans from all causes will have reached 50 million in sub-Saharan Africa, of whom 18.4 million (36.8%) will have lost one or both parents to AIDS (UNAIDS, UNICEF, USAID, 2004).

1.1.1 The key gaps in knowledge

There are key gaps in knowledge of certain aspects of the AIDS epidemic and its impact on child-care that this thesis addresses. All children, not just those who are orphaned, are affected by the epidemic. In poor families in particular, when relatives die and extra children come to live with the family, scarce material

resources have to be stretched even further with a consequent decline in livelihoods. Hence this thesis considers the care of all children in poor families affected by AIDS, as well as those children who are orphaned.

AIDS is intrinsically linked to other aspects of social welfare and the effects of the AIDS epidemic on children's lives have to be examined in the light of the social, economic and political environment in which children and their families live. This research is set in the poorer areas of urban Mbabane, the capital of Swaziland. If poor families are assisted in their care of children affected by the epidemic then there will be less need of new forms of 'community' care for vulnerable children. However, to target assistance effectively, more needs to be known about family child-care arrangements in an AIDS epidemic.

Another consideration is that rather than assuming orphaned children in particular should be targeted for assistance, there may be other non-orphaned children in very poor families who are also very vulnerable. The rise in the number of vulnerable children is not purely linked to AIDS. This research, therefore, also includes poor families, who are caring for children but not orphaned children, living within the same poor setting.

The most salient issues that this thesis addresses are:

How do children perceive the effect of the epidemic on their lives? Has the 'adult lens' missed important issues that need addressing? How are vulnerable children embedded socially, economically and politically in Swaziland? How might this knowledge prove useful in other countries in the region but where HIV prevalence levels are not yet so high? Where are the opportunities and constraints for agencies involved with helping vulnerable children in Swaziland? Are there

insights to be gained that are relevant to children's lives in other challenging settings?

1.1.2 Location of the research

Figure 1: Mbabane the capital of Swaziland, Manzini the second city, and other smaller urban settlements. Scale: 1cm to 20kms. Source: www.lib.utexas.edu



1.1.3 Introduction to Swaziland

The study is situated in Swaziland, southern Africa. The Kingdom of Swaziland comprises 17,000 square kilometres. It is a small landlocked country and shares borders with South Africa and Mozambique. The population in 2002 was estimated to be 991,725 based on extrapolations from the 1997 census. The people are evenly spread over the four regions: Hhohho, Manzini, Shiselweni and Lubombo. In 1997, 23% of the population lived in urban or peri-urban areas. Almost two-

thirds of urban residents live in unplanned townships without access to basic sanitation services.

According to a UNDP National Development Report report in 1998, 47.9% of the population were below the food poverty line, unemployment was at 21.8% and only 52.5% had access to safe water. It is unlikely that livelihoods have improved much since 1998 as Swaziland has slipped from 112th in the Human Development Index in 2000, when it was classed as a medium human development country, to 147th in 2005 when it was classed as a low human development country (UNDP Human Development Report, 2005). The AIDS epidemic in Swaziland was therefore superimposed on a society where conditions would assist it to flourish.

1.1.4 The rationale for researching children in Swaziland

There is a generalised HIV/AIDS epidemic that has not yet reached the endemic stage where the epidemic curve levels off. The demographic structure of the country is undergoing fundamental change. HIV prevalence data taken from sentinel populations at antenatal clinics show an increase in HIV prevalence from 3.9% in 1992 to 38.6% in 2002 (Ministry of Health and Social Welfare, 2002). By 2004, it had reached 42.6%, the highest rate in the world (IRIN, 2005). Where comparative studies have been conducted in the population at large, data from antenatal clinics have been found to reflect the level of infection in the sexually active population at large. Barnett and Whiteside (2002, p 57) state:

'Population based surveys were rare. However, where they have been done they show that in heterosexually driven epidemics the differences between these data

and those from pregnant women are not great. Thus antenatal clinic data may be used cautiously as a proxy for the general population.'

In Uganda the epidemic curve of HIV prevalence in the sexually active adult population peaked at 14% in the 1980s but has since declined to 5%. However, orphan numbers continued to increase for about ten years after the peak in the HIV prevalence curve (UNICEF, 2003). This is due to the time lag between infection from HIV and death from AIDS. This suggests that orphan numbers in Swaziland will also continue to rise for many years to come yet, simultaneously, the number of potential adult carers is diminishing. In 2002, a report by UNAIDS, UNICEF and USAID estimated orphan numbers in Swaziland to have risen from 28,000 in 1990 to 59,000 in 2001. They were expected to reach 87,000 in 2010. Whilst these numbers may not seem large in absolute terms, they represent a large percentage of children aged 0-14 in this small country. The number of children orphaned as a percentage of total children in Swaziland would have risen from 8.2% in 1990 to 22.1% in 2010. In 1990 the report estimated there to be less than 100 orphans due to AIDS in Swaziland. In 2010 the estimate rises to 71,000 due to AIDS i.e. 81.6% of the total number of Swazi orphans. In 2004, UNAIDS, UNICEF and USAID published another report which changed the definition of children from those aged 0-14 years-old to include those aged 0-17. Using this definition, the estimate of total orphan numbers in Swaziland rises to 130,000 in 2010, or 24% of all children. How much higher the figure will rise is obviously related to the course of the epidemic curve in Swaziland. Thus this research is situated in a country with adult HIV prevalence rates of 42.6% and with nearly a quarter of the children facing the loss of one or both parents. Is the fabric of

society, particularly at family level where children receive care, sufficiently robust to withstand this level of change?

Swaziland has strong cultural traditions centred on the monarchy. Often referred to as the “peaceful Kingdom of Swaziland,” it has not been divided by ethnic rivalries due to the relatively homogenous nature of the population. Swazis are predominantly Nguni in culture and language. They belong to the broader Bantu group that originated in east central Africa. Without the internal conflict, which has beset many African countries, it might be expected that, with its strong traditional values, the country would be better placed than many to absorb vulnerable children at family level. However, the forces of modernity have not left Swaziland unscathed.

Men have become migrant workers in the mines of South Africa and some family members have moved to the Lubombo region of Swaziland to work on the sugar plantations. The Swazi cities of Mbabane and Manzini have grown as rural migrants search for work. Notwithstanding the latter, the extended family network has not been affected by war (whether internal or external), or chronic poverty to the point of starvation, as in some African countries. Thus, this study may be able to uncover some of the traditional forms of extended family care in the country and evidence of how they are changing, due to the epidemic, in a way that would not be possible in countries where there has been much more upheaval.

The cultural, political and economic situation in which women and children are embedded in Swaziland has parallels with many other African countries. Barnett (1995, p.171) referring to work in Uganda, Tanzania and Zambia states:

'In many parts of Africa, the woman only has the land in usufruct and her access is controlled by a husband or other male relative. Therefore her rights can disappear on the death of a husband, leaving her unable to provide for herself and her children.'

The rights of women and children are an interwoven thread running through the AIDS epidemic in many African countries. In Swaziland, a woman is currently worth fifteen cattle in a traditional marriage where lobola is paid. She may not open a bank account in her own name and is considered a minor in Swazi law. Land tenure is a problem for both women and for households headed by children. Situating this study in Swaziland may lead to a greater understanding of AIDS-related rights issues affecting women and children in a wider sphere.

Political issues that may affect children include donor fatigue. The Human Rights record in Swaziland (e.g. royal decree overruling the court of appeal, government eviction of Swazis in chieftaincy disputes, lack of free press or the right to associate and demonstrate, absence of political parties) has led to disquiet amongst international donors (Brody, 2003). The debate over the possible purchase in 2002 of a jet for the King, at a cost of US\$72million, also angered donors (IRIN news, 2002). The amount of donor aid to combat AIDS was estimated at US\$13.8 m. in 2001-2 (World Bank, 2002a) but future aid is linked to conditions such as further progress towards the Millennium Development Goals. Economic factors that may impact on the welfare of children, either through loss of income at family level or through more limited public expenditure, include the slow growth in G.D.P per annum. It has dropped from 7% in the 1980s to 3% in the 1990s to 1.8% in 2003 (International Monetary Fund, 2004). With a slowing down in the economy and droughts in the Middle and Low Veld from 2002 to 2004, there

is unlikely to be a marked improvement in children's livelihoods without donor aid. These fiscal constraints are similar to those faced by other AIDS-afflicted countries in the region.

This research focuses on the lives of children from relatively poor urban families who are growing up in an AIDS epidemic. Despite the economic constraints, it seeks to find sustainable ways of improving the livelihoods of vulnerable children that may be of relevance and interest to other countries in the region. AIDS cannot easily be separated out from other aspects of growing up in a poor family, thus in order to gain a deeper understanding of the role of endemic poverty in shaping childhoods in the 'South,' as well as the impact of the epidemic on children affected less directly than through parental death, the lives of all children are included where possible.

These issues are perhaps easier to explore in Swaziland, as it is small enough to be able to consider national-level initiatives for children and how these link up with children's livelihoods at micro-level. There is also a wide variety of orphan-care initiatives in place from informal fostering through to institutional care.

Furthermore, there are representatives from the large international NGOs as well as a number of smaller local NGO, CBO and FBO initiatives. There are insights to be gleaned about opportunities and constraints for assisting children affected by the epidemic that reflect not only Swaziland's unique situation, but insights that are useful to other countries where the AIDS epidemic is rife and the international donor community active. Finally, the location of the study in sub-Saharan Africa contributes to the knowledge of the geographies of childhood in the South in a world where both time and space are shrinking.

This introduction is divided into three more sections. The first section will outline the significance of the problem of vulnerable children and comment on the debate in the literature. The second section considers the importance of the 'voice' of the child. There are references in the literature to the paucity of research from the child's perspective. The current generation of children in Swaziland are the first to grow up in an AIDS epidemic and this research aims to capture their voice where possible. The third and final section is an outline of the progression of chapters in the thesis.

The literature debate centres on the viability of orphan-care within the extended family in African countries. The AIDS epidemic is not the only pressure on the traditional care networks. The need for cash income and the deagrarianisation of rural livelihoods, associated with Structural Adjustment Programmes, have also had their impact on the extended family network and its ability to absorb orphaned children. This first section will also outline the special stresses that AIDS has placed on the traditional care networks and suggest how this research will increase understanding of child-care within families and communities affected by the epidemic.

1.2 The significance of the problem

1.2.1 Changes in traditional family care networks

In traditional family care networks in sub-Saharan Africa, children were often cared for outside their biological homes by other members of the extended family or in non-kin households. A detailed study by Isiugo-Abanihe (1985), prior to the AIDS epidemic, describes the ways in which families in parts of West Africa used their

extended family as caregivers. In his study he found that 17% of male children and 21% of female children were not residing with their biological parents. These children were fostered for variable time periods and for a variety of reasons. For example, when mothers moved to work in urban areas the child might be left behind with the grandmother in the rural area to ensure the child was brought up properly and not affected by the *'modern'* city.

Isiugo-Abanihe refers to the prestige given to rural Nigerian grandmothers who foster the children of urban couples. The grandmother would receive gifts when visits were made and the child, especially if female, would perform household tasks for the grandmother. He gave many examples of reciprocity in these relationships. The fostering arrangement varied from a few weeks to several years. However, he differentiates this type of fostering from the much less common *'crisis'* fostering, i.e. when parents die, which is the type that predominates in the AIDS epidemic. According to Castle (1995), such crisis fostering can lead to lower standards of care. Castle studied child fostering and children's nutritional outcomes in rural Mali. By dividing the fostered children into two groups based on the context of the fostering, Castle found that children who were fostered by force of circumstances had poorer nutritional outcomes than those children who were fostered at the request of the foster-mother.

Some researchers warn against constructing the extended family as a universally beneficial form of child-care. Suda (1997), in a study of the increasing numbers of street children in Nairobi, takes a more critical look at the traditional support networks for orphaned children amongst the Luo of Western Kenya and recognises the potential for abuse within these networks. Kilbride (1994) shows

how on occasions, rivalry between step-children and between step-mothers and step-children was evident in polygamous families. However, Suda acknowledges that traditionally children were highly valued:

'The ideal in nearly all traditional African societies was to have a stable family and as many children as possible. In traditional Africa, children meant wealth and were seen as a source of power and prestige in addition to being regarded as a blessing from God and the ancestors.'

(Suda, 1997, p.200)

It must be borne in mind that there are other pressures on the traditional networks of care that are independent of the AIDS epidemic. Care networks were changing prior to the AIDS epidemic and have continued to do so. In particular, forces of modernity and urbanisation have gradually weakened links with rural kin. Suda (1997) describes the changes which are occurring in the extended family system in Kenya as a result of many modern forces which were relatively uncommon or unknown under the traditional economy and family system, such as the need for cash income, urbanisation, social and economic deterioration, as well as the AIDS pandemic. Suda concludes that the extended family is gradually weakening due to larger social, cultural and economic transformations in modern Kenya.

Deborah Bryceson (2000) refers to the blurring of urban-rural differences across many parts of sub-Saharan Africa and the changing social patterns in rural villages. She refers to the de-agrarianisation of rural livelihoods, brought about by the need for cash income for basic services such as education and health since the introduction of Structural Adjustment Programmes by the World Bank.

According to Bryceson, the cash income earned by both youth and women in the rural household has changed the social relations within rural households and communities:

'There are four major tendencies evident in the current social restructuring, namely: resort to incomplete family units i.e. separation of the reproductive couple for the sake of income earning, reduction in the size of large extended families in the direction of nuclearisation, weakening of dependency ties on gender and age lines within family units, and women's efforts to use matrilineal ties to further their material security'

(Bryceson, 2000, p 4.)

These conclusions were drawn from research in Nigeria, Ethiopia, Tanzania, Congo-Brazzaville, Malawi, Zimbabwe and South Africa. The above studies suggest that the traditional extended family care networks were weakening before the AIDS epidemic began in the mid-1980s and have continued to weaken since. It is therefore clear that changes are occurring in family structures, independent of the AIDS epidemic, in parts of sub-Saharan Africa and this has repercussions on the opportunities for family care of large numbers of orphans. The causes of these changes are complex, dynamic and intimately interwoven within the wider social, political and economic environment. The degree to which these changes, as well as those imposed by the AIDS epidemic, have debilitated caring networks for children, is not fully understood and this study in Swaziland aims to contribute to that debate.

Not only are there many other factors affecting child-care besides AIDS, but the epidemic itself is not uniform in extent or severity and child-care practices vary. Deciding on forms of support for vulnerable children is, therefore, all the

more challenging. Rather than an overarching model, the importance of local context becomes important. This is illustrated below by reference to subtly different research findings in four sub-Saharan countries. In each of the countries cited below, the percentage of children aged 0-17 years who are orphaned, is fairly similar: Zimbabwe 19%, Kenya 11%, Uganda 14%, Malawi 14% (UNAIDS, UNICEF, USAID, 2004). Also, the level of development is similar as all four countries are classed as: 'low human development.' The first three countries have a Human Development Index of 0.49, but Malawi is considerably lower at 0.39 (UNDP, 2004). HIV prevalence levels, in the 15-49 age group, vary from 24.6% in Zimbabwe and 14.2% in Malawi to 6.7% in Kenya and 4.1% in Uganda.

1.2.2 Evidence from Zimbabwe

In the literature, there are those who believe that the traditional family and community coping mechanisms are working despite the additional strain of the AIDS epidemic and that they need support which builds on local initiatives (Foster, interviewed in Kelso, 1994). In Zimbabwe, Foster stresses the importance of local, cost-effective, community-based, organisations and he refers to the Mutare-based Family AIDS Trust, which assists thirty families:

'The most important thrust of the programme is to revitalise the traditional coping system of the communities. We don't need western style means of dealing with orphans. We need to sit quietly and let the community find its way, not by default but with resources.'

(Foster, interviewed in Kelso, 1994, p.251)

However, a few years later, Drew, Makufa and Foster (1998) made a more nuanced point by noting the extended family cannot absorb all the orphans in areas of very high HIV prevalence and that the burden of care is falling on the elderly and adolescents. This is due to the high number of AIDS deaths amongst sexually active adults, the group who form the economic and social bedrock of society. Drew *et al.*, continue to emphasise how helping families at the community level in Zimbabwe is cost-effective, complements existing coping mechanisms, and is preferable to high-cost institutionalised care where children often lose contact with their communities.

1.2.3 Evidence from Kenya

Others (Nyambedha *et al.*, 2003; Aspass, 1999; McBride, 2002) are less optimistic about the current viability of family and community-based initiatives. They suggest the strain of the epidemic is overwhelming some families and communities and many more resources are needed. Nyambedha *et al.*, (2003), working in Kenya, describe how the burden of care of orphans has moved beyond the traditional patrilineal kin for 28% of the 243 orphans in their study, a useful indicator that traditional forms of care are under pressure. Nyambedha *et al.*, suggest there is maltreatment by *stepmothers* and definite favouritism of biological children in the household.

1.2.4 Uganda

In Uganda, Aspass (1999, p 204) notes that orphans are, generally, absorbed within the extended family but that it is a form of '*crisis fostering under very serious*

circumstances'. In contrast to Nyambedha *et al.*, Aspass finds *step-father* heads-of-household are biased in favour of their own children when allocating resources for education, whereas, women head of households were found to distribute resources more equitably between all categories of children.

1.2.5 Malawi

In Zomba, Malawi, McBride (2002) paints a bleaker picture and refers to children who are now beyond both family and other types of community care. McBride describes community care as overwhelmed and breaking down with many orphans socially excluded and feeling disillusioned and desperate.

There are clearly different experiences of child-care emerging in African countries affected by the epidemic and it is not just the children who become orphans who are affected. Orphaned children usually join families where other children such as their cousins live. The lives of these children also change, as fewer resources, including parental attention, have to be stretched further. They become aware not only of the deaths of their aunts and uncles but also the possibility of their own parents dying prematurely.

Although orphaned children have the added burden of parental bereavement to contend with, many of the other pressures they face may be similar to other children living in poverty. Given that orphaned children are often living with other needy children, it may not be appropriate to single out orphaned children as a distinctive category deserving of special assistance over and above that of other needy children. Apart from the resentment felt by other needy

children and their carers, it may lead to stigma and exclusion if children are categorised in this way. This research in Swaziland therefore considers the lives of all children affected by HIV/AIDS, not just those who are orphaned. It aims to add to the knowledge of child-care practices and contribute to the debate on the most viable ways of assisting families and communities in their care of children affected by the epidemic.

1.2.6 The special pressures of fostering children in an AIDS epidemic

It must be borne in mind that, in sub-Saharan Africa, fewer children are orphaned by parental death from AIDS than from other causes such as war, malnutrition, other diseases and it will remain so until about 2010 (UNICEF, 2003). However, in countries where there are very high prevalence levels of AIDS, such as Swaziland, this particular form of orphaning is dominant. Does this bring particular problems that may be subtly different from other forms of orphaning?

Whilst some reference is made in the literature to the specific difficulties of fostering in an AIDS epidemic (Hunter 1990, McBride 2002) there is a need for a more in-depth, nuanced analysis. The author has observed, first hand, some of the challenges to be met and would argue that the AIDS epidemic puts a different type of pressure on the extended family and goes beyond the common forms of shared child-rearing described by Isuigo-Abanihe (1985). It is more akin to the fostering by force of circumstance described by Castle (1995) in Mali, or the 'crisis fostering' described by Isiugo-Abanihe. War, disease and famine are other types of situations where 'crisis fostering' may occur with similar difficulties to those faced by families living in an AIDS epidemic as outlined below:

In traditional family networks there is often reciprocity and status to be gained by the fostering arrangement. It is frequently the rural grandmothers who provide care for orphaned grandchildren, both in traditional care networks and in the present epidemic. However, rural grandmother carers, in the AIDS epidemic, lose any remittances as their urban children become sick and die. Furthermore, in many African countries, rather than status, orphaned grandchildren often bring stigma and fear of AIDS into the foster home. A study in Cote d'Ivoire showed that children, orphaned by AIDS, are harder to place in the kinship group (UNAIDS, UNICEF, & USAID 2002, p.10)

Before orphanhood begins the grandmother or other family members usually care for the sick parents over a considerable period and this depletes household resources. In Swaziland it is common for the female relatives to provide medicine, food and clean linen for relatives in hospital. Rural carers travel considerable distances on a daily basis to perform these duties. The tending of the sick whether in hospital or at home is both labour intensive and expensive. It also reduces productivity in other areas where female labour predominates. In Swaziland when AIDS strikes a household, cultivation can drop to 50% of a farm's available land. When the family head dies of AIDS the average household production of maize per year for a family drops from 35 bags to 16 bags according to a study by the Swaziland Ministry of Agriculture (IRINnews 2003).

The fostered child may be HIV positive and require extensive care. Mother-to-child transmission rates of the virus lead to one baby in three being HIV positive. This rate may increase through breast-feeding. Neviraprine, a drug that reduces mother-to-child transmission, is not yet readily available in Swaziland.

There is some evidence that mothers may neglect children if they discover the children are HIV positive and likely to die in a few years. Presumably, if this is the case, foster carers may also be less well disposed towards HIV positive orphans. Brouwer *et al.*, (2000, p.538), investigated the attitude of mothers towards HIV positive children in Uganda and found:

'according to the counsellors, after the mothers hear that their child is infected, they often think it can die at any moment. Some mothers in the focus group discussions told that they would not take care of the child anymore if they knew it was infected because it would die anyway.'

The soon-to-be orphaned child and the adult carers are often traumatised by the slow, painful, stigmatised, death of the parents so the fostering occurs in a stressful situation. Apart from the poverty caused by nursing sick relatives, the fostered child may be uprooted from his or her own homestead, school, and separated from siblings, on the death of parents. Given the stigma attached to AIDS, it is harder for the child to feel accepted in the new environment where resources are likely to be fully stretched. The child is likely to experience a substantial drop in quality of life for example insufficient funds for school fees. This may lead to withdrawal, anger and despondency on the part of the child, and carers, especially if elderly, may have difficulty coping with such traumatised children (author's observations). The pool of adults in the community, who might normally assist an elderly grandmother carer informally, is being decimated by the epidemic. There is little spare adult capacity to assist. Finally, the fostering is not for a limited period as was often the case in traditional practices.

This research will highlight child-care issues that result specifically from the epidemic.

1.3 Children's Geographies

1.3.1. From human becomings to human beings

The writing of this thesis is a direct result of my engagement with children whose lives were affected by the HIV/AIDS epidemic. I wanted to do research that would be useful for policy-making and that included insights gleaned from the children themselves. During the research process I became aware of the theoretical and philosophical debates surrounding notions of children, childhoods, youths and their lived experience in different times and spaces. I realised there was not a simple binary division between childhood and adulthood or between children's lives lived in either the rich North or the poor South. I found arenas of both difference and similarity in the way children live their lives as well as a connectivity brought about by global communications and global economic restructuring.

Horton and Kraftl (2005) succinctly summarise my situation. They argue that research that is useful to policy-making is not the only thing that is important. They suggest that *'thinking, theorising, philosophising, creating'* (p.132) are also worthwhile and the results of such endeavours may become useful at a future point. The theoretical concepts that develop will then help inform new methods of research that will question and update constructs, norms and taken-for-granted assumptions (p.134). My thesis has therefore evolved into an *'endless moving between'* (Massey, 2002, p.645) as I reflect, in the succeeding chapters, on theoretical issues surrounding children's geographies, as well as the practical

implications for policy. The balance of my research is undoubtedly weighted towards finding practical solutions to pressing problems facing children in the South, where HIV/AIDS is endemic; but I do also contribute to the theoretical debates around childhood, the lived experience of children, and children's interactions with space, at both the local and global level.

The ways in which the study of children has evolved over the centuries is well documented (Holloway and Valentine, 2000; Aitken, 2001; Woodhead, 2003; Ansell 2005) and is not therefore discussed in depth here. It is sufficient for the purposes of this thesis to note that until the 1980s, the disciplines of anthropology, geography, psychology and sociology studied children in ways that were quite separate and distinct. It was during the 1980s and 1990s that children began to be viewed as human beings in their own right rather than adults in-the-making or 'human becomings.' Not only were children credited as people in their own right, they were seen as social actors with agency, actively constructing and determining their own lives (James and Prout, 1990). This change in emphasis, away from a childhood determined by biological developmentism, to one where childhood was seen primarily as a social construction, gathered pace through the 1990s (Holloway and Valentine, 2000). Childhood was no longer viewed as a monolithic, universal, experience but as a social construct that varied over time and space from local space to global space (Aitken, 2001). Even the terms 'childhood', 'children', 'youth', 'adolescent', were contested (Skelton, Valentine & Chambers 1998; Montgomery, 2003), as the importance of 'place' and the lived experiences of children, became centre stage.

My research with children in Swaziland delves into the social construction of childhood and shows both points of convergence with children growing up in the North (for example in chapter five where peer pressure is discussed in relation to sexual decision-making), and points of divergence (for example in chapter six, where I discuss how Swazi children are taught to think of themselves, first and foremost, as part of a kinship group, rather than as an individual with 'rights'). In chapter three, I emphasise the dangers of assuming the transferability of terms used to describe children in the North, in this case the word 'orphan', to children in the South. I also contest the binary division between adults and children as I find the boundary in Swaziland much more blurred: 'adults' of twenty two still attend secondary school in school uniform and 'children' take on the responsibility of caring for dying relatives.

More recently still, there has been increasing interest in academic research with children in the poorer parts of the world and how it informs theoretical concepts as well as relevant policy debates. Ansell and van Blerk (2005) noted at the 2003 Royal Geographical Society/Institute of British Geographers' Conference: *'the fact that all four papers'* (out of a total of sixteen on children and youth in developing areas) *'speak to policy debates is indicative of the potential importance of such research'* (p.145) and *'such research is poised to make important contributions to wider academic debates concerning young people, challenging assumptions and emphasising the significance of context to both social constructions and embodied experiences of childhood and youth'* (p.147).

One area where my research contributes to the theoretical debate rather than merely inform policy, concerns the current emphasis on children as social

actors with agency and the demise of the importance of childhood as a series of developmental stages. I caution against the current neglect of developmentism. I am not alone in this view. Woodhead (2003) argues that however socially constructed childhood is, it is developmental in the sense that there are transitions from babyhood to child to adolescent, so developmentism needs to be incorporated in a multi-faceted approach that recognises both concepts. He also suggests the re-examination of the concept: superior adult, inferior child. If a child can comfort a sick, upset parent then it is relational. Finally, he emphasises the dynamic nature of childhood. It is not static like gender or race: it is a changing phenomenon.

One area where this view is particularly pertinent to my research, is in the way children cope after bereavement, discussed in chapter six. Whilst I recognise the agency of the orphaned children in their quest for survival, I also recognise their special vulnerability as 'children'. I quote a young orphan girl (p.196) who describes looking for love in the arms of an older man as a way of coping with her parents' death. Another quote comes from a boy who describes how he craves the attention, love and approval he used to have from his mother (p.221). I therefore concur with Kesby *et al.*, (2006), working with children in Zimbabwe, where HIV/AIDS is endemic:

'Local understandings of childhood require international recognition if the pandemic is to be tackled. Finally, our exploration of these "margins" of human experience lead us to believe that children must be understood as competent and independent agents of social change and as vulnerable social becomings in need of protection.'

(p.185)

Kesby et al., agree with Robson (2004) and Aitken (2001), that there needs to be an *'unsentimental approach to the study of children'* (p.196) but suggest that in Robson's and Aitken's drive to recognise the resilience, competence and autonomy of children, they underplay the harsh realities of childhood in the global south: *'they also need time to be idle, play, to be loved and emotionally nurtured, to receive respite and relief and often need help to make the right decision'* (Kesby, et al., p.189). Whilst they do not suggest that these recreational, emotional and social needs of children are any different to those of adults', they do state there is a difference between children and adults as social actors in the agency they are able to exercise. Again, they do not link this to the many developmental stages through which children grow, but merely state that the difference between children's and adults' agency is manifest through the resources and experiences on which they are able to draw. They argue that adults therefore have a role and responsibility to guide facilities and develop the repertoire of resources children can use to develop their agency (p.99). Kesby et al., so aptly state: *'children living without the support and supervision of adults are an anathema to both international and local ideas of childhood'* (p.196), and this is producing marginalised 'other' childhoods within the 'other' childhoods of the South.

At this point I diverge with the current, in my view, over-emphasis on the social construction of childhood and ask for a redressing of the balance. I suggest that 'time' and therefore developmentism, is a vital dimension in the acquisition of agency during childhood, universally relevant to all the varieties of childhoods, whichever way it is socially constructed. Though the amounts needed vary from child to child, children do need time to acquire the emotional, intellectual and

practical skills of everyday living to be able to use their agency in an effective way, hence developmentism has to be brought back into our discourse on childhoods: particularly childhoods lived in extreme circumstances such as war, famine, and, in this research, high adult prevalence rates of HIV/AIDS. I am not advocating a retreat to the early studies of children and the discourse of ‘human becomings’ or Dionysian ‘little devils’ or Apollonian ‘little angels’, (Ansell, 2005), rather I am recognising that because of the more limited time children have had to experience everyday living, they are different from, and more vulnerable than, adults when faced with the extreme circumstances described in parts of this thesis. This time-bound vulnerability needs to be incorporated in academic discourse and respected by policy-makers. I move once more along the theory/practice continuum to show how important it is that children’s time-bound vulnerability is recognised, and that they are not expected to take on responsibilities that are beyond them, just because it is the least-cost option:

The experience of many community-based organisations in South Africa is that it [sic, ‘it’ refers to the use of CBOs] reduces the cost of care to the state in the short term, but increases the cost to the family and community, in terms of energy, emotional and material resources to insupportable levels. Further, a strategy for state and community support that does not require children to become terminal care providers under the euphemism of “home-based care” is urgently needed.’

(Desmond and Gow, 2002, p.4)

1.3.2 Global space and local space: webs of connectivity in children’s lives

Another interesting line of inquiry within children’s geographies, concerns the spaces and places where children live their lives and the connectivity between

them. Aitken (2001) and Holloway and Valentine (2000) discuss the ways in which empirically based studies have shown that childhood is not only constructed in different ways in different eras but it also varies according to *where* it is constructed. In addition to the *where*, the *scale* (that is, whether at local or global level) has attracted the attention of geographers interested in the lived experiences of children.

Some of the variation in children's lives has emerged at the local scale over limited space. One interesting study by Bunge and Bordessa (1975) compared the play and learning spaces used by two young girls, one living in a high-rise block, the other in a low-rise environment within the same neighbourhood. Such situated knowledge shows the contrast in the lives of children over a limited space at local level, embedded, as their lives are, within the wider socio/political/economic environment. Other studies have emphasised similarities between childhoods lived far apart in terms of distance, but connected in terms of how they are influenced by global restructuring processes. Katz (2004) carried out a comparative longitudinal study, from 1980 to 1995, of children living in Howa, Sudan and Harlem, New York, to examine: *'the relationship between capitalist globalism and social reproduction in Howa refracted in parallax from the vantage point of New York City'* (p.xii). In the case of Howa, the economy was moving away from small-scale family farming, producing locally consumed staple crops, to large-scale agricultural production of cotton and groundnuts for the international market. In New York, there was a flight from manufacturing, requiring low-skilled workers, to a service and financial economy requiring a highly-skilled work-force. Katz shows that despite the vast distances between the locations,

global restructuring was leaving children, in both places, poorly prepared for the *'employment futures that awaited them'*... *'these shifts have transformed their everyday lives and prospects in sometimes startlingly similar ways'* (p.xiii). A web of connectivity therefore links children across global space.

It is analogous to results from the recent UNICEF report (2007) where over 30 percent of young people aged 15 to 19 years in France, Germany and the United Kingdom expect to be in work requiring low-skill levels despite the dearth of such employment as global restructuring has led to the decline of low-skilled work in these three countries. These European young children are perhaps as ill-prepared for the realities of employment as those studied by Katz (*op.cit.*). Thus, children located across global space in diverse locations, are intrinsically linked to larger global economic forces. Swaziland is no exception.

Throughout the thesis I refer to the link between poverty and: the spread of HIV-infection; the lack of available anti-retroviral treatment (ART); the lack of palliative care; the lack of support for families caring for orphaned children; the lack of monitored foster care; and the lack of well-developed social services. This all impacts on the lived experience of children affected by the epidemic in Swaziland. Some of the poverty may be attributed to the global restructuring (particularly of trade tariffs) that has led to the decline in both the textile and sugar industries of Swaziland (interview with Hugh James, Executive Officer, Swazi Sugar Association, 2004), resulting in correspondingly high unemployment levels and a weakened Swazi economy.

This web of connectivity between childhoods lived in the North and South is evident in many parts of my research. I refer in chapter five, to the way young

people in Swaziland have access to the same films as those watched by youth in the North. Though the same cultural product may be interpreted in many different ways, according to cultural context, it is evidence of a new type of connectivity between childhoods widely separated in physical space. I also suggest that global economic restructuring is creating the poor employment prospects for youth in Swaziland. This leads to a lack of vision for a worthwhile future that, together with high levels of poverty among those living in informal urban settlements, may influence risk-behaviour in sexual-decision-making. I therefore support Aitken (2001) in his approach to the geographies of young people:

'Places are important for young people because these contexts play a large part in constructing and constraining dreams'... 'through our study of local places we should not be silent about larger concerns.'... 'I seek to elaborate larger concerns about the changing nature of childhood, adult moralities, young people's experiences and the embodiment of their political identities as they are embedded in the process of globalisation. How are children and youths contextualised in representations of global economic space and in what ways is it possible for them to attain cultural and social capital that has some power?'

(p.20)

I return to Children's Geographies in the concluding chapter but now turn attention, in this introduction, to the importance of the children's perspectives in current academic research.

1.4 The child's perspective

1.4.1 Children as social actors

The 'voice' of the child has risen to prominence in studies of childhood during the 1990s, after the work of James and Prout (1990). In particular, there is recognition

of both the importance of children's perspectives and their role as social actors in their own right. In the context of AIDS, White (2002), Chapa and Xaba (2002), the World Bank (2002c) and Foster (1998) all note the need for research from the child's perspective. White (2002) suggests how children perceive their options and proposes a "contradiction" and "solidarity" model. White refers to how adults may see teachers in a positive light but, to a child, they may appear as an unapproachable authority figure. It is essential to understand whom children perceive as sources of help and advice. As Bourdieu (1977) mentions, if kinship is imagined as a map, some paths would be much more well-trodden than others. By understanding children's social networks (of kin and beyond), as perceived by the child, it will be possible to identify the point at which the network fails and children become marginalised. Similarly, to intervene to help children the people to whom they would readily turn need to be identified.

Buseh, Glass, McElmurry, Mkhabela and Sukati (2002), showed the importance of considering the child's perspective in a study of AIDS prevention education. The study indicated that Swazi school students would prefer to receive information about HIV/AIDS and sexual behaviour from healthcare providers, rather than from teachers.

1.4.2 Children embedded within families, communities and society

White (2002) and Harper (2002), suggest there is a need for a broader approach when researching children. Rather than viewing children and adults as two separate categories, White stresses the importance of the embeddedness of children within key social relationships. Adults often act as gatekeepers for

children. She stresses that to alleviate a child's difficulties, an understanding of the wider social, economic and political structures in which the child is situated is needed.

In the social structure in Swaziland, the low status of females may lead to the prioritising of education for male children in a family with limited assets. For example, adult 'gatekeepers' may keep girls out of school to care for sick relatives. This may, in turn, compromise the sexual health of the female child. A behavioural survey in Swaziland by Family Health International (2002), showed that out-of-school youth aged 15-19 years were more sexually active in the last twelve months than in-school youth (33% compared with 15.7%). Condom use was also reported to be higher amongst school attendees. If there is a gender bias against females in attending school, it is likely to lead to higher HIV prevalence levels amongst girls in particular. Mehrotra and Delamonica (2002) refer to the link between improving basic social services (access to clean water, basic health care, and primary education) and the welfare of children, especially girls. This is very important in the context of AIDS, as educated girls tend to marry later, have fewer children and experience less income poverty. Improving the livelihoods of children, particularly girls, often requires interventions that improve the livelihood of the whole family in which they are embedded.

Studying children in a family and community setting rather than as individuals will lead to a deeper understanding, as White (2002, p1098) states:

'First, it means that to understand the choices people make and the actions they take, we cannot consider them simply as detached individuals, but have to see their selves and persons as essentially constituted in and through their relationship to others. Whilst this is true of all people, it is all the more striking for women and

children, whose status may be socially and even legally defined as derived from that of an (adult male) other.'

(White, 2002, p.1098)

This thesis therefore considers the way children are embedded in society, at a variety of levels, and how this affects their lives in the context of AIDS. The 'lens' through which children view their embedded lives is integral to this analysis.

1.5 Thesis structure

There are eight chapters in the thesis and rather than the traditional approach, I have followed the new regulations where the guidelines allow a thesis to be based on four papers submitted for publication. I have included five submitted papers in total and all are centred around the core theme of my title: the impact of HIV/AIDS on children in Swaziland: opportunities for, and constraints on, scaling up interventions. Literature is reviewed within each chapter where it is pertinent to the section under discussion. Chapter two explains the rationale of the multi-method research methodologies in more detail than was possible within the word limit of the papers submitted for publication and introduces the field sites where data were collected. The five papers submitted for publication follow the methodology chapter (papers one, two and three are now published). I have merely altered the papers to create one format for the thesis document. After the five papers I include a summary chapter. To help guide the reader, I now include further details of each of the papers presented in the next five chapters, as well as the concluding chapter.

Paper one is titled: *"Childcare in poor urban settlements in Swaziland in an era of HIV/AIDS"* and was published in the African Journal of AIDS Research in 2005. It

explores the role of the family in caring for orphans and other children in poor urban communities in a setting where adult HIV prevalence levels have risen to over 40 percent. A range of family forms was found to be caring for orphans and child-headed households or lone elderly carers were not common. Women of all ages were bearing the brunt of the extra care responsibilities caused by the epidemic with orphan care remaining situated primarily within kin structures. There was limited involvement in children's well-being by agencies of any kind and community-based initiatives were poorly developed. The AIDS epidemic was impacting on families in a variety of ways with a corresponding increase in poverty and vulnerability. However, carers did not perceive orphans as a separate category of children requiring assistance over and above any other vulnerable child, and I argue for welfare-sector policies that strengthen the family model of child-care by increasing support to the poorest families rather than treating orphans as a separate category of vulnerable children and thereby excluding other vulnerable children.

Paper 2 is titled: *"Relationships, partnerships and politics in the lives of the urban poor in AIDS-afflicted Swaziland,"* and was published in the African Journal of AIDS Research in 2006. It seeks to increase our understanding of how poor urban families, caring for children, access help from beyond the kinship group. The fieldwork shows that livelihoods were affected by multiple shocks and families were struggling to provide education, health-care, clothing and food for all children in their care. Orphan status or gender did not appear to affect access to education. Families turned to neighbours, churches and the work place for assistance.

Neighbours varied in their response and were rarely able to give material assistance. Churches did not provide physical resources either but they were seen as sources of emotional and spiritual support. Work place relationships on the other hand, provided material as well as emotional support. Government and NGO assistance was limited and poorly co-ordinated at the beginning of the fieldwork with criteria for selection unclear to many respondents some of whom felt marginalised from community structures. Using respondents' experiences when trying to access education and health-care, I illustrate the importance of the quality of relationships and partnerships at all levels (international, national and local) as well as the need for more synergy between 'top-down' and 'bottom-up' approaches. A much stronger co-ordinating role for government officials and the development of public welfare support are seen as critical to alleviate the poverty in which AIDS thrives.

Paper 3 is titled: "*Sexual discourse and decision-making by urban youth in AIDS-afflicted Swaziland*" and was published in the African Journal of AIDS Research in 2006. It begins by considering the ethics and practicalities of researching sensitive issues with older children and young adults in the context of AIDS. It then explores the effect of the epidemic on adolescents' attitudes towards sexual behaviour and decision-making. Based on qualitative fieldwork within the Mbabane metropolitan area, family caregivers in informal settlements and learners at two secondary schools explain how and where sexual health knowledge is gained and what they consider to be the main influences on sexual decision-making. The findings show that despite the locally high rates of HIV prevalence,

the information reaching youth is still often inaccurate and confusing. Young people wanted to be able to discuss sexual health issues with informed adults close to them in age and in a variety of settings, but peer pressure was found to be an important influence leading to high-risk behaviour for both genders. In addition, alcohol and cannabis were readily available and often found to be linked to high-risk behaviour. Low family incomes, and the perceived need for luxury goods, encouraged female learners to have transactional sex with older men. Furthermore, cultural perceptions of the role of both genders militated against low risk behaviour and left some adolescents feeling marginalised and lonely. I end the chapter by suggesting ways of approaching these issues at community level.

Paper 4 is titled: *“Growing up in an AIDS epidemic: constructions of childhood and coping strategies of orphans and their peers in urban Swaziland.”* It is currently under review at the African Journal of AIDS Research. The paper questions whether the current discourse about the lives of children orphaned by AIDS tends to create an unhelpful homogenised category of children which does not reflect the lived experience of children where high rates of AIDS prevail. Drawing on qualitative fieldwork with key informants, family care-givers and older children affected by AIDS, a more heterogeneous construction of orphaned children’s lives is portrayed. The ‘voices’ of both bereaved children and children not (yet) bereaved are included. The findings show that adult care-givers tended to concentrate on the material needs of all children in their care and often did not perceive orphaned children as a separate category of children with particular bereavement needs. By contrast, most orphaned children expressed social and emotional problems associated with the loss of their parents as well as material

deprivations in some cases. The severity of these feelings increased when children were suffering material deprivations associated with poverty, not in formal school, separated from siblings, experiencing multiple moves and sexual or physical abuse. Orphans also feared exclusion from the peer group or being treated differently from non-orphaned children. Non-orphaned peers showed some empathy with orphaned children as well as anxiety about changes in their own families when orphaned relatives came to live with them. I therefore argue that no child, whether orphaned or not, is left unaffected by the epidemic and poverty exacerbates the problem for all children growing up in the epidemic. Some children reported forms of abuse at family level and I suggest that child protection within families, not just within institutions, is an issue that urgently needs monitoring at community level.

Paper 5 is titled: "Considering child-care options in poor countries affected by HIV/AIDS: perspectives from Swaziland and their implications for development policy." The paper has been submitted to the journal: *Development and Change*. It draws together some of the issues that emerge in the earlier four papers and concentrates on the opportunities and constraints for assisting vulnerable children growing up in the epidemic. In particular, it explores the arguments for assisting families and communities in their care of vulnerable children rather than placing children in residential institutionalised care. Globally, poverty not orphanhood is shown to be the main reason why children are placed in residential care homes, so a strong case is made for cash transfers to families to minimise the need for such institutionalised care. The research findings show that initiatives that aim to

strengthen community care of children need to be context specific and sensitive to local child-care practices. Although there are many criticisms of residential care of children, I show that there are circumstances where it leads to beneficial outcomes for children in poor countries. The corollary is that such care needs statutory regulation and monitoring and the 'voice' of the child must be included in this process. I conclude by suggesting that international donors should support National AIDS Plans rather than following their own agendas and reduce the levels of conditionality applied to loans and grants.

Concluding chapter: The thesis ends with a concluding chapter that briefly draws together the substantive findings, bearing in mind that there are conclusions to each of the five papers. The research findings and limitations are discussed in the light of the original aims of the thesis and suggestions made of where further research may be usefully directed. The relevance of the findings for vulnerable children in other countries is put forward and comment made on the contribution of the thesis to our body of knowledge of childhoods of the South.

2. CHAPTER 2: Research Methodology

2.1 Introduction

I begin this chapter by explaining why I chose this research topic and how my own research identity affected my choice of methodologies. I then position this identity in relation to the theoretical literature on methodology and outline the structure of the rest of the chapter.

As a white European middle-aged mother teaching in Swaziland from 1999 to 2002 I became acutely aware of the AIDS epidemic in the country. In my own school I had the responsibility of helping write and implement an HIV/AIDS policy for the whole school community. I began to meet local NGOs, CBOs, FBOs and Government organisations involved with the epidemic in various capacities.

I also wrote some articles on the epidemic for magazines and journals in the U.K. (Jones, 2001, 2003) and was therefore aware of some of the published data on national HIV prevalence levels and other surveys in Swaziland. However, it was not until I was faced with the lived reality within my school and local community that I began to gain a deeper understanding of the lived experience of the epidemic. For example, as Acting-Principal, I had to decide whether a school maintenance man, already heavily in debt, should receive yet another loan for a family funeral. I had to break the news of parental death to children. On two occasions I took a student home to his bereaved family. In one home there was no food left at all for the remaining children. In the other I observed that the youngest child was also very ill. She later died of AIDS. Families took in extra children but siblings were often, of necessity, separated from each other. I visited and watched as other children and adults died of pneumonia and other opportunistic infections

associated with AIDS. I became aware of the inability of these families to access adequate health-care to stem the ravages of AIDS or to die without pain. The school community became engaged with these issues in many ways, but it was like stemming an incoming tide.

Meanwhile the international community was mobilising in a variety of ways. The United Nations Global Fund for HIV/AIDS was being created, and National AIDS Committees were being set up in countries affected by the epidemic. At the end of my contract, it seemed an opportune moment for me to carry out research into the impact of HIV/AIDS on children in Swaziland and the opportunities for, and constraints on, scaling up interventions that might help them. Most of the research on children in the epidemic in Swaziland that I had been able to access by 2002 was of a positivist empiricist nature. I felt there was a need for a much more nuanced, in-depth, qualitative piece of work, particularly with the poorer urban children who seemed to me to be marginalised from much NGO and government activity. I do not intend to repeat the extensive literature on the respective value of quantitative and qualitative research, but I will elaborate a little on where my research is situated within qualitative research.

I have given some background above as to why I chose this topic for my thesis and to alert the reader to my positionality as a white 'outsider.' Putnam's (1981) view is that there is no single objective truth, and Denzin and Lincoln (2000) observe that no special epistemic privilege can be attached to a particular set of methods that allows us to appraise different knowledge claims. It is therefore clear to me that thick description of my methodology and approach to the

research are important for readers' understanding of my interpretation and representation of children's lives.

Whilst recognising the social production of knowledge and its relativism, I agree with Schwandt (1996, p.59,) that while we must all live with uncertainty, rather than a universal truth, it does not mean we should dismiss commitment and abandon judgement. I have therefore made judgements of issues and policies in the five papers that make up this thesis, knowing that, as Smith and Deemer (2000) argue, a researcher's judgements are not the complete picture, merely a process. My exemplars will be added to and replaced and my judgements re-worked. I can merely give the evidence and the reasons for my judgements. The reader, like the writer, must be cautious in assessing the evidence and any possible prejudice on my part. A prejudice may arise because of the research funding. This does not apply in my case, as I am not aligned to any funding body. I have also noted the tension between representing the under-privileged as victimised and damaged or as persons with resilience and agency (Fine, Weiss, Weseen & Wong, 2000 p. 125). Fine *et al.*, argue that simple accounts of victimisation with no evidence of resistance and agency are flawed, while accounts that highlight individuals who survive, despite their circumstances, often overlook contextual factors and are similarly of limited value. I have tried to avoid both pitfalls, but despite my best efforts to avoid bias, with a lifetime of working with older children, I may have favoured the children's perspective rather than that of the authorities charged with helping them.

Greenwood and Levin (2000, p. 96) refer to action research as '*context centred; it aims to solve real-life problems in context.*' They then explain how such

action research may have application in other locations if allowances are made for the different contextual situation. My aim has been to interpret the lived reality of children's lives in a situation where AIDS is endemic so that it may be applied reflexively to other countries faced with similar challenges. I have noted the comments made by Thrift (1996), Silverman (2000) and Smith (2001) that social and cultural geography in recent years has been concerned with how people represent their world rather than what people actually do in it. My work is concerned with both how marginalised people see their own world and how they actually live their lives. At times in this research I have been part of the 'performance' event (for example, fetching pain-relieving drugs for a dying woman or my role with the education working group of UNICEF) as Smith (2001, p.36) describes it: *'working with performance is working with a conception of knowing and being that goes beyond the visual, the textual and the linguistic.'*

By being part of a performance event I have also recognised the emotional spaces, which Smith describes, where feelings and emotional relations have significant impacts in shaping the world but are often underplayed. These often invisible but real bonds that affect the social world are evident in several areas of my findings. Sometimes the emotional relations were negative, despite a verbal discourse that suggested otherwise, and it was only by examining the 'doing' or 'performing' that I could understand the world I was researching.

Christians (2000) and Denzin (1997) argue against a normative model of individualist utilitarianism in favour of feminist communitarianism, where fulfilment cannot be achieved in isolation but only through human bonding with others in the social realm. In many ways Swaziland is an ideal space for research into human

bonding in the social realm, as traditional African society does not favour individualism and the AIDS crisis exemplifies the benefits of strong community and family ties. To understand the social realm of children, my research has therefore included the voice of family carers and community members, given the way children are embedded in, not isolated from, family and community.

Christians (p.145) argues that interpretive discourse in qualitative research should aim to represent multiple voices, enhance moral discernment, and promote social transformation. I have borne this approach in mind in designing and executing this research but the reader must remain aware that the multiple voices I have chosen may reflect my bias and the way I write is in itself a constitutive force: *'This worded world never accurately, precisely, completely captures the studied world, yet we persist in trying'* (Richardson, 2000, p.923). To help the reader understand how I have captured and interpreted the world I have studied, I have divided the next part of this methodology chapter into four sections. Firstly, I discuss the ethics of researching with children; secondly, my research identity and the role of my research assistants; thirdly, the field sites and research methodologies used. I then conclude the chapter by assessing the limitations and challenges of my research setting and lessons learned for future research. Given that each of the five papers includes a methodology section my aim is to elaborate only on issues where the publishing word limit constrained discussion.

2.2 Ethics of researching with children

2.2.1 Informed consent and confidentiality issues

In chapters five and six I have discussed in some depth the issues surrounding 'informed consent' in relation to children and AIDS research.

One of the problems I encountered was that in one school the Deputy Head did not appear to fully understand the concept of informed consent. In a patriarchal society such as Swaziland, the concept of seeking the child's consent rather than merely using the adult 'gatekeeper's' permission was clearly alien. While the letters I had written informing children of the nature of the research were given out, I could not be absolutely confident, for one of the schools, that the letter (appendix 7a) had been discussed in the way I had requested. The letter represented a western construct of 'informed consent' that was perhaps of limited practical value in the social context of my research. The choice of my research assistants and the 'lens' through which they viewed my research activities with children was therefore much more important in ensuring the children were well informed and protected from harm.

Confidentiality was less of a problem in the school setting as I had access to rooms in the school that had been set aside for the research. Children did not write their names on their written accounts and I undertook not to identify them individually to anyone, particularly their teachers and parents, except if they disclosed something that required immediate action to prevent the child from harm. Two children did in fact write that they had been abused, but the two children in question were clearly referring to past events that had been resolved and both had found alternative adult-carers. Since carrying out my research, a

work with me part-time for several months whilst the former merely helped on the days where school children took part. I took time to train them in how to approach the research. We discussed ways of ensuring that the needs of the child would be prioritised over those of the research goals if a conflict of interests arose.

On the days of the research the children were once more given information about the research, their voluntary role and their right to withdraw at any time, and the way the research would be used. As in the letter given to the children attending formal school, the research assistants also asked children who had been bereaved in recent months not to take part. One child withdrew at this point. One other child started in a discussion and then withdrew. Both received support from one of the research assistants.

The trauma of orphanhood and the duty of care in the procedures undertaken as a researcher guided my approach. From my own experience of comforting children in Swaziland at the time of parental death as well as my subsequent contact with them over several years, I did not consider it appropriate to ask children about their experiences within a year of the loss of a parent. I also chose to work with older children (mainly 14 to 18 years old) as I felt my familiarity with this age-group would allow me to read signs of distress and act appropriately. I also sought advice from Drs Flouri and Buchanan of the School of Social Policy and Social Work, Oxford University, and they concurred with me over both age of respondent and timing after bereavement. Apart from ethical considerations, reliable data are less likely to be obtained from children within one year of a traumatic event, according to Dr. Flouri.

new handbook for researching with children in international settings has been produced and this point on promising only partial confidentiality is covered (Schenk and Williamson, 2005). To further ensure that the child participants cannot be identified, I have not named the field sites precisely so the schools cannot be located easily and any facts that might lead to a child's identity have been changed or omitted.

2.2.2 Minimising harm

Lindsay (2000) writes that in addition to meaningful informed consent, *'there is a duty to ensure that research is not carried out on children unnecessarily, and that the degree of intrusion is minimal'* (p.20). I have therefore sought information from a variety of key informants who interact with children as well as in-country documents and statistics. I also attended workshops and conferences where children's issues were discussed and assisted UNICEF voluntarily in formulating the education section of the draft *National Policy on Children, Including Orphans and Vulnerable Children in Swaziland* 2003. I limited my direct contact with children to the areas where their own perspective was needed.

I used two research assistants for this part of my research. Both were university-educated, black Swazi young women with medical knowledge. They each had experience of working with, and caring for, children. I discuss the limitations of my white skin colour in this research context in section 2.3 below and I took this into consideration when seeking my assistants. One was a medical student the other was already working as a counsellor for young people in Swaziland. The latter lacked full-time paid employment and was therefore able to

To ensure there were beneficial outcomes from the research activity as recommended by Schenk and Williamson (2005, p.15), about an hour was spent on discussing issues relating to HIV/AIDS with the children as a group. Information leaflets and agency phone numbers and other details were supplied. Since these children lived in the urban area they were relatively close to many of the clinics or agencies that could offer them information and services (for example voluntary testing and counselling for HIV, information on sexually transmitted diseases, birth-control and pregnancy). Children in more remote rural areas would have needed more guidance on how to reach services. The research assistant familiar with counselling offered further support for individual children if they required it.

I also carried out research with orphaned children who were not in formal school but attended literacy classes. I had to approach this field site in a different way and with different methods. The Supervisor for Sebenta in the Hhohho region explained that most of the children were double orphans (that is, both parents were dead) and they were only allowed to attend Sebenta classes after a visit to the household had established their vulnerability (interview 27-11-03). I was able to have in-depth conversations with the Sebenta teachers at each field site to gain an insight into the orphaned children's home backgrounds. I was struck by the marked poverty of these children and after discussing their needs with both the children's teacher and my research assistant, I decided, prior to the research activity, to buy some food and school equipment for them. Some of these children had not eaten on the day of the research activities and there were no educational materials for them besides a room and a blackboard, at one of the Sebenta meeting points, and there were no toilet or water facilities either. In section 2.2.3

below I describe the multi-method approach used with children, in school, which included written accounts on AIDS issues and the care of vulnerable children. The children not in school were often barely literate, and I had to rely just on sensitively-handled group interviews led by my research assistant (focus group guide appendix 7e). Two of these were taped and then transcribed, whereas notes were taken at the third group interview after the tape failed.

On one occasion I decided to halt the research as I considered it intrusive and harmful to the young adult. I had unexpectedly been introduced to a young woman of 19 years by a local social worker who knew I was researching the lives of vulnerable children. The social worker described the home as a 'child-headed household'. When, during the conversation, we started asking how she was coping with her siblings I decided that the conversation was insensitive and intrusive, despite the social worker's assurances, and I brought the conversation to a close.

In this way I tried to ensure the research met ethical guidelines as described by Lewis and Lindsay (2000), though my particular research setting presented challenges that sometimes made this difficult and I had to respond quickly in situations that I had not always anticipated. This leads me to conclude that whilst ethical guidelines written by academic research boards are a useful starting point, the researcher in the field must be responsive to the contextual dynamics and make appropriate use of local knowledge, not least the use of carefully chosen research assistants. I had very limited funds, but money spent on well-qualified local research assistants for the child-centred part of my research was very valuable.

2.2.3 Appropriate methodologies

In addition to discussions in papers 3 and 4, I would like to elaborate a little on my choice of data collection methods. In planning my research I had intended approaching children in more informal settings. However, the informal 'spaces' where I encountered children were rarely private enough for children to speak without the presence of an adult as Figure 2 below shows:



Figure 2: a home in an informal settlement within the Mbabane Municipal Boundary

This is not just a problem of research with children in the South as Valentine, Butler and Skelton (2001) note. I therefore decided to approach local secondary schools whose catchment areas covered the informal settlements where interviews with adult care-givers were undertaken. I then had to consider the particular difficulties of using schools as a research setting and these have been explored elsewhere (Morrow 1999). I was most concerned about power relations and how to create an ambience where children understood that their views were

the most valued and that there was no right or wrong answer that would gain my particular approval.

Christians (2000, p.148) explains how the dominant understanding of power is interventionist, exercised competitively in order to control. By contrast, he offers an alternative view where power is relational and may lead to mutual empowerment. It was the latter type of power that I sought to achieve with my child respondents. To help reduce the hierarchical power relations of teacher-child, I rearranged the classroom and sat amongst rather than in front of the children. The young research assistants led the early discussions and helped create a relaxed atmosphere. I situated myself as a research student and learner, not a teacher. I explained that they were the first generation to grow up in an AIDS epidemic and they each had knowledge and experiences that adults lacked and that were valuable to those with the resources to improve children's lives.

The range of activities introduced (that is, written accounts, focus group discussions, one to one conversations and whole group discussions) was open ended and entered into voluntarily. Each methodology has advantages and disadvantages (Dockerill, Lewis and Lindsay, 2000, p.52) so by using several I was attempting triangulation and capturing multiple voices. Some children chose several activities whilst others read leaflets and chose only one activity. Dockrell, Lewis and Lindsay (2000, p.55) advise that making a statement rather than asking a direct question, elicits a fuller response from children as children may interpret negatively a question that may seem neutral to an adult. For example, asking whether they played football after school last night may be seen as an attempt to find out if they were involved in the fight that took place nearby at that time. I

therefore tended to use statements from some of my interviews with adult carers or other children, as well as questions, to generate conversations and to stimulate written responses from children (appendix 7b and 7c). This seemed to work well. I also decided to stay with those children writing their responses and let the young Swazi research assistants carry out the focus group discussions in another room (the focus group guide is in appendix 7d). I recognised that a researcher's 'race', gender and ethnicity will affect the research situation wherever work is undertaken. Denzin and Lincoln (2000 p.18) refer to the situated researcher:

'Behind these terms stands the personal biography of the researcher, who speaks from a particular class, gender, racial, cultural, and ethnic community perspective'

I therefore thought that my 'outsider' positionality would have a different effect on the focus group discussions from that of the two black Swazi young women research assistants. I realised that I would inevitably miss some of the non-verbal cues that I would have observed and instead I would have to rely on the tapes and the observation notes taken by the second assistant. As Denzin and Lincoln (2000) explain, post-positivism relies on multiple methods as a way of capturing as much of reality as possible, and this is the approach I undertook.

2.2.4 Beneficial outcomes for children

Some of the benefits of the research process are intertwined in the above section, particularly that on minimising harm, however there are others. The children had many inaccurate understandings about the HIV virus, its transmission and control that we addressed. Splitting the focus groups by gender and age, allowed for

issues to emerge that were unlikely to be discussed in a mixed gender or age group. In both secondary schools there was limited engagement with the AIDS epidemic within the formal curriculum, and children were in need of reassurance and accurate information. The activity created a forum for discussion that the children appeared to welcome. Their views on sexual behaviour and ideas on HIV prevention education were passed on to the Director of the National Emergency Response Committee on HIV/AIDS in Swaziland prior to publication in the *African Journal of AIDS Research* in 2006 (Chapter 5 in this thesis).

2.3 Research identity and the role of research assistants

2.3.1 Situated identity

During the past twenty years the complex effects of the positioned researcher has led to discussion in the literature (McDowell, 1992; Rose 1997, Skelton, 2001) about how much researchers should disclose about himself or herself to the reader. There has been a call by post-colonial feminists in particular to recognise that all knowledge is produced within certain economic, political and social circumstances (Butler, 2001, p.266, Rose, 1997). Self-reflection has become an important part of the qualitative research process from fieldwork through to producing the written account (England 1994). The privileged position of 'northern' academics in relation to people in the 'south' and the effect of the colonial past are considered particularly challenging (Katz, 1992; Skelton, 2001). Guided by this literature, I have already described aspects of my positionality in relation to this research. I am aware, however, that some authors consider this self-reflection has perhaps gone too far (Silverman, 1997) and urge a more cautious approach so

that as Ley and Muntz (2001, p.245) posit: *'So the question becomes where, when and how we draw the important line between reflexivity as rigorous contextualisation of qualitative data and narcissistic, emotionally motivated navel gazing.'* I have therefore positioned myself in the text of this thesis from time to time where I consider it will help the reader interpret my meaning. As Mohammad notes (2001, p.114) *'readers may change and/or supplement meanings through the act of reading.'* I share Skelton's anxiety (2001, p.95) about the responsibilities of publishing and disseminating cross-cultural research but take heart from Butler's conclusion on the need to include the author's positionality: *'Recognition of motivation, differences of position and an awareness of personal reasons for the promotion of particular issues can all be put to valuable use to piece together a more complete picture of society'* (Butler, 2001, p.274).

2.3.2 Fluid identities

During the research I found it necessary to stress different aspects of my identity according to the company I was in. Whilst never creating a false self, my identity was constructed to ease the path of my research as each different setting arose. Angrosino and Mays de Perez (2000) refer to fluid identities where identity is constructed and dynamic: *'roles mutate in response to changing circumstances and are never defined with finality'* (p.684). Mohammad (2001) elaborates on the complexity of this fluidity by showing how her status changed from 'insider' to 'outsider' during research with the Pakistani community, depending on the level of self that she revealed and to whom she was talking.

I have already described the identity I adopted with child participants to try and diminish my power-laden identity as an adult white outsider in a school setting. During interviews with adult care-givers in family settings I listened carefully to advice from my research assistant. I wore appropriate clothing and made use of the limited siSwati I had learned. I observed cultural practices such as removing my shoes at the doorway of homes, showing appropriate deference to culturally defined gender roles. Conversations had to start slowly and gradually proceed to the semi-structured in-depth discussions. I played a subservient role to my Swazi research assistant, who acted as interpreter, though we had perfected a method of communicating when I wanted her to pursue a topic in more depth or she felt we needed to try a different approach. Some participants spoke English but older women usually spoke in siSwati.

Our identity as two researchers changed during the months that we visited the community. Family members already interviewed would sometimes approach us with further thoughts and my outsider positionality seemed to lessen. This was in part due to my age, gender and motherhood. Skelton (2001) describes how being open about her lack of motherhood created a change in the power relations with women she was interviewing in Montserrat. My research assistant also explained that people were pleased that someone from 'outside' was taking an interest in their lives and that their stories were considered valuable and useful to others in a similar situation. Isabel Dyck (2000) also notes this positive element of research in her study of women with chronic illness.

There were occasions where my own experiences of death (of my husband when my children were very young) and serious illness of one of my own

children allowed me to enter a new level of trust and empathy with some of the women I was interviewing. It was as if our mutual struggle to raise children in difficult circumstances (for our respective cultures) created a female bond that transcended some of the obvious differences in our lives. It was an identifiable '*emotional space*' (Smith, 2001) that had significance for my researcher role. For example, one widowed mother of three children was scrubbing her doorstep when we arrived at her *mud-and-stick* home. Initially she was reluctant to spare the time to be interviewed, as she was due to go to the street to sell fruit and vegetables. However, she changed her mind and allowed us into her home. When our eyes had adjusted to the dim light, we could see a very small but neatly kept room. There was a double bed and a small single mattress. A cupboard divided this part from the kitchen area where a primus stove and bowl were positioned ready for cooking. It transpired that since her husband had died she had been unable to pay the rent and school fees. She had down-sized from two rooms to one. Her own family were too poor to help her and her husband's family were suspicious of how her husband died and were now very cool towards her (wives are quite often blamed for the transmission of AIDS). She said her neighbours were in the same poor position and though she went to church she felt too proud to ask for help. At this point the woman began to weep.

This was not the only time I was to be struck by the dignity and pride of people struggling in abject poverty. The research assistant was visibly moved and I sought her advice on how we could help the woman. Her cultural lens on such issues was indispensable. She felt it was appropriate for us on this occasion to offer some money for the third child who was most behind with school fees. I

asked her to explain that I had been helped in a similar way after the death of my husband when my daughter was very ill and I would like her to pass the kindness on to someone else when she could. It was learning of each other's lives in this way that led to the constant reconstruction of my identity during the community level fieldwork.

Skelton (2001, p96) writes about the wider implications of cross-cultural research and its impact on the researcher as an individual: *'I cannot abandon the history and relationships I have with the place and the people because doing cross-cultural research is hard.'* She argues that it is *'a rare and privileged opportunity'* to learn from others and to challenge unequal power relations. This fieldwork had a similar effect on me.

There were situations where I chose to emphasise my academic credentials, professional identity and institutional association with Oxford University in order to further my research inquiry. Without such an identity it is unlikely I would have succeeded in bypassing gatekeepers within organisations to access the most powerful key informants. I dressed to fit this professional image and conducted interviews in a more formal manner. Interestingly, it was often the 'off the record' comments in the lift or over coffee that proved the most informative. It is this identity that I also presented to UNICEF and that led to invitations to attend workshops, conferences and to become a member of the education working group helping to formulate the Swaziland National Policy on Children.

There were also times when I provided only external cues as to my identity and did not divulge any personal details or act in a way that made it easy to fit me into a particular category of white person living in Swaziland. While

relationships between people of different colour in Swaziland are not problematic in a post-apartheid sense, I observed marked differences in material wealth and patterns of living. I did not find poor white people living in the informal settlements or any vulnerable white children. There were distinct parts of the city where black people shopped and very few white people were in evidence. There were other areas where white and black shopped together but this tended to be the car-owning wealthier section of the black community. When I travelled by public transport I was always the only white person waiting in the bus rank. I rarely saw a white person travelling in the minibuses that I used and which form the main means of transport for local black people. I observed during fieldwork that it was unusual for white people to be invited into a Swazi home. I therefore conclude that my white skin indicated my position as 'other' and a person with access to other social spaces from which poor black people are excluded. Skelton (2001, p.93) describes how whiteness remained a significant factor in her research in the Caribbean and how each interview was a new negotiation of power and positionality. Being white might facilitate or mitigate any particular research encounter. My experiences were similar and again the cultural lens of the research assistant sometimes helped me discern when subtle barriers were being created to prevent or make difficult a potential interview or research activity. Sometimes I would have the permission of a person higher in the hierarchy of an organisation to carry out an activity but I might encounter thinly disguised resistance at a lower level. Sometimes the resistance might be directed at me as an 'outsider', at other times I understood the resistance to be independent of me as a researcher but aimed at thwarting those in authority within the organisation. If repeated attempts

to renegotiate my position failed with the 'gatekeeper,' then I had to readjust my research plans and data collection activities. I used my research assistant's perceptions of power relations to help inform my approach to such difficult situations. Fortunately 'resistance' did not occur too frequently but it does indicate the importance of identity construction and perceived power relations in cross-cultural research settings.

2.3.3 The cultural lens of research assistants

I have already exemplified situations where the cultural lens of the research assistants helped in both the design and execution of certain research activities. This lens helped me respect and work with 'difference.' I was able to perceive power relations and complexities that I may not have discerned through my own Eurocentric lens, even having lived and worked in the country for three years prior to the research. One of the two research assistants was seeking a permanent position with an NGO within Swaziland. I decided another beneficial outcome of the fieldwork should be to help the assistant gain new research and computing skills and exposure to new contacts in the NGO community from where employment might arise. This meant the research process was of mutual benefit as she was indispensable to me for my community research where little English was spoken and siSwati was essential, and she would be more likely to enjoy the research work if there were likely to be some longer-term prospects. I would also be assured of a useful contact for future research if we had such a symbiotic relationship. Fortunately, she achieved a suitable position with one of the U.N. partners before my fieldwork finished.

2.4 Research field sites, methodologies and data analysis

2.4.1 Introduction and research questions

In chapter one (p. 18) I referred to the salient issues that this thesis addresses. With these issues in mind, I designed specific research questions. The latter are questions that make it clear which data are needed in order to answer the questions concerned (Punch 2001). The six questions used are shown below and I referred to them continuously whilst in the field as I had to either redesign or refine my data collection methods:

1. Are traditional extended family networks able to absorb the increasing number of orphans? Is the form of care changing e.g. from patrilineal to matrilineal, to child-headed households, to informal non-kin fostering? How is support given within the extended family? Has family care reached breaking point and if so, what are the triggers?
2. What affect does the AIDS epidemic have on child-care within these families? What are the main issues when fostering orphaned children? What are the challenges of caring for all children in an AIDS epidemic?
3. Who do care-givers turn to for help? What support is there available within the wider community and from formal agencies? How is support accessed and what are the barriers to gaining help?
4. How do children perceive the affect of the epidemic on their lives? What affect is AIDS having on their attitudes to sexual behaviour and decision-making during adolescence? How are they affected by bereavement and orphanhood? How are they responding to the challenges they face?

5. Where are the opportunities and constraints for agencies involved with helping vulnerable children in Swaziland? What are the main forms of non-kin child-care that are emerging? Are they sufficient or are there gaps to be plugged?
6. How can this research contribute to an understanding of children's lives in the context of AIDS? What can this research contribute to both the literature on the care of children in an AIDS epidemic and to the literature on the geography of childhoods in the South? How can it help inform policies in relation to vulnerable children in other countries?

To investigate my research questions I needed to gain access to three different types of field site: family respondents in their homes, children in 'private spaces' away from adult carers, and key informants both in the community or organisations. I also acted as a participant observer (as a performer) and as a situated learner. Finally, I accessed in-country textual sources that I had not been able to obtain from outside the country.

2.5 Field site one: families living in informal settlements in Mbabane

In the context of orphans, studies in Zimbabwe note that rural, peri-urban and urban communities may have different needs (UNICEF & UNAIDS, 1999a; UNAIDS, 2001). With the increase in urbanisation in sub-Saharan Africa (Stock, 1995, p.53) there is an increasing need to understand how children experience their childhoods in poor urban areas. I therefore decided to concentrate on vulnerable urban children and their families. The community-based part of this

study was based in informal settlements within the metropolitan boundary of Mbabane, the capital of Swaziland. Although I visited several informal settlements, most of my fieldwork was with families in one informal settlement. It was home to families who have lived there many years with their extended family as well as families who have migrated from rural areas more recently and had little extended family nearby. It was a well-established informal settlement where some houses had electricity and piped water, but many did not. There were active church groups, community committees and some agencies (NGO and government) present in the community.

2.5.1 Entry points to the community

I had to take into consideration the difficulty of gaining access as a white female foreigner. Some members of the community knew of me from my three-year period of teaching work in Swaziland as a few members of the community worked in the same school as administrators, cleaners or in the maintenance department. I was also associated with the AIDS epidemic in a broad sense through work on a voluntary basis involving HIV/AIDS workshop help sessions for these workers, provision of information on medical care for opportunistic infections, access to condoms, help with funeral food, and bereavement support.

I did consider approaching another community, where I had no connections, to overcome criticisms concerning power relations between the researcher and the researched. However, I was no longer employed at the school and the AIDS work I had undertaken with families was, in any case, voluntary and not all formally related to my employment situation. It takes a long time to be

called “sisi” (sister) in such situations, and it would be difficult to carry out the semi-participatory research that I intended, to the same depth, in a community unknown to me.

I had also to consider language barriers and personal safety. Some members of the community spoke English well but I was aware that I would need a research assistant who could act as an interpreter and decided to seek guidance from community members as to who would be the most appropriate in terms of gender, age and acceptability. In terms of personal safety, I knew I would need to dress appropriately for the culture, not carry any expensive items, avoid the drinking areas where men congregated (shebeens) and only carry out visits by day arriving on foot. A car would have emphasised my ‘outsider’ positionality.

My first entry point was through a Swazi woman friend of my own age who had known me for four years. She also suggested a young Swazi female graduate interpreter, who became my research assistant, and asked me to accompany her to church. There were several non-denominational ‘charismatic’ churches in the community and it was to one of these that I was invited. My friend introduced me formally to the congregation that had gathered for a service in a local schoolroom, explaining that I was her personal friend and could be trusted. She went on to say that I was nothing to do with any agency and joked that I was a student and did not have any money so there was no point in asking for any. With the help of my newly appointed interpreter I was then asked to speak about my project. In this way I began to meet my respondents.

A second entry point was through the Zone Leader. The informal settlements in Mbabane are divided into Zones by the City Council and each Zone

has a Zone leader and a committee to represent the community. After explaining my project and showing him letters from both Oxford University and the Director of the National Emergency Response Committee for HIV/AIDS, he said he would tell his committee and let people know about me. He gave me permission to use his name when I approached families.

Next, I made use of my principal research assistant who had worked for an NGO in this community and was aware of some families who were caring for orphans. We used some of these families to start a 'snowball' system of accessing other families. However, I wanted to have a variety of families, not just those caring for orphans, in order to understand the range of children's lived experience in this poor setting. We therefore also walked through different parts of the settlement and chose homes where there were children's clothes on the washing line or children playing nearby. It soon became clear that very few families had not taken in orphaned children and after fifteen families had been interviewed, their lives seemed increasingly familiar. In all we interviewed twenty-five families.

2.5.2 Semi-structured interviews with families and other conversations

The main methodology was semi-structured interviews (appendix 1) with families and impromptu conversations with those we met in the community. These are described in the relevant chapters of the thesis. We carried out the interviews over several months as the research assistant had other work and I wanted to carry out other parts of my research (for example, key informant interviews and textual analysis of in-country documents) so that my understanding deepened before all the community work was completed. Each evening, I would transcribe the notes

from the in-depth interviews (appendix 2). Since I was using an interpreter, some meaning may have been lost, though I repeatedly asked her to speak in the first person and translate as precisely as possible. The process was slow, but respondents seemed to enjoy taking time to gather their thoughts and I was at least able to read the non-verbal cues. The interview always started with a demographic survey of all who lived in the household (appendices 5 and 6). I also completed an environment index for each home (appendices 4 and 9c). These data were used to help me gain a deeper understanding of the lived experience of the families, and I used the information to help conceptualise their livelihoods and kinship relations.

2.5.3 Analysing community data

Jackson (2001, p.202) laments the lack of transparency in the way qualitative data are collected and analysed: *'All too frequently, the actual process of interpretation remains opaque with vague references to key themes having simply "emerged" from the data.'* I suspect that this opaqueness may be due to word limits applied by publishers, as in the papers included in this thesis. A fuller explanation of my own methods of analysis follows.

Having transcribed my written notes under the relevant sections of the semi-structured interview guide, I then copied all the responses to a question on to one sheet. I was then in a position to start looking for common themes among participants. I used a preliminary list of codes for each of the major topics explored in the interviews. This coding scheme was revised and expanded as key issues emerged from a preliminary reading of the interview material (appendix 3). I was

then able to identify the main themes that emerged and use appropriate quotes to illustrate these. I often needed to refer back to the specific family to understand the response in context or to look for reasons for an unusual response. I also compared responses with the family trees that I constructed from the demographic data. I colour-coded these diagrams so that I could see at an instant the number of children in the household and their particular circumstances. For example, whether they had lost a mother, father or both parents; whether they were fostered or abandoned by their parents; whether they were attending any formal school, or Sebenta literacy classes. I constructed other diagrams, excel charts (samples are shown in appendix 9a, 9b, 9c) and graphs so that I could quickly retrieve data for each family and by using the environment index (appendix 4), I compiled a table to show other livelihood assets. This allowed me to compare data across all the families (appendix 9c). The repeated working of the data in this way helped keep the families very familiar to me and allowed me to notice points of similarity and difference between families. I did consider using a computer package for analysing text, but, given my use of an interpreter, I had already 'lost' some of the accuracy of the spoken word in translation and I felt my familiarity with the data and the way I could relate responses back to individual families was more useful to me. The Oxford University Computer Department was unable to suggest a way of portraying my complex colour-coded hand-drawn charts, so I continued to work from one 'fair' copy, though I could have compiled another from the raw data if necessary. In this way, I began to gain deeper insights into the lived experience of these families and, I hope, avoided 'cherry picking' quotes that were unrepresentative of my respondents (Jackson, 2001, p.202). I realise that another

researcher may have coded my data differently and drawn different insights, but I have tried to be transparent in presenting my own methods of analysis.

2.6 Field site two: Children in 'private spaces' away from adult carers

I have given a detailed description under the ethics section in this chapter as well as in papers three and four as to much of my methodology with children. I will merely elaborate on choice of field sites and the problems of gaining access to children in a setting suitable for this research.

2.6.1 Choice of field sites and the challenge of 'gatekeepers'

At the planning stage of my research I expected to be able to interview children in their family settings. I had underestimated the lack of privacy. Since I wanted to compare orphaned children's lives with those of other children living in a similar environment, I needed to be able to identify orphaned children. I realised the ethical dilemmas of singling out children who had been orphaned and had planned, in addition to the family setting, to meet with street children in Mbabane many of whom I expected to be orphaned. I also planned to meet children in orphanages where staff would be able to inform me of children's backgrounds and I would gain insights as to why care within the kin group had broken down. None of these plans materialised.

At the time I lived in Swaziland (1999-2002), street children were noticeable in Mbabane. When I returned in 2003 and 2004, I struggled to find a child living on the streets. Gcinile Buthelezi the Head of Public Health and Social Welfare at the Mbabane City Council explained during interview (15-1-04) that she

had managed to return nearly seventy children to their relatives and had an on-going project to help new arrivals.

Meanwhile, the letters I had written in advance to arrange a visit to an orphanage had not borne fruit. The orphanage I had previously known well was accepting only boys and only those from 'God fearing families.' I didn't want to limit my sample in this way, so tried two other large orphanages. The first was unwilling to allow me access after initially giving a positive response. The second orphanage seemed a more hopeful prospect. After meetings with the director I appeared to have been granted access. However, despite my repeated attempts, further meetings with those immediately in charge of the children were not kept. My research assistant advised me that, while she couldn't give an explanation, she was of the opinion that these 'gatekeepers' were never going to co-operate. I therefore had to devise a new strategy to meet with children.

While planning my research I had decided against accessing children through secondary schools. This was partly because of the research difficulties in such a setting, as already discussed, and also because the most vulnerable children were not likely to be attending secondary school. In the event, I decided to find schools with catchment areas in the informal settlements. My research assistant and another Swazi teacher friend, whose son I had helped in the past, facilitated my introduction to the formal education sector. I was able to use two government secondary schools with catchments in the informal settlements, and two government literacy centres ('Sebenta' centres), also sited in informal settlements, for children not in formal school. I still had the problem of differentiating orphaned children from other children. In the case of children in

school, I had to rely on this information being disclosed voluntarily, during data collection, which often happened. The children attending Sebenta literacy classes to enable them to catch up and return to formal school were all orphaned, as mentioned above, so this was not a problem.

2.6.2 Limitations of the data

My data from children are therefore compromised in a number of ways. I cannot match my child respondents with their adult carers and this would have given greater insight into inter-generational communication in relation to HIV/AIDS, orphan care and bereavement experiences. While some of the school-children participants were very poor, others came from formal housing areas and were therefore likely to have more secure livelihoods than the families interviewed in the informal settlements. I did not find a way to confirm this. Another limitation was that ethical considerations made the identification of orphaned children difficult in the school setting. I had to rely on children in school voluntarily revealing their orphan status through the spoken or written word. I could not just rely on the absence of a parental carer (as stated on the written accounts), since some Swazi children with parents alive, are placed with kin in a foster arrangement (as evident from the family interview data).

It is with these data limitations in mind that I have written papers three and four. However, by rapidly rethinking strategies to access children, the 'voice' and lived experience of children through their own 'lens' remained an integral part of my research.

2.7 Field site three: key informants in the community and in organisations

2.7.1 The space between words and actions

I have already described the identity adopted in relation to key informants. It is with key informants that I began to notice the importance of Smith's (2001, p.31) point that it is not enough to be concerned with how people speak about their world. What a person does in it, that is their performance, will give other valuable insights. I began to notice the tensions between certain key 'players' on the AIDS 'stage' in Swaziland. Whilst purporting in speech to be working in collaboration with each other, the actions of certain players contradicted this verbal message. This tension is described in papers two and five.

2.7.2 Accessing key informants

I did not receive many replies to letters sent from the U.K. prior to the research, but once in the field I began to access key informants and gain referrals to others. By stressing my professional research identity, I conducted in-depth interviews with thirty-three key informants across a wide range of organisations and departments (appendix 8a), most of whom were willing to be quoted. To ensure a meeting was secured, I always visited in person to make the arrangements as appointments by telephone often failed. There were occasions when I was let down several times, but by persisting politely I usually gained access eventually.

2.7.3 On the record and off the record data collection

Most interviews lasted about an hour and I usually asked to tape the conversation. However, I found that after bringing an interview to a close and with the tape

switched off, other interesting comments were made but I was asked not to quote directly. On some occasions I did not tape conversations, either because the person requested I did not or because I perceived such a request would be unwelcome. Immediately after each meeting, I noted other points and any leads I needed to follow up. I sometimes had follow up meetings either to gain further information or to give feedback on some of my findings so that my research was not merely an extractive, exploitative process. It was for this reason that I undertook participant observation and became part of the doing or performance and gained '*direct experience of social practices in action*' (Smith, 2001, p.31).

2.7.4 Participant observation, compromised identity?

UNICEF invited me to take part in the education working group helping to compile the Draft National Policy on Children, including orphans and vulnerable children. UNICEF was the driving force behind this initiative. My role led to meeting with other key personnel involved in policy making at national level. I began to understand the power relations between different agencies and the some of the political complexities of gaining statutory approval for such policies. These insights informed papers two and five in particular. I was not paid by UNICEF but had to consider whether, by taking part, my identity as an impartial researcher was being compromised. I seemed to be subtly crossing the insider/outsider identity border as described by Mohammed (2001). While I did not want to break the trust being placed in me as an 'insider' as my relationship with other 'performers' deepened, I wanted to represent the world I was researching as accurately and truthfully as possible. With each paper submitted, I have felt this tension as I have given

opinions and made judgements, often checking and rechecking the evidence on which these are based. It is analogous to Skelton's '*crisis of production in the "post-fieldwork" context*' (2001, p.95). As Smith (2001, p.28) notes, texts may not convey the meaning the author intended and '*they become open to contestation, to negotiation, to multiple readings.*'

2.7.5 Situated learning

My role as 'situated learner' was less problematic. Evans (2003) questions whether the very participation process obscures what is being studied. Rather than an active role (such as the education working group just described) she suggests that more in-depth understanding is achieved by 'situated learning' where the researcher tries to be incorporated into the respondents' lives more passively in order to understand what people are experiencing in their social situation. Evans urges researchers 'to suspend your certainty.' She notes the emerging new field where the emotional experience of doing research and the emotional transformation of both researcher and respondent is being recognised. In the light of her work, I incorporated some situated learning into my methodologies. One example is a visit to King Mswati's Kraal on 14th January 2003 when the King summoned the nation to the Kraal to hear whom he would choose to be the next Prime Minister (Figures 3 and 4 below).

In the ensuing chapters I make it clear that issues of gender and unequal power relations help drive the AIDS epidemic and are intimately linked with the lived experience of children's lives. I have already alluded to the difficulty of gaining statutory authority for the National Policy on Children. I consider the lack

of democracy in Swaziland and the patriarchal society headed by a King who has twelve wives, to be another driver of the unequal power relations that impact on women and children's lives in particular. I decided to suspend my certainty and try to understand the role of the monarchy a little more by attending this occasion.



Figure 3: Swazis, many in national dress, gathering at the King's Kraal for the pronouncement of King Mswati's choice of Prime Minister.



Figure 4
A tradition of gendered lives: police guide female spectators at the women's entrance to the King's Kraal. On the other side of the pallistrade the women sit on one side of the arena and men on the other.

I attended other public meetings and workshops of various agencies in my situated learner role to help gain a fuller understanding of the society in which I, along with the Swazi children and their families represented in the following pages, was immersed.

2.7.6 Textual sources

The final methodology used involved a careful reading of numerous in-country documents produced by the many organisations working with children in the context of HIV/AIDS. Silverman (2000) argues that texts need to be analysed in terms of who wrote them, for what purposes and for what audience. I used texts to understand the agenda, resources and working partnerships as well as to widen

my knowledge of the broader aspects of the AIDS epidemic in the country and the role of respective key players in combating it.

2.8 Conclusion

This chapter has elaborated on the methodologies described in each of the following five papers that make up the main part of this thesis. These methodologies were designed to suit a wide variety of people in heterogeneous spaces: people who ranged from government ministers, heads of UN organisations to very poor orphaned children and spaces that ranged from families in small wattle and daub huts to national level committee meetings and to virtual spaces where Swazi children connect with 'northern' culture. It has also covered some of the challenges of working in this cross-cultural environment and the limitations these posed for data collection. It has set the scene for the qualified knowledge claims made in the ensuing chapters.

Although this thesis is made up of papers rather than the traditional book approach, the papers all adhere to the central research question posed for this thesis and therefore form a coherent whole. In the chapters that follow I have used the methods described in this chapter to unravel that world a little and suggest the opportunities and constraints there are for scaling up interventions to improve the lives of children affected by the AIDS epidemic. In the next chapter, I start from the perspective of the adults caring for vulnerable children.

3. CHAPTER 3: Child-Care in Poor Urban Settlements in Swaziland in an Era of HIV/AIDS

3.1 Introduction

'I take an orphan to be a child who has no relatives. In Swazi culture any child who has a relative is not an orphan. This is why we don't have orphans in Swaziland,' explained a grandmother carer interviewed in this research. Although the numbers of orphans is increasing rapidly in sub-Saharan Africa, the targeting of resources to assist orphans is hampered by the incomplete understanding of cultural constructions of orphanhood and the care-giving arrangements that occur in families and communities as well as by the lack of accurate numerical data. In compiling their joint report, UNAIDS, UNICEF & USAID (2004) use mathematical models to estimate orphan numbers and to separate out orphans who have lost parents due to AIDS. Caveats are included as to the accuracy of these estimates, given that they are based on less-than-perfect demographic and epidemiological data (p.34). In the 2004 report, children under eighteen years-of-age rather than under fifteen have been included for the first time, in line with international definitions of childhood. The report suggests that 12% of children in the sub-continent have been orphaned. This gives a total figure of 43.4 million orphans in sub-Saharan Africa, of whom it is estimated that 28% or 12.3 million are orphaned because of AIDS.

This paper aims firstly to explore the Swazi cultural construction of fosterage and secondly assess the changing child-care role of poor urban families in an AIDS epidemic where HIV/AIDS prevalence in 2002 reached 38.6% in the

CHAPTER 3: Child-Care in Poor Urban Settlement in Swaziland in an Era of HIV/AIDS

adult population, the highest rate in the world (Ministry of Health and Social Welfare, Swaziland, 2002). Using qualitative methods in areas of informal urban housing in the capital Mbabane, the field work examines child-care arrangements in twenty-five families and includes children orphaned by AIDS or other causes (crisis fostering), children fostered under more traditional kinship arrangements (parents alive), as well as children living with a biological parent(s). A more nuanced understanding of family child-care arrangements is needed to help target resources to the most vulnerable children within families. The paper illustrates that the 'northern' way of looking at orphanhood is too simple and in reality does not work. The fieldwork illustrates the dynamic nature of the Swazi family. In particular, the emergence of unmarried mothers remaining within the matrilineal extended family and the diminishing role of patrilineal kin in the care of orphaned children. There was little evidence of children living entirely alone without an adult care-giver and most orphans were being looked after within kinship groups alongside other children. It is argued that any intervention should therefore target the most vulnerable children as identified by the community, rather than singling out orphaned children as a separate category. Finally, the paper ends with some policy recommendations.

Research into the social, cultural, economic and political situation of orphaned children in particular, is still relatively embryonic (Madhavan, 2004). Building on the valuable work of studies of orphan care and fosterage patterns in sub-Saharan Africa (Goody 1973, 1975; Isiugo-Abanihe, 1985; Castle, 1995; Suda, 1997), there has been intensive interest in the role of the extended family in caring for orphans in an AIDS epidemic (Ankrah 1993; Foster *et al.*, 1995; Aspass

1999; Foster, 2001; Nyambedha *et al.*, 2003). The debate has centred on whether the extended family or other unrelated carers is a robust enough network to act as the focus of initiatives aimed at community-based support for children orphaned by AIDS, and, if it is, what form such initiatives should take.

The African extended family is clearly dynamic, evolving and used to responding to change, as Bryceson (2000) shows, in a wider context, in her work on social change in rural families in seven African countries (Nigeria, Ethiopia, Tanzania, Congo-Brazzaville, Malawi, Zimbabwe and South Africa):

'There are four major tendencies evident in the current social restructuring, namely: resort to incomplete family units i.e. locational separation of the reproductive couple for the sake of income-earning; reduction in the size of large extended families in the direction of nuclearisation; weakening of dependency ties on gender and age lines within family units; and women's efforts to use matrilineal ties to further their material security'

(Bryceson, 2000, p.3)

Madhavan (2004) suggest that support networks are perhaps changing rather than breaking down and that non-kin are perhaps increasingly seen as sources of support. He warns that without an understanding of the social context of families targeted for help, external forms of intervention may be wasteful of resources and even exacerbate conflicts within the community to the further detriment of children's well being.

3.1.1 Ambiguity of terms used in the AIDS literature

One of the problems in the AIDS literature is the definition of such terms as: community-based care, fostering, orphan. Community-based care is an

ambiguous term with a variety of meanings (e.g. care in the community, care by the community) as Ansell and Young (2004) found in Lesotho and Malawi. They suggested policy responses should target households rather than assuming an *'identifiable static community to which orphaned children and their guardians belong,'* (p.4) as, *'in practice communities were found to have minimal involvement in caring for in-coming children,'* (p.6).

The term fostering is also ambiguous. In some cases it is used to mean the relocation of children away from the natal home for a period of time such as for educational advantage or domestic service, thus increasing family ties. This type of fostering is referred to as traditional fostering in this paper. In other cases, the child may have lost contact with the parents due to armed conflict, fleeing as a refugee or the parents may have died. The latter type of fostering, common in an AIDS epidemic, may be termed crisis fostering and it is not new to the African family (Isuigo-Abanihe, 1985; Aspass, 1999; Tolfree 2003).

Aspass (1999) refers to the wide body of literature on culturally-sanctioned fostering in sub-Saharan Africa. This fostering often involved reciprocity between the natal family and the foster family and strengthened family ties. However, as Aspass notes, fostering in an AIDS epidemic is more akin to the less common *'crisis fostering'* described by Isuigo-Abanihe as *'child relocation resulting from the dissolution of the family of origin through divorce, separation, or death of a spouse'* (Isuigo-Abanihe, 1985, p.57). Akresh (2003) has worked more recently on fostering arrangements in Burkina Faso and tested the assumption that the decision to send a child to another household should influence the decision to receive a child in an equal and opposite way, and while he found rational

CHAPTER 3: Child-Care in Poor Urban Settlement in Swaziland in an Era of HIV/AIDS

economic reasons for sending a child to another household, the household receiving the child did not necessarily benefit. Akresh concluded there was a need for a richer model that incorporates altruism in fostering arrangements, and, indeed, this is pertinent for some families in Mbabane. Given the lack of reciprocity involved in crisis-fostering, this fieldwork in Swaziland examines some of the reasons, such as a sense of kinship duty, for undertaking the long term care of children orphaned in an AIDS epidemic.

The term orphan is also problematic and has different meanings in different contexts and again the author questions the rationale of targeting resources for one category of children. Although UNAIDS, UNICEF & USAID (2004) have now adopted international definitions of childhood and included children under eighteen years-of-age, rather than under fifteen, in their estimate of orphan numbers, the social construction of the word orphan within families and communities is less clear or may be misused for perceived personal gain. For example, Carr-Hill *et al.*, (2002) have noted the challenges of keeping accurate records of orphans in Tanzania, and suggest that data on the extent of orphanhood will remain difficult to determine in many countries. Enumerators were found to confuse orphans with foster children, that is, children who live away from their biological families with other members of their family and double-counting sometimes occurred when children moved from place to place. Further problems arose with the term orphan because of particular connotations with the AIDS epidemic. They noted: under-reporting of orphans due to stigma associated with the cause of death of parents, fear by ailing grandparents that children may be

removed from them; and over-reporting of orphans in order to receive more material help.

3.1.2 Inclusion or exclusion of 'other children

Apart from the above discussion on ambiguity of terms used to describe categories of children, there are problems associated with singling out orphans to the exclusion of other vulnerable children. This paper therefore focuses on all children cared for by family respondents, not just those orphaned by AIDS. Children whose parents have died from AIDS may be constructed by demographers as a separate category, but, in reality, they live alongside other children within families. Furthermore, while orphans due to AIDS have specific needs and make up the majority of orphan numbers in countries with high prevalence levels of the disease, there are the remaining orphans to be considered. In addition extremely poor children with parents alive must not be forgotten. They are also affected by the epidemic as orphaned children join their households when relatives die and meagre resources are shared between more children. How is greater synergy to be achieved between those wishing to improve the lives of children made vulnerable by the AIDS epidemic? It seems unlikely that a piecemeal approach to certain categories of children is likely to succeed. However, some authors disagree with this argument.

Case argues *'policies that are aimed at reducing the bias against orphans should operate by reducing the price of investments in orphans relative to non-orphans, for example, through educational subsidies or non-transferable vouchers for schooling that are earmarked for orphans'* (Case, 2004, p.481). However,

specific targeting of orphans, rather than more general poverty alleviation measures, may not produce the gains she envisages. For example, the household-level under-reporting and over-reporting of orphans, and the serious problems this causes for the provision of education, are well documented (Carr-Hill *et al.*, 2002). In addition, the absence of accurate records, including birth certificates (UNICEF 2003, p.41), to establish a child's parentage and orphan status are tangible problems, but there are also intangible difficulties such as the social and cultural perceptions of interventions that favour some children over others. Williamson & Donohue (2001) noted that in Malawi some communities were coming to see orphans as a privileged group and resented this because it undermined extended family mechanisms. Meintjes, Budlender, Giese, & Johnson (2003), researching child-care in South Africa, also argue against treating orphans as a separate category of children for similar reasons.

3.1.3 Identifying stress in extended family care-giving

There is much agreement in the literature that family care is more appropriate and cost-effective than institutional care (UNAIDS, UNICEF & USAID 2002; Dunn, Jareg & Webb, 2003) and that close relatives are preferable. Case states: '*our finding that investments are higher among orphans who are cared for by closer relatives may suggest that policies that are aimed at keeping orphans with close kin may be beneficial*' (2004, p.481). Although this is not possible for every orphan for reasons beyond the scope of this paper, it is argued here that policies must be designed to strengthen current caring networks at household level in a culturally sensitive way that does not separate orphans from other needy children. Some

CHAPTER 3: Child-Care in Poor Urban Settlement in Swaziland in an Era of HIV/AIDS

authors question whether in areas of very high HIV/AIDS prevalence such as Swaziland, the kinship group is still robust enough to absorb further orphans. They cite child-headed households and increasing numbers of street children as indicators of an extended family system which is close to breakdown. Again, these assumptions require further contextual analysis.

Masmas *et al.*, (2003) refer to how Foster *et al.*, (1995), consider that where siblings are caretakers of orphans in Zimbabwe it is an indicator of stress in the extended family. However, in Masmas *et al.*'s study in Guinea-Bissau, five percent of orphans lived in the care of a sibling but in all cases this was a much older adult sibling. They suggest that the age of the sibling caretaker should be taken into account before assuming it is an indicator of stress in the extended family. Such simple definitions do not take into account the social setting, such as the presence or absence of close support of other family members and neighbours, the age and gender of the children or access to food, education and income, when assessing the vulnerability of this type of family unit.

Some authors suggest that as families become overwhelmed by AIDS-related deaths and impoverishment, children will no longer be absorbed within the kinship group and that some may become street children who lack the skills to fit productively into society (Barnett & Whiteside, 2002, p.211). Cornia (2002) refers to children whose parents are so impoverished by AIDS that they abandon them: '*And in Swaziland, the number of social orphans now exceeds that of natural orphans*' (p.12). Given that there are no really accurate figures for the number of orphans in Swaziland (only estimates from mathematical models), it is difficult to comprehend this assumption about '*social orphans*' in Swaziland. Bray (2003) has

warned about describing very vulnerable children as a threat to society without basing such descriptions on empirical evidence.

Apart from the confusion and ambiguity caused by categorising children into specific groups whether as social orphans, street children, child-headed households, it masks the reality of the much more complex lives of children and does not help target resources effectively.

The need for a more nuanced contextual understanding of child-care arrangements in different spatial settings is also apparent. This small study in a poor Swazi urban settlement does not claim to reflect child-care arrangements in other settings, such as the rural areas of Swaziland. In contrast to village communities, the spatial delimitation of what constitutes *'community'* is less clear in informal settlements, and developing community-based HIV/AIDS responses needs more co-ordination and structure. Kelly refers to the lack of a sense of community in informal settlements: *'such communities often represent new social formations with little shared history and few previous ties,'* (Kelly, 2004, p.10). This fieldwork supports these findings and those of Campbell (2003) who notes the difficulty of creating a cohesive vision at community level where social connections and obligations are not necessarily confined within a local geographical space.

Frayne (2004) notes the importance of urban-rural linkages for food supply to the urban poor in Windhoek as intra-urban sources of food between non-kin were not well developed. He therefore found that the most vulnerable urban families were those with limited employment and with weakest links to rural areas. In the main, Frayne's findings are echoed here. Given that rural-urban migration continues apace in sub-Saharan Africa and that the number of orphans is

predicted to increase even after the epidemic peaks (Cornia, 2002, p11), there is a need for a greater understanding of how poor urban families care for children where AIDS is prevalent.

The fieldwork is presented in three sections in the remainder of the paper:

1. The research setting and the methodology used.
2. Cultural constructions of orphanhood.
3. Kinship relations and changes in family forms: the impact on child-care arrangements for orphaned children, traditionally fostered children and those living with their biological parent(s).

3.2 Research setting

Swaziland has strong cultural traditions centred on the monarchy. Often referred to as the 'peaceful Kingdom of Swaziland,' it has not been divided by ethnic rivalries due to the relatively homogenous nature of the population. The extended family network has not been affected by war (whether internal or external), chronic poverty to the point of mass starvation (Swaziland ranks 137th in the 2004 United Nations Human Development Report), or apartheid policies and the like, as in some other African countries. In such a setting, the extended family might be expected to be a strong feature of family life. However, in other respects there are similarities with other kinship groups in sub-Saharan Africa, and the forces of modernity referred to above have not left the Swazi family unscathed. Rural-to-urban migration in search of waged labour has led to the rapid growth of the main towns, especially the capital city, Mbabane, and the industrial town of Manzini.

CHAPTER 3: Child-Care in Poor Urban Settlement in Swaziland in an Era of HIV/AIDS

The patriarchal society and lower status of women and children in Swaziland has resonance with many other sub-Saharan African countries (Barnett, 1995; Momsen, 2004). The rights of women and children are an interwoven thread running through the AIDS epidemic and their gendered position inevitably impacts on their ability to provide care for orphans. In Swaziland, a woman is currently worth about fifteen Nguni cattle in a traditional marriage where lobola (bride price) is paid. She may not open a bank account in her own name, and is considered a minor in Swazi law. Security of land tenure is therefore difficult to achieve, though attempts to change this have been made in some of the informal settlements of Mbabane where this study took place. Even securing ownership of household possessions on the death of a husband is not guaranteed, as some of the women in this study explained.

The study area was selected with the aim of capturing the voices of the urban poor where the *'forces of modernity'* mentioned above might have had more impact on weakening kinship ties-in comparison with the rural areas, and where migrant family units might be expected to be smaller, with fewer members to absorb increasing numbers of orphans. In Swaziland, rural areas have 82% of the 'core poor' and over 70% of the population live in the rural areas (World Bank, 2000). Given these statistics it is perhaps not surprising that most of the agencies involved with poverty alleviation and care of orphaned and vulnerable children in Swaziland have concentrated on the rural areas. However, the Gini index in urban areas is 0.55 compared with 0.46 in rural areas, indicating that incomes are more unequally distributed in urban areas. In fact rural-urban income differentials are negligible for the poorest 18%, and both rural and urban poor have similar

CHAPTER 3: Child-Care in Poor Urban Settlement in Swaziland in an Era of HIV/AIDS

consumption levels (UNDP, 2001, p.57). With some exceptions, the 18% of 'core poor' in urban areas tend to remain marginalized, and, ironically, unable to access services despite their physical proximity within the city.

The AIDS epidemic in Swaziland is more evenly distributed spatially than poverty although this varies with different age cohorts. In 2002 the overall HIV prevalence rate reached 40.6% in urban areas compared with 35.9% in rural areas. Prevalence has risen sharply in the 15 to 19 years age group in urban areas, reaching 34.9% but it has levelled off at 28.1% in this age cohort in rural areas. The highest level is 54% for the 25 to 29 years age cohort in urban areas compared with a rate of 41.9% in rural areas (Ministry of Health and Social Welfare, 2002). Situated in the informal settlements of Mbabane, this study is therefore set in the context of an HIV epidemic that is continuing to increase to very high levels, especially among urban youth and among those of an age to be parents. In the absence of accurate orphan numbers and with only just over 50% of births registered in Swaziland (UNICEF 2003, p41), mathematical models indicate that 18% of children under 18 years-old were orphans in 2003. Of these, 63% had become orphans due to AIDS (UNAIDS *et al.*, 2004). It is assumed that 30% of these children live in the urban areas, reflecting the general census figures on population distribution (National Emergency Response Committee on HIV/AIDS, 2003, p.7).

The small capital city of Mbabane has a population of over 58,000 and about 60% of the housing stock is in informal settlements that cover 21% of all

residential land (City Council of Mbabane, 1997)¹. According to the Structure Plan, the overcrowded conditions of housing stock in the informal settlements are exacerbated by the poor quality of infrastructural services. Only 18% of households have access to tap water on their plot, 15% have access to electricity, 16% to rubbish removal and 70% of houses are constructed of stick and mud. The physical environment of the study area broadly reflected the findings of the Mbabane Structure Plan for informal settlements. There were no tarmac roads to access the areas, no street lighting or surface drainage. After heavy rain in summer, even the wider tracks became inaccessible by vehicle as the land is steep and soon developed ruts in heavy run-off. About half the plots were large enough for cultivation of some crops, and some small livestock was kept. Avocado trees, useful for cash income, grew on some plots (Figures 5 and 6, page 100)

3.3 Methodology

The author worked as a teacher² in a secondary school in Mbabane from 1999-2002 but to help overcome the limitations of the author's position as a white European outsider, a locally recruited Swazi female research assistant³ advised on culturally sensitive issues and helped with family interviews. The skill and

¹ Some of the informal housing has been incorporated into an urban upgrading scheme as part of a joint project between the Swazi Government and the World Bank. This scheme gives security of tenure including to women, through 99-year leases. However, the scheme has, for the moment, lost its momentum and is behind schedule. The majority of inhabitants of informal settlements continue to lack the necessary security of tenure for financial institutions to be willing to extend loans, which, in turn, could be used to improve the low quality housing.

² Whilst working as a teacher in Swaziland, the author helped design and introduce an HIV/AIDS policy for the whole school community where the author was employed. Apart from specifically education-based aspects, the initiative acted as a springboard for many other intertwined community activities. Relationships were formed with families caring for very sick relatives and with children who became orphaned. Some of these families with whom the author remains in contact, were invaluable in providing an entry point to some of the respondents in this study.

³ The research assistant was a graduate with counselling experience. Where possible, families found to be in particular difficulties were given help

involvement of the Swazi research assistant is fully and gratefully acknowledged. While it was probably unhelpful to be a white European, especially with only conversational SiSwati, it was helpful that the author had known some members of the community for several years and at a time when their family members had become ill and died of AIDS. Being a doctoral student and older woman with children, perhaps helped some respondents see the author in more neutral, detached terms as a sympathetic but external observer. The research took place over five months between September 2003 and January 2004 with a short follow up visit in November 2004.

The study population included a wide variety of people who either lived and/or worked in the informal settlements of Mbabane. Informal in-depth interviews were undertaken with twenty-five families each of whom cared for children. Ankrah (1993) refers to a variety of definitions of the African family; in this study it was defined as a kin-based group who lived in a dwelling(s) occupying a single compound and who recognised a common family head. Using a variety of entry points, purposive sampling was used to select families caring for children (whether orphaned, fostered or indigenous) with the aim of gaining a deeper understanding of child-care practices occurring in the informal settlement. The Swazi female research assistant took the lead role and acted as interpreter. Respondents were encouraged to speak in either siSwati or English, whichever they preferred. The author took notes as it was considered culturally inappropriate and alienating as well as impractical to use a tape recorder in this very poor setting.

CHAPTER 3: Child-Care in Poor Urban Settlement in Swaziland in an Era of HIV/AIDS

Where possible, the head of the family was interviewed, sometimes with the help of other adult family members. Most heads of family were elderly women. Family participants were assured of confidentiality and they gave verbal informed consent. To begin with, the assistant made a note of demographic data and kin relationships of family members (age, gender, relationship to head of the family, whereabouts of parents of children in their care, years of residency, rural kin connections, adults in employment). A note was also made of kin temporarily away, for example, working away and returning at weekends or those who were ill in hospital. Meanwhile, the author carried out a simple environment index by discrete observation (wall and roof condition, building materials, access to utilities, furnishings, plot size and garden crops grown, and other observations such as brewing beer) and data was recorded immediately after leaving each family.

An open-ended interview guide was used on the themes of: extended family relations and support given and received; child-care practices for the children in their care; vulnerabilities and coping strategies. The author used body language cues to decide whether or not to explore themes more fully or to develop new themes that arose during the interviews. Interviews lasted about an hour. Some family members spoke informally on other occasions at chance meetings, as the fieldwork occurred over several months. Participants seemed eager to have their voice heard. After fifteen families had taken part, respondents' constructions of their lives became increasingly familiar as they repeated similar concerns and experiences. Two families were in sufficiently difficult circumstances as to require immediate help. This help was arranged but it highlights the difficulties of research

in very poor settings⁴. The data from the family interviews were grouped by theme and, using direct quotes from the urban poor, the main issues, which emerged, are presented in the remainder of the paper

Further insights were gleaned from other sources; a focus group discussion with social workers assisting poor urban families as part of a non-government- organisation out-reach programme; child-care documents and reports produced by Mbabane City Council and non-government-organisations; in-depth interviews with a variety of key informants (such as: community leaders⁵, religious elders, teachers, staff of non-government-organisations caring for children, Mbabane City Council and Swazi Government officials).

3.4 Research Findings

3.4.1 Cultural constructions of orphanhood

It was clear from the fieldwork that there was incongruence between '*global*' (i.e. international development organisations) and '*local*' notions of orphanhood. Yet, without accurate census data on orphan numbers, household surveys are used to establish orphan numbers, or community members may be asked to help identify orphaned children. In either case, cultural constructions of orphanhood are likely to yield different and possibly unreliable results from those expected.

⁴ One entry point for the survey was through a church group. A close Swazi friend introduced the author to the all black congregation. She described me as a woman who had experienced both death and childhood illness in my own family. She said that as a (doctoral) student, I did not have access to funds but I would faithfully tell their story to the outside world. No family respondent asked me for money during the fieldwork despite my white western appearance.

⁵ A community leader (Zone Leader) is elected for each informal settlement of Mbabane and supported by an elected committee. However, respondents did not consider the Zone Leader and his committee to command the same level of authority and respect as a Chief in rural areas. The chieftom system and traditional structures remain in rural areas.

One male grandfather respondent explained: *'in our culture there is no orphan. We have been brought up to believe that we should help each other. If I see a child who is hungry, I must give the child food. It is the zone leader or chief who should ensure this.'* A female grandmother echoed these sentiments: *'I take an orphan to be a child who has no relatives. In Swazi culture any child who has a relative is not an orphan. That is why we don't have orphans in Swaziland'* (family 6). For most of those interviewed, if a child was inadequately cared for then it was considered an orphan whether the parents were alive or not. One great-grandmother described three types of orphan: *'there are different types of orphan. There are orphans where the parents are dead, orphans where the parents have abandoned them, and orphans where the parents can't afford to care for them'* (family 10). How children were cared for was the prime consideration, not the presence or absence of a parent, when deciding if the child was an orphan. For example, as this Swazi great-grandmother, who was caring for four orphans but was relatively well-supported by her own children, explained:

'A needy child is a needy child. They shouldn't just look at if the parents are alive. How would you separate her children (referring to her neighbour whose own children were not in school) from these here who are in school?'

(Family 5)

Once more at local level, the practical difficulties are apparent of singling out orphans and excluding other vulnerable children identified by the community.

3.4.2 Perceptions of the extended family, urban-rural linkages and constructions of 'home.'

When discussing links with kin living elsewhere most respondents considered their family ties to be strong and this extended to child-care support with some children moving between urban and rural family members for periods of time. Exchange in the form of money, goods, labour and emotional support as described by this 70 year-old urban grandmother occurred in some families:

'We do have strong family ties. My brother who works in Manzini and my son support me. They give me food and money. I know I can count on them. I do the same for my family where I can. If there is a death they know I will go and help with the funeral arrangements.'

(Family 6)

However not all families were able to support each other financially. Only five families described reciprocal money arrangements with extended family members living elsewhere who both gave and received money. It was more common for the urban families to be giving money to their kin in the rural areas without any financial reciprocity in return (ten families). However, rural kin did supply food for some families: *'I do go to my maternal home and get maize if the crop has been good'* (Grandmother, family 8).

Some urban plots where the families lived were large enough to grow some food and for these families rural food remittances were not therefore important (Figure 5). Other families, particularly more recent arrivals who tended to rent their plot off another family, lacked the space for food cultivation and were more vulnerable in times of hardship (Figure 6)



Figure 5: A well-established homestead with livestock and vegetable plot in a Mbabane informal settlement



Figure 6: Heterogeneous housing within the informal settlements of Mbabane. Some housing was of brick construction with sanitation and electricity, as in the foreground. Other housing was constructed of mud and wattle and lacked services or vegetable plots.

Rural kin also helped with child rearing: *'I got pregnant at school so my daughter was living with my mother and she is now in school so when I came here looking for work, I left my daughter back home.'* (Mother, family 15) *'Our four children are looked after by Gogo⁶. It is easier as we are both working and it is free with Gogo. We provide everything for the children'* (family 1). The poorest families were unable to offer material support to their kin: *'we help each other in times of need but we don't have much'* (family 14). Four families said they no longer had links with kin living elsewhere as they had migrated to Mbabane over 30 years ago. Thus twenty-one of the families were linked in some way to other kin living outside the informal settlement. This linkage was expressed by exchanges of money, food, clothing, care of children, and help with funeral arrangements although flows were not necessarily equal in both directions. The poorest families were limited to providing emotional support only, and no material help was exchanged. In some cases, links with paternal kin had withered altogether, and there was evidence of women relying more on maternal family.

The pattern of migration and link with rural kin impacted on their sense of belonging in the informal settlement. One of the notable features of this, and perhaps other urban informal settlements beyond Swaziland, is respondents' varied perception and attachment to their home in the informal settlement. As Massey (1991) has argued, a sense of place is composed of a set of real or imagined social relationships rather than a bounded conception of local. Given the years of residency of some families, the common thread of similar economic circumstances, the close physical proximity of neighbours, the daily contact

⁶ Gogo means grandmother in siSwati.

brought about by footpath access, a strong sense of locality and community might be expected to have superseded the importance of links with rural kin. Families who had strong ties with relatives back in the rural area continued to view the latter as home and the urban existence, even after twenty-five years, as a temporary necessity:

'I will never see this as home. Helping each other as a community doesn't happen here. We only have a zone leader, not a chief. It happens more in the rural area as opposed to here where we have to buy everything. We are busy working and there is no time. I don't think the Zone Leader is effective because we all have our original homes to go to. The infrastructure isn't there for the Zone Leader to carry out his task. The community in general doesn't support him.'

(Grandfather, resident since 1978)

At the other extreme, were several respondents who no longer had family in rural areas and to them the informal settlement was home. A third group no longer had kin in the rural area but were reluctant to identify with a permanent existence in the informal settlement:

'People don't think of it as home. It was somewhere we came to work but our parents are dead now so we don't really have roots back home. There is a mixture of those who see it as home and those who don't. We all mix though and people respect the Zone Leader.'

(Female, resident since 1983)

This disparate perception of 'place' and 'community leader' is indicative of the heterogeneity of the social worlds occupied by the families and the weak sense of community felt by some. One woman community volunteer described the response to a community road improvement, which the Zone Leader had initiated:

'We worked on the road but only a few turned up. They don't seem to care. They will use what you do but won't help you do it. Perhaps the funerals at weekends are taking their toll. We have to travel back to the rural areas.'

(Family 25)

At the time of the fieldwork child-care remained within kinship groups and involvement at community leadership level was relatively embryonic. As the epidemic continues some urban children may eventually have no kin support but establishing sustainable community-based orphan-care may need a different approach to that in rural areas in such a setting of complex and spatially distant social obligations.

3.4.3 Changes in the Swazi extended family and the gendered nature of child-care

Swazi clan and lineage is through the male line only. Although legally bound to the to the patri-kin, children are emotionally close to the *'mother who bore me,'* (Kuper, 1986).

Traditionally, the man pays bride price or lobola to the woman's family on marriage and the woman goes to live with the patrilineal kin. Kuper stresses the dominance of the father's authority over his children as someone to be both feared and respected (p.28).

In traditional Swazi custom, the wife is expected to remain with the husband's family even if her husband dies. The in-depth interviews indicated that customs were changing and that many different forms of family were emerging. In particular, the presence of young women who bore children out of wedlock, by

more than one male, and who did not live with patrilineal kin. Christiansen (2005) refers to a similar fluidity of family forms in Uganda and the subsequent emergence of children born of unstable unions. In Swaziland, as in Uganda, women were strengthening ties with matrilineal kin as a survival strategy. One grandmother summed up the situation:

'In Swazi culture a wife is a wife. They should stay in their in-laws' home until they die: but now they are often not married and therefore not entitled to remain with their in-laws after death.'

(Family 6)

Women often described themselves as *'abandoned'* by the father of their child and had not entered either customary or civil marriage. There were two families where children were cared for by young unmarried women living on their own without help from paternal kin: *'there is no link with my boyfriend's family as we didn't marry. He isn't helping since we split up'* (family 24). The second mother had two children by different fathers and had not married: *'the father of my first child died and the second abandoned me. I've never really been part of their families'* (family 15). Nine unmarried mothers caring for fourteen children all of whom had fathers alive, had remained living within the maternal family without any support from the fathers. According to the 1997 Swaziland Population and Housing census, the percentage of persons over 15 years of age who had ever married was 38.6% and 75% married according to Swazi Law and Custom (unfortunately there are no comparable data from the previous census, but the decline in marriage was commented on by both families and key informants).

Another change in traditional practices occurred where women who had entered a customary marriage and moved to live with paternal kin, returned to the

maternal side after their husband's death. Paternal kin cared for only two of the 23 paternal orphans living in the 25 families. Even the mother of these two children had returned to her maternal family. During a visit to one family, a bereaved woman was just returning with her children to live with her maternal kin. She explained that her husband's family had agreed to this now that a mourning period of a month had passed. Some married women said that they were not '*well treated*' by their paternal kin once their husband had died and preferred the support of their own maternal kin. One woman described how her paternal relatives took everything on the death of her husband. Women were still tending to marry according to Swazi law and custom, which gives wide-ranging marital power over land and property to the husband and his family. A civil marriage that protects the rights of women is possible, but involves undertaking an ante-nuptial contract prior to marriage (Thwala & Dlamina, 2003, p.34). From the women interviewed, it appeared that the obstacles to undertaking a civil marriage '*out of community of property*' which would afford protection to the woman and hence her children, are more complex than just lack of knowledge of the existence of such a law. One unmarried woman explained:

' Women are aware of the need to marry out of community of property but it's viewed negatively, as if the marriage won't work if this is entered into. Because I'm a Christian, I don't think this is a good idea. You should have trust.'

(Family 25)

It would seem that women in this setting have religious, cultural and social constraints that restrict the negotiation of their marital position. Their inheritance, however meagre it might be, and that of their children, remains unprotected. Given

the dominance of maternal family care of orphans, this further exacerbates their vulnerability.

The number of unmarried mothers remaining with maternal kin, the increase in the numbers of women returning to their maternal home on the death of the husband, the presence of some young mothers choosing to head up households alone, and unmarried couples living together, are all signs in this community of change in traditional, culturally sanctioned kinship relations. The specific role of AIDS in these processes in comparison with other factors such as the growth in the search of waged labour by both genders and exposure to other cultural norms is less easy to unravel. One great-grandmother summed up the effect of waged labour on family ties:

'We all used to live in one homestead and farm but now we all work and are more tied so just have less time (i.e. for helping each other). It's not necessarily weaker ties. We work to change our lifestyles. I prefer the olden times because everything was accessible. We all helped each other. Now everyone has to pay for everything. For me to be able to cook I have to buy firewood and I have to rely on my children to buy it for me.'

(Family 5)

The Zone Leader for this community of about 500 households described the strength of the extended family, the poverty in which some families live, and the stigma that still surrounds AIDS:

'The extended family is still strong even though many of the young have died and many children are with elderly carers. Some do not even have a pension! There is a pension for the poor elderly but it is not enough to buy mealie meal let alone pay for school fees. I think people are still marrying. Lobola is still happening. It's about ten to twelve cows but it's usually a compromise between the two families.'

Because of AIDS, we are trying to stop Kungenwa (levirate)⁷. AIDS is still a stigma. Nobody mentions it even though when you visit someone who is sick you know what it is. AIDS is still associated with prostitutes and sinful so how can you say to your wife you are positive? She will immediately ask 'how is this?' We don't have an AIDS committee in the zone but we should have one and we don't have a list of all the orphans but we need one.'

(Interview)

Changing kinship relations, more fluid family structures and child-care arrangements are thus emerging, but cultural perceptions of the extended family and the gendered position of women seem to be changing more slowly. Momsen (2004 p.66) notes that *'activities carried out to maintain and care for family members are generally ignored in national accounts, but they are essential economic functions which ensure the development and preservation of human capital for the household and the nation.'* This work of social reproduction falls mainly on women in Swaziland and yet AIDS has had a seriously debilitating affect on some of the families, particularly those that no longer have many younger adults healthy enough to do paid work. In such families, female carers are surviving by such activities as tending small gardens, providing child day-care for other working women, making mats from plastic rubbish or dried grass, brewing beer, selling avocados, or taking in washing.

⁷ Levirate: At the end of the mourning period a Swazi widow may be provided with a substitute husband chosen by her in-laws. The levirate's duty is to exercise control over her and to ensure the widow bears children on her late husband's behalf.



Figure 7

Girl weaving a mat from dried grasses

AIDS has brought extra pressures to these homes both in terms of loss of income (cost of medicine for the sick, cost of funerals, loss of waged income) and increased domestic duties (care of orphaned children, hospital visiting, nursing of the physically and mentally sick, funeral preparations). This extra burden of caring duties has fallen heavily on women. It is as if women, even very elderly women, are expected to have an elastic capacity to undertake more and more unpaid work. Unemployed men did not appear to be engaging with the extra work caused by the epidemic. Perhaps because of the patriarchal nature of Swazi society, there does not seem to have been any restructuring of culturally determined gender roles. The male Zone Leader of this informal settlement explained:

'The men are lazy. If I took you there now you would see men sitting around. They are lazy. Maybe we need a doctor who can cure laziness! These men will not help grow the vegetables they want to have with their porridge but they will expect it when they come to eat. I don't know why they are lazy. Even in the rural areas it is always the women who tend the gardens.'

(Interview, 11.11.03)

Whilst community-based initiatives to support orphaned children are widely supported in the literature (Drew, Makufa & Foster, 1998) as well as by most

donor agencies, it is often assumed that women will take on these duties in addition to their household level commitments, yet this really is unlikely to be sustainable in the long term.

There was a limited amount of non-kin assistance to families but it did not reach all those in need, it was uncoordinated, it tended to categorise children as orphans and respondents were not always clear as to why some children were chosen over others. Apart from Red Cross food parcels received regularly by four families, three families were receiving assistance with school fees from another non-government organisation. Respondents did not mention any other agency assistance. Mutual support of kin members remained the principal source of orphan care. With the increasing number of parental deaths how are these changes in family forms and kinship relations, affecting the care of children?

3.4.4 Kinship care of orphaned children

The twenty-five families where in-depth interviews took place were caring for a total of 111 children under eighteen-years-old, 57 of whom were orphaned (23 were paternal orphans, 12 maternal orphans and 22 double orphans). The maternal kin were caring for the majority of orphans, with only thirteen orphans remaining with paternal kin. Eleven of these orphans had lost their mother (i.e. they were either maternal or double orphans); the remaining two had stayed with paternal kin after their father's death but the mother had returned to maternal kin. The head of the family where children lived was very varied. There were no strictly '*child-headed*' households as commonly referred to in the AIDS literature, as the one older sister carer was over 18-years-old. In one of the informal settlements

CHAPTER 3: Child-Care in Poor Urban Settlement in Swaziland in an Era of HIV/AIDS

where families interviewed lived, there were over five hundred households, but there were no cases of child-headed households known to the family respondents or to the Zone leader interviewed. Despite the poverty of many households, orphaned children were being absorbed within kinship networks, however stretched those networks might be.

Where grandmothers or great-grandmothers headed the families in this study, there were often several generations present and therefore other younger females living in the household who could help with caring for the orphans (Table 1). Only five orphans were cared for by a single elderly carer with no other adult female in the household. Thus, grandmothers struggling absolutely alone and coping with large numbers of orphans, were not a common feature in these families. The number of adult women present in the household emerged as one of the more useful indicators of vulnerability, rather than the status and age of the head of the family unit.

Table 1: Variety of family forms where in-depth interviews took place

| <u>Type of family unit</u> | <u>Number of families (n=25)</u> |
|---|----------------------------------|
| Four generations living within extended family | 6 |
| Three generations living within extended family | 7 |
| Nuclear family, mother and father present | 6 |
| Single female parent (one was widowed) | 3 |
| Single female parent, shared husband | 1 |
| One generation (i.e. siblings) | 1 |
| Grandmother living alone with grandchildren | 1 |

3.4.5 Reasons for crisis fostering of orphaned children

Some respondents felt coerced into accepting orphans, and for most families foster arrangements were relatively ad hoc and unplanned:

'My granddaughter was married and her husband died. She stayed with her husband's family until she died early this year (2003). The (paternal) grandmother brought them (the great-grandchildren) to me and asked me to look after them. She just dumped them and I had no choice. I have never seen the grandmother since and I don't receive any help from the father's side.'

(Maternal great-grandmother, family 5)

'I didn't have a choice. The parents were living here when they died.'

(Grandmother, family 12)

A few respondents volunteered to care even though they were not the closest kin:

'It was voluntary. I just saw there was no arrangement made. She was three months old, so I took her.'

(paternal aunt, family 11)

In one case the family were paying another kin member to support two children unrelated to any of them because *'we felt sorry for them'* (family 1).

The maternal kin of orphans often mentioned that the mother of the orphan was not married, so there was no other option: *'my daughter never got married to this man and she always lived with me so the children have grown up here with me and when she became sick I was the next of kin'* (grandmother family 8). In rural western Kenya, Nyambedha *et al.*, (2003) suggested that the use of culturally *'inappropriate'* caregivers, such as matrilineal kin or strangers, was the result of the patrilineal kin being overwhelmed by numbers of orphans.

However, given the apparent change in attitude to marriage, the number of unmarried mothers remaining with maternal kin and the low number of orphans cared for by paternal kin, the findings in this study may reflect not just the effect of AIDS but the evolving dynamic extended family described by Madhavan. There was a loosening of traditional paternal kinship care practices in some families in this urban setting, but orphans did continue to be absorbed within family units, though family migration patterns had an influence on this process.

The fifteen families who had lived in the settlement for over twenty years often consisted of much larger extended family units and were caring for 49 of the 57 orphans. By contrast, the nine families who had migrated to this urban area in the past ten years were much smaller family units, and all lived in rented accommodation. The remaining eight orphans were cared for by five of these families. It is as if the extended family common in rural areas has replicated itself after a generation of living within the informal settlement, due to further in-migration as well as growth of the family in-situ, and was still able to bear the brunt of orphan care despite the multiple deprivations and poor living conditions of many families.

3.4.6 Kinship care of non-orphaned children

The kinship care of the 54 children who had both parents alive was equally varied with twelve of these children being in a foster arrangement. Isiugo-Abanihe (1985) describes child fosterage as an accepted means of raising children in West Africa partly as a need to reallocate resources within the extended family. This strengthens kinship ties and ensures the survival of the unit. Five children were

subject to a foster arrangement where they were sent to live with grandmothers in the rural areas because of cheaper education. Four urban families were receiving children from kin living elsewhere for varied reasons: the children's parents lacked jobs and were too poor to provide for them; schooling was perceived to be better in the urban area; or parents were away working, for example, in the low veld of Swaziland.

Only eighteen of the remaining forty-two children (ones neither orphaned nor fostered) were living with both parents. A further fourteen lived with their mother in the maternal extended family and were described as having been '*abandoned*' by their father, though they had given the father's name to the child in every case. In both customary and common law in Swaziland, a child born out of wedlock is entitled to bear the mother's name. However, in practice this is not the case. '*So strong is the association of children with their fathers' families that there are men and women who do not view children as equally related to their parents, but as related more to the father and his kin,*' (Aphane *et al.*, 1998, p.25). This is another indication of the primacy of paternal kin relations so important in Swazi culture. Three children lived with their father in the paternal extended family and were described as '*abandoned*' by their mother. Seven lived with their mother as head of house, again with the father described as having '*abandoned*' them. Out of these forty-two children, only seven were living in a family unit that was not caring for orphaned children.

These figures show that, while children in the families interviewed are all being cared for by kin of some kind, the family forms are varied and evolving. Another outcome of these living arrangements is that nearly all children are in

direct contact with peers who have experienced the loss of one or both parents. These lost parents are often the aunts, uncles, or older brothers and sisters of children who have not (yet) lost their parents. No child whether orphaned or not, is left untouched by the epidemic, either physically or emotionally. In the previous twelve months seven families had lost at least one family member and an additional three families had an adult in hospital who was described as 'very sick.' None mentioned AIDS when describing the deaths or illnesses:

'My son died in hospital then my daughter got ill and died too. They died one after the other. My daughter was visiting my son in hospital and very shortly after, she was sick too, so two children have died this past year within a month of each other.'

(Grandmother, family 12)

3.5 Conclusion

Despite the high levels of poverty of some families, orphans were mainly living with kin in a variety of family forms in the informal settlements. Non-traditional family forms are emerging and matrilineal care of orphans was dominant. Chronic poverty in the form of multiple deprivations over a sustained period, as described by Hulme & Shepherd, (2003), was evident in some families and affected both orphans and other children. Evidence from this study suggests that community-based initiatives to support vulnerable families may require different implementation strategies from those used in rural areas where there are well-understood traditional structures, land to grow crops if weather permits and more cohesive communities. Careful co-ordination of all agencies is needed to ensure a community participatory approach which engages men and youth in particular.

CHAPTER 3: Child-Care in Poor Urban Settlement in Swaziland in an Era of HIV/AIDS

The families in this study, did not perceive, or appear to treat, orphans as a separate category of children. While not denying the special needs of orphans, these needs should, as far as possible, be incorporated through state provision of education, health and social welfare that in turn reflects the pressing needs of all poor children. The Millennium Development Goal of free universal primary education, the provision of special classes to allow the reintegration of non-attendees, school feeding programmes, equitable provision of anti-retroviral treatment for the urban poor of both genders, child support grants and pensions for the elderly are national level policy issues that need pursuing urgently with the help of the international donor community. Swazi families strengthened in this holistic way will be able to continue to care for the majority of their orphaned kin so that the grandmother's words remain true: *'because of our culture there are no orphans.'*

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

4. CHAPTER 4: Relationships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

'It depends on who you know as to whether you get help. The really needy people don't get it. I got the form from the Headteacher at the school and filled it in but I heard nothing. You never get a reply.'

(Grandmother carer of an orphaned grandchild, informal settlement, Mbabane, Swaziland)

4.1 Introduction

4.1.1 Governance issues and the response to HIV/AIDS

In 2003 there were three potential sources of primary school funding at national level for orphaned children in Swaziland: the Ministry of Education, the National Emergency Response Committee for HIV/AIDS (NERCHA) and a fund provided by King Mswati.

Yet, as this grandmother's comments show, the ability to access these resources was proving problematic. Despite well-intentioned national level policies, the implementation at local level was piecemeal and uncoordinated. Swaziland is not the only country where there is a gap between macro-level policies and their successful implementation at local level. Kelly (2004) describes the difficulties caused by lack of capacity at local government level: *'It is much more difficult for funders to engage with government at local level, as sub-national level systems of governance are often poorly organised, supported and administered...'* (p.4). Kelly also argues that HIV/AIDS merely highlights the problems of underdevelopment more generally, and argues that local government

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

structures need strengthening so they become the sustainable, co-ordinating, mechanism at local level.

Another aspect of governance in response to HIV/AIDS is the setting up of National AIDS Committees as a conditionality of Global Fund money. Piot (2005) refers to the importance of having one national AIDS strategy, managed and monitored by one national level authority. While this is clearly much easier for donors, it changes some of the political dynamics within countries. It sets up another well-funded, and therefore powerful, body that has to decide how to allocate funds. The level of trust and quality of relationships between the national AIDS committee and the recipients of the funds becomes critical, as it is the committee which is directly accountable to the external donor for the funds, not the implementers. Implementers may be: government officials, NGOs and community-based organisations (CBOs). There are also likely to be other actors, with alternative sources of funding, carrying out their own projects in response to the AIDS epidemic, but not necessarily tightly co-ordinated by the National AIDS Committee. As Kelly (2004) rightly points out, there is a gap in co-ordination at local level, which could be filled by local government officials. He notes that 'the capacity for national HIV/AIDS programmes to absorb funds, depends on spending at local level' (p.4). Satterthwaite (2001) agrees, and argues that, given that official aid agencies and development banks merely fund rather than implement most projects, *'the scope and potential success of any international agency's urban projects are thus dependent on the quality and capacity of their local implementers'* (p137).

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

Besides new power dynamics, the setting up of a national AIDS committee leads to a singling out of HIV/AIDS as a separate issue when, at local level, HIV/AIDS is much more tightly interwoven with other aspects of social poverty. Rather than emphasising the uniqueness of HIV/AIDS, this paper seeks to show how HIV/AIDS is thoroughly embedded alongside other aspects of poverty. There are HIV/AIDS-specific issues which need addressing, but these need incorporating within an improved public welfare system. This paper argues for sustainable solutions through the strengthening of government institutions, especially at the local level, and more careful co-ordination of all players. This requires improved linkages within and between government departments as well as stronger horizontal partnerships, for example between local government officials, NGOs and CBOs. The alternative seems to be a mosaic of unsustainable and often uncoordinated 'development' activity, more bureaucracy, either piecemeal spatial coverage or duplication, and no direct accountability to the recipients of the development process. Governments on the other hand are, with some exceptions, accountable through the ballot box.

4.1.2 Understanding relationships at the local level

Apart from the lack of co-ordination of various players at local level, there is a need for more research into social organisation and processes at the local level. Fraser, Thirkell and McKay, (2003) argue that without a better understanding of social capital in terms of how the poor feel about groups, leaders, and institutions, it will not be possible to end their social exclusion. Kelly (2004) also notes the importance of relationships:

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

'The term 'social capital' is increasingly being used to understand ways in which susceptibility to HIV/AIDS reflects a breakdown or poor development of coherent and cohesive social fabric which fundamentally orders the relationships within communities and determines the relationships of communities to the broader environment.' He continues: *'there has been relatively little systematic investigation of the relationship between social capital/cohesion and the impact of HIV on communities, including the response of communities to HIV/AIDS.'*

(Kelly, 2004, p11)

The term 'social capital' has its limitations, and these are discussed elsewhere in the literature, in particular, the absence of the political element. Bourdieu recognised that social capital constituted much more than just connections to other individuals and groups:

'The volume of the social capital possessed by a given agent thus depends on the size of the network of connections he [sic] can effectively mobilise and on the volume of the capital (economic, cultural or symbolic) possessed in his own right by each of those to whom he is connected.'

(Bourdieu, 1986)

Fine (2001, p198), also highlights the conceptual limitations of 'social capital.' He considers it a neutral term that neglects the importance of power, conflict, the economy and the role of the state. Harriss and De Renzio (1997) refer to the limitations of social capital for analysis and suggest breaking it down into six different categories, one of which is political capital.

Against this nebulous backdrop of exactly what constitutes social capital in the development literature, this paper takes a broad interpretation of the term and focuses on the quality of the relationships entered into by the urban poor as they seek assistance for their livelihoods from beyond the kinship group. It considers

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

the effect of gender, age, cultural norms and economic resources, on the quality, strength and balance of power, in relationships.

The survival strategies of the poor are intrinsically linked to the quality, rather than physical proximity or volume, of relationships. For example, the social network may include immediate neighbours who are not trusted and who therefore act as 'negative' social capital. At community level, those who are recent arrivals, or more transient members of informal settlements, may be marginalised from local-level social organisations compared with those of longer residency. At the scale of citizen-state relations, Government officials may give a less satisfactory service when approached by citizens from informal settlements who are perceived to lack any form of power or agency. At international level, their voice may not be heard at all. Satterthwaite (2001) describes how the partners of official aid agencies and development banks are relatively remote from the reality of the poor and that they are only as effective as the local partners who implement the urban projects. He notes that the urban poor have no formal means of influencing donors:

'This means that the people whose needs justify the whole development industry are the people with the least power to influence development and to whom there is least accountability in terms of what is funded and who gets funded.' (p.141)

Thus when some project funded by a development bank or a bilateral aid agency fails, they are not accountable to the intended recipients. This lack of voice of the urban poor has now been incorporated within discussions about equity in

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

the development literature. The World Bank (2006) defines equity in terms of equal opportunities (that a person's life achievements should be determined primarily by his or her talents and efforts) and secondly avoidance of deprivations in outcomes (particularly in health, education and consumption). Equity requires greater equality of access to political freedoms and political power. The report stresses the importance of strengthening the agency of poor and excluded groups so that their voice is heard and there is more political accountability.

The above issues of giving 'voice' to the urban poor are explored using qualitative research methods in areas of informal housing in Mbabane municipality in Swaziland, Southern Africa. HIV prevalence, according to antenatal clinic data, has reached 42.6% in the adult population, the highest rate for any country in the world (IRINnews, 2005b). The paper aims:

1. To identify the main problems faced by poor urban families caring for children in the context of the AIDS epidemic and to give a more nuanced understanding of the intrinsic link between poverty and the impact of HIV/AIDS.
2. To analyse the opportunities and constraints the urban poor face in accessing support at a variety of scales, from beyond the kinship group. (The importance of kin is discussed elsewhere by the author: Jones, 2005)
3. To illustrate the need for public welfare support and government co-ordination of implementers to achieve an effective response to HIV/AIDS and poverty alleviation at local level.

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

Thus, as well as examining the connectivity of social relations in informal settlements, the contextual dynamics of those relations are discussed.

4.1.3 The descent into persistent poverty in the context of HIV/AIDS

Whiteside (2002) outlines how there is not a simple causal relationship between the epidemic and poverty. He cites Botswana with its high per capita income and high HIV prevalence levels as a case in point. Economic growth may in itself create opportunities for the epidemic to spread (e.g. more long distance truck drivers away from home) and traditional norms may weaken with exposure to the different norms and cultural practices of migrant and foreign labour. He also shows that where economic growth is inequitable there may be sectors of the population more at risk. For example, in South Africa there has been a restructuring of industry leading to a decline in jobs in the primary and secondary formal sectors with an increase in jobs in the informal and tertiary sectors. Lower socio-economic groups may therefore have slipped out of formal employment into the less secure informal sector and have fewer resources to combat the disease whilst other socio-economic groups, for example, those employed in the new, highly-skilled tertiary sector, may have more resources. However, Whiteside sums up the link between poverty and HIV/AIDS: *'in simple terms the poorer the households and communities, the worse the impact'* (p. 320).

Hulme and Shepherd (2003, p407) describe how *'the more dimensions on which an individual is deprived, the less likely s/he is to escape poverty as the exit routes will be limited.'* They also stress that poor people are likely to be more vulnerable to shocks as they are likely to have fewer assets to draw on in times of

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

difficulty. Mitlin (2003) attempts to summarise the main contextual factors determining the incidence and extent of urban chronic poverty: access to the labour market; access to cash income; access to basic services; exposure to discrimination; limited legal and political rights; groups in transition (for example, recent urban migrants) who have a limited range of income sources. Mitlin reviewed literature on ways of escaping from falling into chronic poverty and concluded that urban households most likely to avoid chronic poverty had diverse income sources, access to education, the ability to grow some food stuffs on their urban plot, and connections through grassroots organisations such as traders' associations.

Set in this context, it seems that the urban poor in this study are likely to be in a downward spiral of increasing deprivation and vulnerability, given the high HIV prevalence levels and the resultant multiple shocks facing families, as they cope with illness, deaths and increasing numbers of dependent, orphaned, kin. Yaqub (2003) has used data from twenty-three developing countries to show that downward social mobility is correlated with increased household size and number of dependents. The AIDS epidemic provides these very conditions in poor families. Any assets are likely to be liquidated to provide medicine for a relatively long period of illness, waged employment may be lost, and, after the expense of a funeral, there may be orphaned children to support thereby increasing the number of dependents. The lack of funds for education, adequate food and clothing, may lead to the loss of human capital and a more persistent form of longer-term chronic poverty as described by Hulme and Shepherd (2003), with even fewer exit routes. The prevention of HIV/AIDS, the treatment and care of those infected and

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

affected by HIV/AIDS, is therefore intrinsically linked to poverty. Poverty affects not just the material lives of the poor but their social relations and inner dignity, as this paper will show. In turn, this affects both to whom they turn and how they negotiate help. The importance of embedding HIV/AIDS responses within more general poverty-alleviation interventions, whether provided by NGOs, CBOs or the state, seems obvious. The manner in which this might be achieved is more problematic.

4.2 Research setting

Swaziland has strong cultural traditions based on a patriarchal society where women are considered subordinate to men both in law and custom. Women are considered minors in Swazi law, and this affects land ownership, inheritance, marital authority and commercial transactions. Although polygamy is less common now, men may have several wives. Given the role of women in childcare, including both young widows and elderly grandmothers, this subordinate status affects their agency when negotiating with the multiple actors who control child-care resources. This iniquity is becoming a more pressing problem as mortality rates continue to rise and more women and children become vulnerable. By 2002 HIV adult prevalence levels have reached 40.6% in urban areas compared with 35.9% in rural areas. The highest level was 54% for the 25 to 29 years age group in urban areas (Ministry of Health and Social Welfare, 2002). The preliminary findings of the Ministry's 2004 9th HIV sero-prevalence survey show a further increase to 56% in this age cohort nationally, though urban/rural figures are not yet available.

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

Swaziland is classed as a middle-income country and is ranked 137th in the 2004 United Nations Human Development Report. However, income inequality is reflected in a Gini coefficient of 0.5, which is higher than the average of 0.44 for sub-Saharan Africa, and there are pockets of deep poverty in both rural and urban areas. Thus, 18% of the 'core poor' live in the urban areas (World Bank, 2000a) and have similar consumption levels to the 'core poor' in rural areas (UNDP 2001, p57). Given that the majority of the poor are in the rural areas of Swaziland, most aid agencies have concentrated their efforts in these areas rather than in the urban areas. Bebbington (2004) has noted that NGO presence is often uneven, though the reason some locations are favoured over others is not fully understood. This uneven coverage is cause for concern when considering ways of scaling up interventions to support poor families and is reason to reconsider the co-ordinating role of the state in welfare provision at the local level as Satterthwaite suggests:

'New means must be found to engage with and support local government staff, where they have potential to become more effective. The International Institute for Environment and Development, in its work in different centres around the world, often finds local government officials who are struggling to fulfil their roles and responsibilities within local government structures that have made considerable improvements in terms of accountability and representation, but who are ignored by development agencies and by foreign consultants. It is also common to find cities in which different international agencies are busy funding "their projects" with no coordination between them and with little attempt to strengthen the capacity of local institutions.'

(Satterthwaite, 2001 p.147)

The Alliance of Mayors' Initiative for Community Action on AIDS at the Local Level (AMICAALL) was one such 'new means' unfolding at the time of the fieldwork. In 2001 in Swaziland, AMICAALL was launched as a specific HIV/AIDS co-ordinating organisation for the urban areas of Swaziland. It aimed to: *'facilitate*

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

the promotion, implementation and evaluation of effective multi-sectoral responses to the HIV/AIDS epidemic under the auspices of the Swaziland National Association of Local Authorities and the Local Authorities Managers' Association of Swaziland,' (AMICAALL, 2002, p2). In each of the eleven municipalities in Swaziland, a Municipality HIV Team drawn from representatives from a broad range of organisations involved with the fight against AIDS, was set up to play an advisory role. Finally at grass roots level, AMICAALL was in the process of setting up Community AIDS Action Committees (CAAC) made up of volunteers elected by local communities. To help facilitate the work of CAACs, AMICAALL provides a salaried Local Co-ordinator.

In August 2003, AMICAALL reported that five of the eleven Swazi municipalities were without any form of 'care and support activities for orphans' from any type of organisation (i.e. whether government, community based, NGO, faith based etc.). In Mbabane there were two NGOs (SOS Herman Gmeiner International Organisation and Save the Children Fund) and some church support for orphans (AMICAALL, 2003, p.75). At the time of the fieldwork the AMICAALL Local Co-ordinator for the Mbabane municipality was trying to form a CAAC to help enumerate the number of orphans. However, it was proving difficult to recruit reliable unpaid volunteers, respondents were giving false information in the hope of receiving assistance and enumerators were favouring their own relatives. Undeterred, the Local Co-ordinator explained during interview that seven of the twelve Mbabane electoral wards had been enumerated and the data were at least an estimate of the situation. AMICAALL clearly has the potential to play an important role in fostering partnerships between actors at local level in the urban

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

areas but it was still at an embryonic stage at the time of the fieldwork and HIV/AIDS activities in Mbabane remained largely uncoordinated (AMICAALL, 2003, p.76).

In this study the main non-kin actors helping poor urban families were: informal networks of neighbours, church groups, work-based organisations, international NGOs, and Local Government officials. Qualitative research methods were used to gain deeper insights into how these relationships were acted out.

4.3 Research methodology

The research took place over five months between September 2003 and January 2004 with a short follow up visit in November 2004. The study population mainly lived or worked in the informal settlements of the small capital city of Mbabane. In-depth interviews were conducted with a variety of key informants (teachers, directors of NGOs, religious and community leaders, government officials) and a focus group discussion took place with NGO social workers working in the informal settlements. Various local government reports and consultancy documents provided further information. Using purposive sampling through a variety of entry points, in-depth interviews were carried out with 25 families¹ who had responsibility for children, whether of their own or fostered or orphaned. Families gave informed verbal consent and were assured of confidentiality. The families were caring for 111 children in total, 57 of whom were orphaned. The families were mainly housed in mud-and-stick dwellings that were prone to damage in the

¹ A family was defined as a kin-based group who lived in dwelling(s) occupying a single compound and who recognised a common household head. Where possible the household head was interviewed, often with the help of other adult family members. The author, who had worked in Mbabane for three years, was assisted by a Swazi graduate research assistant who acted as an interpreter during family interviews.

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

heavy summer thunderstorms. Seventeen families did not have tap water and unventilated pit latrines provided sanitation. Six families had electricity. Some plots were large enough to grow vegetables and keep chickens; others were very small.

Mitlin (2003) notes the need for caution when using the term 'urban poor' as it does not differentiate between the chronically poor and those experiencing less intense or long-lasting poverty. Thus, it is recognised here that the term 'urban poor' is being used to describe a range of livelihoods from those who were living in one rented room through to a few families who lived in block built-houses with an outside tap and electricity. Length of tenancy also varied, from well-established families to those who were recent arrivals. However, none of the families had legal security of tenure and none paid rates. Therefore there were no municipal services for rubbish collections, surface drainage or vehicle access.

The family interviews were transcribed and coded to draw out the main themes. The extracts used in the remainder of the paper reflect the themes which recurred with greatest frequency and which were of most concern to respondents as they cared for family members.

4.4 Multiple deprivation and vulnerability to shocks

After a rapport was established, the family respondents were encouraged to describe the main challenges they had faced in recent months and the specific difficulties they had in looking after the children in their care. They were then asked how they tried to overcome these difficulties and with what measure of success. In cases of severe deprivation, the author and research assistant

**CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of
the Urban Poor in AIDS Afflicted Swaziland**

attempted to find sources of assistance. The most pressing difficulties were: accessing and paying for health-care, financing education, and coping with bereavement. Other vulnerabilities included: loss of jobs, rent arrears, and concerns about witchcraft. Seven families mentioned the death of one or more family members in the past year. Ten families had struggled with health costs and funeral expenses. The following extracts reflect these general issues:

'I do have rent problems. I sometimes can't afford to pay. My children get chased away from school every now and then because I can't afford their fees, so I am going through a lot of money problems which are a real headache. I had to beg the headmaster to have them back but I don't know how long for as I haven't paid the rest of the fees.'

(Family 11, married mother caring for five of her own children and one orphaned niece)

'My mother-in-law was sick and we paid the expenses at the government hospital. We have had a lot of funerals to pay for because of sickness. If you include the coffin, transport, food, a funeral costs about 3,000E² (about U.S. \$150)

(Family 1)

'I had eight children in total, two boys and six girls. I am only left with two girls and they live with the paternal side. I had three children dying last year and I had no-one to turn to, to help me.'

(Family 13, great-grandmother caring for two orphans helped by an 18 year-old granddaughter)

²Emalengeni are equal to South African rand

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

When asked specifically about child-care issues, fourteen families gave, as a primary concern, their inability to pay education expenses. Nine families were also concerned with providing sufficient food for their children. Clothing, medical expenses, over-crowded housing, and fear of the carer dying before the children were grown-up, were other concerns. Although most families concentrated on the physical care of children, some described their anxiety about the vulnerability of their teenage children in relation to HIV. Many said they tried to engage with their teenagers on the issue but with limited affect. Typical of the more vulnerable families was a 62 year-old grandmother who was working part-time by taking in washing and cleaning for a local pastor and paying school fees for the two youngest of her five grandchildren:

'I'm really concerned about the future as I am old. I pray to God that he keeps me here until they are grown. My main concerns are education and food. I really struggle because if the pastor stops paying for them I have no way I can take them back to school. The eldest two have dropped out and I ask for handouts to scrape money together for the other one. I do have a lot of problems with the teenage children. They don't want to help me at home. They want to be out with their friends. I think teenagers definitely respect their friends more than their parents. I do talk to them about HIV/AIDS and I collect pamphlets to give them.'

(Family 8, widowed grandmother, lone carer)

This woman was not receiving assistance from any source and her mud-and-stick home was devoid of any obvious saleable assets. She was cooking over an open fire of sticks. Her grandchildren were not yet orphaned but she did not expect her sick daughter to return from hospital. The two eldest children, who were no longer in school, were challenging her authority. Whilst not specifically implicating her own grandchildren, she said that teenagers she knew *'get into*

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

problems with drugs and alcohol'. With limited extended family support available to her, this family was one of several where their livelihood was increasingly precarious and on a downward trajectory. The following section considers the ability of such respondents to negotiate beyond the family for material assistance, education, health-care and emotional support after bereavement.

4.5 Support from beyond the family

4.5.1 Negotiating neighbours

Neighbours were a source of emotional support during sickness and bereavement for many families but there was little mention of material exchange. *'We are here to help each other as neighbours but we all have our own problems so we can't do much.'* (Family 10) and *'everyone struggles too much in this community so we can only help emotionally,'*(family 12). In one part of the settlement neighbours were suspicious of each other: *'we don't go to neighbours, as there is a lot of witchcraft about. I can't exactly tell. We just all know there is lot of jealousy and people pull each other down,'*(family 16). Some women did not feel safe after dark and feared being raped. Smoking of dagga (cannabis) and alcohol abuse by younger men in particular, was a concern: *'I don't feel safe after dark. There's these boys who smoke and it is just not safe,'* (mother, family 24).

4.5.2 Church communities

There were several different church groups attended by respondents and some regarded church as a source of emotional, but not material, support. Comments such as: *'church members helped uplift my spirits,'* (bereaved grandmother, family

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

12), were made by four respondents. Others were reluctant to turn to the church for help out of pride or dignity and sought comfort elsewhere:

'I wouldn't want to be a burden at church'

(Family 25, grandmother)

'It's a personal problem. I find it hard to share my problems with my neighbours or church members. I do go to church. I do get on with the women I sell with and we talk about things.'

(Family 21, widow)

This mother of three paternal orphans was still coming to terms with the death of her husband and became upset during the conversation. Selling fruit at school gates was no longer sufficient to pay for food, clothes, health-care or rent. She owed money for school fees and had moved from two rooms to one, as she owed her landlord rent. Her own family were too poor to help her and relations with the paternal family were no longer cordial since the death of the husband (sometimes, families suspected the wife of being the source of HIV infection). Given these 'shocks' to her livelihood it is perhaps surprising that she did not feel able to turn to neighbours or her friends at church. Pride and dignity are important parts of what constitutes 'being human' and, in this case, acted as a barrier to accessing support. Dignity was mentioned in several contexts during the fieldwork: respondents described a lack of dignity for family members in hospital, social workers described children who were unwilling to go to church as they had no 'suitable' clothing, and respondents were reluctant to speak to neighbours about their poorer circumstances. Mbonda (2004 p.278) writes *'no matter which criterion is used to define it, poverty cannot avoid infringing human dignity.'*

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

Besides the barrier to seeking assistance created by pride and dignity, there was evidence that Swazi churches do not fully engage with practical help, though their role in bereavement counselling was important for many families. Reverend Patricia Wright, Swaziland co-ordinator of Care Nakekela, had worked with churches in thirteen chiefdoms in Swaziland as well as churches in informal settlements. She found there was not a tradition of church-based community outreach programmes for material assistance (interview 25/11/03). One church elder, in the informal settlement, echoed this sentiment:

'The churches are strong but there are a lot of different ones so the church is not really unifying. The youth are not active in our church. Teenagers these days don't like to go to church. There are not that many men at church either. We have talked about women of the church helping orphans but we haven't done anything yet.'

(Interview, 10/12/03)

The importance of cultural context is again evident when considering the role of faith-based organisations in relation to scaling up interventions aimed at supporting vulnerable families.

4.5.3 Productive work-based relationships

Women employed in both the formal and informal sector were likely to consider work relationships as potential sources of support, particularly emotional support but also for financial assistance. One woman described a mutually supportive relationship:

'I go down to Durban on the bus and buy clothes, hats, accessories, blankets and sell them round the offices. My husband isn't working but I can borrow money from

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

the women I work with. We try to help each other as sisters. We have formed an organisation between ourselves to give each other loans. We have registered it.

We started three years ago and there is a membership fee. I'm not sure what happens if you don't pay back a loan. They look at how long you have been a member and at your credibility. Now this child is grown, she's four weeks old, I hope to go back to work.'

(Family 22)

Others in the formal sector described seeking loans from employers for funeral expenses or school fees. Without security of tenure, respondents in informal work had difficulty obtaining loans and had to resort to illegal moneylenders who charged high rates of interest.

4.6 Children's access to schooling

4.6.1 Swaziland's progress towards free, universal, basic education

The Millennium Development Goals include eliminating gender bias in schools by 2005 and providing primary education for every child by 2015. Mehrotra and Delamonica (2002, p.1106) note that educated girls marry later, have fewer children and provide better care for their children than uneducated women. They also argue that this improvement in child-care at household level *'has a large macro-social effect.'* They refer to the synergy between social development, income-poverty reduction, child well-being and economic growth. Swaziland, like other developing countries in the midst of an AIDS epidemic, thus needs to use education to help protect and develop the next generation of human capital, not least, that of its female children.

For Swaziland as a whole, Ministry of Education figures show that net enrolment ratios for formal primary education are similar for boys and girls (74%:

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

71% respectively in 2001) but continuing to fall from the highs of the mid-nineties (80.3%: 80.3% in 1995). However, many children (16 per cent in 2001) repeat years as they drop out of education for periods when parents cannot afford the fees and it takes on average thirteen years to complete the seven years of primary education. Expenditure is heavily biased towards tertiary education, which in 2001-2 received 21% of the education budget compared with 37% for the primary sector (European Union Feasibility Study, 2003). By comparison tertiary education in South Africa absorbed 14.6 percent of the education budget in 2001/2 (United Nations Organisations for Education, Science and Culture, 2005). When pupil numbers are taken into account this means a student in tertiary education in Swaziland absorbs 40 times more funds than a primary school pupil. Meanwhile, many low-income families struggle to pay primary school fees and few of their children reach tertiary education.

During interviews families often mentioned that children had periods when they dropped out of school for a term or so, as they could not afford the fees. Basic primary education in Swaziland should take seven years to complete (referred to as grades one to seven) and starts the term in which the child reaches seven-years-old. Thus primary education should be completed by age fourteen, but children in this study were often two or three years over-age for their grade in school. Of the fifty-four children aged seven to seventeen years attending primary school from these families, thirty-six were orphaned (fifteen double, fourteen paternal and seven maternal orphans). School fees for seven of these orphans were paid for either by a charity or a deceased father's pension. Unlike in some studies (Aspass, 1999), there did not seem to be any favouritism of children living

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

with their biological parent(s) over orphans, in school enrolment, in the small number of families in this study. Whilst bearing in mind the qualitative nature of this work and the small number of families surveyed, it was interesting to note that the gender of orphans did not seem to affect school enrolment decisions as nineteen girl orphans and seventeen boy orphans were attending primary school. Of the sixteen children aged seven to seventeen years who were not attending school, eight were orphans (four girls, four boys), five were fosters (i.e. children with parents alive but living away from them) and three were children living with their biological parent(s). Six of these children had never attended school (ages ranged up to thirteen years), two had completed primary school and the rest had dropped out before completion, most often in grade four. All respondents cited the cost of fees as the reason for non-attendance.

With primary education taking so long to complete, those in secondary school were often over eighteen and therefore adults. There were six children under eighteen-years-old attending secondary school (three of each gender), as well as a further sixteen adult family members (eleven males and five females), with ages ranging from eighteen to twenty-four years. In terms of family situation, the twenty-two family members enrolled in secondary school (i.e. both those above and below eighteen-years-old) consisted of nine children living with their biological parent(s), eight orphans and five fosters. With the exception of one family, these family members all came from families with at least one person in formal employment. Once more, in this small sample, there did not appear to be a bias against orphaned family members attending secondary school; the main determinant seemed to be regular income.

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

4.6.2 Negotiating relationships: power, agency and leverage

Despite the government's policy in 2003 of allocating funds to headteachers for orphaned and vulnerable children, families in this study had difficulty securing help. The allocation of subsidies was not understood and appeared, to some respondents, to depend on patronage. A widow, supporting three paternal orphans by informal work selling fruit and vegetables, explained:

' I have unpaid school fees for my third child. I could manage if I had help with education. It wouldn't be nice if they had to stay at home. The headmaster was only giving forms out to grandmothers. I had to fight to get a form. I don't think my form was passed on.'

(Family 21)

This grandmother who was responsible for one orphaned grandchild, suspected cronyism:

'It depends on who you are and who you know as to whether you get help. The really needy people don't get it. I got the form from the Head of school and filled it in but I heard nothing. You never get a reply.'

(Family 25, grandmother with one orphan)

However, a Ministry of Education spokesman explained the system and it appears both these families had a 'right' to receive support:

'The target is orphaned and vulnerable children. We tell the headteachers that they must give forms to the double orphans first then single orphans. Third in line are the needy children whose parents are alive but poor. The form needs to be signed by the Head, the Chief, or someone else in authority, and the chairman of the governing committee. It's not perfect but with several signatures it helps. We found some chiefs were charging a fee for signing the form. We gave 13,699 primary bursaries but that still leaves about 75,000 school age children out of school. We need stronger coordination between the Ministry of Education, the

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

Kings Fund and National Emergency Response Committee who also give primary bursaries. We have asked headteachers to check for duplication of bursaries.'

(participant observation: Education Working Group, National Conference on Orphaned and Vulnerable Children, 5-11-03)

4.6.3 Lack of vertical linkages

Apart from confusion between the various players involved with issuing bursaries, some headmasters did not receive the funds promised by the government and were therefore reluctant to allow bursary-funded pupils into school as the 2003 school year progressed. The same occurred in 2004 and by November the Head Teachers Association was threatening to close schools down. However, partial bursaries did reach some of the urban primary schools in September 2004, to the benefit of some respondents in this study. Seen in this light, the relationship between the poor families and the headteachers was likely to be sullied by the government's inefficiency in the distribution of funds. The relationship between the poor and the implementer at local level, in this case the headteachers, was affected by the failure of vertical linkages within the Ministry of Education. Why were some Swazi schools allocated their funds but not others? How were these decisions taken? Who monitors and evaluates the distribution? Who decides on the time frame?

4.6.4 'Top-down' and 'bottom-up' leverage

While the very vulnerable families quoted above lacked leverage to affect the distribution of funds, the slightly less poor in another area near Mbabane were more vocal. In January 2005, at the beginning of the school year, police had to disperse an unruly crowd of parents that had gathered outside Khuphika Primary

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

School near Mbabane. The Minister for Education had instructed heads to allow orphans into school and promised to forward payment for them. Out of 761 registered pupils, only 86 paid their school fees on the opening day of school. Those children who were not orphaned, and who had not paid their fees, were sent home. The parents protested they were being discriminated against because their children were not orphans or classed as 'needy' by the Khuphuka school committee and hence they were obliged to pay fees (IRIN, 2005).

Given the difficulty of accurately establishing which families deserve assistance in the context of orphanhood and poverty, this piecemeal approach to education provision may lead to the erosion of good community relations and the stigmatising of certain groups of children. Being an orphan is not necessarily synonymous with being the child most in need of assistance. In this fieldwork, as shown above, orphans were equally as likely to attend school as other children in the family, were not spoken of as a separate category of children by their carers, and nearly half of the orphans (28/57) lived in the better homes (as indicated by block construction, access to tap-water and electricity). The problems associated with targeting a specific group of children are well documented elsewhere (Williamson and Donahue, 2001). Such an approach may not target the most needy children and is unlikely to build strong social fabric or 'bonding social capital' considered essential for community-based care of orphans.

Kelly refers to the lack of a sense of community in informal settlements: *'such communities often represent new social formations with little shared history and few previous ties,'* (Kelly, 2004, p.10). In contrast to village communities, the spatial delimitation of what constitutes 'community' is less clear in informal

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

settlements, and developing community-based HIV/AIDS responses needs more co-ordination and structure. That is, stronger vertical linkages within government departments so that local government officials are informed, supported, effective and accountable, as well as stronger horizontal linkages between implementers at local level.

Campbell (2003) stresses the need for both 'top down' and 'bottom up' approaches in relation to HIV/AIDS interventions, but she notes the difficulty of creating a cohesive vision at community level where social connections and obligations are not necessarily confined within a local geographical space. Campbell's findings have resonance with the families in this study. Twenty-one families had links with kin living elsewhere, and many families were reluctant to consider the informal settlement as home.³ The high HIV prevalence levels also exacerbated the lack of social cohesion. The sheer multi-faceted, debilitating impact of AIDS on poor families leaves little spare energy, time or resources for engaging in activities which are likely to promote social cohesion to the point where they accrue power, agency and hence influence. This is not to suggest the urban poor are inert and passive, rather that they are already engaged in unpaid reproductive work so physically and emotionally demanding, and poorly resourced, that there is little spare capacity to engage in forms of collective activism which might create the agency to influence events in a major way.

Although there was some 'bottom up' pressure, the power largely rested with stakeholders at national and international level. In this example, national level actors such as the Swaziland Head Teachers' Association, the National

³A fuller analysis is given in Jones 2005.

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

Emergency Response Committee (NERCHA), and more indirectly, international actors such as the IMF and the UN, were creating the leverage to bring about change. For example, extracts from the United Nations Resident Country Coordinator's speech at the National Stakeholders Conference on Orphans and Vulnerable Children, indicates such pressure:

'Politics is about the allocation of resources and power. We have been here this week, to advocate for allocation of resources to children. That cannot happen unless we address issues of governance and how power is used.....Let me talk for a moment about the international community, and its response to the crisis that children are facing. I have observed, over my four years here, that there is a reservoir of international goodwill towards Swaziland, and of sympathy for the HIV and AIDS crisis that the Nation finds itself in. But like the levels of the water in the nearby Maguga dam, the levels of that international goodwill have been lowered over the last few years.'

(Alan Brody, November 7th 2003)

After referring to the IMF's message to the Swazi Government, of the need for fiscal discipline, he outlined that Global Fund money was already available in the country and that further money may be available, under certain conditionalities:

'Other assistance is in the wings. The European Union will soon start its next cycle of assistance, which includes a major project to support pre-school, basic and vocational education. I believe that other bi-lateral donors who have left Swaziland are also ready to enhance support, once they receive clear signals of seriousness from the Swazi government, in the form of its own investment priorities.'

(Alan Brody, November 7th 2003)

In terms of the three aims of this paper, the above section illustrates that the urban poor prioritised education as a prime concern. They were having difficulty accessing and sustaining education for all categories of children in their

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

care and that methods of bursary allocation by headteachers were uncoordinated and lacked transparency in 2003. Respondents caring for orphaned and vulnerable children often felt powerless to challenge these decisions at local level. In turn, headteachers lacked the power to access the resources supposedly allocated to them, and had to make arbitrary allocations in a situation where demand for bursaries far out-stripped supply. Kelly (2004) writes in relation to inadequacy of local governance:

'one of the most glaring problems is the mismatch between mandates and budgets where local governments are expected to provide services for which there is no fiscal provision and little opportunity for raising local revenues. There appears to be an emerging realisation that the challenges facing local government have much to do with why national AIDS programmes are not rolling-out as hoped at the local level.'

(Kelly, 2004, p16)

In addition to gaining a school place for their children, access to health care was another major concern of families and the next section examines the opportunities and constraints the families faced at community level.

Strengthening the lines of communication within government departments as well as empowering local government officials to co-ordinate government, NGO and CBO activity at local level had begun in relation to health-care. By 2004, better vertical and horizontal partnerships had been formed, monitoring and evaluation was in place and a more co-ordinated approach was beginning to benefit the families in the informal settlement.

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

4.7 The role of relationships in accessing health care

4.7.1 The contextual background of health care in urban Swaziland

The inability of hospital infrastructures to cope with the magnitude of AIDS-related deaths and illness in sub-Saharan Africa, and the need to provide community-based palliative care, is widely recognised (Harding *et al.*, 2003). Buve *et al.*, (2003, p.46) suggest that the management of opportunistic infections in HIV-infected patients should, in principle, be manageable at health centres and district level hospitals. They claim that the typical infections (tuberculosis, pneumonia, chronic diarrhoea, candidiasis) do not require sophisticated laboratory technology and special drugs that are not within the reach of public health services. Given the relatively slow roll-out of anti-retroviral (ARV) drug treatment, the need to cope with large numbers of dying patients at community level is likely to continue for some time. The 2004 WHO Progress Report on the aim to have three million people on ARV treatment by the end of 2005, states that while the number on ARVs in sub-Saharan Africa had reached 310,000 by December 2004, this represented only eight percent of those who needed it.

In Swaziland, by December 2003, NERCHA was developing an extensive coverage of HIV/AIDS voluntary testing and counselling centres throughout the country and using these as an entry point for ARV treatment. With the initial allocation of Global Fund money, the aim was to treat 4 100 of the 30 000 thought to have a CD4⁴ count of under 200, the point at which ARVs become necessary. However, if further funding became available, it was hoped to increase this

⁴ CD4 levels are an indicator of immune health. In a healthy person the CD4 count is over 1,000.

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

number substantially by 2005.⁵ NERCHA was aware of potential problems of gender bias in allocation, given the inferior status of women, and the need to consider ways of encouraging the treatment of infected children. A multi-stakeholder National Palliative Care Association was just being formed to consider ways of improving the lives of the terminally ill. Thus, while an efficient well-thought-out programme was being developed at national level, the community care of the dying would have to continue meanwhile.

At community level the Swaziland Rural Health Initiative (SRHI) was developed in 2002 in order to ease pressure on the overcrowded hospitals. The aims were to support families caring for relatives at home, and to promote HIV/AIDS risk reduction by building on existing structures and personnel, such as the Rural Health Motivators (RHM). The SRHI was a partnership between four stakeholders: Swaziland Ministry of Health and Social Welfare, University of Illinois at Chicago College of Nursing, Bristol-Myers Squibb Foundation, and the Cabrini Mission Foundation (Chicago College of Nursing, 2003, p.2). From the perspective of the urban poor in this study, the interface with the SRHI occurred through the RHM. Although referred to as 'rural', the RHMs worked in the peri-urban informal settlements, and were key actors in accessing some services for the twenty-five families studied.

A further source of potential health support available to the families was through the traditional healers or *inyanga*. However, strict cultural practices, based

⁵ Based on interviews at NERCHA, 16/9/03 and with UNAIDS, Mbabane 29/11/03

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

along gender lines, are enforced. A study of Swazi families found that a woman cannot consult an inyanga without the permission of her husband or his family, and would be treated with great suspicion if she did:

'Should it happen that a husband or partner require medical attention, say, in instances of critical illness, the woman is required to consult with members of his family before taking him for treatment. She does this for her own protection. As interviewees pointed out, taking decisions of where and how her husband or partner is treated makes her vulnerable to accusations of witchcraft. Death, in Swazi custom, is rarely attributed to natural causes,' and, 'Interestingly, similar precautions are not taken with regard to women. Her life does not seem to be valued in the same way as a man's is.'

(Women and Law in Southern Africa, 1998, p.59)

In addition to the local RHM and inyanga, the families in the informal settlements of Mbabane had access, in terms of physical distance, to a small private health clinic (frequented by many Government officials and members of the Royal family), and the Mbabane Government Hospital. The choices made by the urban poor and the way relationships were negotiated with the various actors involved is discussed below.

4.7.2 The lived reality of home-based care and access to health care in informal settlements

A few families had a strong and trusting relationship with traditional healers, particularly where witchcraft was suspected. However, they seemed to be used in conjunction with Western medicine rather as an alternative. However, for some families, it illustrates the cultural constraints which may affect AIDS-related health

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

initiatives in a poor setting, including encouraging the use of ARVs for people of either gender:

'My husband was sick for six months. We had witchcraft problems. He was bewitched by someone at work. We went to several inyanga and that solved it.'

(Family 3)

The author had worked in Mbabane from 1999 to 2002 and during this time visited patients, including children, in two government hospitals. The wards were sometimes over-crowded with patients sleeping on the floor. Nurses struggled to keep patients clean and immune-suppressed patients were, therefore, particularly at risk. During the course of fieldwork, one grandmother described, with pride, how she had nursed both her mother and daughter at home and 'kept them clean' until the end. She had a fear of ending her days on ward 18, the female ward at the Mbabane Government Hospital, and felt the care was inadequate and the patient's dignity not respected:

'ts getting worse. It's more over-crowded. There are people under the beds, baby cots with two in. Sheets are a problem and there are not enough blankets, even mattresses. You must have a helper. They don't say you must but you will not get food or medicine (from the nurses) without.'

(Family 25, Grandmother, 23-11-04)

The cost of services at the government hospital are heavily subsidised but not free. Respondents claimed that a hospital stay of one week cost 50 rand. Outpatient consultations were 10 rand, X-rays 7.5 rand and individual laboratory tests 7.5 rand. For some, the cost was a barrier to accessing services:

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

'I don't have money if they (children) fall sick. My main concern is health. I can't afford health-care. I would like some health-care for the elderly and the young. I would appreciate it if they could help old people. My health is failing now and I can hardly walk to the toilet now.' (This was an outside pit-latrine a few metres down slope from the house).

(Family 13, great-grandmother, caring for two orphans with help of an adult granddaughter)

Many families cared for relatives at home and, to a casual observer, the sick are not conspicuous. The mid-term Swaziland Rural Health Initiative evaluation report (Chicago College of Nursing 2003, p.2) refers to the problem of stigma: *'individuals, families, and communities seek to avoid shame and isolation by practising denial of the HIV status of ill persons.'* The demands of nursing AIDS patients in poor settings has been described elsewhere. It is sufficient to remark on the obvious difficulties of home-based-care of a relative with chronic diarrhoea and vomiting, in houses without indoor sanitation, or access to tap water, as was the case in many of the homes visited (Figures 9 and 10 below). However, there is also a high emotional toll on carers as the relative reaches near death.

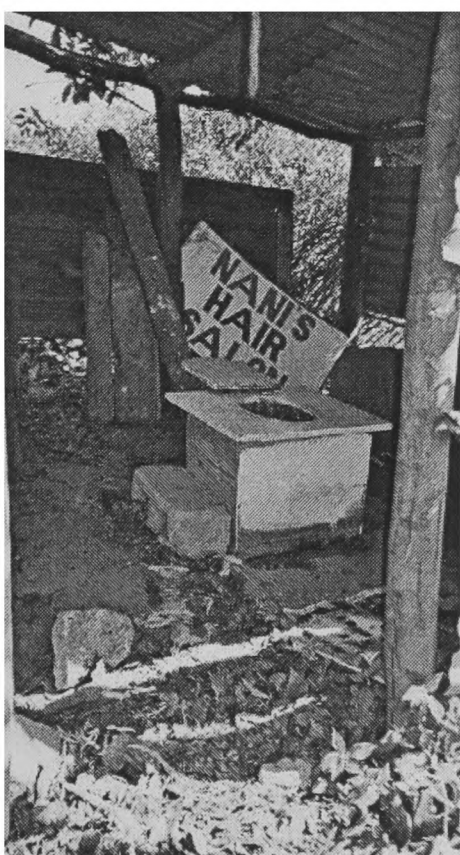


Figure 9: Sanitation
Unventilated pit latrine
typical of informal housing

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland



Figure 10: Families lacking piped water relied on springs such as this one

The author regularly visited one family where the adult daughter was dying. Her mother, devoid of money after the expense of the long illness, was trying every means possible to obtain pain relief for her daughter. Unable to afford the private clinic, knowing the conditions in the government hospital, aware that the local RHM had little medication, her options were limited. The pharmacist provided the strongest over-the-counter medicine available, but the daughter was unable to swallow it. Without a nurse to administer an injection or set up a drip, it was impossible to relieve the pain. The feeling of intense anguish in the bedroom was palpable during the last few days of this young woman's life. So much so, that the adults present, including the author, paid little attention to the dying woman's nine-year-old daughter who was also in the house at the time. In the last forty-eight hours a nurse from an NGO, Hospice at Home, finally arrived and set up a

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

drip. The woman died relatively peacefully. The realities of 'palliative care' within the community were harsh.

It is against this contextual backdrop that the following extracts need to be assessed. The SRHI report (Chicago College of Nursing, 2003, p9-12) referred to the many difficulties faced by RHMs: lack of adequate resources (for example: the allocation of only ten panado/acetaminophen tablets for pain relief per nurse, per month), lack of transport, low pay (100 rand a month) and large caseloads (an average of about 44 homesteads). RHMs receive a few weeks training in home-based care and HIV/AIDS prevention education. Most were women, with an average age of fifty.

Many of the comments made by families in this research indicated their unrealistic expectations in relation to the resources, workload, and training received by RHMs. At the time of the fieldwork, the RHMs were also responsible for the allocation of Red Cross food parcels to improve the nutrition of the poorest families. During discussions with families, the problem of using low-paid, over-worked, community members, in this case RHMs, to distribute resources to the urban poor, was soon apparent.

Eight families had been registered with the Red Cross to receive a food parcel every three months. The Director of the Swaziland Red Cross (interview, 23/10/03) explained that they had initially intended using their own personnel, chosen from beyond the community, and their own criteria, for establishing which families should receive assistance. However, the Red Cross had been requested by the government to work with the RHMs rather than create a duplicate system. Thirteen of the twenty-five families said they had been visited by an RHM. Eight

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

families received the first food parcel in March 2003, but by September only four families were receiving the parcel and some residents felt marginalised by the RHMs and that there was a lack of transparency in how resources were allocated:

'Rural Health Motivators have never been to my house. They show favouritism. If you are a friend you get it whereas some of the really needy miss out. It would be better if the Zone Leader called a meeting and people chose a group from the community to go round to each homestead. There are so many churches you couldn't do it through the churches. The trouble is, people don't turn up for meetings.'

(Family 25, grandmother)

'I get a food parcel from the Red Cross once every three months of ten kilograms of maize because I am widowed. The RHM did register the orphaned children and they may receive help in the future.'

(Family 5, great-grandmother)

'I got one Red Cross food parcel when she (RHM) called, but they didn't register her (an orphaned niece) so I only got it once. I'm a bit wary of her so I haven't had the courage to talk to her about it.'

(Family 11, mother, informal work, caring for six children, in arrears with rent and school fees)

'There is no help because we are just tenants. The RHMs are not interested in hearing tenants out. We have never had a visit from an RHM, tenants are left out.'

(Family 23, mother)

The need for greater material and emotional support of RHMs was recognised by some leaders in the informal settlement:

'The Government and the Red Cross are training caregivers to help Rural Health Motivators but it won't work. The care-givers are voluntary but they are anticipating payment, eventually, like the Rural Health Motivators, and doing it for that reason.'

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

The caregivers are so poor themselves that they are likely to take things meant for the very poor. The main problem is greed but you can't expect a very needy person to help another very needy person. The Rural Health Motivators need supporting too. It is too stressful. They are not providing any medication so people are not keen to let them into their houses.'

(Male, Community Health Committee member)

In the AIDS literature, community-based initiatives are recommended for many facets of the AIDS epidemic besides palliative care of the dying. Drew, Makufa & Foster, (1998) refer to the success of community-based orphan-care using carefully selected and trained volunteers drawn from within a defined community. In their case study in Zimbabwe, the community volunteers were mainly women, many of whom were widowed. These volunteers identified and registered orphans and made an average of eighteen visits per month in the latter part of 1996. Material assistance, where provided, was channelled through the volunteers. Careful monitoring and evaluation as well as the motivating support of paid co-ordinating staff were seen as some of the key steps for successful implementation. Drew *et al.*, suggest that such low cost initiatives may be 'replicated and scaled up.'

It is highly questionable whether the use of unpaid community volunteers (usually women, and often poor women) is a sustainable model of community-based responses to HIV/AIDS. Kelly notes: *'Partnerships which strongly rely on the services of volunteers are not necessarily sustainable in the long-term or up-scalable unless the motivations of volunteers are taken into account and met.'* (Kelly, 2004, p24). Akintola (2004) argues: *'There is a need to refine volunteer-based programmes -providing stipends and/or designing them to be steps for*

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

career development and formal job employment, in order to make it attractive and to reduce attrition rates' (p5).

Some of these steps were taken for RHMs during 2004, and the services to the community improved. RHMs received a small pay increase to 150 rand per month; they had further training, and were provided with a volunteer helper. Pay for the latter was under negotiation and in the author's view, is essential for sustainability. Careful monitoring and evaluation of recipients of assistance had made the process more transparent. Trust between poor families and the RHM had increased as this grandmother (family 25) who had complained of favouritism in 2003 explained:

'RHMs are better trained now and they have a helper. It's mainly aimed at home-based-care. People are now less reluctant to let RHMs into their homes and are now more willing to disclose information. They (the RHMs) are giving panadol and medicines for thrush and other things. They are also very involved with the zone leader and the M.P. when deciding who qualifies for orphan assistance. People cheat to get help (from the Red Cross), the child may not be orphaned but they try to get help. The people go to the Red Cross in zone 6 and then the Red Cross brings the names to our zone leader to verify that they are needy. The Zone Leader called out five or six names of people getting help from the Red Cross. No one spoke up. No one knew them, so they were disqualified. They shouldn't have been on the list.'

(Interview, 23-11-04)

Again, as with the education sector, stakeholders at national and international level, in partnership with the government, initiated and monitored the SRHI, and were important catalysts to change at local level. Once effective vertical and horizontal linkages were in place and properly co-ordinated the assistance to poor families became more effective. Care-givers and the RHMs took part in the SRHI mid-term evaluation process and created 'bottom up' feedback. Once there

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

was greater feedback between those taking the decisions and those receiving the benefits, it became possible to create stronger relationships and better co-ordination between local actors (in this example, the community Zone Leader, the M.P., the local Red Cross clinic and the RHM). It also gave government officials the agency to carry out a monitoring and evaluation role at local level. In turn, given that the Zone Leader is elected locally and RHMs chosen locally, it increased the voice and agency of the poorest. It seems unlikely that the improvement of services provided by RHMs would have occurred without the strengthening and co-ordination of relationships between these vertical and horizontal players. In particular, the strengthened role of local government officials, created a sustainable structure. If the current non-government partners (i.e. Bristol-Myers Squibb Foundation, and the Cabrini Mission Foundation) moved on to new projects, there is a government structure in place which, in the absence of government funds, other donors could step into support. The coverage of RHMs is national rather than piecemeal, and fits within the overall National AIDS Plan for community-based-care of all those affected by HIV/AIDS.

4.8 Conclusion

This paper has attempted to shed light on the nature of relationships between poor urban families and those from whom they seek assistance, in the context of the high AIDS prevalence levels. The quality, strength and power balance in relationships affected access to resources irrespective of the institutionalised 'right' to those resources. Although many authors, such as Lamboray and Skevington (2001), stress the importance of 'bottom up' processes and the

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

formation of 'AIDS competent' communities, this small case study suggests that further research is needed before assuming this is possible in poor urban settings, where very high levels of HIV prevalence pertain.

This fieldwork found that families had social obligations beyond the informal settlement and this led to an ambivalent perception of 'home.' This ambivalence, and the heavy burden of reproductive work associated with the epidemic, meant that families had a diminished emotional and physical capacity to engage with activities much beyond the immediate needs of their own household. Whilst not denying the need for political engagement by the urban poor, support from actors at local, national and international level, as shown here in relation to schooling and home-based health-care, is critical. The importance of international pressure from external actors is particularly important in a country such as Swaziland, where political parties are banned and activism is treated with mistrust.

The paper advocates that NGOs of various kinds, work within the National AIDS strategy, rather than pursuing their own agendas, which may give piecemeal coverage and lack sustainability. Similarly, it calls for the strengthening of horizontal and vertical linkages within government departments so that local government workers are more effective, particularly in a co-ordinating, monitoring and evaluation role. For example, rather than having a separate HIV/AIDS activities budget within the health department of the Mbabane City Council, each department could integrate HIV/AIDS mitigation activities into its core functions. This inclusive holistic approach would be particularly beneficial in departments such as those providing water and sanitation services to the urban poor. Finally, it calls for the inclusion of the voice of the urban poor in the decision-making

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

process. The 'bottom up feedback' in the SRHI mid-term evaluation, is an indication of the importance of monitoring, evaluation and reflexivity of partnerships to improve the trust and respect in the vertical and horizontal relationships of all the actors involved. There is a real need for service providers to be accountable to the recipients of those services. To achieve this more research is needed at the local level to identify where and why resources sometimes fail to reach the most vulnerable in resource poor settings.

Once more, as in pre-structural adjustment days, the role of the state in protecting the vulnerable is necessary. Whilst 'community-based-care' is the policy thrust of the main players such as UNAIDS and the World Bank, research by the Economic Policy Research Institute (2004), emphasises the importance of comprehensive state welfare policies for the elderly and children. Desmond and Gow (2002, p.41) support this view and cast doubt on the efficacy of community-based organisations:

'The experience of many community-based organisations in South Africa is that it reduces the cost of care to the state in the short term, but increases the cost to the family and community, in terms of time, energy, emotional and material resources to insupportable levels. Further, a strategy for state and community support that does not require children to become terminal care providers under the euphemism of 'home-based care' is urgently needed'

According to Akintola, programmes in Uganda are 'community-oriented' rather than 'community-based' and there is 'substantive co-ordination and networking between hospitals, NGOs, religious sects and communities to override the limitations of individual organisations,' (Akintola, 2004, p4). This paper has

CHAPTER 4: Relationships, Partnerships, Partnerships and Politics in the Lives of the Urban Poor in AIDS Afflicted Swaziland

attempted to show the challenges of coordinating HIV/AIDS responses at the local level and the difficulties of separating out AIDS issues as a separate category. It also highlights the potential of AMICAALL to play a pivotal role within municipalities by fostering partnerships and encouraging the flow of information between the main actors so that limited resources are not duplicated or wasted.

The AIDS epidemic is unprecedented in extent and duration. Piot (2005), Head of UNAIDS, has described the epidemic as exceptional because there is no plateau in sight for the epidemic, the severity of its impact is 'undeveloping countries,' and it is more than just a health issue. He described the epidemic as being driven by inequality of all kinds and emphasised the need for activism at all levels and leadership at national and international level. It is unfortunate that Mbeki's statement about poverty causing AIDS, rather than a virus, was taken in its literal sense as poverty exacerbates the spread of disease and an holistic approach to tackling poverty by all the players involved, and which includes the 'voice' of the poor, may still prove the best method of bringing the epidemic under control.

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

5. CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youth in AIDS-Afflicted Swaziland.

5.1 Introduction

This chapter seeks to explore the ways Swazi secondary school learners interact through social networks to gain knowledge about HIV/AIDS and how these networks influence their sexual behaviour. What choices are they making? What are the main influences that lead to these choices? What do young people think is needed to encourage safer, healthier, sexual behaviour? How could these findings be used to help in HIV/AIDS prevention? These questions were explored during qualitative fieldwork with 25 families and 84 secondary school learners within the city of Mbabane, Swaziland, between September 2003 and January 2004. This work is part of a wider study on the impact of HIV/AIDS on children and their families in Swaziland and also draws on other data collected between 1999 and 2005.

It has become clear since the start of the AIDS epidemic, that efforts to prevent the disease spreading, by bringing about changes in high risk sexual behaviour, are difficult to achieve. Research has proven many times, that giving correct information about transmission and prevention does not necessarily lead to behaviour change in most individuals (UNAIDS, 1999). Furthermore, the focus on behaviour change of individuals using cognitive theories and models of health behaviour, has been criticised for its narrow framework (Airhihenbuwa *et al.*, 1999), because sexual behaviour involves negotiations between two people who are each, in turn, influenced by social, cultural, and economic factors. This has led

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

to more multi-dimensional behaviour-change models that consider not only decision-making at the individual level, but also the influence of both localised sub-cultures and the socio-economic conditions in the wider community. In addition, there is a need to study the specific influence of HIV/AIDS itself.

Varga (1997) gives a comprehensive review of literature on sexual decision-making and negotiation amongst adolescents and concludes that: *'few studies have addressed adolescent sexuality, self-perceived risk and sexual decision-making in the context of HIV/AIDS'* (p.49). In relation to research on adolescents in Africa in particular, Varga notes that the few African studies that exist tend not to include the male perspective or the socio-cultural context and interpersonal factors which determine adolescents' sexual behaviour.

Even by 2004, only limited progress had been made on achieving behaviour change among youth, in areas where AIDS is endemic. Programmes targeting youth prior to sexual debut have shown the most promise. Gallant & Maticka-Tyndale (2004), reviewed eleven school-based HIV/AIDS-risk reduction programmes for African youth, in several African countries. They found that programmes were generally unable to affect a change in sexual behaviour of older youth, aged 17 to 18 years, though one programme did lead to an increased use of condoms. Programmes that targeted younger school children had greater success in influencing sexual behaviour. They conclude that *'it is easier to establish low risk behaviours than to change existing behaviours,'*(p.1349), and that *'knowledge and attitudes are easiest to change, but behaviours are much more challenging.'* (p.1337). It is clear that more research is needed into how young people make decisions about sexual behaviour in the context of AIDS, how

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

they are influenced by their sexual partners, and how they are influenced by economic, social and cultural factors in the communities in which they are embedded.

5.1.1 Constructions of childhood

The way childhood is socially constructed and the way children are perceived in society has a bearing on how they gain knowledge about AIDS and sexual behaviours. In the literature, there has been increasing recognition of children as social actors in their own right. They are not merely 'adults in the making', going through a series of mental and physical developmental stages, but persons who actively help construct their own social world. Their interaction with the social and economic environment in which they are embedded leads to a wide variety of potential childhoods. There is, therefore, no single universal childhood that AIDS risk-reduction programmes can target. There may be commonalities between childhoods in similar socio-economic and cultural settings, but a more nuanced understanding of the local context becomes of paramount importance. James & Prout (1997), note that:

'Childhood¹, as distinct from biological immaturity, is neither a natural nor universal feature of human groups but appears as a specific structural and cultural component of many societies. Childhood is a variable of social analysis. It can never be entirely divorced from other variables such as class, gender, or ethnicity. Comparative and cross-cultural analysis reveals a variety of childhoods rather than a single and universal phenomenon' (p.8).

¹ Using the internationally agreed definition of childhood as the period from birth to the age of eighteen, drawn up in 1989 by the United Nations Convention of the Rights of the Child (UNCRC).

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

They argue that children are not just passive subjects of social processes but that they actively engage in constructing their own social lives and that to understand these processes it is necessary to carry out research with children to understand the world through their eyes. This view of children as persons with agency developed through the 1990s and has led to increasing demands for the voice of children to be heard in matters concerning their lives (Burr & Montgomery, 2003; Kirby & Woodhead, 2003; Ostergaard & Samuelson, 2004; Ansell & Van Blerk, 2005).

A further consideration is the binary division between adults and children as if they are entirely separate categories. In fact, this division is rather artificial, and neglects the relational aspects of children and adults (Kehily, 2003). In the context of AIDS, there is a marked blurring of this division as children comfort and nurse sick parents, care for younger siblings and assume responsibilities normally associated with adulthood. Therefore, while children clearly grow physically and mentally through development stages, there are wide global variations in the types of childhood experienced. Their lives are also socially constructed, and they are social actors in their own right. Their voice therefore needs to be included in behaviour-change models, and these models must reflect the local context.

Whilst the term 'children' is defined internationally as a person from birth to eighteen years, other terms such as youth or adolescents or teenagers are used in the AIDS literature, as well as in this paper, to include those both under and over eighteen years of age (Varga, 1997; Nnko & Pool, 1997; Gallant & Maticka-Tyndale, 2004). It is common to have learners aged 18 years and over attending secondary school in Africa and some of the respondents in this study are therefore

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

young adults. While not denying the relevance of the development transitions of childhood and their influence on sexual decision-making (such as the age of puberty and associated hormonal changes), this paper concentrates on gender relations and the social construction of sexual behaviour of young people in urban Swaziland. It also investigates the agency each gender has in their sexual relations and the influence of socio-economic factors on sexual behaviour. If these processes were better understood, it would help in the design of more appropriate behaviour change interventions.

For example, in Swaziland, a 15-year-old girl 'choosing' to have unprotected sex with a much older man can be understood as a rational choice if the contextual detail of the girl's poverty is included. The girl's inability to negotiate the use of a condom, by the older man, is unsurprising in a Swazi context. Swazi social and legal construction of women and children accords them lower status than men, and children are expected to be submissive and respectful towards male adults. If the girl sees lobola paid when a woman marries, and if she perceives that women are viewed as objects to be traded, rather than as people of equal status to men, it is more likely that she may consider her body as merely an asset for transaction. If she hears and sees that female fecundity is highly regarded, the need for contraception may seem a contradiction. If a boy witnesses his father having multiple partners, and is encouraged by adult males to think that it is a 'Swazi' tradition and a mark of masculinity for men to have multiple partners, he has to consider whether abstinence from sex, or being faithful to one partner, will have repercussions on his male relationships and his social position amongst his peers. If the Swazi King has many wives and lobola is paid, this further

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

cements the patriarchal mores of the society. In other words, changing young peoples' sexual behaviour depends partly on wider social relations and requires an holistic approach which extends far beyond the classroom to engage the social world beyond. The social inequalities that exist between genders, between generations and between different socio-economic groups in the wider community, all impact on young peoples' lives, including their sexual decision-making.

The next section examines what can be gleaned from large-scale national surveys about sexual behaviour and HIV prevalence in Swaziland and this leads into the qualitative fieldwork carried out by the author.

5.2 HIV/AIDS prevalence levels and Swazi youth

5.2.1 Biological markers as indicators of sexual behaviour

Like any data set, data from antenatal clinics (ANCs) have come under scrutiny, and extrapolation to other population groups must be carried out with caution. However, national ANC surveys do suggest high levels of HIV prevalence amongst urban youth. The 2002 Swazi Ministry of Health and Social Welfare 8th HIV sentinel serosurveillance report based on ANC attendees, shows that the number of young females aged 15-19 infected with HIV rose steadily nationally from 17.8% in 1994 to 32.5% in 2002. The prevalence levels are a little higher in urban areas where they reached 34.9% in 2002 for the 15-19 age cohort, compared with 28.1% for the same group in rural areas. The increase in national prevalence levels at ANCs is even greater in the 20-24-age cohort, rising from 18.8% in 1994 to 45.4% in 2002.

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

The education data in the report is not disaggregated by age group for more specific analysis of younger age groups, but in the same 2002 survey, the level of educational attainment of pregnant women aged 15-49 did not seem to protect against HIV infection. There was little difference in HIV prevalence levels in the latter group between those who had, and those who had not, attended school. For example, those women aged 15-49 who had never attended school at all had the lowest infection rates (37.1%), those who had attained secondary level education the next lowest (38.3%) and those who had attained primary level education had the highest rate of HIV infection (40.1%).

Age cohort data is given for marital status and shows that being married does not appear to protect Swazi young women from infection: in the 15-19 age group, ANC attendees who were married had a higher HIV prevalence rate of 38.8% compared with 29.5% for those who were not married; possibly the result of infection from the husband.

The 2004 9th HIV sentinel serosurveillance report is not yet published in detail, but national HIV-prevalence rates of attendees at ANCs rose from 38.6% in 2002 to 42.6%. However, in the 15-19 age cohort, prevalence levels declined a little from 32.5% in 2002 to 29.3% in 2004, and fewer teenage pregnancies were reported. It is hoped that this reflects the beginning of a change in sexual decision-making amongst youth, either through sexual abstinence or the use of condoms for safer sex. Another source of data for this paper was a behaviour survey carried out in Swaziland, in 2002, by Family Health International in conjunction with the Swaziland Ministry of Health and Social Welfare.

5.2.2 Behaviour surveys as indicators of sexual behaviour

In 2002, the Swaziland Ministry of Health in conjunction with Family Life Association of Swaziland (FLAS), conducted a national behavioural surveillance survey (BSS), which included a survey of youth in and out of school. In the survey, in-school youth respondents were aged 15 to 19, while out-of-school youth were aged 15 to 24, care needs to be taken when comparing the data sets. When just the 15-19 age cohort is compared for both groups, the mean age of sexual debut was 16.3 years for in-school youth compared with a surprisingly, slightly higher, 17.4 years for out-of-school youth. However, 33.2% of out-of-school youth aged 15-19 reported being sexually active in the previous twelve months, compared with only 15.7% of in-school youth. Other key findings in the BSS survey include *'stigma and misconceptions about HIV/AIDS were observed across all surveyed populations,'* (Family Health International 2002, p. 4). Only 20% of in-school youth, aged 15-19, had no incorrect beliefs about AIDS, compared with 11% of out-of-school youth, aged 15 to 24, and condom use at first sex was much lower for out of school youth (37% compared with 74%). Overall, it does suggest that those in school do practise less risky behaviour, even though there is limited sexual-health education in the curriculum. Local context is again shown to be important as findings differ from country to country. Unreliable information on HIV/AIDS was found to be a problem in a West African study of urban youth (Ostergaard & Samuelson, 2004), and concurs with findings in Swaziland, whereas Kelly (2000) found youth had good access to accurate HIV/AIDS information, though not through schools particularly, in six survey sites in South Africa.

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

Other key findings of the 2002 Family Health International BSS survey include: *'multiple partners were common among both the adults and youth populations surveyed'*, and *'female youth both in and out of school tended to have sex with partners older than themselves'* (p 4). There are no other Swazi behaviour surveys at a national level, but a more limited survey in 2003 of randomly selected households in two rural areas, was encouraging. Only six percent of girls aged 15-19 years were HIV positive, according to evidence from blood tests, though this jumped to 40% in older girls (UNICEF, personal communication). Whether this is an indication of more widespread behaviour change, including in urban areas, is difficult to judge.

Kelly (2000) notes that in addition to large-scale descriptive surveys of youth responses to HIV/AIDS, there is a need for qualitative research: *'until further qualitative data are gathered we can but speculate about what lies behind some of the trends observed'* (p43). Ostergaard & Samuelsen (2004) discuss the difficulty of researching sensitive issues, such as sexual practices, and in their study of urban youth in Burkina Faso and Senegal, they used a range of qualitative methodologies. The author was faced with similar dilemmas when delving into the reasoning behind sexual behaviours of urban youth in Mbabane and these are discussed below.

5.3 Multi-method qualitative research

The fieldwork took place over five months and consisted of in-depth conversations with twenty-five family care givers, focus group discussions (FGD), one-to-one conversations, written accounts, key informant interviews and participant

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

observation. The field sites were in the municipality of Mbabane, the small administrative capital of Swaziland. Youths in two government secondary schools participated, as well as some young community members.

5.3.1 In-sights from family settings

In order to gain a better understanding of the influence of family background on sexual behaviour of youth, informal in-depth interviews were undertaken with twenty-five families who lived within the catchment area of the two schools selected as field sites. Other matters concerning childcare were also discussed, but are beyond the scope of this paper. Given that the learners from the two government secondary schools were drawn from several informal settlements within the urban boundary, as well as from some formal housing, these interviews were used to gain insights into adults' constructions of youth sexuality, in the context of AIDS, rather than any attempt to comprehensively cover all social economic groupings or to match young respondents with their respective homes. In any case, the family setting was not considered appropriate for interviews with both young people and their adult care givers, due to the lack of privacy and the need for respondents, both adults and children, to be assured of confidentiality. Valentine, Butler & Skelton (2001) discuss the problems of finding private spaces for research of a sensitive nature with children:

'The dangers of attempting to conduct a "private" interview in most familial homes, where space is at a premium and other household members may be tempted to eavesdrop, are self-evident' (p.122).

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

The in-depth interviews with adult caregivers took place during school hours when school attendees were not present. The families, each of whom cared for children, were selected using a variety of entry points. They were caring for a total of 111 children of less than eighteen-years-old, 57 of whom were orphaned. Sixteen of the families had family members in the 15-19 age group. Ten of the families had children attending secondary school. Ankrah (1993) refers to a variety of definitions of the African family; in this study it was defined as a kin-based group who lived in a dwelling(s) occupying a single compound and who recognised a common household head. The physical environment, where the twenty-five families lived, broadly reflected the findings of the Mbabane Structure Plan (City Council of Mbabane, 1997) for informal settlements. Only seven homes were of block construction, the remainder were made of *mud-and-stick*.

The adult, caregiver participants were assured of confidentiality, and they gave informed verbal consent. Hunter writes in relation to AIDS research:

'A context-rich self-conscious research programme avoiding self- and other-alienation has some necessary and simple dimensions: stay awhile; teach, live, share; incorporate indigenous researchers in your projects; train them during the project execution; take the pain to transfer your skills; listen to their ideas, their conceptualizations, their pain'

(Hunter, 1990, p.689)

The author worked as a teacher² in Mbabane from 1999-2002, but to help overcome the limitations of the author's position as a white European outsider, two

² The author had the responsibility of introducing a comprehensive AIDS policy, the first of its kind in Swaziland, to the school community. Apart from specifically education-based aspects, the initiative acted as a springboard for many other intertwined community activities. Relationships were formed with families caring for very sick relatives and with children who became orphaned. Some of these families with whom the author remains in contact, were invaluable in providing an entry point to some of the respondents in this study.

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

locally recruited Swazi female research assistants³ advised on culturally sensitive issues and helped with family interviews and focus groups with children. Older adults preferred to speak in SiSwati, whereas the school learners used both English and SiSwati, depending on the activity. Teaching at both schools is conducted in English. The author was present at all caregiver interviews, and an assistant acted as an interpreter. This part of the research took place over five months between September 2003 and January 2004 with a short follow up visit in November 2004.

5.3.2 The ethics of researching with children in the context of AIDS

The author was very aware of the stigma and denial that still surrounds AIDS in Swaziland, especially its link with culturally inappropriate sexual behaviour. A further consideration was the possibility of some children reporting sexual abuse. Other research with children in the context of AIDS has led to distress, despite careful preparation by the researcher. Foster *et al.*, (1997), in their research into children's perception of orphanhood in Zimbabwe, carried out focus groups discussions with children aged 9 to 16. They took care to gain consent from both orphans and their caretakers, assured them of confidentiality, and had community visitors on hand 'for children who became upset during focus groups discussions,' (p.393). However, they write:

'During one focus group discussion, the facilitator asked about changes experienced following parental death. One boy stated his stepmother mistreated

³ Both research assistants were black Swazi young women. One research assistant was a graduate with counselling experience the other was a medical student. Where possible, families and learners found to be in particular difficulties were given help.

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

him whereon a 12 year-old boy started crying and continued sobbing throughout the rest of the discussion.'

(Foster *et al.*, 1997)

It is difficult to see how the information about the behaviour of the stepmother would remain confidential in the presence of other children, and it seems inappropriate to leave a child, as it appears, '*sobbing throughout the rest of the discussion,*' rather than allowing him to withdraw.

Nyamukapa & Gregson (2005), describe in-depth interviews, with children and their primary caregivers, where they were seeking views on the care and education of orphaned children. Again, children, aged twelve and thirteen, became upset during interviews (p.2161-2162). Such research, however beneficial the findings, highlights the ethical difficulties facing researchers. Eyber (2003) has researched adolescents' perception of war-related stress in Angola, and suggests that general questions should be used with groups, while individual questions, requiring personal accounts, should be left for when the child is alone. She also suggests that researchers working with children should be trained in coping with emotion if the child becomes upset. Lewis (2003) describes the concept of 'fully informed consent', where child participants are given information, at an appropriate level, in advance of the research: they understand what their role will be, they know it is voluntary to take part, that they will not be identified and that they may withdraw at any time, and they know what the research will be used for.

On the basis of these findings and the author's own experience of working with Swazi bereaved young people, the qualitative methodology was designed to try to protect children from any distress. While the results pertaining to sexual behaviour are discussed here, the research also included experiences of

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

orphanhood. Preparatory work involved visiting the two schools prior to the research, discussions with teachers in each school, and guidance from the Swazi research assistants, as well as older Swazi children known to the author. Focus group guides were piloted with children before the larger survey and amended where necessary. Individual letters, based on the principles outlined by Lewis above, were given to learners in Standard 7 and 9 (selected by the school as neither year group had external exams) with the aim of recruiting about fifty volunteers from each school. The median age of the 84 participants was sixteen years for girls (range 14 to 24 years) and seventeen years for boys (range 14 to 20 years). Any learner who had lost a close relative in recent months was advised both in the letter and on the days of the research, not to take part. The author also repeated that taking part in some or all of the activities was voluntary and they could withdraw at anytime. Both research assistants were prepared with strategies to help any child who became upset. Teachers advised that the volunteers consisted of both orphaned and non-orphaned children. To avoid stigmatising orphaned children, no obvious attempt to single out such children was made, but during data collection and analysis their orphan status was sometimes disclosed in the written accounts or in the focus group discussions.

5.3.3 Creating an ambience for researching sensitive issues

Each school provided a private room and space away from other learners and staff. In order to use the research as a beneficial AIDS intervention, advice and information about HIV/AIDS was included in the introductory activities at both schools, and helped to create an informal rapport with learners. Harpham *et al.*,

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

(2005) researching poor families and their children in Vietnam, describe the need to take time to establish a rapport with children so that they relax with interviewers. The author sought to create an informal, participatory atmosphere. Learners were treated as 'authorities' as they were the first generation to have experienced the pressures of growing up in an AIDS epidemic. The researchers were situated as learners. During the 'warm up' activities, discussions included some stimulus material compiled from dominant themes that had emerged during caregiver interviews. The themes included other issues besides sexual behaviour but they are beyond the scope of this paper. At the point where learners seemed to be relaxed and speaking freely, a range of voluntary activities was introduced.

64 of the 84 learners in the two schools chose to write about their views on teenage sexual decision-making and sexual behaviour (38 females and 26 males). Some commented on the stimulus material discussed, others ignored it and wrote in a completely open-ended fashion. Privacy was assured during this process as the rooms used were large and some learners had left to take part in focus group discussions in another venue. The author remained with the writing group, while the two Swazi research assistants facilitated focus group discussions. The discussions were taped and one assistant made additional notes. Five focus groups (three with girls, two with boys) took place, differentiated according to gender and school year group. Some learners also engaged in one-to-one discussions, or informal small group conversations, with the author. Others read information booklets provided, and asked questions on aspects of AIDS, either privately with a researcher, or in groups.

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

The transcribed family interviews, transcripts of school focus groups, learner's written accounts, researchers' notes on other conversations and observations with youth, teachers and community members, were interrogated and coded to gain a more nuanced understanding of sexual decision-making and sexual behaviour of young people. The main themes that emerged are discussed in the remainder of this paper with the help of representative extracts from both young people and caregivers.

5.4 Caregivers attitudes towards teenagers' sexual behaviour

5.4.1 Communicating the link between sexual behaviours and AIDS

In a study of gender-focused responses to HIV/AIDS in Swaziland, UNDP (2002a) found that: *'discussing sexuality issues with children is still considered a taboo by many people in Swazi society. The majority of the population was said to rather turn a blind eye and pretend that their children are not sexually active than discuss sex issues with them,'* (p.26). Yet Marwick (1940) in his ethnographic study of the Swazi gives a more nuanced insight to traditional sexual education within the kin group. He describes the custom of *ukujuma* practised by unmarried young people. It involved sexual arousal to the point of climax but without the act of penetration: *'among the Swazi it is part of normal education of children to have this custom explained to them'* (p.87). Kuper (1986) stresses the role of grandmothers in child rearing and this is likely to include the explanation of such customs.

Despite the explanation of such practices by specific family members, Sexual discourse within the Swazi family may be less overt than in some cultures but the research findings from the family interviews showed that many care-givers,

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

including elderly grandmothers, did try to discuss sexual behaviour and the risk of AIDS, though not always very effectively. Nhongo (2004) refers to the important role older people play, in Africa, as advisors to their families and communities, but he notes that older people are often excluded from information and education about HIV/AIDS prevention, and may even perpetuate misconceptions and *'contradict prevention messages targeted at youth in their care'* (p.9). Although lone grandmother carers were not a common feature in the Swazi families interviewed, grandmothers were often the head of a household of several generations and well respected in their households. Several grandmother respondents said they talked about AIDS and risky sexual behaviour with their teenagers but later, in the school survey, it became clear that exchanges with most adult care-givers, of whatever age, were limited in extent and rather vague in many cases.

Another difficulty for adult caregivers is the use of appropriate language. Chamberlain *et al.*, (2003), in a study of life-skill programmes in South African schools, found that language was a barrier to speaking about sex: *'Several teachers said it was particularly difficult to teach about sex using a language other than English, and that they would struggle to find words that are not vulgar in Sotho or Zulu'* (p.38). In an interview with the author, a Swazi director of an orphanage explained: *'we don't have the vocabulary about sex in SiSwati. We have words but it would be an insult to use them. When my own children challenge me, I have to relate in English.'* It seems that children, in the presence of adults, also find it difficult to use words that specifically refer to sex or sexual behaviour. In this research, as in similar work in schools in Tanzania (Nnko &

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

Pool, 1997), when talking about their behaviour, children often described sexual intercourse as 'doing this thing,' and avoided the specific words sex or sexual intercourse.

Though the nature of the exchanges were not explicit and need further research, most of the care-givers in the schools' catchment areas felt they did talk with teenagers about AIDS and risky sexual behaviours:

'I do talk to them about HIV and tell them to abstain or be loyal to one person'

(Grandmother caregiver)

'I do talk to them a lot about HIV/AIDS and our lives in general. I try to make sure they feel proud of where they come from and to resist pressure from their friends.'

(Mother)

'I talk openly with them about everything. Drugs, sex, HIV, everything.'

(Grandmother caregiver)

Some caregivers felt that their attempts to communicate were ineffective:

'I talk to them about HIV/AIDS every day but they don't listen.'

(Great-grandmother caregiver)

'If the parents are not educated, the educated teenager assumes they know everything. We were brought up differently.'

(Mother)

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

'Kids know the information but they are choosing to ignore it and they continue to sleep around.'

(29-year-old mother, supporting teenage sisters)

Others were critical of some caregivers:

'Teenagers make decisions on their own. There is no communication between parents and children. I will try with mine when they are older.'

(Mother)

'I do see some parents are trying but children don't listen. Some of the parents are drinking, that is why there is no discipline.'

(Mother)

5.4.2 Key influences on teenage sexual behaviour according to caregivers

Caregivers described friends as the dominant influence on teenage sexual behaviour, particularly when acting as part of a group. A second important theme was the influence of older men on girls. Some felt teachers were respected and effective at communicating with their teenagers and that schools could do more. Church leaders were not seen as particularly effective because many older teenagers did not attend church. In addition to the influence of different groups of people, the effect on young people of drugs, alcohol, poverty, and lack of opportunity were interlaced throughout conversations (alcohol is often home brewed and the street value of Swazi-grown cannabis is low, so both are readily available even to poor youths). These themes are exemplified in respondents' views below:

'The teenagers are listening to each other. When you do things as a group you tend not to remember what your parents and elders have told you. Drugs and alcohol are the number one problem. They are having sex without using condoms (condoms are available free of charge at health clinics and in several public

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

buildings such as Mbabane library but many factors besides availability affected usage). *Poverty is the cause of the spread of HIV. Girls do sex because men promise them things and they see it as a way out of poverty.*

(Mother aged 30, living with teenager siblings)

'I feel most teenagers listen to their friends but they do listen to their teachers so teachers could be more involved. The boys are involved in drugs and alcohol and teenage girls are prone to falling pregnant. I really fear my daughter will get pregnant.'

(Mother)

'The main problem I am seeing with teenagers in this area is they are really into drugs and alcohol. They smoke all day. It impairs their judgement. They have no vision and they are dropping out of school.'

(Grandmother caregiver)

'There are no jobs when they finish school so they are getting into drugs, pick-pocketing and breaking into houses. With the girls, they are falling pregnant and don't even finish school. I don't think they understand AIDS or they wouldn't be sleeping around.'

(Father)

'Teenagers these days don't like to go to church. The youth in our church are not very active. There are not many men at church either. Its peer group pressure, most are involved with drugs and alcohol so can't achieve a better life. There are a lot of teenage pregnancies. Men drink a lot too.'

(Grandmother caregiver and church elder)

'I think there is enough knowledge but they don't think it will happen to them. Once they are intoxicated with drugs they forget about safe sex. There must be talk about the link between AIDS and drugs. They are influenced by their friends to get involved with drugs and then they get into sex and problems of HIV/AIDS.'

(Mother)

Caregivers frequently expressed concern that their girls would 'fall pregnant,' a fear of girls becoming infected with HIV was mentioned much less often. The main concerns with male children centred on alcohol and drug abuse and where this

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

might lead. Again, becoming infected with HIV was not mentioned as the prime concern, despite the high prevalence levels in the neighbourhood and the high number of deaths.

5.5 The 'voice' of young respondents on gaining sexual knowledge

5.5.1 Sexual discourse in the family setting

Swazis are predominantly Nguni in language and culture. In traditional Nguni culture, the responsibility of providing sex education is usually delegated to the grandmother or in her absence, an aunt or uncle. Although, as mentioned above, there is a cultural emphasis on sexual abstinence and traditionally virginity was preserved by the practice of non-penetrative sex (UNAIDS, 2000a), new social sexual mores are developing that lead to a confused message for these urban teenagers. The gap in communication between caregivers and their teenage children remains for many young people. Some teenagers in the study did feel at ease gaining information from grandparents, aunts, uncles and parents, but the majority felt unable to talk openly about sex with adult family members. Both genders wanted their parents to discuss sex issues with them, especially in relation to AIDS, and to offer more guidance, as the following extracts show.

Focus group comments with in-school males:

'It is difficult to talk about it. Some of us are ashamed to talk about changes in our bodies. Even our parents didn't talk about HIV/AIDS with us. They say "you are not man enough, just wait a little bit until you are older," but that time never comes.'

'We are scared to speak to our parents. They will think I have started having sex.'

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

'Parents must talk to us convincingly. The advantages and disadvantages of this virus. How is it going to affect our lives and in what way? We need to know.'

'I talk to my aunt.'

'I talk to my brother.'

'I don't think it (the parent-child gap) can be bridged. We respect them (parents) too much, conversation consists only of greeting and asking for things.'

Focus group comments with in-school females echoed the above sentiments:

'At FLAS (Family Life Association of Swaziland) you can talk freely there, unlike at home. When you say, hey mom, what do I do when it happens to me? She will just misjudge you, you see, so you are not free to express yourself at home. The parents must be taught first 'cos, seemingly, where there are ones who are taught and their parents are left behind, we feel scared to tell them the truth. Maybe they should have a club for the parents to talk about sex and stuff. Maybe tell them to be open to their kids and stuff.'

'When your parents tell you: "hey you are going to the shops, you'll get pregnant," you get furious and then you want to do this thing without thinking, but when your parent comes down and tells you "you know what, my child, this happens, this happens, and this happens," you take your own decisions.'
(the facilitator asked the girl what 'thing' meant and she replied 'sex').

'At home there is no one that I talk to. My father came from a meeting where they were told about AIDS. He returned and just left the book on the table without talking about it.'

A few girls felt they could talk to female relatives:

'Mom and I talk about condoms. She tells me that when you sleep with someone, don't do it just like that, use a condom every time you do it. We talk about the consequences of unprotected sex without a condom, STDs.'

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

'My aunt does something like every month, call the teenagers in our family and she shows us a video about AIDS and says "if you do that and that you will get STDs and stuff.'

These findings are in accord with Ostergaard & Samuelson (2004) in West Africa:

'In relation to sexual and reproductive health matters, it seemed parents rarely talked with children about sexuality or bodily functions and most of our female informants had not received any information at all about the menstrual cycle from parents or from other adults in their household.'

(p. 108)

However, the importance of local context needs emphasis as in a larger quantitative survey at six sites in South Africa, Kelly (2000) found parents did talk about sexual health as 27% of respondents aged 15 to 22 chose parents as one of their top two sources of information about AIDS. Youth in S.A. are similar to Swazi youth in other respects though, as they both favour health sources of information above other sources such as teachers.

5.5.2 Sexual discourse with teachers

The Global Campaign for Education Report (2004) refers to evidence from seventeen countries in Africa and four in Latin America that *'better educated girls hold off longer on sexual activity, and are more likely to require their partners to use condoms'* (p 9). It is not just access to facts about HIV/AIDS but the empowering nature of education that places girls in a stronger negotiating position, according to the report. However, in Swaziland, the effects of education have not yet been reflected in the HIV prevalence levels of educated women attending

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

antenatal clinics, as shown earlier in this paper. In the 7th HIV sentinel serosurveillance report in 2000 (Ministry of Health and Social Welfare Swaziland, 2000), it was recommended that HIV/AIDS education should use *'new learning techniques such as project work, discovery based learning, child-to-child and youth-to youth techniques'* (p.61).

Given the poorly resourced schools, the support Headteachers need, to effect such changes in the curriculum, is large. The Deputy Head at one of the field site secondary schools, sums up the pressures facing teachers and learners and the desperate need for more resources:

'We have some learners who haven't paid fees for three years but we have kept them on to do their exams. Learners come to school without eating. Sometimes they haven't eaten for two days. Food is basic. Some are staying with Gogos (grandmothers). The Gogos have no social welfare. Some can't even afford school uniform. Most of the parents are not employed (in formal employment), so they go to shylocks (for loans for school fees). We do have pregnancies too. The rural area is better than the urban area. I am from the rural areas and you have land and can grow food. There is the traditional social structure. In my family, I can't take all the (orphaned) children so we split them up. We concentrate on them going to school and staying with a relative. We face the problems at home and in school. Its double. Swaziland is a religious country but you just don't know how to cope. There are kids with so many problems that sometimes you just don't want to hear more. We do encourage learners to tell us their problems but we encourage them to face their own problems. Being an orphan shouldn't be an excuse. When they moan about a stepmother, I talk about rights and responsibilities. They are affected a lot when their parents are sick. They have to leave class to take their parent to hospital. When I ask "Why you?" They say: "There is no-one else." Their work does drop off especially during their parents' sickness.

(Deputy Head interview, November 2003)

To help such learners cope, the Deputy requested food donations from teachers and other learners and asked Form 5 leavers to donate their uniforms to the school. The evidence from this fieldwork showed some engagement with

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

HIV/Education in both schools but it was often limited to formal learning approaches in science lessons.

A teacher in the first school remarked: *'We haven't done much on HIV/AIDS with Form 4 (standard 9) but Form 2 (standard 7) have.'* A Standard 9 learner told the author: *'we only do things on HIV/AIDS when we get to that bit in the book in the syllabus,'* and she showed the relevant part of a biology book. Standard 7 learners said they had discussed AIDS and condom use in class and they knew condoms were not 100% safe. In the second school the deputy head said *'we encourage teachers to talk about it, especially in Science,'* and, in this school, some learners mentioned teachers as possible sources of information and advice. Most learners were embarrassed to discuss sex issues with teachers and preferred the FLAS organisation in the town: *'teachers talk to us but we can't ask questions in class because they (other learners) laugh'* (female, focus group) and *'sometimes teachers tell us more about HIV/AIDS but we feel shy to approach them and ask more about the disease,'* (female, written account). Teachers are important role models as this learner explained *'the same people that teach us are those we see in town doing the things they say we shouldn't'* (male, focus group).

Research in other parts of Africa has also highlighted the barriers to providing sex education in schools (World Bank, 2002c; Chamberlain *et al.*, 2003, Gallant & Maticka-Tyndale, 2004; Global Education Campaign for Education, 2004). These barriers include: embarrassment on the part of learners and teachers, sexual abuse by some teachers, lack of training and support for life skills educators, lack of community approval for teachers to be teaching sex issues. Swaziland is therefore experiencing similar difficulties to some other countries in

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

delivering effective HIV/AIDS education within schools. These findings partly support a survey by Buseh *et al.*, (2002) that found Swazi adolescents preferred information from health-care workers.

5.5.3 Gender issues at health clinics

Learners mentioned two clinics that they used for advice on sexual issues and treatment of STDs. However, boys found it more difficult to use the clinics than girls, due to the perceived negative attitude of nurses, disapproval from peers, and fear about the way AIDS is portrayed, as these male Focus Group comments show:

'Most of us feel that when we go there, to FLAS, most of the people are girls so we feel shy.'

'FLAS people shouldn't frighten us too much with the facts, talking about AIDS as if it's a completely different disease, unique. They should normalise it.'

'I'm scared to go (to a clinic). They'll tell you you've started having sex.'

'If I go there my friends will think I'm no longer cool, you see.'

Girls were much more confident about using the health clinics:

'They teach us about HIV/AIDS and we have discussions.'

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

5.5.4 The influence of mass media

Buseh *et al.*, (2002, p.528) found, in their questionnaire survey of 941 Swazi secondary school learners: 'the majority of participants reported the print and broadcast media as their primary source of HIV/AIDS information.' The research findings here show that Swazi school learners are exposed to a range of conflicting messages on sexual issues. UNDP (2002a) describes one regular radio programme, which is hosted by Jim Gama, an authority on Swazi Law and custom: *'the host of the radio programme believes neither in condom use nor the rights of women,'* (p.26). Press reports in the Times of Swaziland have also questioned the reliability of condoms. Many learners in the survey had negative or inaccurate views on condoms:

'They (her friends) said that they don't want to condomise because this oil in the condom has AIDS, but they are not sure about that, they just think and talk. The problem is that they don't know about that oil so we have to get some people who will talk and describe this condom.'

(Female, aged 14, written account, describing her friends)

'They tell us that condoms are not protecting us from getting this disease HIV/AIDS.'

(Female, 15, written account)

'Nowadays we are told that even condoms carry the virus. It is better not to use them as we teenagers are not supposed to be having sex.'

(Male, aged 18, written account)

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

'I think you have to demolish the idea of condoms. The condoms now are useless. Because now they are saying that the condom is not 100%. So really, the 100% is to abstain, not to condomise. Because if you start to use the condom, sometimes you use the condom twice, which is not good.'

(Male, focus group)

Whilst homes may lack electricity, battery powered T.V.s are used in some and several learners, of both genders, referred to watching sexual behaviour on T.V. programmes, videos and what they described as 'porn movies.' They noted that actors and actresses often had several sexual partners and that condoms were not used:

'Who I think influences teenagers is the adolescent stage and these romantic and nude movies. What they see on these movies they will try to do experiments so that is why they don't abstain. They also see these actors changing partners now and then and they will want to do the same.....in none of these movies and dramas do they show them using condoms so they will want to know how it is like when you don't use a condom.'

(Male, 15, written account)

Meekers & Calves (1997), researching HIV high-risk behaviour amongst young people in Cameroon, suggest that exposure to western values through television, movies, novels and magazines might be one reason why adolescents start having sexual intercourse, but that other more context-specific factors, such as gaining sexual experience and financial or other economic factors, were more important. Ganguly-Scrase (2004), also describes how media images and Hindi films may encourage Indian girls to contest notions of women's sexuality, including arranged marriages, but concludes: *'in most cases their defiance is ultimately muted and*

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

their hopes of remaining unmarried are quickly dissipated,' (p.54). In both these examples, while global images of other sexual behaviours are now accessible in many poor countries, the influence of local social norms, values systems and economic circumstances still appear as the dominant influence on sexual behaviour.

The above section shows that these young people in secondary school wanted to have more accurate knowledge of HIV/AIDS and sexual issues, and that most wanted more discussions and guidance from their families, as well as other sources. They were poorly equipped with accurate information about the role of condoms in disease control and tended to hold negative views about condoms. The final part of the paper considers how they made choices about their sexual behaviour. It emphasises the need for multi-dimensional behaviour-change models that take into account the importance of gender in sexual negotiations, the influence of local social sub-cultures and the socio-economic conditions in the wider community.

5.6 Making choices about sexual behaviour

5.6.1 The range of options

The data collected portrayed a range of decisions about sexual behaviour across genders and ages. There were those who had decided to abstain, those who were having sex with condoms, and those who were having multiple partners without protection. Those abstaining were frightened of becoming infected and sometimes associated AIDS with moral failure. Sometimes the male decided against sex: 'I

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

told her I didn't want to catch up with HIV and did not want to go to hell' (male, 15, written account). Some implied they were using condoms:

'About the ABC (abstain, be faithful, use a condom) message, it is a fact that most teenagers do not take it seriously and to tell the truth, they really aren't even considering A and B.'

(Male, 17, written account)

'In the ABC message, like in A, girls are like "damn! Abstain? I've tasted it already." Others are like: "Abstain? I also want to taste what it feels like having sex." Some teenagers are faithful and condomise (when) they do it.'

(Female, 16, written account)

Others implied that multiple partners without using condoms, were quite common and some were fatalistic about AIDS, sex and death:

'Teenagers now don't take ABC messages seriously because they think that if you abstain your chances of marriages are going to be limited. They say it is a must to have more than one boyfriend to avoid disappointment. There is this slogan, usually said by boys, which runs: "you can't eat a sweet which is inside a paper, you won't have the taste," and they don't use condoms.'

(Female, 16, written account)

'We believe that, as young people, we have to enjoy ourselves. It's still our time. Yes. So as to enjoy ourselves we don't look at the generation. We don't look at these times, but there is this disease that is killing us. We apply the way where the developed countries are doing it. In America, my friend can have a boyfriend but she cannot get HIV. We still believe "I can do it" but we don't do it the way they do it.'

(Female, focus group)

'You know what? You will die sooner or later so why waste your life? It's better doing it.'

(Female, focus group)

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

'We are all going to die anyway.'

(Male, focus group, in discussion about condom use)

5.6.2 The importance of gender in sexual negotiations

There is much literature on the subordinate position of women in many sub-Saharan African cultures. Swaziland is a similarly patriarchal society where women are accorded the status of a minor in law. In 1940 Marwick wrote: *'as among the other Bantu tribes the female occupies a characteristically humble position in most spheres of life'* (p.60).

Kuper (1986) writes: *'no equality is expected or desired between Swazi husband and wife. He is the male, superior in strength and law, entitled to beat her and to take other women'* (p. 28). Despite the attempts of women activists to improve the rights of women and children, progress has been very slow and often meets with resistance (Aphane *et al.*, 1998, p.156). Even more recently a UNDP report on gender-focused responses to HIV/AIDS, states:

'Most cultural expectations and practices were found to contribute to women's vulnerability to HIV/AIDS. The Swazi society expects women to be subordinate and submissive; allows men to have multiple sexual partners; and polygamy, which exposes women to HIV infection, is legal in the country.' *'Condoms are generally available in the country, however, their usage is still very low, partly because of the myths surrounding them.'*

(UNDP, 2002a, p.2.)

The sexual negotiations between school-attending young people in the study generally reflected the subordinate position of females and low self-esteem, but, sometimes, males felt pressurised by their girlfriends to have sex. The

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

decision whether to use condoms or not was mainly taken by the males. Both sexes noted that drugs or drink-affected decision-making:

'Sometimes its not that we do not take it (AIDS) seriously, it's because of our boyfriends...they will be like: "Oh you do not like me."... Our boyfriends like flesh to flesh, they think it is more enjoyable without a condom.'

(Female, 16, written account)

'Others don't use condoms because they practise sex while they drink and everything happens automatically so they don't remember to use a condom.'

(Male, 18, written account)

'The lifestyle we lead now, exposed to parties where there is booze and drugs. We get exposed very young. We have a couple of drinks and a guy comes a long that you fancy and you forget about condoms. It is not necessarily because the man forces you to have sex.'

(One to one conversation with female, 18)

Female focus group comments on whether boyfriends insist on sex:

'No, he is not pressuring. I might be the one! I might be the one doing the dumping if he doesn't talk about it (sex).'

'Sometimes you feel pressure to have sex, to keep that man. Sometimes I enjoy it. Not always.'

'You know, some girls are not confident enough about their bodies, about themselves, they think, "I'm a virgin, I don't want to do this." Then some man will convince you some way or another. Then you think: "Oh what the hell! Let me just do it because everyone does it.'

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

This orphaned girl mentioned loneliness as the driving influence to have sex:

'You know how it feels when you don't have parents to love you, to look after you. You turn to someone. Some of them will even, like, go to older men and look for love in their arms. Its just like that.'

(Female, focus group.)

The place where sexual intercourse took place was varied but quite often within the home when parents were absent:

'You go home with the chick with the condom in your pocket. Your parents go to work. At the weekend, maybe they go home home,' (the homestead in the rural area), *'and you have the whole weekend.'*

(Male, focus group.)

5.6.3 Social sub-culture and economic drivers of sexual behaviours

For both genders, peer pressure, from their own gender, was very important and usually encouraged young people to engage in sexual intercourse. However, some girls encouraged each other to resist peer pressure. Boys felt particular pressure to have sex with their girlfriends as a sign of their masculinity and feared being marginalised and ridiculed by their male peers if they did not. This resulted in some males feeling unhappy and lonely. Girls also feared being mocked or losing female friendships but a wider range of options were seen as acceptable. In addition, in the written accounts, the most frequently mentioned reason for girls having sex was the need for money. Sometimes, this money was for necessities such as food or school fees but sexual transactions for goods such as mobile phones, jewellery and fashion clothes were frequently mentioned. Transactional sex was normally with older men but sometimes same-age male partners gave money. Boys were very aware of the role of older men and, as a consequence,

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

sometimes irritated by their inability to compete materially. The extracts below illustrate some of these points:

'Some teenagers feel that abstaining and being faithful to their boyfriends does not make them cool. They have many boyfriends so as to get recognition. They want to be the coolest kids at school and abstaining will make their boyfriends dump them. Teenagers should be encouraged to use condoms because they do not want to abstain. The condoms should be provided at school.....Sugar daddies have got cars and a lot of money so most girls are after these things. In return for these things the older men want to have sex with the girls without a condom. They do not have sex with only one girl. After they get what they want they dump you. Even if you are pregnant they do not accept the child. So in this way the virus is spread very quickly among teenagers.'

(Female, 17, written account)

'My own sister wanted to have a 18ct necklace and her friend had to come and take her at night to go to some place where they were going to make cash.'

(Male, 17, written account)

'When you don't make love to your girlfriend your friends laugh at you saying that you are shy, your lover will run away from you and look for sex.'

(Male, 16, written account)

'As teenagers we listen to each other and we have a strong influence on each other compared to the influence our parents have on us. For example, if a boy comes to me and says "have you had sex?" and I say "no" he laughs his lungs out giving the idea that I am a fool and he is clever. I have to have sex too which is very wrong.'

(Male, 20, written account)

'Parents, they do not give their children money. And these children look for people who can give them money and these people have sex with them and pay money for it.....Majority of us like cell phones and if someone who said that I must

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

have sex with him will give me a cell phone I will simply have the sex and get the cell phone.'

(Female, 16, written account)

Teenagers are also influenced by sugar daddies who would buy jewellery, have money and do luxury things for the teenager and by that way they would be influenced because they don't get those luxuries at their homes. Teenagers are also influenced by their parents who told them that nobody is going to have food on the table for them and no one is going to pay the bills. So in that way, teenagers think that the best way to have all this is to go to the streets at night, have sex with a lot of males and then they could have the cash to maintain the bills and put food on the table.

(Female 16, written account)

Teenagers are influenced by their friends. When they see they're having money for lunch they tend to have relationships with old people who will give them money to be like their friends. Fashion also influences teenagers to love sugar daddies because they want money to buy those fashion clothes.'

(Female, 16, written account)

5.6.4 Young respondents conclusions on what is needed to promote low risk sexual behaviours

During the course of the fieldwork, young people made various comments on what they felt they needed to help them make wiser decisions about sexual behaviour. More accurate information about the HIV virus and the protection afforded by condoms was often mentioned. They also wanted more help in decision-making and more opportunities to talk about sexual issues. Males in particular, felt isolated and confused. Whilst fearing HIV/AIDS on the one hand, male peer-pressure to practise high-risk behaviour was intense. Both genders wanted their family care givers to be more open with them about AIDS and sexual issues. They suggested peer education and links with youths in other schools and the use of well-informed educators who were close to them in age.

5.7 Conclusion: linking the research findings to some practical solutions

5.7.1 The main findings and their limitations

This small-scale, qualitative study set out to give a more nuanced understanding of how young people in Swaziland make decisions about sexual behaviour in the context of high prevalence levels of HIV/AIDS. It draws on respondents from a relatively poor urban area and youth in other settings may have different experiences. Researching sexual decision-making and sexual behaviour with adolescents is obviously difficult given the desire to impress peers and the personal nature of the subject. While these limitations must be borne in mind, by using a variety of data collection methods and a variety of respondents, this fieldwork supports the evidence from the Swazi BSS survey as well as findings in other parts of sub-Saharan Africa (Varga, 1997; Meekers & Calves, 1997, Kinghorn, 2002, Ostergaard & Samuelson 2004). There was inadequate knowledge about the disease, its transmission, and the efficacy of condoms. There were cultural and economic drivers of high-risk sexual behaviour superimposed on the development stage of adolescents, where peer pressure is of particular importance. Drugs and drink were also strongly linked to high-risk behaviour. The perceived need for cash was a dominant cause of high-risk behaviours amongst school-attending females in the study. The negotiation between sexual partners was dominated by males in most cases and reflects Swazi attitudes towards gender. Some teenagers were choosing to abstain from sex and girls may support each other in this decision. However, cultural constructions of masculinity were problematic for those male youths who wished to follow less risky sexual behaviours.

5.7.2 Recognising the vulnerability of adolescents

The results show that Swazi young people have similar adolescent experiences to adolescents in other cultures in many respects: anxiety over changes in their bodies, a desire to be liked and accepted by their peers, difficulty in communicating with their parents and a desire to make their own decisions. Some were clearly lonely, confused and feeling vulnerable about sexual decision-making and sexual behaviour. Surrounded by unemployed relatives, death and illness, and unsure of their own future prospects, some adolescents seemed to be retreating into childhood as a form of denial rather than embracing the perceived uncertainty of adulthood. Choosing to ignore confusing 'safe sex' messages and deciding '*it is still our time*' and '*we are going to die sooner or later,*' may partly reflect the development stage of adolescents and the need to break away from authority, but it may also reflect the deep fear, insecurity and uncertainty they are experiencing. Denial of the reality around them may be a coping mechanism for some. Young people wanted much more discussion and guidance from well-informed adults and a more positive vision of their future where low-risk sexual behaviour could become part of the pathway to achieving that vision. The agency of children and the need to listen to their experiences and their coping strategies is increasingly recognised. Cunningham (2003) refers to children as social actors entitled to be involved in decisions that affect them. He argues that children have an important role to play in their own protection, though he cautions against giving them more responsibility than they can manage.

5.7.3 Youth and the elderly as part of the solution at community level

Parker (2004) also stresses the need to move from top-down approaches to participatory approaches at community level to achieve behaviour change. He sees people and communities as agents of change, and calls for a move away from a focus on individual behaviour to integrating communities in assessing issues of concern at local level.

These findings in Swaziland, and the literature referred to above, suggest that young people, with adequate adult support and guidance, could be much more actively involved in promoting low risk sexual behaviour. Agha (2001) evaluated a peer-led HIV prevention programme in a secondary school in Zambia and found that peer education provides information in a setting adolescents are comfortable with and is effective. Given the present reality of young people's sexual behaviour, prevention education must extend into empowering each gender to have choice over their sexual behaviour and a right to sexual health. This includes the right to choose abstinence if they wish. Abstinence and delaying sexual debut is too late for some in the 15-19 age group. It must become the norm for youth to take regular HIV tests in easily accessible, youth-friendly clinics. HIV negative youth have an incentive to stay that way. It must be the norm for results to be shared with partners and not just taken on trust. Respect for each other's sexual health must extend to accurate practical knowledge of how female and male condoms work and how they can fail to protect if used carelessly.

There is much more older, unemployed youth in communities could do. Resources for community centres, perhaps based in schools after hours, not just for health education but to provide recreational opportunities and vocational advice

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

for youth, would help break the cycle of boredom, lack of vision/drink/drugs/unprotected sex. These centres could provide well-informed peer educators who would also be able to reach marginalised out-of-school youth. Some salaried youth development staff would be required and, given the levels of poverty and perceptions of community work, assuming high levels of youth volunteerism is unwise. The author interviewed the young male Mbabane Urban Youth Network Secretary. He felt that youth needed some incentive to be involved with community work. He was helping with a community soup kitchen but remarked: *'for many of my friends, community work doesn't look glamorous.'* He suggested the provision of education scholarships for those who showed commitment to community service over a period of time.

Peer education could be extended to include elderly peer educators so that grandparent caregivers become well informed. The Islamic Medical Association of Uganda (IMAU) found that whilst mass information campaigns help some people, many needed a more personal approach:

'Overall, individuals are more likely to adopt safer sex practices if they are perceived as the norm prevailing among their peers and community. It is crucial to work at the community level to personalise social norms, such as mutual fidelity and the moral responsibility not to endanger others.'

(IMAU, 1998, p.14)

5.7.4 The importance of schools

The difficulties of providing better HIV prevention education in under-resourced schools have been discussed, but there are ways that schools can help empower youth over sexual decision-making. The Global Campaign for Education (2004, p.15) suggests that free primary education in Uganda, introduced in the mid-90s,

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

and the inclusion of AIDS education in the classroom, led to a 'sea change' in sexual behaviour *'in one school district in 1994, more than 60% of learners aged 13-16 reported that they were sexually active. In 2001, the figure was fewer than 5 percent.'* Schools need to be better resourced to include a wide range of life skills in a revised curriculum. Kinghorn (2003) refers to the low importance of life skills in the curriculum in other African countries and how often the best staff do not teach it.

Ostergaard & Samuelson (2004) describe how sexual relations require negotiation among partners and: *'young people, particularly young girls who are disempowered and without strong communication skills, find themselves incapable of negotiating condom use'* (p111). Creating open-ended learning styles in all subject areas where girls are encouraged to analyse, discuss and form their own opinions and where boys are encouraged to consider wider constructions of masculinity, are needed. The forum for such discussions needs to be non-threatening and participatory. Occasional provision for lessons split by gender may encourage more female engagement. It takes time for such initiatives to take effect but the evidence that education protects against HIV infection is strong especially if started before sexual debut (World Bank, 2002c).

5.7.5 The role of the international community.

Youth in Swaziland are an integral part of the larger society around them and Bray (2003) warns us of the dangers of labelling groups of children, in this case children affected by AIDS, according to just one aspect of their lives without considering the wider social and political setting. As Piot (2005) emphasises, AIDS is far more

CHAPTER 5: Sexual Discourse and Decision-Making by Urban Youths in AIDS-Afflicted Swaziland

than a health issue and is driven by inequality of all kinds. Whilst health issues and the roll-out of anti-retroviral treatment are absolutely vital, the international community must also continue to help AIDS afflicted countries in their fight to reduce the rate of new infections. Supporting education and community initiatives, as suggested in this paper, is part of the solution. Another part is to work towards reducing the poverty and lack of opportunity experienced by youth in poor settings so that they have a positive vision of an achievable, disease-free future.

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

6. CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

6.1 Introduction

Based on qualitative fieldwork with older children in the poorer urban areas of Mbabane, the capital of Swaziland, this paper questions whether the macro-level discourse about the lives of children orphaned by AIDS reflects the lived experience of families where high levels of HIV/AIDS pertain. Does this discourse reflect a 'northern' perception of childhood and does it take into account sufficiently the contextual setting? Bray (2003) describes how certain categories of children are in the spotlight for a short time such as '*street children*,' '*trafficked children*,' '*child soldiers*,' until a new group of vulnerable children, in this case AIDS orphans, emerges. There is then a tendency to pathologise the category of children '*whilst ignoring their many links into mainstream society*.' (Bray, 2003, p.52). She question whether this leads to appropriate programmes particularly in cases where there is no consultation with children and their families about how they live their lives. Bray writes:

'The raft of critique written in the 1990s of the approaches to street children during the previous decade ought to warn us of the dangers of labelling groups of children according to one aspect of their lives.'

(Bray, 2003, p.52)

Further contextual research with street children has shown that there are a wide variety of livelihoods experienced by children on the street and these livelihoods

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

are closely intertwined with wider social, economic and political issues. In other words, targeting 'street children' with a particular programme without an adequate understanding of the lived experience of the children may undermine rather than improve their livelihoods. Glauser (1997), researching the lives of street children in Asuncion, Paraguay explains:

'My practical difficulties had therefore led me to discover that the terms and concepts used about street children were not only imprecise but also lacked operational value. The same terms were used in different parts of the world to refer to very different types and situations of children.'

(Glauser, 1997, p.151)

Glauser was also concerned that creating categories of children might mean that other children, less visible and less of a concern to society than street children, might be ignored (for example, child domestic workers or children in permanent institutionalised care).

Despite recognising the limitations of categorising children in this way, reports with titles such as: 'Policies for orphans and vulnerable children: a framework for moving ahead' (Smart, 2003) or research papers such as 'Psychological distress among AIDS orphans in rural Uganda' (Atwine *et al.*, 2005) continue to appear. Given that HIV serology rarely occurs on death certificates in Africa, such research often entails asking community leaders to identify those orphaned due to AIDS yet such approaches in NGO policy reports and academic research merely increases the stigma and isolation felt by children orphaned because of AIDS and widens the gap between the lived reality of poor families affected by AIDS and those who seek to help them.

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

More recently UNAIDS, UNICEF and USAID (2004) have avoided using acronyms such as OVC (for orphans and vulnerable children) or the term 'AIDS orphan' because: *'experience has shown that such jargon eventually becomes used at the community level to identify particular children. When asked what they prefer to be called, children have said, "Just call us children" (p.6).'* Caregivers rarely differentiate children according to cause of parental death or according to whether they are orphaned. Their perception of vulnerability is usually centred on children's poverty, whether or not their parents are alive, as both this fieldwork and the work of Chamberlain *et al.*, (2002) shows. Given that the development vogue is for community-based initiatives to alleviate suffering and improve livelihoods, a deeper contextualised understanding of children's lives is needed if these initiatives are to be sustainable in the longer term, long after the donor community has moved on to the next category of vulnerable children.

There has been much concern about the consequences for society if children grow up without parents (Cornia, 2002, Barnett & Whiteside, 2002). Cornia describes the mental health problems that may occur:

'But even if they were assured of material resources, the AIDS orphans would face an uncertain future and a considerable affection and socialisation deficit. In the best of circumstances, the death of parents means they have to live with relatives or in orphanages, face emotional deprivation and psychosocial stress and possibly suffer from ill mental health (sic). They may also become more aggressive, represent a menace to society, commit crimes, turn to drugs or become sex workers.'

(Cornia, 2002, Chp 1, p.12)

Bray (2003) argues that there is insufficient research evidence to support these pessimistic scenarios. However, this sort of negative discourse has helped to

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

focus attention on children orphaned by AIDS as a distinct category of children as if they are a relatively homogenous group. There is the additional problem that donor programmes that target certain categories of children over others may be culturally inappropriate. Policies that target orphaned children but exclude other extremely poor children whose parents are alive cause resentment at community level (Williamson and Donahue 2001; Chamberlain *et al.*, 2002). Boyden & Levison (2000) argue that *'policy must develop more pluralistic concepts of childhood that lead to the understanding that children's experiences are extremely varied'* (p.56), and *'universal policies based on external notions of what is in children's best interests are unlikely to serve children effectively'* (p.56). Both Glauser (1997), in relation to street children, and Bray (2003), in relation to families affected by AIDS, question whether policy makers consult sufficiently with children and their families to gain an understanding of their lives.

Boyden & Levison (2000) argue for context-specific programmes where the community is involved in identifying the most vulnerable children, given that this often has to be done in resource-poor settings where not every child can be helped. They argue that it is important not to cast children as victims and to respect the ability of children to help themselves, while recognising that some children are more resilient than others. It may also be a mistake to assume that parental death from AIDS is inevitably linked to stigma and isolation in a way that is different from children in other challenging circumstances. As Tolfree (2003) points out, the issues faced by children, families and communities affected by AIDS have some similarities with issues faced by children separated from their parents through armed conflict, genocide and civil war. He notes that in most

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

cases there are large numbers of separated and often traumatised children who urgently need care and protection in settings where social services infrastructure is weak. Apart from sharing research and programming from these situations, he argues that to develop worthwhile policies, the agency of children should be recognised and their voice included.

Participatory research with children has increased significantly in the past two decades in the North. However, Boyden & Levison (2000) comment on the *'lack of child-centred information from the South'* (p.8), and the danger of applying northern models of childhood to other regions of the world. Glauser (1997), referring to *'Third World societies'* writes: *'there is very little knowledge about the way the children who are themselves directly affected by serious problems of life and survival think about their situation. The dominant ways of speaking about street children for example are discourses "about others",* (Glauser, 1997, p.151). Robson (2004, p. 241), researching care-giving by young people in Zimbabwe, argues that the universal discourse on childhood is dominated by northern *'myths of childhood'* as a time of play, schooling and innocence. She goes further and connects children's lives as caregivers in AIDS-affected households to macro-level policies of privatisation of public welfare services. Robson also recognises that there are impacts on children who are not (yet) orphaned, but that the needs of such children get little international recognition.

This introduction has outlined the need for more in-depth participatory research into the lived experience of children and families affected by AIDS. The fieldwork presented here seeks to contribute to a more nuanced understanding of childhoods in the South where AIDS is endemic. It goes beyond the material

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

needs to include social and emotional challenges faced by children and their carers in a resource-poor urban setting with some of the highest AIDS prevalence rates in the world.

In particular it asks:

1. How do adult caregivers react and adapt as children are orphaned in their extended families? Do they perceive orphaned children to have any special needs?
2. What do young people feel about the illness and death of their parents? How do they adapt to their circumstances? What insights do they give on building their capacity to cope? What are their preferred options?
3. How do young people who are not themselves bereaved, react and adapt as their cousins and friends lose their parents? What insights do they have on the experience of bereavement during adolescence?
4. How might these insights help inform the policies and programmes of those seeking to mitigate the effects of orphanhood?

6.2 Methodology

The author worked as a teacher in Mbabane from 1999 to 2002 and became aware of children coping with parental death. Some of these children, now adult, have remained in contact with the author and continue to share their experiences of growing up through the challenges presented to them. Whilst their lives are not directly referred to in this paper, they gave insights that helped guide the research design for this study. The fieldwork took place from September 2003 to January 2004 with a short follow up visit in November 2004. The aim was to allow the

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

'voice' of older youth to be heard in as sensitive a way as possible without creating further trauma. 110 young people volunteered to take part. Of these, 84 were from two government secondary schools and consisted of a mixture of orphans and those with parents alive. The schools' catchment areas covered a range of socio-economic groups from those living in *mud-and-stick* dwellings in informal settlements through to some middle-income housing in formal settlements. At the request of the deputy headteachers, the school learners were all from Forms 2 and Form 4, as these years did not have external exams. The mean age of participants was 16 years for both girls and boys but there were a few much older learners resulting in an age range of 14 to 24 years. Given the aims of this research, their insights were also included where relevant.

The remaining 26 participants were not in formal school but attending literacy classes part-time in two informal settlements. Their ages ranged from ten to seventeen. The government provided these classes for mainly orphaned children who were too far behind to be absorbed in formal school and judged by local government officials to be too poor to pay school fees.

Preliminary visits were made to the field sites to explain the nature of the research and to stress that anyone who had lost a close relative in recent months should not take part as the research included discussing family life, bereavement as well as growing up in an AIDS epidemic. Letters were also given to the 84 literate school volunteers in an attempt to achieve 'informed consent.' Teachers at each location helped to ensure learners were well informed and not recently bereaved. No attempt was made to distinguish orphans from non-orphans. However, orphan status often emerged during FGDs, first person written work or

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

one to one conversations with the author. Two locally recruited young Swazi female research assistants (one a medical student, the other with experience as a counsellor) were recruited to assist the author and on the days of the research they also reminded children that the activity was voluntary, that they could withdraw at anytime, and again participants bereaved in recent months were advised not to take part. One child decided at this point to withdraw. After some warm-up activities to help create a participatory atmosphere and to help learners relax, they were asked to take part in focus group discussions (FGD) or, for those in formal school, to write down their views if they wished. Some participants chose to have one-to-one conversations with the author.

At both secondary schools lessons were taught in English, but participants were encouraged to use either SiSwati or English, whichever they preferred. Nearly all of the 67 written accounts were completed in English. Some SiSwati was used in FGDs. Five in-school FGDs were completed and each was taped and notes were made by the second research assistant. Transcription took place the same day. Children not in formal school took part in three FGDs. They spoke mainly in SiSwati and translation of transcripts and notes from the three FGDs was necessary.

Other information came from: in-depth semi-structured interviews with 19 families who lived within the schools' catchment areas and who had taken in orphaned kin; in-depth interviews with key informants working with children in the area (teachers, NGO social workers, directors of orphanages, government officials) and participant observation by the author. A research assistant acted as

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

an interpreter for the author at family interviews where SiSwati was the preferred language. An interpreter was unnecessary for most key informant interviews.

The interviews, FGDs, written accounts and author's observations are drawn upon below to represent the experiences of orphanhood in urban Swaziland through the lens of three groups: firstly adult care-givers, secondly orphaned youth and thirdly youth not orphaned but living with or attending school with those who are.

6.3 Adult care-givers experiences of caring for bereaved children

The 19 family care-givers who took part all lived in informal settlements but the range of livelihoods varied from those with brick-built structures serviced by tap water and electricity to those living in one room mud-and-stick dwellings without on-site services. Using a variety of entry points, purposive sampling was used to select families caring for orphaned children. Interviewing continued until little new material was emerging. The families were caring for a total of 57 orphans of whom 46 were living within 15 large, well-established, extended families. Nearly half (28) of the orphans lived in the better quality homes with only 18 orphans living in the poorer mud-and-stick, unserviced houses. Child-headed households (that is, a household of children without an adult care-giver), a term much used in the AIDS literature, were surprisingly few in the informal settlements visited in 2003/4. Despite the very high adult HIV prevalence rates of 40.6% in urban areas (Ministry of Health and Social Welfare, 2002, p.25), relatives were still managing to care for the majority of orphaned children. Most families had absorbed orphaned children on an *ad hoc* basis out of a sense of kinship duty or because there were no other

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

kin left. In some cases the parents or single mothers lived within the extended family at the time of death, and the children just stayed on with the remaining relatives. Some carers felt coerced into taking in kin, while others had volunteered. None mentioned any formal arrangement or discussion prior to parental death.

Ansell and Young (2004) researching families in Malawi and Lesotho, found that guardians who received related children into their families concentrated on material needs of food, clothing and education. 'Guardians were often less aware of young people's psychological needs' (p.6). The findings in Swaziland are similar. Families prioritised the same three material needs of food, clothing and school fees as well as children's medical costs and the children's future care after they died. A few carers made comments about the emotional needs of orphans, but most carers did not consider orphans needed any more help than other children in the family as this great-grandmother explained: 'orphans do have special needs as they don't have anyone to run to but other children have needs too.' She lived in an extended family where there were both orphaned and other children. When asked why she had agreed to take them in she said: 'there was no formal request. It was my kids' children so when they died I automatically took them.' Having taken in orphaned kin, the overwhelming concern centred on school fees and food. This grandmother's response was typical:

'My main concerns are education and food. I really struggle because if the pastor stops paying for them I have no way I can take them back to school.'

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

Teachers and NGO social workers often faced the same problems as those in the community whom they were seeking to help. Decisions about placing children within families were based on material practicalities as this teacher explained:

'In my family I can't take all the (orphaned) children so we have to split them up. We concentrate on them going to school and staying with a relative.'

Such sibling dispersal did not involve discussions with the children and was undertaken reluctantly. Young and Ansell (2003a) refer to similar practices in Lesotho and Malawi and the feeling of isolation bereaved children experience when separated from siblings. One NGO worker referred to changes in the dynamic of her own family after she took in her bereaved nieces and nephews: *'my own children see there is less cake to be divided in all spheres, including attention.'*

The care-givers interviewed did not appear to discriminate against orphaned children in their care (for example orphaned children were as likely to be attending school as other children in these families), and it is possible that once a child is absorbed within the family it is taken for granted that the orphaned child's wider emotional and social needs are met.

How personal feelings are expressed within families varies in different cultural contexts, and the subtle ways Swazi children cope with bereavement and benefit from a sense of belonging and security within the kinship group may be different from richer countries where non-kin professional counsellors may be consulted more readily. European and North American cultures tend to stress the

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

rights of the individual child, whereas Swazi culture is more oriented towards the needs and responsibilities of the whole kinship group in which the child is embedded. Kuper (1986) explains this difference:

'Swazi classify kin into a limited number of broad categories, embracing within a single term relatives who, in more specialised and isolating societies, are kept distinct. Thus the term "father" is extended from one's own father to his brothers, half brothers, and sons of his father's brothers.' (p. 27)

Within the common category of father Kuper describes different degrees of closeness so that *'the father who bore me'* is distinguished from *'my big father'* (father's older brother) or *'my little father'* (father's younger brother). However, *'behaviour towards all "fathers" is modelled on a single pattern'* (p.27). Kuper explains that this system, where kinsmen are covered by a single term and share a common social identity, allows kin to substitute for each other in times of need: *'an assumption only tenable in societies where specialisation is limited and where greater importance is attached to the kinship group than to the individual.'* (p.28). This attitude towards kin was exemplified by one young Swazi adult respondent who explained that as he grew up he was taught that it was selfish to think in terms of his own needs and he was always encouraged to think of himself as part of the kinship group, referred to as the spirit of 'ubuntu.' It was not the norm to speak about his own feelings or to challenge the comments made by older members of his family. His duty was to cast his eyes downwards, listen respectfully and learn from his elders. His sense of belonging to the larger kin group meant he felt able to visit, eat and stay with any of his relatives without prior

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

arrangement. In turn, his family would extend the same hospitality to kin who visited. Problems were discussed at family gatherings, and children had the right to discuss matters with their grandmother. The grandmother's word on the matter would be final and the parents would not be able to over-rule her. The grandmother was like the final court of appeal for children. The author has observed these types of relationships in Swazi families over several years and the resultant sense of belonging and loyalty to the kinship group that it gives to children. The importance of the grandmother was again emphasised by a key informant who explained that families would still return to 'gogo's place' to discuss important family matters, even after her death.

The current research and NGO interest in 'psycho-social' needs of orphans and vulnerable children will need to consider such cultural nuances. Consulting counsellors from outside the kinship group may seem alien and disrespectful particularly where grandmothers are caring for orphans, for example. Apart from the difficulty of providing properly-trained counsellors (four week intensive courses based on Northern practices of counselling in order to 'scale-up' interventions may do more harm than good), it may undermine the local, in this case Swazi, way of providing support for children experiencing grief and loss.

Despite sometimes having insufficient basic essentials of food and clothing, the families in this study were taking in an average of three orphans each, and very few children were left to fend completely for themselves.

There is much research and NGO discourse around psycho-social needs of children affected by AIDS, but this is pathologising the lived experience of children as if there is a 'medical fix' for this one aspect of their lives. The voices of

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

children in this paper, particularly those who were not in formal school, show that their lives were often dominated by grinding poverty and multiple deprivation, which in themselves may cause mental health problems. Harpham *et al.*, (2004) studying mental health amongst youth in a low-income urban community in Cali, Colombia, found that poverty-related factors were linked to poor mental health. The most important risk factors were: being female; no schooling/incomplete primary; and being a victim of violence. Chamberlain *et al.*, (2002) argue that children orphaned by AIDS do face some unique challenges, but many of the vulnerabilities they face are shared with other children living in poverty, and they should not be therefore be treated as a separate group: *'we strongly recommend that a service response to the needs of this group of children (orphans) be integrated into a broader response to the needs of children living in poverty'* (Chamberlain *et al.*, 2002, p. 37). When orphanhood is used as the criterion for assistance, problems often arise (Chamberlain *et al.*, (2002); UNAIDS 2001; UNAIDS, UNICEF, USAID (2004); Chamberlain *et al.*, (2003); Phiri and Webb (2002).

The author's view that children's coping strategies after bereavement should not be 'medicalised', and that poverty alleviation measures should be used to strengthen families coping strategies (such as the provision of anti-retroviral drugs which prolong parents' lives and social welfare grants for the elderly) is not intended to trivialise the challenges bereaved children face or to romanticise the role of extended family care. The next part of the paper reflects the serious issues children affected by AIDS face, whether living within or outside the family.

6.4 Children's lived experience of parental loss

6.4.1 Grief, loss and coping strategies

The following extracts are from orphaned youth both in and out of formal school. Orphans enrolled in secondary school described their feelings of emotional loss and sadness as well as their struggle over basic material needs. However, the orphaned children attending literacy classes, but not enrolled in formal school, mentioned a wider range of material deprivations and were much more likely to describe feeling isolated and excluded. It should not be assumed that all in-school children were substantially better off in terms of basic needs than out of school children as one Deputy Head at the field site explained:

'We are experiencing a lot of change and we are aware it's because of HIV/AIDS. Learners come to school without eating. Sometimes they haven't eaten for two days. Some are staying with gogos (grandmothers) and gogos have no social welfare. Some can't even afford school uniform. There are a lot of poor children in urban schools.'

(Interview, Nov. 2003)

The following extracts illustrate some of the challenges faced in resource poor settings after parents die:

'I think that these orphaned children should be provided with the most important things first like counselling. Even if a child has lost only one parent maybe the mother or the father she will be very disturbed. I for one lost my mother last year (in) May. I now live with my father and two younger sisters (the father only comes at the weekends). Sometimes I would stand at the door and look at the direction she used to come from every evening after work. I would swear that I had seen her and break down and cry. The pain I felt is humungous (sic) and there is nothing I can do about it. That is why I think that there should be counselling provided for these children as they are made upset by the most simplest things.'

(Female, maternal orphan, in school, written account)

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

The unhappiness felt by some orphans lasted many years and was exacerbated if the child had experienced several unsatisfactory homes. This girl's father died ten years ago and mother six years ago, she had moved several times as one carer was jailed and a second attempted to abuse her. She is now living with neighbours who are not kin and she is separated from her brothers. Despite these traumas, she has been very resourceful in finding ways to cope:

'Sometimes I cry when I think of my parents and the happiness we used to have as a family and now we are split apart. I love my brothers. I wish to be with them, especially the younger one but I can't. I never used to worry about things like school fees when my father was still alive but now it is happening. I'm not sure what killed my parents but they both suffered from long illness. Sometimes I wonder if my family was cursed because how could they both die and leave me with their children? Life is sometimes unfair, why at least mom should have lived so that she can take care of us then die when we have fully grown.'

When I was supposed to go to Form 1, the person paying my fees was put in jail so I stayed at home again. Then I went and told the headteacher about my story and she found me a sponsor at Salvation Army. I am now living with another family whom I am not related to. Their lifestyle is very different to the one I was living before. They provide me with accommodation and food but not things like clothes, pads and body ointment. I have to buy them for myself. I only manage if at school they buy the sweets that I sell. I am trying to find sponsors for them (her brothers who have dropped out of school) but it is difficult, but I hope when I finish school next year I will be able to get a job and pay for them.'

(Female, double orphan, in school, written account)

In a one-to-one conversation with the author, one male learner described losing his mother. He had never known his father but he had been told he had died too. His stepfather remarried and he felt badly treated by his stepmother so he went to live with his uncle. He was now being teased at school because he didn't have a girlfriend, but he felt frightened about trying to love someone in case he lost them. He also wrote:

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

'When you don't have parents and you mix with some children who have parents and talk how much their parents love them, how they buy them gifts, it is the most painful thing to listen to knowing that you've got no-one to tell you how much they are proud and love you. It really kills me inside. There is a hole in my life and that is I missed being loved and for that reason I don't know how to love.'

(Male, double orphan, in school, written account)

In contrast to the accounts above, children who had been placed with a relative they liked and had not endured several moves seemed much less affected by parental loss. In line with findings in Malawi (Tolfree, 2003), this schoolgirl spoke highly of her grandmother's care:

'Nothing has changed since my mother has died. My gogo sees to everything. I do miss her but my life has carried on as normal thanks to my gogo.'

(Female, maternal orphan, in school, conversation)

6.4.2 Orphaned children experiencing abuse and exclusion

Institutionalised care is heavily criticised for its potential to allow abuse to remain undetected: 'anecdotal evidence suggests that children abused in institutions may have greater difficulty in reporting abuse, escaping from the situation, or getting help from outsiders,' (Dunn *et al.*, 2003, p.9). Given that institutionalised care is too expensive for poor countries to afford (Phiri and Webb, 2002) and 'does not provide the holistic care that children are entitled to for all round development' (p.15), the donor community is emphasising community-based initiatives. Yet, as Ansell and Young (2004, p.4) point out, the term 'community-based care' is ambiguous and it assumes that there is a 'readily identifiable static community to

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

which orphaned children and their guardians belong.' In Lesotho and Malawi orphaned children were seen as the family's responsibility, not the community's. Ansell and Young therefore argue for policy responses to be directed towards households.

The findings in urban Swaziland mirror those of Ansell and Young (2004). Orphaned children were also seen as the family's rather than the community's responsibility. At the time of the fieldwork there was very little assistance beyond the family. There were several NGOs assisting orphaned children and elderly caregivers at household level in the urban area, but the coverage was piecemeal and lack of long-term funding made sustainability an issue. When asked about their own community initiatives for orphans, respondents were unaware of any discussions or plans by community leaders or churches in the settlement. The concept of community as a bounded urban space was problematic, as many residents had allegiances and loyalties to family members living in other places, including rural areas. The community leader did not have a list of orphaned children and felt that the extended family was still strong: *'even though many of the young have died and many children are with elderly carers.'* His main concerns for the community were centred on improving housing and the dirt roads that were often impassable after heavy rain (interview 11.11.03). A church elder and community committee member complained that few people turned up for community meetings and that it was difficult to mobilise community projects:

'It is somewhere we came to work but now our parents are dead so we don't really have roots back home. There is a mixture of those who see it as home and those who don't feel so loyal. Some are tenants or they have a home that is rented or they think of as only temporary. Less than twenty turned up for our last meeting.'

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

They don't seem to care. They will use what you do but won't help you do it. They are lazy.... They don't have time. Perhaps the funerals at the weekends are taking their toll. We have to travel back to the rural areas.'

(Interview 10/12/03)

Like the findings in Lesotho and Malawi, the concept of community involvement in orphan care is at best embryonic, and Swazi orphaned children in urban areas are likely to remain cared for within households where a relative is present or lives near by. However, there is no room for complacency in relation to child-protection issues with this form of care within the community, particularly if the children of a family have been 'shared out' amongst relatives so that the children are far from other adults and friends whom they trust. Boyden and Levison (2000) argue: *'although policy assumes, intuitively, that children are better off in the care of foster or adoptive families than in institutions, this is effectively an act of faith, in that there is very little evaluative information comparing the well-being of children in these different settings'* (p.58). Even in rich countries with well-developed social welfare legislation and well-trained social workers, it can be difficult to protect children living within households from various types of abuse. Boyden & Levison (2000) researching the agency of vulnerable children suggest that: *'policy will need to focus on enabling children both to access systems of referral and support and to better protect themselves'* (p.56). In FGDs and written accounts, some orphans reported relatives no longer being supportive after parents died, and children were unaware of where they could seek help. The following extracts indicate that some orphaned children within households need much more protection from emotional, physical or sexual abuse. In many cases the children

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

took action to avoid the abuse, but not all were successful. It is also noteworthy that material poverty featured heavily in these children's lives:

'The most important thing I have noticed is that these children are no longer safe at all. Another thing is they are being isolated such that even the people who were close relatives start to neglect that child. The children who are left with their fathers witness abuses from their own fathers who they trust. I am one of those children.'

(Female, maternal orphan, now living with an aunt, written account)

'In 1999 when I was doing Standard 5, my Dad died after a long sickness. We were left with my mom. People from my family came and took all the furniture in the house. During the year 2001, my mother died too. My brothers went to stay with my uncle who is not working. Because there is no money they drop off from school. My father left us some money at the High Court; nobody is helping us get that money. We don't know what to do.'

(Female, in school, written account)

Exclusion featured heavily in orphaned children's lives. Children both in and out of school described their dislike of feeling 'left out' or different from other children whose parents were alive. Where they were aware of parental death or sibling sickness from AIDS there was additional stigma, and most children tried not to disclose the nature of the illness:

'I was in Form 1 when my mother died and the Salvation Army helped me. They told me to come for counselling with them whenever I wanted. I didn't tell anybody at school that my mother had died, let alone of HIV/AIDS. I was worried I would be picked on, as there was not much talk of HIV. I missed my mother. She was my closest friend. I notice that even boys talk to their mothers more than their fathers. Fathers are more for financial things. I prayed my mother would be taken as she was suffering so much but when she died I felt guilty.'

(Female, in school, one to one conversation with author)

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

Brown *et al.*, (2000) have described the burden of home care for AIDS- infected relatives and the effect on siblings. In addition to the physiological effects of AIDS, the social and cultural context may lead to stigma and shame that impacts on the emotional well-being of children in the family. De Guzman (2001) has described the negative impact home-based care may have on female children in particular. It is girls who often take on the burden of care. Apart from the effect on their school attendance and performance, if ill informed about necessary hygiene, there is the possibility of contagion from the infected relative they are nursing as this Swazi girl describes:

'I am staying with one of my sisters who is suffering from AIDS. She only found out eight months ago and she does not want to accept the fact she is positive. This is difficult for me because I have to look after her. I have to wash her sores, give her food, medicine etc. She is now giving up because she believes that when you have the disease you are going to die. All that she needs right now is love and support from her family and close relatives. In most cases if a person has the disease and wants to tell the parents, what they normally do is they think twice because they tell them to pack their bags and go or they ask them not to tell anyone about it.'

(Female, paternal orphan, in school, written account)

Orphaned children not attending formal school tended, in FGDs, to describe a wider range of deprivations in addition to feelings of exclusion. They were more likely to say they had at least one day a week when they did not eat and that they never attended the health clinic or hospital when they were ill. They described being given traditional herbal remedies and being left at home until they healed: *'my father says there's no money to take us to hospital. He doesn't care. He is always drinking.'* They often described situations where they felt different from their peers: *'the most difficult things is seeing others going to school and me*

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

staying at home.' Others described being laughed at because they were not in school. Life at home left some orphans feeling marginalised:

'I have a lot of difficulties because I do not stay with my parents. When I ask for anything they never give me but the other children have what they want. I am not well taken care of in this household. I have to look after the livestock after school

(literacy classes). If one goes missing I am not allowed to come home or go to school until it is found.'

(Male, double orphan, FGD)

'I live with my stepmother but she is only there at weekends. I do everything for her children. I do their washing but they don't help. I try to tell my father but he says I am lying or he gets violent because he is often drinking.'

(Female maternal orphan, out of school, conversation with the author)

6.4.3 The agency of orphaned children

Tolfree (2003) refers to children's resilience and capacity to cope in challenging circumstances and argues that it is against children's best interests to label them as a category of vulnerable children:

'Children frequently reveal clear and well-considered views about their needs, problems and capacities, and about their preferred options for care. Child participation should be embedded in all programmes concerned with their protection and care'

(Tolfree, 2003, p.10)

One of the aims of this research was to identify ways children's agency could be enhanced and to find out what children themselves felt they needed after bereavement. In contrast to the emphasis on material needs by adult care-givers,

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

orphaned children attending school often mentioned emotional needs with FGD comments such as: *'make them (orphans) feel welcome, like they are needed and let them know there is someone who still loves them,'* and practical ideas such as: *'I think the youth should start on introducing youth clubs where everyone should be welcome, whether HIV positive or not'* and *'Games in the youth centre can make them busy so they do not think other bad things.'* They felt they were not consulted about which relative they would like to live with and did not want to be separated from siblings or friends: *'nothing is explained, they're just taken'* and *'when your parents are gone you have no choice.'* They also wanted more information on what to do if a parent died, so they know *'how to handle it when it comes to you being an orphan.'* Material needs centred on school fees, food and clothing. Orphans not in formal school were much more concerned with basic needs such as food, clothing school fees and housing as well as various forms of neglect and abuse. One such orphan said *'protect us from abuse and kill or punish the adults who abuse children, like a life sentence.'*

6.4.4 From exclusion to inclusion: helping orphaned children return to school

The introduction in 2001 by the Swazi Government of a few hours of classes for the poorest out-of-school children had made a major difference to the lives of the 26 young respondents in the study. The scheme called 'Sebenta' was originally implemented in the 1960s to improve adult literacy, but in recent years an innovative primary-level curriculum has been developed specifically for very poor children who are not in formal school. The aim has been to provide a 'fast track'

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

education for mainly orphaned children so they can catch up and rejoin their peers in formal school. A Government community health worker, in conjunction with a regional Sebenta official, selects the children. One of the two Sebenta centres visited was well equipped but the other was merely a building without running water or a toilet, a blackboard was the main resource, and the children did not have pencils or paper at the time of the fieldwork. At the better-equipped centre the children received bread and a drink and worked with books. Teachers at each centre were educated to at least Form 3 level and were paid a small allowance.

According to the teachers, each child respondent had lost at least one parent. Children often came to school without having eaten and this affected concentration. One child had alerted them to sexual abuse by an uncle, and they had obtained counselling for the child and the uncle was prosecuted. Chamberlain *et al.*, (2003) argue, from research in South Africa, that being noticed by a teacher represents an orphan's best chance of getting help. One teacher remarked: *'often the children who are fostered end up doing jobs, acting as a maid or looking after cattle.'* Some children told their teachers that their carers drank beer all day. Despite these challenging circumstances and sometimes being teased by other children for not attending 'proper' school, the impact on these marginalised children of this limited financial investment was marked as the following FGD extracts show:

'Sebenta classes help me feel like a student.'

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

'Because of Sebenta I will be able to get a job as a domestic or office cleaner as I will be able to speak English.'

'They teach me maths so I can add up the change and sell in the market.'

'It will help me obtain a brighter future because without education you can't get anywhere in life.'

'It will help me get a better lifestyle and get a job and not sell vegetables at the bus rank.'

'They have taught me to read. I'm really glad about these Sebenta classes. I'm back at school because of them.'

'What I'm really enjoying about Sebenta is that I can read and write and use the previous education that I had got and forgotten.'

'Being at Sebenta stops me doing bad things like pick pocketing.'

'We are also getting life skills on how to behave as a woman and a man. I now know about pregnancies and how you fall pregnant and how to avoid it.'

'(Before Sebenta) I was ill-treated at home by being over worked because I was at home all day.'

'I would tell them (other orphans) to come and join us at Sebenta.'

Negative comments included:

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

'The most difficult thing is not having a uniform and not knowing what grade I'm in at Sebenta. I get laughed at for that.'

'Some are supportive but others claim that with my Sebenta education I do not have a future but I explain that I will be able to take the Standard 5 exam and return to school.'

'I feel different to other children who go to school wearing uniform.'

'My parents don't take Sebenta seriously so they don't think twice about letting me miss school.'

With some individual exceptions, the positive psychosocial outcomes shown by the children are: a feeling of inclusion, increased self-esteem, a chance to form meaningful relationships with adults and peers, the development of basic skills needed for employment, an awareness of social behaviour and a sense of hope for the future. Rather than 'medicalising' the needs of bereaved children by developing separate psycho-social programmes, concentrating on the Millennium Development Goals and getting children into well resourced schools would surely provide much of the psychosocial support bereaved children need.

6.5 The 'voice' of children growing up in the epidemic but not (yet) orphaned

The discourse that has developed around children orphaned by AIDS has tended to neglect other children, with parents still alive, who are also growing up in the

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

AIDS epidemic and are affected by it. Ansell and Young (2004) describe the resentment felt by children in the household when orphaned relatives are taken in. Some Swazi children felt this, too, but others were accepting of the situation as these FGD responses show:

'Sometimes it happens that may be, let's say, your aunt may have died and your cousins are living with you, most of the time the parents start to take more attention of them than you. They start to ignore you. They take this one as their own and they start not taking the care they have in the past.'

(Male)

'I don't mind in anyway because they (parents) explain the reasons why he has come to stay, we even share clothes.'

(Male)

Children were well aware that some of their orphaned peers were treated differently from other children in the family as these FGD comments reveal:

'The ones that are there will discriminate against the new arrival, "I've always been here, you don't have the right to ask for anything."

(Male)

'They are treated worse. A lot of the time the ones that have moved in do most of the work around the home. Even the clothes they wear, you can tell' (that they are different).

(Female)

'You feel bad for them.' (Female)

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

Sexual abuse of orphans, crime and drugs were mentioned by several in written accounts:

'They face a problem of caring for their families due to loss of parents. One is selling her body along the street or to neighbours to get money for her younger brothers and sisters to have food to eat. Many orphans have been abused by their relatives having sex with them as a payment for help just because they are needy and have nowhere to go and no one to care and report the matters they faced. They end up pregnant and HIV positive.....that person who has caused the problems has promised to kill her if she tells anyone. One is engaging himself in criminal activities because of earning money for a better living and to have food.'

(Female)

'I think children whose parents have died suffer a lot of depression and they always seem to be stressed. Their performance rate at school drops and weight loss is experienced. Their behaviour changes. My closest friend was a very quiet guy. He never harmed anyone but when his mother died a couple of years ago he then decided to be a bully.....if young people can only make our community drug free that can help because some of them turn to drugs because they think their lives are over.'

(Male)

When asked what support their bereaved peers needed to help them rebuild their lives they tended to stress the emotional and social needs of their friends as well as practical material help as these FGD comments show:

'We as a community should provide games and clubs that the orphans can join.'

'People only concentrate on their need for money, while these people have emotional troubles too.'

'These kids must not be taken from their old friends.'

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

'They should be loved, it should be evident to them that they are loved.'

'Tell them that there is life out there, there is still hope.'

'The government should make sure they get money left by their parents.'

'The government must organise (school) fees.'

In one urban community youth were already pro-active:

'In my community there are many orphans but they do not struggle as in some communities. The youth have formed an organisation and they do projects like keeping chickens, gardens and doing concerts. All the money they get goes to the orphans. Last year the youth built two big houses for the people who have lost their parents. In this house they have an adult who looks after them because the children have been through lots of things.'

(Male, in school, written account)

Even when parents were alive some children growing up in this urban community faced multiple deprivations. This fifteen year-old girl lived with her mother and some of her siblings. Her father visited infrequently, preferring his other two wives:

'My mother works at night in a restaurant so we are left at home cos my father does not come. She is sometimes afraid at night. She also sometimes cries at home and I, as her first born, try to talk to her when she tells me her problems. I then sometimes cry with her. Sometimes the whole family cries. It is too painful for me to see the way my mother works for us, just to try and get a lot of money to feed us.'

(Female, in school, written account)

6.6 Conclusion

This chapter began with the problems of labelling categories of children according to one specific criterion, as if it could be singled out from the social, cultural and economic setting. Apart from creating stigma and exclusion, such categorisation tends to simplify the lived experience of orphaned children in their extended families and communities and tends towards a 'victim' approach. This fieldwork has shown that orphanhood is a varied experience; from one child who felt her life had changed very little since her mother's death through to very traumatised children who had been shunted around to different places and abused in the process. When a new opportunity arose such as the literacy classes, or some other form of assistance was given, children were quick to capitalise on it and described themselves in much more positive terms. The fieldwork discussed suggests that the agency and resilience of children in challenging circumstances is, as Tolfree argues, something that should be recognised and built upon.

The ability to cope with bereavement was greatly enhanced if children did not get separated from their siblings and undergo a series of moves. The importance of 'place' in emotional well-being needs further research. Spencer and Woolley (2000) in reviewing literature on personal identity and place find that attachment to place during childhood and having a sense of where we belong is important in developing a positive sense of identity. In addition Schaefer-McDaniel (2004) notes that when young people feel they belong to a school or neighbourhood they are more likely to make friends and mix with their peer group. Mallman (2003) suggests that adolescents really fear isolation and discrimination from the peer group. The peer group is essential for adolescents as they question

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

and even reject adult guidance as they strive towards independence. Yet children in families affected by AIDS often undergo multiple moves between households making it more difficult for children to form supportive relationships with peers.

This is undesirable as the peer group in this research often, though not always, proved empathetic to the social and emotional needs of orphaned children. Children suggested youth clubs and other activities such as sport would help bereaved orphans feel included. They also highlighted the need for increased awareness of child abuse at household level and the need for clear referral structures at school and within the community so that children know who to turn to if they are abused or if they need assistance over legal matters such as inheritance or property grabbing by relatives.

Chamberlain *et al.*, (2002), researching with children in South Africa, argue that teachers with their daily contact with children are in a prime position to identify vulnerable children who are struggling to cope and that there must be clear referral guidelines. However, the links between social workers and teachers are weak and they listed many inadequacies of current provision in South Africa. They suggest that children's perception of school as a place of authority and discipline may make them reluctant to disclose home circumstances. Given the size of classes, there may be limited scope for individual attention. These problems notwithstanding, this fieldwork in Swaziland shows that individual teachers had been pivotal in securing assistance for some orphaned children, and with more NGO support for schools the role of teachers and peer groups could be strengthened. It also shows the increased vulnerability of children too poor to attend formal school. Schools obviously provide a daily routine and give much

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

needed structure to the lives of orphaned children. Apart from the direct investment in human capital that education provides, being in school gives children access to a wider range of potential support from peers and teachers.

A whole development industry has evolved around AIDS as a health issue, yet so much of the disease and its associated problems are rooted in the deep pervasive poverty in which the poorest families live. One of the limitations of this fieldwork is that the family caregivers were all drawn from relatively poor informal settlements within the catchment area of the two schools. Further work is needed to see if caregivers in higher socio-economic groups, less burdened by anxiety over basic needs such as food and clothing, do give more consideration to non-material needs of orphaned kin.

This work is a modest attempt to begin to understand the lives of children growing up in an AIDS epidemic. Whist the author's long experience of working with older children helped in the design of child-sensitive participatory activities, the ethics of carrying out such research was a constant challenge during the fieldwork. Methods had to be adapted and the needs of the child, not the research, had pre-eminence. However, it is hoped that the work provides a more nuanced understanding of children growing up in an AIDS epidemic. Further child-centred research is needed to construct a more meaningful geography of childhoods in the South that reflect children's lived experience. This small qualitative study in urban Swaziland finds that rather than being a threat to society, many of the orphaned youth who have 'spoken' in this paper are sensitive towards others who are sick, bereaved or unhappy; display an active sense of responsibility towards friends and family; and often show resilience in very challenging circumstances. They remain

CHAPTER 6: Growing Up in an AIDS Epidemic: Constructions of Childhood and Coping Strategies of Orphans and their Peers in Urban Swaziland

hopeful of a better life in the future and for most, aggression is far from their minds. As one out-of-school orphaned girl explained to other orphans: *'Don't give up hope. God is watching over us even if things are hard now.'*

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

7. CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy.

7.1 Introduction

There were 43.4 million orphaned children under eighteen years of age in sub-Saharan Africa in 2003, 28% of whom had been orphaned due to AIDS. By 2010, in Botswana, Lesotho, Swaziland and Zimbabwe, more than one in five children will be orphaned. In Swaziland where this fieldwork was undertaken, there were estimated to be 100,000 orphans in 2003, with 65,000 (63%) of them due to AIDS. By 2010, this will rise to 130,000 so that 24% of children in Swaziland will be orphans (UNAIDS, UNICEF & USAID, 2004). The UN global target of three million people on antiretroviral treatment by the end of 2005 has not been met, and there is increasing concern in poor countries about the affordability of second-line antiretroviral drugs that are needed when resistance builds up to the initial course of antiretrovirals. It therefore seems likely that parents will continue to die and orphan numbers will continue to increase in sub-Saharan Africa in the coming decade.

Despite the debilitating effect that the disease has on the livelihoods of families affected by HIV/AIDS, extended families have assumed responsibility for over 90 percent of orphaned children in 40 countries in sub-Saharan Africa (UNICEF, 2003). However, there are some questions that need to be addressed. In particular, what are the most desirable care options for those children who are

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

now beyond the kinship safety net? What type of support do families need to prevent more children becoming marginalized from kin and community structures? Which levers need pulling to achieve these ends, and what are the constraints to be overcome? This paper seeks to explore these issues and is divided into four parts:

1. The first part of the paper is a critique of institutionalised care practises using evidence from a variety of countries.
2. The second part is an analysis of how to strengthen family forms of care at community level so that vulnerable children remain included rather than excluded from society, thus minimising the need for large-scale institutionalised residential care.
3. The third part draws upon fieldwork in Swaziland to examine the reality of putting these care options into practise.
4. Finally the paper concludes with an assessment of lessons learned and calls for a fresh approach to development partnerships at all levels.

7.2 A critique of institutionalised care of orphaned and vulnerable children

7.2.1 The link between poverty and children entering institutionalised care

While there are no reliable figures on the global number of children in residential care, Tolfree (1995) suggested in 1995 that there might be as many as 8 million.

The reason for institutionalised care is usually poverty rather than orphanhood,

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

and children often become disconnected from living kin. Ducci (2003, p.19), describing reasons for such care in Italy in 2000, writes: *'poverty is still the main reason why a child is removed from the family, together with difficult or inadequate family care.'* Similarly in Chile, Antognini (2003) found that the main reasons for placing a child in institutional care were related to the socio-economic and psychological conditions of the family as well as the child, rather than parental death.

7.2.2 Lack of statutory regulation and the dangers of child abuse in institutions

Dunn, Jareg & Webb (2003) comment on the absence of national standards and guidelines regulating children's institutionalised residential care in many poor countries. Despite governments often being signatories to the UN Convention on the Rights of the Child, the regular evaluation of a child's placement in residential care (article 25) is often ignored. In order to protect children from abuse and ensure their individual needs are considered, Tolfree (2005) stresses both the importance of children having the right to consult, in privacy, adults outside the institution, and the need for regularly reviewed individual care plans. Even if these statutory safeguards were in place in poor countries, any abuse of children by carers is likely to be more easily hidden within an institution than in the community where other adults have contact with the child. The author, for example, during fieldwork in Swaziland, found it difficult to negotiate gatekeepers who controlled access to children in residential care, and this is discussed below. Besides child

**CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by
HIV/AIDS: Perspectives from Swaziland and their Implications for
Development Policy**

protection issues there is also a need to focus on the way child-care is provided in institutions.

7.2.3 Totalitarian forms of care in institutions and segregation from society

What is the evidence of the effect of institutionalised care on a child's emotional, social and spiritual development? Dunn *et al.*, (2003) describe institutions as often being a form of totalitarian child-care, where the needs of the regime override the rights of the child. Ducci (2003) considers institutionalised care to be incompatible with the fundamental values of human dignity and liberty that should accompany any educational process. She asserts that such care must be the last resort for children in a crisis, of limited duration, and the residential centre should participate in, and be compatible with, the standard of living of the local community.

Hutchinson (2004) working in Malawi, notes that some types of institutionalised care are considered by parents to be preferable to family care because of the provision of food and schooling beyond that which the parents themselves can provide. Munck (1999) concurs, and suggests that the very existence of children's homes may draw in children from poor families. Yet studies show that children as opposed to parents attach more importance to emotional attachment than material comfort: Dunn, Jareg and Webb (2003), referring to research in Malawi, found that while *parents and other adults* prioritised economic factors when making informal fostering arrangements, *children's* placement preference was based on where they feel they will be loved and best taken care

**CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by
HIV/AIDS: Perspectives from Swaziland and their Implications for
Development Policy**

of. It therefore suggests that few children would choose institutionalised care over a family setting if their “voice” were included when decisions are made.

To develop properly children need continuity in their close relationships, but in many countries children in residential care are moved from one institution to another, and relationships with staff and peers may be interrupted (Munck, 1999). Relationships with any remaining relatives also dwindle over time. As mentioned above, studies from different parts of the world show that despite the majority of children in care having relatives still alive, less than half have any contact with them and family contact gradually dies out (Munck, 1999; Hutchinson, 2004). Tolfree (2003) describes children in care in Tanzania, Zaire, Rwanda, Sri Lanka and Liberia. In some cases children were reunited with their families, but in others, he comments: *‘usually completely unregulated by governments, frequently these homes do nothing to try to reconnect children with their own families and do not consider alternative, family-based care arrangements’* (p.3). If children orphaned or made vulnerable by AIDS enter such unregulated institutionalised care, there is a real danger they too will become disconnected from remaining kin.

In addition, institutional care may not prepare children sufficiently for independent adult life. Children are marginalised from everyday life and relationships and inevitably need support and advice on how to reintegrate into society when residential care finishes (Daileader Ruland *et al.*, 2005). However, even with such programmes in place there may be problems. Tobis (2000) describes the difficulties of reuniting a person with his or her family once those bonds have been broken through living in residential care, and how the

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

reintegration programmes in Romania, for example, have been only partially successful. Phiri and Webb (2002) are particularly critical of institutionalised care for children in Africa and Asia as: *'children in institutions have tenuous cultural, spiritual and kinship ties with families, clans and communities. These ties are especially important in Africa and Asia as they are the basis for people's sense of connectedness, belonging and continuity. Children raised in institutions struggle to be accepted or fit into traditional rituals and ceremonies as well as contracts and alliance arrangements'* (p.15).

7.2.4 The economic argument against institutionalised care

Given the scale of the AIDS epidemic and the increasing numbers of vulnerable children, particularly in sub-Saharan Africa, the cost of providing institutionalised care has been shown to be prohibitively expensive in a variety of African countries (Phiri & Webb, 2002). In Zimbabwe, for example, Powell (1999) estimates that institutions are 14 times more expensive than traditional arrangements. Cost comparisons in Uganda show the operating costs of an orphanage to be 14 times higher than those for community care, and in, Tanzania, residential orphan care is six times more expensive than foster care within a family (UNAIDS, UNICEF and USAID, 2002). However, a move to community-based support may not be a cheap option. Tobis (2000) explains that residential care serves only a small number of vulnerable individuals, but once support is provided within the community, more of the vulnerable are likely to seek assistance. In terms of poverty alleviation and

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

community development, this is obviously beneficial, but the challenge will be how to provide sustainable community programmes to support vulnerable children.

Witter, Calder & Ahimbisibwe (2004) carried out a critical assessment, on behalf of Save the Children UK, of its Child Social Care Project (CSCP) that was implemented in Rakai District in Uganda between 1991 and 1996. The CSCP aimed to provide a workable system of support for orphans and vulnerable children. Seven years after Save the Children exited from the project, many CSCP activities had a lasting impact, but the authors conclude: *'CSCP should not have been ended so abruptly. Greater attention should have been paid to developing mechanisms to sustain activities within Rakai after Save the Children UK exited'* and *'this experience reflects the dangers of the NGO pilot project approach,'* (p.8). *'The model is sustainable but only if all parties- government, donors, NGOs and communities- make a serious and long-term commitment'* (p.9). The need for strong, inclusive, partnerships between stakeholders to achieve sustainability is also evident in the fieldwork in Swaziland discussed below.

7.2.5 Is there a need for any institutionalised provision for vulnerable children?

The above critique might suggest that there is little to be gained from any form of institutionalised residential care of children. This needs balancing with some caveats. Christiansen (2005) researched child-care for mainly orphaned and vulnerable children in two institutional settings in Uganda: a secondary-age boarding school and, secondly, a residential facility at a Catholic mission which

**CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by
HIV/AIDS: Perspectives from Swaziland and their Implications for
Development Policy**

made it possible for the children to attend a local technical school. She argues that there are circumstances where such care can provide children with an education and a range of skills that will create more opportunities for future advancement than if the child had remained within an impoverished extended family. Thus Christiansen concludes that some types of institutionalised child-care should be seen in a more positive light. Similarly, Wolff and Fesseh (1998), researching orphanages in Eritrea, challenge the view that *'orphanages are breeding grounds of psychopathology and must therefore be avoided at all costs'* (p.1323). They conclude that it is possible, even in resource poor settings, to create humane social environments that cater for children in an holistic way, but that it depends to a large extent on providing an environment that is organised to guarantee close and stable personal relationships between staff members and children, and a style of management with inclusive decision-making and which respects the individuality of the child. Boyden and Levison (2000) refer to the lack of research on the formative impact of care arrangements for children separated from their families. *'This means that although policy assumes, intuitively, that children are better off in the care of foster or adoptive families than in institutions,there is very little evaluative information comparing the well-being of children in these different settings'* (p.58). They stress the need for more research that includes child-centred methodologies and that it must not be assumed that children will always be well cared for within a family-type setting.

Family settings, whether the primary carers are kin or non-kin, may on occasions be detrimental to the well being of the child. Tolfree (2005) notes that where there are high levels of poverty and other forms of stress within the family

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

setting, the care environment may break down. In some cases it is therefore no longer in the best interests of the child to remain within his/her family setting, and the child may need protection from the primary carers. Even then, Tolfree suggests, alternative family-type care should be sought rather than institutionalised care.

However, finding a suitable foster family takes time, yet the child may need removing from the primary family carers quite urgently. Ansell and Young (2004), working with orphaned children in Lesotho, describe the unhappiness children experience when foster arrangements fail and multiple migrations occur. They stress the importance of finding sustainable care if children migrate when parents die. Multiple moves are traumatic for children, and the provision of care through small-scale, well-regulated and monitored residential institutions may be needed, at least in the short term, until a carefully-matched alternative foster arrangement can be made.

For a small minority of children, finding a suitable foster family may prove difficult, because some children are perceived by potential family carers to be undesirable fosters. A situation analysis of children orphaned by AIDS in Côte d'Ivoire, showed that it was more difficult to find family-level placements for children orphaned by AIDS than for children orphaned by other causes (UNAIDS, UNICEF & USAID, 2002). The author's own fieldwork in Swaziland uncovered situations where certain perceived stigmas made foster placement more difficult. For example, when a child was disfigured, HIV positive, or the parents were in jail, and the children were considered to be of 'bad stock.'

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

In concluding this first section on institutionalised care, it is clear that strengthening families to enable them to care for their own children as well as kin and non-kin fosters, in conjunction with community led strategies, is likely to remain the main thrust of care programmes for the orphaned and vulnerable children of sub-Saharan Africa as well as other countries affected by HIV/AIDS. It is also likely that some institutionalised care provision will be needed, of relatively short duration in most instances, and there is sufficient evidence of best practice models to suggest how this can be achieved. These models, based on the evidence presented above and the author's own fieldwork, may be summarised as being: small-scale residential units which are well monitored by statutory regulation; well-integrated within local communities and readily accessible to the child's living relatives; staffed by personnel who understand the importance of a caring child-focused environment; where individual care plans are drawn up for each child, and where the plans are regularly reviewed and implemented. The next section considers ways of strengthening family care so that the need for such institutionalised care is minimised.

7.3 Minimising the need for institutionalised care of vulnerable children

7.3.1 Cash transfers to poor families

Dunn, Jareg and Webb (2003) comment on how states often fail to provide social protection systems for children in poor families, yet poverty rather than orphanhood, as already discussed, is often the main reason for a child becoming institutionalised. Given that most orphaned children in sub-Saharan Africa are still

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

cared for within the kin group, they advocate providing resources at family level to improve the quality of child-care. This has proved to be an effective strategy in South Africa and Brazil, where such cash transfers have had a significant effect on reducing poverty at family level. In South Africa, Cornia (2002) and Desmond and Gow (2002) describe means-tested grants given to poor children and fostered children and how this has helped reduce child poverty. Cornia estimates that about 18% of eligible poor children and 20% of fostered orphans were reached in 2002. The relatively low uptake is partly because of the formal procedures required for cash transfers (for example the need to show birth certificates though births are often unregistered or birth certificates lost as children move between carers), and partly because of the slow processing of applications. Cornia also cites the lack of capacity of welfare ministries, not just in South Africa, but in other poorer African countries as well. Yet there is increasing evidence that such social protection is effective. Barrientos (2003) and Barrientos *et al.*, (2003), argue that such measures need the support of international donors, because of the low tax base and weak civil service in poor countries. In a study of non-contributory pensions for the elderly in Brazil and South Africa, Barrientos *et al.*, (2003), found that pensions were shared amongst all members of the household, making all members of the household less vulnerable to poverty. Children benefited because 64.2% of older people in South Africa were found to co-reside with children, and 33.4% of older people in Brazil. The authors of the study suggest that reducing poverty and attaining the United Nations Millennium Development Goals will remain elusive without the establishment of non-contributory pension programmes.

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

With the misappropriation of Global Fund monies by the Ugandan Ministry of Health in 2005 (United Nations Integrated Regional Information Network, 2006), the large international donors may be reluctant to move towards even greater direct budgetary support to ministries (and hence the possibility of state cash transfers to families) unless strict monitoring and evaluation of government ministries is in place. It also changes the power dynamics between donors and governments, as donors do not have direct control over their own projects or the projects they typically carry out with a limited number of partners. Apart from long-term sustainability, Franks *et al.*, (2004) argue that such donor projects often bypass the existing institutional capacity in poor countries. They suggest that supporting government institutions by sector-wide approaches and direct budgetary support offers a way forward, and that there needs to be more equal partnerships between governments and donors. Lockwood (2005) goes further, and argues that donor micro-management and conditionality have held back development in Africa by preventing governments from experimenting and learning how to manage and implement pro-poor policies.

Whilst the Poverty Reduction Strategy Papers introduced in poor countries in 1999 were aiming to allow such collaboration between all stakeholders interested in poverty reduction, there is increasing critique of how participatory this process really is and how much the voice of local actors, as opposed to that of large international donor institutions, is really included (Fraser, 2005; Choudhury, 2005). The unequal power dynamic between donor and beneficiary and the conditions attached to loans and grants are often a critical stumbling block to really effective partnerships and Swaziland is no exception to this. This research in

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

Swaziland does however suggest that effective partnerships and international support for cash transfers at family level, through direct budgetary support, would greatly benefit vulnerable children and lessen the likelihood of child-care within the family breaking down. When breakdown does occur, the provision of foster kin with unrelated adults in a family setting is another alternative to institutionalised care.

7.3.2 Non-kin fostering of vulnerable children

Fostering within a family setting but outside the kin group is not common in most parts of southern Africa, and for children to avoid exploitation the practice of fostering needs to be introduced carefully (Tolfree 2003). Tolfree notes that many poor countries have weakly developed social services and are too-poorly resourced to be responsible for developing and monitoring non-kin foster placements. Referring to experience in Rwanda, he explains how fostering needs to be embedded within the community, both in the selection and preparation of non-kin carers, as well as in the monitoring and support of the placement. He states that a Western model that relies totally on agencies to carry out this role is '*neither realistic nor sustainable*' (p.7), though there is a monitoring and support role that NGOs may play. Similarly, youth could be more engaged in supporting orphans and vulnerable children at community level.

Daileader Ruland *et al.*, (2005), using evidence from Zambia, Cambodia and Zimbabwe, refer to the benefits of involving youth in service provision. For example, in the Children in Distress project in Cambodia, adolescents are involved

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

with the provision of social welfare, education and social support to vulnerable children of all ages. The youth receive a small stipend (US\$3 per week) in return for their community work with families. Such integrated, community-based initiatives aim to empower families and communities to be more self-reliant. Daileader Ruland *et al.*, also note that engaging youth in this way can also serve as a protective factor against HIV infection, as they are directly involved with the consequences of AIDS.

The first two sections of the paper have explored some of the issues surrounding the care of vulnerable children, in particular, the care options when the care environment with kin has broken down. The third section is an analysis of these issues in Swaziland, the country with the highest HIV prevalence levels in the world (42.6% of adults in 2004) and where nearly a quarter of the children will be orphans by 2010 (UNAIDS, UNICEF & USAID, 2004).

7.4 Fieldwork findings in Swaziland

The author sought to gain a deeper understanding of such questions as: are there many children already living beyond the kinship group? Is it possible to encourage and develop more family and community support for such vulnerable children? What are the policies towards institutionalised residential care and how is such care developing in Swaziland? How can co-ordination of all the key stakeholders be achieved so that duplication of effort and piecemeal coverage is avoided?

The fieldwork evidence from Swaziland is presented in three parts. The first part describes the research methodology and data sources. The second part

**CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by
HIV/AIDS: Perspectives from Swaziland and their Implications for
Development Policy**

develops the argument for strengthening families by cash transfers since most vulnerable children remain within Swazi families despite the decimation caused by the AIDS epidemic. The third part is a description and critique of the emerging forms of non-kin child-care and the power dynamics that have developed between the key players.

7.5 Research methodology

The data presented were gathered between 1999 and 2005. In terms of positionality, it was probably helpful that the white European female author had worked in Swaziland as a teacher for three years (1999-2002) and become involved with the HIV/AIDS epidemic both within the school community and through voluntary work with families affected by HIV/AIDS. The relationships built up with individuals and NGOs may have helped remove some of the significance of being a white outsider when the author returned for several months in 2003 and 2004 to carry out research at the community level. On the other hand, being seen as a sympathetic “outsider” and researcher from a well-respected university, helped facilitate access to some key informants, as well as inclusion at various stakeholder meetings.

The author was asked by UNICEF to contribute voluntarily to the working group responsible for formulating the education part of the Draft National Policy on Children that was being compiled in 2003, and this led to a more in-depth understanding of the relationships between key actors and the stages on which they operated. Thus it was possible to research the complexities of providing

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

support for vulnerable children from a variety of standpoints, and from national to community level. In addition to interviews with families living in informal settlements, in-depth interviews were carried out with a wide range of key informants in Government, NGOs, Community Based Organisations (CBOs) and Faith Based Organisations (FBOs). The author also carried out participant observation at stakeholder meetings and at the national conference on orphans and vulnerable children held in November 2003. Further information came from in-country reports and documents supplied by organisations such as the National Emergency Response Committee on HIV/AIDS (NERCHA). The remainder of this paper reflects the understanding gained from these fieldwork sources.

7.5.1 The difficulty of identifying vulnerable children in Swaziland

The lack of accurate national records on orphaned and vulnerable children is not unique to Swaziland. Carr-Hill *et al.*, (2002) have noted the challenges of keeping accurate records on orphans in Tanzania, and suggest that data on the extent of orphanhood will remain difficult to determine in many countries.

The lack of accurate knowledge on both the number of vulnerable children and the way they are embedded socially and economically in Swazi society, makes it more difficult for NERCHA to decide how best to coordinate activities that aim to help orphaned and other vulnerable children. According to the 1997 census, there were 522,000 people aged 0-19 years in Swaziland, but there are no comprehensive surveys to indicate the number or location of the most needy children, particularly those no longer cared for by kin. However, the evidence of

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

relatively low numbers of both street children and child-headed households suggested that most children remained within kin structures, despite the very high levels of HIV prevalence amongst Swazi adults.

Some authors suggest that as families become overwhelmed by AIDS-related deaths and impoverishment, children will no longer be absorbed within the kinship group and some may become street children (Barnett & Whiteside, 2002, p.211). The empirical findings from the small Swazi capital city of Mbabane do not suggest either a plethora of unsocialised street children abandoned by their families (social orphans), or street children whose parents are dead and the kin unwilling to absorb them into their households. However, poverty was acting as a driver for children choosing to leave their families to become “street children” in Mbabane.

Gcinile Buthelezi, Head of Public Health and Social Welfare at Mbabane City Council with, a *total* department budget of US\$400 per year allocated to street children, traces the children’s families and returns them to their homes. In the period 2001-2003 nearly 70 children have spent periods living and staying overnight on the streets of Mbabane. Remarkably few stayed long. In this interview in 2004 it was noticeable that she did not refer to the street children as orphans, and that it was possible to reunite children with their kin:

‘Some are as young as eight years old but the average are males between fourteen and seventeen years old. We rarely get females. We introduce ourselves and try to befriend them more as relatives rather than officials. We haven’t found any with no relatives. They leave home because of poverty, hunger, and sometimes drinking stepfathers who beat them. They come from the zones (urban informal settlements), especially Corporation and Msunduzi, also Manzini and

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

Piggs Peak areas (other towns, see figure 1). Some gogos (grandmothers) cry because they are sad there is no food and they have done their best to find them. They think the child has to understand the family situation. I don't know of any child grant (for food or clothing)'

(Interview, 15-1-04)

In Manzini, the other main city in Swaziland, the findings were similar, with poverty rather than lack of kin willing to care for children, acting as the driver for children choosing to live on the streets. Father Larry McDonnell of Manzini Youth Care, a FBO caring for homeless children, described (interview, 8-1-04) how his field workers befriended children on the streets and sought out their families. The children often came from more rural towns such as Piggs Peak and Nhlangano, and lived with impoverished grandmothers or other relatives who were struggling to care for them. Even after returning children to their families, they would often soon reappear in Manzini in search of a better livelihood.

These vignettes suggests that most street children have access to kinship care, but they exemplify how the stresses placed on poor families caring for extra children may lead to family breakdown, as described by Tolfree (2005) above. Again, resources targeted at the poorest households are likely to benefit the most vulnerable children in Swazi families, some of whom will be orphaned.

7.5.2 Child-headed households as an indicator of family breakdown

The term child-headed household, commonly referred to in the AIDS literature, must be used with caution. It is not always clear whether the term refers to

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

children where both parents have died or where the children are just not living with a parent or adult care-giver. Neither does it indicate the social setting of the child and the proximity of other adult relatives who may or may not offer assistance. The number and ages of children in such a household and their access to resources also varies from household to household. For example, in their study in Guinea-Bissau, Mamas *et al.*, (2004) found that five percent of orphans lived in the care of a sibling, but in all cases this was a much older adult sibling. They suggest that the age of the sibling caretaker should be taken into account before assuming it is an indicator of stress in the extended family. The limitations of the working definition of child-headed household must be borne in mind when assessing the evidence below.

In one of the poor Swazi informal settlements where fieldwork was undertaken, there were over five hundred households but, according to the families and the community leaders interviewed, there were no cases of children under 18 years old (whether orphaned or not) living alone without an adult carer. Despite the poverty of many households, orphaned children were being absorbed within kinship networks, however stretched those networks might be (Jones, 2005).

The low incidence of child-headed households in at least some parts of Swaziland is further supported by Neves (2003). In her study of 803 mainly urban households, identified as particularly vulnerable with the help of a local government health worker, there were only 26 households (three percent) headed by children. In addition, Dudu Dlamini, the Swazi director of an NGO that is

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

assisting orphans within informal settlements in the towns of Mbabane and Nhlanguano, explained:

'There are not that many child-headed households. Sometimes the child looks as if they are more capable than the adult carer. There are not that many who are truly alone. Here, I know one truly child-headed household and in Nhlanguano I know of three. You do find relatives who are not very capable.'

(Interview 4.12.03)

Dhlamini explained that she believed it was possible to support and strengthen the family in-situ, so that children are not abandoned. Similar views were expressed in a focus group discussion with non-government social workers assisting families in informal settlements in Mbabane. They described the problem of sick or very elderly carers who were unable to care properly for children. Poverty in the form of hunger, inadequate clothing, overcrowding, lack of health care and poor school attendance was mentioned by all of these key informants, but orphaned children living and coping completely alone was not common. Key informants from organisations working in the rural areas also described finding child-headed households but not in overwhelming numbers. Reverend Pat Wright, co-ordinator of Care Nakekela, a faith-based non-government organisation, had carried out participatory action research in thirteen Chiefdoms located in all four regions of Swaziland, and estimated that under five percent of children were living in child-headed households. With varying understandings of what constitutes a 'child-headed' household, it is difficult to establish accurately the number of such households.

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

One final piece of evidence that suggest the majority of vulnerable children remain within kin structures is a survey of Child Headed Households carried out in 2002 by the Deputy Prime Minister's Office. There are many caveats in the report outlining the limitations of the survey method, the accuracy of the findings and the lack of properly trained enumerators. Bearing these limitations in mind, the survey found there were 10,664 'children' (the age limit was not defined in the report) living in child-headed households without an adult care-giver. The survey covered 22 of the 55 administrative districts (Tinkhundla) of Swaziland. The national figure of children in child-headed households might therefore be extrapolated to be about 24,000. In 1997 census there were 522,485 people aged 0-19 years, and 413,129 children aged 0-14 years. Thus an estimated 4.5 to 5.7% of children, depending on the age definition used, were not living with an adult carer. This corroborates the other qualitative findings described above.

7.6 The case for cash transfers to Swazi families

Despite adult HIV prevalence levels of 42.6% in 2004, and no comprehensive social welfare provision at family level, the evidence above suggests that the Swazi family was still caring for the vast majority of extra bereaved and vulnerable children in its midst. How many of the remaining children could be absorbed if cash transfers to families were a priority of NERCHA and the international donor community? AIDS obviously creates large numbers of orphans, but the ability of the extended family to absorb these children is undermined by poverty. While acknowledging the shortcomings of the qualitative data presented for Swaziland,

**CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by
HIV/AIDS: Perspectives from Swaziland and their Implications for
Development Policy**

they do suggest that cash transfer to families, as already described in Brazil and South Africa, would be effective in strengthening family level child-care so that even more children might remain within kin networks. In Swaziland in 2004 there was no child support grant, foster grant, non-contributory pensions for the elderly, or any comprehensive social welfare grant that might benefit vulnerable children. Attempts to introduce targeted help for orphaned and vulnerable children, for example education grants, had piecemeal coverage at the time of the fieldwork (Jones, 2006a).

7.7 Key actors and stages

7.7.1 The emergence of a National Policy on Children

NERCHA and UNICEF, two of the key players spearheading initiatives for needy children in Swaziland, were favouring community based approaches, but there was some tension in the way this was developing. Neither NERCHA nor UNICEF favoured the scaling up of institutionalised residential care (for many of the reasons given at the beginning of this paper), and both were collaborating, along with other key stakeholders, in writing the National Policy on Children, including Orphans and Vulnerable Children. This policy was completed during 2004, but still had not been presented and approved by cabinet and Parliament by June 2005 (personal communication with UNICEF, Mbabane, 10-6-05). Much has been written about the need for strong political leadership to combat the impact of HIV/AIDS. NERCHA, a government body, and UNICEF were showing strong leadership, but the slow presentation of the Child Policy to Cabinet and Parliament

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

suggests that parts of the Swazi Government had more pressing concerns than the youngest, most vulnerable members of its future human capital. Meanwhile, a plethora of relatively poorly co-ordinated activities was evolving in an attempt to care for children who were beyond the kinship group.

In 2002, NERCHA and UNAIDS produced a directory of organisations involved with HIV/AIDS interventions (NERCHA and UNAIDS, 2002). The table below (refer also to appendix 10) is a breakdown of the different organisations implementing activities for orphans and vulnerable children according to the Directory:

| | |
|---|----|
| Community Based Organisations | 11 |
| Commercial sector | 4 |
| International donors (mainly UN bodies) | 8 |
| Faith - Based Organisations | 9 |
| Government sector | 9 |
| Non-Government Organisations | 22 |

The co-ordination of these activities was underway at the time of the fieldwork, but there was some confusion over the roles and visions of the different key players. NERCHA had the mandate to co-ordinate all HIV/AIDS activities in the country and to distribute Global Fund monies. However, it was often perceived by other organisations to be an implementer and in its own literature there is some

**CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by
HIV/AIDS: Perspectives from Swaziland and their Implications for
Development Policy**

ambiguity: *'NERCHA is not an implementer but only a co-ordinator. However NERCHA through its Directorate can identify gaps and propose interventions to implementing agencies'* (NERCHA, 2004, p.4). In 2003, NERCHA had identified four areas of intervention for orphan care: socialisation, food security, economic empowerment and psycho-social support. It was assumed that the extended family was struggling to take on the additional burden of feeding and caring for orphans, and that the gap could be filled by developing support at community level. On the other hand, institutionalised care was considered too expensive and alien to Swazi cultural norms.

7.7.2 Community-based approaches to support vulnerable children

The Director of NERCHA explained during interview (8-9-03) that the vision was to revive the traditional care structures at Chiefdom level. This would involve revitalising the lapsed tradition of the communally-tilled 'indlunkhulu' field found in each of the 360 chiefdoms in Swaziland. The orphans and vulnerable children would also help till this field and the food would be stored at Chieftaincy level. Each chieftaincy would have an HIV/AIDS committee that would register orphans and vulnerable children. Each chiefdom's committee would select, from local married women, suitable care-mothers ('lutsango') who would be trained in psycho-social support and assigned a number of orphans to oversee. The care-mothers would be given a small incentive such as food from the indlunkhulu field, and were presumed to consider it an honour to be chosen.

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

The Director stressed that NERCHA's vision was one of equity where no orphan would be left out. HIV/AIDS services would be planned with a national vision and implemented with a community focus. He also stressed the value of the Christian churches as a medium to revitalise moral values of the young to help defeat the spread of the epidemic. However, the author interviewed Swazi key informants who questioned the influence of the churches (Jones 2006a) and as one Swazi male key informant, with experience in both NERCHA and the NGO sector, but speaking in his personal capacity explained:

'When Christianity came in, our traditional practices were considered evil. This confused Swazis. Some changed their names and no one went to church in traditional gear. People over 40 tend to have English names but those under 40 have more Swazi names. Once we started competing with other countries like in football, people became keener to identify with their culture again. I don't believe we are a Christian country, we are simply Swazi. I believe that is a religion on its own. We believe in a God (Mlentengamunye) and we believe in ancestors. When someone dies they move closer to God.'

(Sibusiso Dhlamini, interview, 10-9-03)

Meanwhile another key actor, UNICEF, was encouraging the development of support for vulnerable children at a lower level. Each chiefdom is further subdivided into between six and ten smaller communities called 'sigodzi'. Each sigodzi has a headman or 'indvuna' who reports to the Chief. UNICEF introduced the concept of Neighbourhood Care Points (NCPs) for each sigodzi, after a local woman set up a feeding centre at Chiefdom level in the Hhoho region. The centre was soon overwhelmed with over 100 children, so UNICEF realised that such centres would need to be at the lower neighbourhood (sigodzi) level. The NCP would act as a meeting point where neighbours come together to monitor the

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

welfare of children at the homestead. It was expected that each NCP would cater for up to 100 pre-primary and primary-school children per community. UNICEF would use local NGOs, volunteers, government health workers, and trained community mothers, to implement the delivery of basic services to children. There would be group preparation of meals, supervision of children, health promotion, psycho-social support, and play activities. UNICEF estimated that 37,500 children would be reached by 2005.

NERCHA's Director of Impact Mitigation thought UNICEF's NCP concept was sound but that the women working voluntarily at these NCPs needed some way of protecting their own livelihoods (Interview, 24-11-03). A UN observer visiting the country, (name withheld, interview, 29-11-03), described an NCP where just two women with cooking pots were preparing a meal, while many hungry children watched. The women were unable to supervise the children properly, the older children were taking the food from the younger children, and some merely had time to dip their fingers in their cup before it was snatched away. Some of the children had walked several kilometres, and had perhaps used up more calories than they obtained. According to the UN observer, the children looked bored and did not seem to play.

However, despite such limitations at some NCPs, they have made vulnerable children visible within the community. They are no longer hidden within poor homes. Whether or not NCPs will develop and be sustainable as a long-term solution for vulnerable children, they are creating important 'bottom-up' pressure, through media attention, that is difficult for the Swazi Government to ignore.

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

Through 2003 to 2004, it therefore appeared that two community care systems for vulnerable children were being developed, one based on service delivery at chiefdom level, the other at sigodzi level. Whilst NERCHA and UNICEF were, respectively, the principal drivers of each system, a range of NGOs, both large and small, undertook implementation at grassroots level. Sometimes this led to unexpected problems as activities were not always well co-ordinated, and NGOs, whether acting alone or as a group, often pursued their own agendas with unexpected results.

For example, from August 2002 to June 2003, the World Food Programme, with the help of other NGOs, was distributing monthly food rations, including cheap maize bought or donated by other countries, to poor families living in the drought- stricken middle and low veld areas. Over 100,000 people were assisted with free food aid (WFP, 2003). This led to a slump in demand for locally grown maize, and Swazi maize growers protested as they struggled to sell their own maize and began defaulting on loans (maize production was possible on the wetter High Veld). The Chairman of the Maize Marketing Advisory Committee placed whole-page statements in the Times Of Swaziland (1-12-03) requesting that: *'donors should source the food supplies locally in order to avoid harming the Swazi maize industry'* and *'recipients of food assistance should be carefully monitored in order to avoid giving food aid to people who are not in desperate need and may end up re-selling the donated food.'* If poor families had received cash benefits rather than free food, this money could have been spent supporting locally-grown produce until such supplies had been used up.

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

The Director of the Red Cross in Swaziland noted during an interview (23-10-03) that other problems of the WFP food distribution included creating a 'dependency' attitude, and tension between neighbouring communities because of the difficult decision on where to draw the line between distributing in one community and not in another. During 2004 WFP planned to solve these issues by phasing out free monthly food rations in favour of food in return for work or training and to collaborate with both NERCHA and UNICEF by distributing food via 40 of NERCHA's chiefdom community storage centres and 100 of UNICEF's NCPs.

7.7.3 Issues of piecemeal coverage, confusion and sustainability

Unlike in Brazil and South Africa, none of these community-based initiatives to help vulnerable children were based on strengthening families through cash transfers. In addition, by developing new structures (UNICEF's NCPs) or revitalising traditional ones (NERCHA's Chiefdom centres and indlunkhulu fields), there would be no strengthening of the existing poorly-resourced social welfare department or the even more poorly-developed mental health services within the Ministry of Health. Would these alternative new initiatives be sustainable? For example, deciding to provide married women (lutsango) with a few days training in psycho-social support might well meet NERCHA's goal of national-level coverage, but how effective would such training be and how acceptable would it be to Swazi families? Both systems expected children to receive support from women who would not necessarily be relatives of the children.

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

Furthermore, both systems concentrated on the rural areas and a separate system, co-ordinated by the Alliance of Mayors' Initiative for Community Action on AIDS at the Local Level (AMICAALL), was in the process of being developed for the 30 percent of the population who lived in urban areas. However, in 2003-2004, coverage was piecemeal, and the adult caregivers in urban informal settlements were struggling to access services earmarked for the needy children in their care (Jones, 2006).

Partnerships were clearly embryonic in 2003-4 and there was some confusion between various NGOs, community leaders and NERCHA. The NERCHA service delivery at chiefdom centres was a much more 'top down' approach than the more participatory community based 'NCP' concept being developed by UNICEF, but neither system was fully understood by Swazis at community level or by the smaller grass roots NGOs involved with orphaned and vulnerable children (OVC). With the help of UNICEF, the smaller NGOs had formed a group called the OVC Network. In 2003 it comprised 25 NGOs drawn from across the country. At a meeting of the network in September 2003, a member of the Deputy Prime Minister's Office spoke of the confusion about NCPs at community level:

'There is a problem in the community as it (NCPs) is viewed as a UNICEF programme, rather than a partnership of government and UNICEF assisting communities. The communities are separating programmes by donor. It is important that we stress it is a UNICEF/Government partnership.'

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

At the same meeting, directors of the small NGOs expressed concern at the development of a two-tier system of food distribution, that is, at Sigodzi and Chiefdom levels. One delegate queried: *'why can't NERCHA do what UNICEF does and work through NGOs? Our planning is bottom up, NERCHA's is top down.'* Meanwhile, UNICEF expressed concern at the lack of careful accounting of funds given to the NGOs, and asked for more detailed monitoring and evaluation.

The author found some NGOs felt marginalised from many of the structures so far described. Instead they carried out their own funding (often through foreign church groups) and worked to their own agendas. Apart from a lack of co-ordination of players, there was very little regulation or monitoring of those seeking to work with vulnerable children. To highlight some of these issues, the next section uses evidence from several smaller organisations working with vulnerable children.

7.7.4 Children in residential care

In addition to the large NGOs and the work of NERCHA within the community, the author found a plethora of activities where orphans and vulnerable children were being cared for in a variety of residential homes. Whilst there has been a move away from institutionalised residential care of vulnerable children in Swaziland, in line with global trends, there are some orphanages run by NGOs and Faith-Based Organisations. The largest are probably the SOS Herman Gmeiner Children's villages, but even here the Director described a move towards the support of children within families and communities, rather than an expansion of the more expensive residential care. SOS was supporting 490 orphans within the

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

community in 2003, and the plan was to expand this to 2,500 children in 2004. The support included food rations, clothing, health-care, a visiting community social worker paid for by SOS, and sometimes school fees. The Director was intending to seek funds from NERCHA and UNICEF in addition to those supplied by SOS, but had not yet approached either donor.

The author noted that SOS seemed marginalised from many of the national initiatives concerning orphaned children, despite years of experience caring for such children. During an interview (8-9-03), the Director of NERCHA mentioned the high cost of SOS style '*westernised*' residential care, and his strong disapproval of institutionalised care in general on the grounds of cost, and because institutionalised children were insufficiently '*socialised*' to fit within society as adults. Yet as Christiansen (2005) and Wolff and Fesseh (1998) argue above, there may be favourable outcomes for children in residential care, and this appeared to be the case with some Swazi NGOs providing residential care for vulnerable children. In addition, the author found examples of residential care that were sustainable and well integrated with local society. Two examples are given below.

Zondle (SiSwati for take care of yourself) Mother's Organisation was set up in 1967 and provides residential care for over 40 boys and girls. It is economically sustainable as income is generated through farming, sewing and knitting. In the words of the Director, Judith Simelane: '*1,500 children have been brought up in the organisation. Suffice is to say that we have produced university*

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

graduates, teachers, nurses, mechanics and all are leading productive lives and none has been known to fall into a life of crime.'

Another example of sustainable residential care is Manzini Youth Care, an FBO directed by Father Larry McDonnell. Father Larry related how the poor and sick in the peri-urban area seem forgotten despite their increase in numbers. He described his frustration when seeking funding. On accessing Global Fund monies: *'It's the limited criteria. The criteria just don't fit. They won't finance buildings or staff. The whole process is so complicated.'* On E.U. funds: *'the micro-finance form is about 14 pages! It's the bureaucracy of it.'* He suggested there should be an independent consultant who would act as a link between NGOs and donors and monitor how the money was spent: *'e-mail is no way to monitor how it is spent.'* Father Larry was concerned about the lack of monitoring and evaluation of NGOs: *'there is no regulation of NGOs. People are setting up as NGOs with a number given out by the Ministry of Justice, room 18,'* (interview, 8-1-04). This concurs with Lockwood's description of corrupt *'briefcase'* NGOs in other parts of Africa (Lockwood, 2005, p.59).

Manzini Youth Care is funded partly through churches in Ireland and through European contacts made through its volunteer programme. Manzini Youth Care also runs a small food-preserving factory, which, with the help of Fair Trade Netherlands, exports produce to other African countries as well as Oxfam shops in Europe (figures 11 and 12). These funds are used to sustain residential homes for 120 street children and orphans, education programmes to help 150 out-of-school children catch up and return to state schooling, help with school fees for 512

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

children in 2003, vocational skills training (140 youths per year), youth clubs for 250 participants per week, community food support for 150 families. For the reasons described, this impressive initiative seemed marginalised from the largest donors wishing to help children affected by HIV/AIDS.



Figure 11:

Food preserves produced by the Eswatini factory and marketed to help support Manzini Youth Care



Figure 12: Eswatini food preserving factory that helps fund Manzini Youth Care

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

Whilst these two examples (Zondle orphanage and Manzini Youth Care) appeared to the author to be examples of sustainable practice with favourable outcomes for children, there is clearly a need for a much stronger government role of monitoring children in such institutions. The lack of capacity of the poorly resourced Social Welfare Department to carry out this function is evident in the final example of grass roots residential care: an FBO called New Life Homes.

The Director of New Life Homes explained during interview (27-11-03) that their goal was to provide residential care in a family-type setting for groups of 8-10 orphaned or abandoned children. In order to develop as well-adjusted, self-reliant young people who are adapted to their culture, the family-style units are headed by Swazi surrogate parents. Although funded through churches abroad, each family unit has land on which to cultivate food and keep small animals, and the aim is to sell excess produce so that the initiative is sustainable in the long term. When the author visited, eggs, chickens and rabbits were being produced commercially and sold to local supermarkets. The Director had approached NERCHA for Global Fund monies, but had been unsuccessful, as such residential homes had not been included in the original national proposal and there was very little leeway under Global Fund rules to move away from the 12 approved objectives. Instead, NERCHA was concentrating on community care of vulnerable children, as already described.

The Director of New Life Homes described the bureaucracy involved in setting up residential care for children. Contact had been made with four ministries and after nine months the NGO had still not gained recognition from the Ministry of

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

Health and Social Welfare. The Director was referred to the Child Unit in the Ministry of Health and Social Welfare. Here she was told there were no policies or regulations concerning children's residential homes, but the need for them was recognised and help in building them up would be appreciated. Initially the Director of the Child Unit was reluctant to refer children to New Life Homes as the government was aiming to keep children on their own homestead, but within weeks referrals began to come. One child, for example, was living with a very elderly grandmother and both were starving. The local pastor, local police and the Chief reported that there was nowhere for the child within the community, and asked New Life Homes to consider her. The Director of New Life Homes contacted the social worker for the region, and was advised to take the child as the social worker lacked transport to carry out a home assessment visit but would check on her at a later date.

Two other referral circumstances cited by the Director were: a young child who had been abandoned, his proper name was not known and relatives had not been traced; and a maternal orphan who had been sexually abused and feared to be HIV positive and relatives did not want to take him in. The Director of New Life Homes had made further visits to liaise with the Child Unit for child referrals, but found the Unit had become defunct as the Director had moved to work for NERCHA and no replacement had been found.

These vignettes from the front line of non-kin child care in the Swazi AIDS epidemic show the challenges facing the poorly resourced Social Welfare department, the inadequate statutory protection of Swazi children, whether in large

**CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by
HIV/AIDS: Perspectives from Swaziland and their Implications for
Development Policy**

or small residential units, and the perceived difficulties of accessing Global Fund money. Non-kin child-care was a far cry from the best practice models described in the first part of this paper, and it was an issue that needed urgent attention from those with the power and agency to bring about change.

7.7.5 Agendas, power, personalities and accountability

To understand the difficulties of co-ordinating the plethora of 'actors' working with vulnerable children in Swaziland in 2004, the different agendas and power structures need to be considered. For example, large international NGOs and other donors have to report to their Head Office and may need eye catching 'results', which will encourage further donations from donors. Being a bit-part player within a National AIDS plan may not permit this. Swaziland is a small country and in-country directors of international NGOs may well be in the early stage of their careers and in need of short-term success if not necessarily sustainable results. Lockwood (2005, p.54) when describing the pressure for donors to disburse funds notes: *'lending volume has been linked to career progression in donor institutions.'* In turn, whilst NERCHA had the task of co-ordinating activities at national level, it was constrained by conditionalities attached to the Global Fund allocations. At a public meeting in 2003, the Director of NERCHA explained:

'NERCHA is the Principal Recipient (P.R.) of the U.N. Global Funds and is responsible for the funds. That's why it is controlling receipts and payments. There is very little leeway under Global Fund rules. If the money is misused the P.R. has

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

to pay back the Global Fund. The P.R. is also responsible for outcomes, which is difficult as NERCHA is not the implementer. NERCHA has to give very detailed reports to the Global Fund. Each activity is funded per quarter. Money must be spent each quarter or the next quarter is reduced.'

(Director of NERCHA, 17-9-03)

Besides international and local NGOs, NERCHA also has to liaise with government departments, some of which may resent the power that accrues to NERCHA as Principal Recipient of Global Fund monies. Piot (2005) stressed the necessity of having a separate body for ease of monitoring and evaluation of Global Fund money, rather than allocating money to separate ministries. The misappropriation of Global Funds by the Ministry of Health in Uganda in 2005 is a case in point (UNIRIN, 2006). NERCHA had certainly developed a tight accounting system, but some tensions were developing with government departments.

For example, NERCHA had developed a computerised system of drug roll out to meet the stringent Global Fund conditions. In January 2004, the Ministry of Health, had issued anti-retrovirals to 400 patients without first registering them on NERCHA's computerised system. NERCHA had also submitted the names of 8 doctors to the Ministry of Health, but was still awaiting approval of four of these doctors to oversee the national drug roll-out programme, another conditionality of the Global Fund. Strong partnerships between national-level players are therefore crucial to the successful implementation of any National HIV/AIDS policy. If donors are to be encouraged to coordinate their activities and support individual ministries (the SWAPs approach), this fieldwork concurs with Lockwood (2005) that success depends on political commitment at the highest level.

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

7.8 Conclusion

This chapter has attempted to explore the complex issues surrounding the care of children made vulnerable by HIV/AIDS. Though Swaziland is developing its own unique community-based systems which may not be applicable elsewhere and have yet to be tested in the long term, there are some facets which may be relevant to other countries faced with children who are beyond the care of the kinship group. Firstly, even with the highest rates of HIV prevalence in the world, many families continue to care for related children and where children leave home poverty is a major driver. Cash transfers to carers would help stem the flow. Secondly, co-ordination of key actors is made more difficult when the agenda of individual organisations is outside the national HIV/AIDS plan. Thirdly, the national plan is only as strong as the partnerships between players. Personalities and the desire for power and influence have an important impact on outcomes. Strong political leadership is therefore critical. Fourthly, Global Fund monies need to be made more flexible, accessible and accountable for the very valuable work of smaller NGOs. Finally, It should not be assumed that all forms of residential care lead to detrimental outcomes and are financially unsustainable.

A latent force in all these issues is the underlying politics created by a lack of deep understanding between those trying to alleviate children's suffering. Despite the move away from the Washington consensus to Poverty Reduction Strategy Papers, development in Africa remains elusive. Perhaps Lockwood is right (2005, p.127) in urging donors *'to reward and support development outcomes, however reached, so as to allow governments the space to learn and*

CHAPTER 7: Considering Child-Care Options in Poor Countries Affected by HIV/AIDS: Perspectives from Swaziland and their Implications for Development Policy

experiment,' and to interfere less: 'donor micro-management and conditionality have severely dampened the learning dynamic in Africa over the last 30 years.'

There is evidence in this paper that micro-management and conditionality continue to stifle initiatives with regard to child-care, thus perpetuating the poverty in which so many Swazi children live.

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

8. CHAPTER 8: Conclusion

Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

8.1 Introduction

Although there is a summary to each chapter, this conclusion provides an abbreviated version of the substantive findings as I revisit the research questions in turn. I also show the relevance of my work to current literature on the nature of childhood in Africa, in the context of HIV/AIDS, and the significance of the findings for policy on child care in resource poor settings where AIDS is endemic. The limitations of the research were explored in chapter two and I use them here to inform my suggestions for the direction further research might take. I end the thesis by looking through a much broader lens to show the relevance of my research for the overarching 'development' debate.

8.2 Revisiting the research questions

Research question 1: Are traditional extended family networks able to absorb the increasing number of orphans? Is the form of care changing from patrilineal to matrilineal, to child-headed households, to informal non-kin fostering? How is support given within the extended family? Has family care reached breaking point and if so, what are the triggers? **(Chapters 3, 4 and 6)**

In the fieldwork presented, I have shown that the extended family continues to absorb most children, though traditional family forms have become more heterogeneous. I found patrilineal care of orphaned children was diminishing

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

in favour of matrilineal kin, and there was little evidence of non-kin fostering. Material support was exchanged between kin where resources were available. Most material transfers were from urban to rural kin, though not all families had ties remaining with rural kin, as families had grown in situ in the urban area and through further migrations. Kin were the major source of emotional support during hardships such as illness and bereavement.

My research in the informal settlements of Mbabane showed that orphaned children were not necessarily the children with the most disadvantaged livelihoods, and that the presence of only one adult female carer was often a useful marker for the presence of very vulnerable children. Families had not (yet) broken down, but I did find families that appeared to be slipping into chronic poverty as they coped with AIDS-related expenses and extra domestic work. Families reported a lack of food, inadequate shelter, lack of cash income for medical care and family deaths.

Given that orphaned children were living alongside other needy children in poor families and that nearly half the orphans were living in the better-off families, I argue strongly that singling out orphaned children for special assistance above other vulnerable children is counter-productive. It stigmatises orphaned children as a special category of children and would not necessarily target resources judiciously. I do however, recognise that orphaned children have special needs in relation to parental loss, but show that the family, school and community are where these needs should be met, rather than by 'medicalising' bereavement and setting up separate psycho-social counselling structures more akin to western practices. I therefore suggest strengthening family-care practices by donor

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

support, and encouragement for welfare payments in the form of cash transfers to the poorest families and a continued emphasis on the social protection provided by the Millennium Development Goals in respect of children.

Research question 2: What effect does the AIDS epidemic have on child care within these families? What are the main issues when fostering orphaned children? What are the challenges of caring for all children in an AIDS epidemic? **(Chapters 3, 4 and 6)**

The research findings suggest that caregivers believed they treated children equally and did not differentiate between orphaned and non-orphaned children. Children gave more varied responses. While some felt well treated in their 'new' households, others did not. The orphaned children who were subjected to multiple moves were more likely to encounter forms of abuse. Other children in the family gave similarly varied responses. Some were aware of unfavourable treatment of the newcomers, while others felt the orphaned relatives had been assimilated without discrimination. They also sometimes felt their own lives had been changed detrimentally by the new additions to the family, particularly in terms of parental attention. Material deprivation was mentioned by all categories of children, not just those who were orphaned, in this poor urban setting.

Suda (1997) warns against a 'romanticised' view of the African extended family, and I give evidence of how the Swazi family is dynamic, and evolving in response to a variety of stimuli, not just because of the AIDS epidemic. While advocating that the primary focus of care of orphaned children should be by the

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

strengthening of the family through social welfare measures, I recognise that abuse of children may occur within families as well as residential institutions and the issue needs addressing at the community level.

In contrast to the children, most adult care-givers tended to emphasise material rather than emotional needs of orphaned children. Many families struggled to provide education and food for all categories of children in their care, not just those who were orphaned. With fewer resources to share between more children, orphaned siblings were sometimes shared between relatives and therefore separated from each other. Care-givers viewed this as an undesirable but pragmatic solution in difficult circumstances.

Given the very high HIV-prevalence levels and high number of deaths of economically active adults, it is perhaps surprising that the AIDS epidemic was not the paramount child-care issue mentioned by care-givers. I found care-givers' prime non-material child-care concerns to be: teenage girls becoming pregnant, drug taking, lack of jobs for the young and hence youths turning to stealing. Becoming infected with HIV was cited rather less frequently, but this may reflect more immediate poverty-induced concerns, the stigma associated with the disease, as well as the long time interval (six to eight years) between becoming HIV positive and succumbing to opportunistic infections associated with AIDS.

Research question 3: Who do care-givers turn to for help? What support is there available within the wider community and from formal agencies? How is support accessed and what are the barriers to gaining help? (Chapter 4)

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

There was very little non-kin support for families, and community initiatives were still poorly developed. Most NGOs were concentrating on the rural poor and the access and distribution of assistance in the urban area was often piecemeal and open to abuse. Where good practice did occur, it was characterised by strong linkages between government officials at national and local levels, bottom-up feedback from the community and appropriate support, monitoring and evaluation by NGOs, CBOs and government officials working in relative harmony.

By delving into the quality of relationships within the community, I show that there were a variety of barriers that marginalised some families from resources that they had a right to receive. I also found that the urban informal settlements lacked cohesion, as relationships and obligations extended beyond the immediate locality. The AIDS epidemic was creating so much extra domestic work for women, in particular, that I did not find the concept of community care using volunteers, who are often poorly paid women, a sustainable option. Once more, as in pre-structural adjustment days, I conclude that the state, assisted by the donor community, has an important role to play in protecting its most vulnerable citizens. I find that the AIDS epidemic cannot be separated from the poverty in which it flourishes.

Research question 4a: How do children perceive the effect of the epidemic on their lives? What effect is AIDS having on their attitudes to sexual behaviour and decision-making during adolescents? (Chapter 5)

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

My results also show that global communications and the 'shrinking' world exposed Swazi urban youth to the sexual behaviours of other cultures. I was unable to assess whether this influenced sexual decision-making, and there is scope for further research in this area. The major contribution of this work was perhaps in allowing the 'voice' of teenagers in Swaziland to be heard and reported so that it may influence policy makers concerned with prevention education. There is little participatory research with teenagers from the 'South' in the literature, and a particular paucity in the context of sexual decision-making when growing up in an AIDS epidemic.

Once more I am able to show the limitations of separating out AIDS as a health issue as if it is suspended in limbo and detached from the society in which it is embedded. To achieve behaviour change and safer sexual practices amongst Swazi and other African youth, I suggest the economic and cultural drivers of this behaviour have to be addressed. Accurate knowledge through prevention education is just a beginning, and I provide evidence of effective strategies for achieving this. I conclude that to achieve safe sexual practices, youth need a more positive vision of their future prospects and role in society.

Research question 4b: How are children affected by bereavement and orphanhood? How are they responding to the challenges they face? (Chapter 6)

Although bereavement is another sensitive topic, I have tried to explore the issue through a range of culturally appropriate methodologies. Once more I emphasise the importance of the guidance provided by the two locally-recruited research

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

Sexual behaviour and sexual decision-making is obviously a very difficult topic to research with adolescents, especially in the context of AIDS. I have explored the potential shortcomings of both my methodology and findings at some length. Cognisant of the importance of cultural setting and my 'outsider' position, I also emphasise the very important role the two female Swazi research assistants played in guiding my approach to this stage of the fieldwork. Notwithstanding the caveats mentioned, I believe I have been able to provide a deeper understanding of the sexual issues faced by Swazi children growing up in an AIDS epidemic, and added to the body of knowledge of childhoods in the 'South'. The findings clearly demonstrate that while the global provision of anti-retroviral drugs has progressed, adequate preventative education in Swaziland and some other neighbouring countries lags woefully behind, and the spread of the epidemic continues.

Perhaps not surprisingly, my findings show there were many similarities with youth in other cultures. For example, in addition to the social construction of adolescent identity, the developmental stage of adolescence and its concurrent insecurities and peer group pressures were found to affect sexual decision-making. Similarly, while most adult care-givers suggested they discussed sexual behaviour and HIV issues effectively with children in their care, the children's views contradicted this in the main. Using the concept behind White's (2002) contradiction and solidarity model referred to in the introduction, I unravel the children's perception of which adults they can and cannot turn to on sexual issues. I find there are some gender differences in these networks, for example, girls were more likely than boys, to access information through health clinics.

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

assistants, one of whom worked with me for several months. Given the relatively limited literature on participatory research with youth in the South, I had to reflect on my fieldwork continuously and be prepared to make adjustments to my original plans. The reported findings are therefore adding to our relatively embryonic knowledge of the challenges of participatory research with children in a different cultural context and may prove fruitful for other researchers.

Giving 'voice' to children with various experiences of bereavement, I have shown once more that there are dangers in assuming there is a medical 'fix' for this aspect of children's lives, that children orphaned by AIDS should not be singled out for special attention, and that children show remarkable resilience and agency. I argue that inclusion in school is absolutely critical to the lives of these children, as, apart from formal structures that may be introduced in schools (for example school feeding schemes, counselling for bereaved children, teachers trained in child protection issues and abuse), there are many informal peer support structures which operate through schools, thus giving children a sense of inclusion. Overall, my research shows that bereaved children feared exclusion from their peers and emotional deprivation far more than any material deprivation they might suffer.

Research question 5: Where are the opportunities for and constraints on agencies involved with helping vulnerable children in Swaziland? What are the main forms of non-kin child-care that are emerging? Are they sufficient or are there gaps to be plugged? (Chapters 4 and 7)

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

This part of my research draws together many of the threads that have emerged in the earlier chapters. I find that Swaziland is similar to other countries with high levels of HIV prevalence in that most orphaned children remain within kin structures however fragile they may be. My fieldwork shows the ingenuity and agency of women, in particular, as they find livelihood survival strategies in the face of greater domestic work associated with the epidemic. I therefore favour social protection through pensions and cash transfers to chronically poor families, so they may be build on these initiatives, rather than the creation of new community care systems.

I explored the new systems of community care that were developing in Swaziland and found that there was a lack of understanding and co-ordination between different actors. I conclude that it is unproductive for NGOs to work outside the National AIDS plan in African countries, but call for a more flexible system for the allocation of Global Fund monies. In particular, I suggest that smaller NGOs often carry out valuable work with children, but find the Global Fund monies difficult to assess and should therefore be given further administrative guidance and support.

While community-based care for children no longer absorbed within kin structures is the main thrust of most national AIDS plans in African countries, including Swaziland, I argue the case for reassessing the current negative view of all forms of residential care of children. I show that there are situations where this form of care, if properly monitored and backed by statutory legislation, has favourable outcomes for children in certain situations. I provide evidence of sustainable residential care that is linked to income-generating activities and

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

integrated within the local community. I do not advocate high-cost residential care where children are isolated from the community and hence their cultural background. I argue that access to other adults in the community helps minimise the potential for child-abuse in residential settings.

The development of a Child Policy in Swaziland that would offer protection for vulnerable children in both family and institutional settings has been primarily donor led and appears to have met with resistance, as evidenced by its very slow introduction to Cabinet and Parliament. As Foucault (1980) explains, wherever domination is imposed, resistance will inevitably arise: *'There are no relations of power without resistances; the latter are all the more real and effective because they are formed right at the point where relations of power are exercised'* (p142). This is not the only pro-poor/vulnerable policy that has been slow to have the assent of Parliament and effective implementation in Swaziland (personal communication with the Prime Minister's office).

Whitfield (2004) argues, more generally, that Poverty Reduction Strategy Papers are still driven by donors, the I.M.F. and the World Bank, and just repackaged with little citizen involvement. She found that a lot of policies were not implemented, and concluded that PRSPs were not sufficiently country-driven for Governments to be committed to these donor-driven policies. My findings have unravelled some of the power relations between the main actors involved with the Child Policy in Swaziland, and I support Whitfield's contention.

Research question 6: How can this research contribute to an understanding of children's lives in the context of AIDS? What can this research contribute to both

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

the literature on the care of children in an AIDS epidemic and to the literature on the geography of childhoods in the South? How can it help inform policies in relation to vulnerable children in other countries? **(Chapter 7)**

By making use of the 'voice' of children through participatory research and by being guided by two young Swazi graduate females, this research has illuminated some of the challenges children face when growing up in an AIDS epidemic. Given that children are embedded in families, communities and the wider society, I have also included the 'voice' of many other actors that have a role to play in the lives of children. While there are similarities with childhoods experienced in other parts of the world, I have shown the importance of local context in its broadest sense.

During the 1990's the literature moved away from viewing childhood as a universal, time-bound, developmental experience to one of a multiplicity of childhoods. The social construction of childhood and a greater respect for children as persons in their own right has emerged as a dominant theme. The agency of children is now recognised, hence the need to research with children to understand their lived experience of childhood through their own lens. My research with children adds to this body of literature in several ways, but adds a note of caution to the current move away from the developmental transitions children experience as they grow.

It is very clear from my findings that the social and cultural contexts have profound effects on children's lived experience. However, I do provide evidence of the development transition of adolescents, and suggest that this has similarities

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

residential care. However, this form of care has to be developed in a culturally appropriate way that ensures favourable outcomes for children and protects them from abuse. There are best-practice models on which to build, and I have referred to some in this research.

In the introduction to the thesis I referred to the lack of domestic upheaval in Swaziland and how this might result in a more cohesive extended family than in some other neighbouring countries also affected by the epidemic. I also stress the importance of contextual understanding. However, there are outcomes of this research that have relevance to other settings. In particular, the recognition of the agency and resilience of children and the different 'lens' through which they perceive their experiences of growing up. Similarly, the nuanced insights into the importance of relationships and power relations at family, community, national and international level are pertinent to other countries in a development context, not just countries experiencing an AIDS epidemic.

8.3 Further reflections

8.3.1 Reflecting on methodologies

In chapter two I describe the wide variety of methods that I used to gather information from children, families, key informants, and textual sources. I now reflect on the relative strengths of these varied approaches. Each method has contributed valuable data for this thesis but some methods yielded more information, and were less difficult and time-consuming to facilitate, than others. The most challenging part was undoubtedly my research with child respondents.

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

drawn up beyond Swaziland, have an important bearing on this. I conclude that to overcome these shortcomings, all players should contribute to, and work within, a country's National AIDS Plan, but rather than a universal set of conditionalities surrounding the Global Fund, PEPFAR or other donor monies, a more context-specific arrangement should be developed and credence given to local rather than 'bought-in' expertise. The time spent building up strong partnerships between actors, collaboratively creating clear implementation guidelines that are readily accessible, as well as adequate monitoring and evaluation procedures, is likely to be time well spent.

In democratic countries, the elected MPs, as citizen's representatives, should be included far more in policy-making. My fieldwork in Swaziland shows that locally-elected politicians seemed remote from the Draft National Policy on Children, and it remained a low priority on the agenda of the Cabinet private secretary. Vulnerable children in Swaziland are, in the main, unprotected by effectively implemented legislation.

In terms of the implications of my research findings for child-care policy, I conclude that families in countries affected by AIDS should be strengthened in their role as child-carers by donor-assisted, government-led, social protection measures for the poorest families. Women, in particular, should be trusted to maximise cash transfers effectively. I also conclude that new community-based structures for non-kin child-care are not likely to be effective and sustainable unless devised by the community and children are given a part in their design and execution. Similarly, there are likely to be some vulnerable children in poor countries affected by AIDS who would benefit from the opportunities offered by

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

I describe in chapter two, the difficulties I had in gaining access to children in private spaces. I had hoped to interview children living in residential care but I did not succeed in overcoming the barriers presented to me. Perhaps a three month placement as a volunteer worker or similar, carrying out what I have described as 'situated learning' (p.87), within such an institution, might be the best approach. However, having gained access to schoolchildren, I then faced some ethical dilemmas. I found that, though I was granted access to the children, one of the 'gatekeepers' was relatively dismissive of my attempts to gain 'informed consent'. It was as if he felt his authority was sufficient and children, as minors, should not need to be consulted. I therefore tried to ensure children participated voluntarily, as I had requested, by both writing a letter to each child about the nature of the research and their role in it, including the right to withdraw at anytime, and by further discussion, with the children, about the meaning of 'informed consent', on the days of the research. In terms of the ethics of the research and the need for beneficial outcomes for children (Schenk and Williamson, 2005), the participating children did benefit from the accurate health education information provided, and they had the opportunity to discuss the material with informed adults.

The actual data collection methods of focus group discussions (FGDs), open-ended written work, and one to one informal conversations with children, worked well. Evans (2006) refers to similar success, when researching with street children in Tanzania, using participatory methods such as focus groups, drawings, and photographic exercises. In my work, the findings showed that children sometimes portrayed their lives in a very different way from the description given

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

by their adult carers. In chapter six, this is evident where adults were shown to concentrate on the material needs of bereaved children, whereas the dominant concerns of children (gathered through child-centric methods) centred much more heavily on their emotional needs. In this way, the research methods have successfully enabled children to represent their own lives. Fungisai, *et al.*, (2005), researching sexual issues with children in Zimbabwe, note:

'...children are willing to converse with adults about their sexual knowledge and attitudes. Indeed we would encourage researchers to be even bolder in terms of the topics they address and types of questions they ask, and not to let themselves be too constrained by the apprehensive and conservative feelings of various gatekeepers and partners.'

(p.215)

My research methods support this view as children have not only openly expressed their views on sexual decision-making and sexual-behaviour but they have called for more discussions with parents, other adults and peers (see chapter five). Madriz (2000) argues that focus groups are an important way of allowing the voice of oppressed people to be heard and it encourages their own agency:

'For those social scientists interested in social change, the hope embedded in the use of focus groups is that they may contribute to some individuals' recognition and awareness of their own subjugation. Using their own words and their own framework, this awareness may lead to participants' involvement as change agents in the affairs that affect their neighbourhoods and their communities.'

(Madriz, p.848)

A beneficial outcome of the focus groups conducted with children in my research, might be that they felt more empowered to report abuse by carers and to take more responsibility for their own sexual health. The plural voice of others that

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

emerged in the FGDs may also have encouraged more openness and solidarity between those children made vulnerable by the epidemic.

One final point on my research methods with children concerns the relevance of cultural context. In chapter two I explained the importance of: creating a child-friendly ambience, using culturally appropriate language, diminishing adult/child power relations, and remembering the ethics of working with children. Methods that work well with children in the North may need adapting for such a different cultural setting. Griessel *et al.*, (2002) working with young people in Johannesburg, and using psychometric tests developed by Battle (1981) and Nowicki *et al.*, (1973), note:

'Finally, more attention needs to be given to the translation, adaption and creation of culture-sensitive psychometric instruments for non-western groups.'
(p.99)

Eyber (2003) researching post-traumatic-stress-disorder with adolescents in war-torn Angola, questioned the transferability of psychometric tests developed in the North, for Western cultures, to settings in the South. Though I was not using psychometric tests, I was attempting participatory research that required a deep understanding of cultural sensibilities. Living and working with Swazi children for several years immediately before the research, and engaging locally recruited research assistants, were important elements in creating a culturally sensitive approach and a successful outcome to this part of my work.

In contrast to the research with children, the data collection with the twenty-five families was relatively straightforward. Entry points via the Zone Leader of the informal settlement and the Swazi friend who introduced me through her church community, worked well. The compilation of a demographic sheet for

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

each household was invaluable for untangling the web of family relations during data analysis, and the environment index aided my understanding of the livelihoods of respondents. The use of a semi-structured interview was also very successful despite the constraint of using an interpreter (discussed further in 8.3.2 below). The interview structure was sufficiently open-ended in style to allow families to expand into areas I may not have considered, and it facilitated analysis afterwards. I was able to code responses and discover the main issues, opportunities, and constraints facing families caring for children in the midst of an AIDS epidemic. By extending this data collection over several months, I was also able to have informal conversations with other community members, or further conversations with some of the families already interviewed. Meanwhile, the interviews with key informants, undertaken during the same period, helped inform this household-based research.

Although the setting up of key informant interviews involved the laborious process of appearing in person, to arrange a suitable time, it did minimise effectively the number of rejections I received. Unlike with the community level research, I did not need to use an interpreter or research assistant as respondents used English in the work place for all written communication and for most conversations. I taped some interviews, but often found that respondents revealed additional information after the recorder was switched off. These in-depth interviews were very effective for revealing the strength and weaknesses in relationships, both within organisations and between organisations.

In addition to in-depth interviews, I learnt more of the power relations and agendas of organisations by participant observation. However, by accepting an

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

invitation, by UNICEF, to contribute voluntarily to the Education-Working-Group that was helping to compile the Draft National Policy on Children, Including Orphans and Vulnerable Children 2003, I felt slightly compromised when assessing national-level policies suggested by UNICEF. While it did not affect my own research with families and children, I had to guard against such voluntary work affecting my objective appraisal of UNICEF initiatives. At the time of my research, UNICEF was a major donor and important international NGO working with children affected by HIV/AIDS in Swaziland. As I developed deeper relationships with some UNICEF personnel, I found I had to refrain from letting these cordial relationships colour my judgement of UNICEF policies. For example, it became much more difficult for me to appraise UNICEF initiatives negatively, such as the introduction of a national network of neighbourhood-care-points, despite the evidence presented to me (see p.265). It made me aware of the potential conflict of interests, in any research project, especially if research funding is involved, and the responsibility placed on the researcher to observe the tenants of honesty, fairness and equity throughout the research process.

My final methodology was the textual analysis of many in-country reports produced by different organisations involved with the HIV/AIDS epidemic. Many of these reports and documents are not easily available outside Swaziland but they proved an invaluable source of data. They revealed the agendas, working partnerships, and resources available to different organisations. These textual sources also revealed the lack of reliable statistics on the lived experience of children, such as the often-quoted figure of 10,000 'child-headed-households' (see p.256) and the inappropriate comparison of unsuitable data sets (see p.171).

8.3.2 Research assistants/interpreters and 'whiteness'.

For some of the research questions that I pose in chapter two (p.73) I recognised that I would need to employ facilitators and, in some situations, an interpreter. Madriz (2000) refers to the extra costs incurred that need to be included in the research budget but she recognises that '*the rules of interaction*' (p.846) may be different in other cultures and that language differences may create problems of communication. Research assistants were needed in parts of my data collection to help overcome these barriers of cultural nuance, language as well as my 'whiteness'.

I have referred, during the preceding chapters, to the patriarchal nature of Swazi society. Even though I was interviewing urban families, many of the traditional cultural norms remained important within these relatively poor families. I was also aware of their lack of exposure, within their own homes, to people of white skin colour. My position as powerful, white, 'other' had to be carefully negotiated to allow respondents 'space' to describe their lived experiences. It was partly chance that, through a Swazi friend, I found a local, black, female, graduate, research assistant, from a similar urban background to the respondents, who was in need of paid work. She guided me over simple practices such as: the ways of approaching a household, taking shoes off at the door, the need to greet male family members first, and with due respect.

Older family members did not speak English fluently and the assistant assumed the role of interpreter, using the semi-structured interview guide that I provided. I maintained eye contact with the respondent as she/he spoke and I acted as an attentive listener. I had to read body language and verbal-clues (such

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

as increased tempo or agitated voice) to constantly check with the interpreter if other issues were emerging that needed further exploration. These interviews were lengthy, due to the translation involved, but this process allowed both myself, and the respondent, to reflect and extend answers and questions if necessary. Even if I had been fluent in the local language and able to interview alone, I may have missed some of the subtle communication that my research assistant noticed, and my white skin colour would have been more of a problem both in terms of gaining entry to households and the discourse that ensued. The research assistant actively negotiated my position as interested observer, not as a prospective donor. On several occasions, the research assistant told me that the respondents were heartened that someone wanted to write about their lives.

I needed a second facilitator to assist on the days of research with children in schools in order for my research activities to be carried out simultaneously, and disruption to lessons minimised. Swaziland has English-medium schools, thus secondary-school-aged children are used to speaking and writing in English, therefore language was much less of a barrier to this part of my research. During focus group discussions, children did, however, use some SiSwati words and phrases that the assistants then had to translate during transcription. My second assistant was also a female, black, young graduate.

I considered the gender and age of my assistants as important factors in empowering the young people to speak more openly about their lives. I thought my own age (54) and skin colour, would create barriers in focus group discussions, and I chose to remain with the children writing their accounts while the FGDs took place with the two assistants in a different room. Some children did talk to me on a

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

one-to-one basis, just outside the classroom, and did not seem inhibited. Privacy and empathy seemed to me to be crucial elements in encouraging such exchanges; skin colour and age appeared less important to those children who chose to speak to me.

This collaborative research methodology not only helped uncover the complexities of difference created by race and culture but also allowed the similarities of the human condition to emerge in a way that transcended our differences. There were several times when the principal research assistant and I witnessed human suffering that led to a communion of spirit between us, empowering us both to act to alleviate that suffering. Much has been written about the dominance of the Euro-American paradigm and its creation of 'otherness' and the need for more scholars of colour in the academy (Ladson-Billings, 2000). This will undoubtedly lead to a greater variation of representations and discourses of people's lived experiences. I would suggest that new epistemological stances are most likely to emerge through collaborative research where social scientists from different cultures work together as we did. Ladson-Billings (p. 257) contrasts the epistemology of the individual as presented by Descartes, with the African concept of *Ubuntu* where the individual's existence and knowledge is '*contingent upon relationships with others.*' By researching alongside each other, new ways of representing knowledge may emerge and the gulf between North and South that I describe in the last sentences of this thesis might become a little narrower.

8.3.3 Children's Geographies revisited

In this section I reflect on the outcomes of my research and the ways in which it contributes to the literature of children's geographies, particularly aspects of research methodology. In chapter two I discussed the methods used to create a research setting conducive to working with children, especially the problems of: my 'outsider' positionality; power relations between researchers and the researched; the ethics of participatory research with children; and creating an ambiance and range of methods that allows the multiple voices of children to emerge. The main findings of my research with children are presented in chapters five and six.

My discussion of the successes (for example, the candid ways children wrote about their lived experiences) and limitations (for example, the difficulty of gaining access to children in 'private' spaces) contributes to the literature on research with children in many settings, not just the urban poor child in the South. Many of my observations concur with the work of Punch (2002) where she advocates that: *'reflexivity should be a central part of the research process with children, where researchers critically reflect not only on their role and assumptions (Davis 1998), but also on the choice of methods and their application'* (p.323). I constantly had to reflect on my methodologies and adapt as situations evolved (see p.81, when 'gatekeepers' were a problem, p.62 when interviewing a bereaved young adult).

Punch discusses the need for building rapport, using 'child friendly' language and spaces, and making the research fun and interesting. These are all aspects I have engaged with in chapters two, five and six and my findings support

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

her work and, in the main, are independent of race. Where I do consider that my white skin colour and the children's black skin colour was an important consideration I have referred to it (p.65). I have discussed 'whiteness' in more depth in 8.3.2. (p.297).

Valentine, Skelton and Chambers discuss how the validity and reliability of research with young children is often debated (1998, p.22). They note:

'All research accounts, whether provided by a 17 year-old gang member or a middle-age business man, are just that- "accounts", which are mediated by the tellers' experiences, by their perceptions of the researcher and of the research context, and by their own agendas. Thus all research accounts are equally likely to be a cocktail of the "experienced", the "perceived", and the "imagined".'

(p.22)

There are examples in my work that support this view. I refer to the findings of Carr-Hill, *et al.*, (2002), where the research context led adults to give false information on the number of orphans in a household in order to gain more material assistance (p.94). It is the reason why I took particular care in creating an appropriate research context and ambiance with the children in this work (see also: Morrow, 1999; Punch, 2002; Harpham *et al.*, 2005). I wanted to minimise power relations and reassure them that their voice was unique and highly valued (see p.178). By providing a range of data gathering activities, particularly the opportunity to write privately and anonymously, the children portrayed their lived experiences readily. Robson and Ansell (2000, p.178 and 179) give a critique of using story-writing with children in Zimbabwe and my findings are similar: the method allows children to reveal as much, or as little, as they wish, but, *how* the exercise is set up may affect what they write, so they must be read '*as texts and forms of discourse*' (p.179). Some topics are likely to be more sensitive to

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

research than others and validity may hence be more of a concern. I discuss this in chapter five in relation to sexual decision-making and sexual-behaviour.

In chapter five I have researched children's sexual decision-making and sexual-behaviour to explore and discuss: social relations within and between different age-groups; power relations within and between genders; the connectivity between youth in the North and South; and practical ways of encouraging safer sexual-behaviours. I show evidence of the children's vulnerability and link this to both the ways their lives are embedded politically, economically, and socially within Swazi society, *as well as* to the development stage of adolescence. Others are beginning to engage in this area: Fungisai *et al.*, (2005), researching sexual issues with children in the context of HIV/AIDS in Zimbabwe, have encouraged researchers, interested in children's geographies, to apply the ideas in this sub-discipline of Geography to the study of children's sexual health in southern Africa.

In chapter six I engage with children who have been bereaved or have experience of bereavement and my findings support those of others researching children's geographies in the South. I recognise the resilience, competence, and agency of the children but I also stress the constraints imposed by gatekeepers who control resources (see inheritance, p.224), their feelings of exclusion and marginalisation, and their exposure to physical, sexual and emotional abuse (p.224) by adults with whom they live.

Whilst the experiences of orphanhood are diverse, my research portrays some very vulnerable children (some orphaned, some not) who need emotional and material assistance as well as protection. Not all researchers agree with my interpretation, as it veers towards the theory of the development stages of

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

childhood: children who need nurture and guidance in order to reach their full potential as social actors in society (see also 1.3.1)

Robson (2004), in her work with child-carers in Zimbabwe, argues against the International Labour Organisations' essentially 'northern' vision of a labour-free childhood. In a time of HIV/AIDS where so many children are carers, Robson sees this as an inappropriate paternalistic and protective view of childhood that hides the contribution that children make to society in the South. Conversely, Kesby *et al.*, (2006) working with children affected by HIV/AIDS in Zimbabwe, write of children existing at the '*margins*' of human experience and while recognising children's agency, they also note their vulnerability.

Given the extreme circumstances that pertain to some children's lives around the globe, I suggest it is time to rework theories of childhoods and conceptualise the existence of *chronic childhoods* that children may slip into for parts of their lives, and that therefore merit particular attention, at least conceptually. The caveat is that there are innate dangers in categorising certain children, and such a concept as '*chronic childhoods*' needs to be treated with due caution lest it leads to inaccurate representations of the lived experiences of children.

Aitken (2001, p.187)) draws attention to the way certain places and people are '*mythologised*'. He describes the discourse that developed around a shooting incident carried out by a 15-year-old boy in a Californian school in 2001. The subsequent headlines in the Los Angeles Times helped create a '*mythic geography of fear*' (p.186) as if this one incident was typical of white American youth across the nation. The adult rhetoric around such incidents represents

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

youths generally in terms such as *'delinquent youth'*, ... *'angry young men'* (p.187).

This tendency to mythologise youth also occurs in the South.

In chapter six (p.205), I describe how some researchers regard orphaned children, as a potential menace to society. Cornia (2002) begins by categorising children who have lost parents due to AIDS as 'AIDS orphans' and then describes the various deprivations they might suffer and speculates: *'they may also become more aggressive, represent a menace to society, commit crimes, turn to drugs or become sex workers'* (p.12). Bray (2003) argues there is insufficient evidence to support these pessimistic scenarios or, as Aitken prefers, *'mythic geographies of fear'*. However, this discourse has helped focus attention on children orphaned by AIDS as a distinct category of children with relatively homogenous lives. Glauser (1997) showed how such categorisation disguised the lived reality of street children.

My findings in this thesis concur with those of Bray and Glauser. The evidence presented in chapter six illustrates the heterogeneous lives of bereaved children and that, far from being a menace to society, they actively engage with their new circumstances to construct new ways of everyday living. This includes sensitivity towards others who are sick, bereaved or unhappy. Very few children expressed aggression or anger about their situation despite some children reporting physical, sexual and emotional abuse. However, they did express fear of exclusion from the peer group and fear of being moved to a new place where they would be separated from their siblings and friends.

The importance of 'place' in emotional well-being is discussed (p.234) and may help explain some of the differences observed between childhoods in the

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

North and South. Robson and Ansell (2000) have carried out preliminary research in Zimbabwe with children who are caring for others and compared the discourse around such caring with that used to describe 'child-carers' in the north. They argue against imposing northern normative notions of childhood on children in very different social contexts (p.174). Young Zimbabwean carers '*did not generally imply that caring was a problem*' (p. 191), unlike the way that it is portrayed in northern literature. The children in the study tended to describe caring in much more positive terms than is typical in the North.

My own observations of children caring for sick relatives in Swaziland leads me to speculate that the experience of 'place', and connectivity patterns of social relations, may partly explain this apparent North/South difference in the discourse of caring, and it is worthy of further study. I have already mentioned the different perceptions of identity and 'self' in Swazi society (see p.216) and the obligations felt towards kin. In chapter three, I have explored the links between kin and the way this may lead to material exchange or support, casual visiting, and more fluid child-care arrangements. During my fieldwork I also observed the open-air interactions between members of the neighbourhood as many everyday activities were carried out in the open. The child-carers were therefore less physically isolated from social interaction, and more likely to be able to ask for advice or be praised for their kindness than might be the case for a child in the North, 'hidden' within a house, and in a society where 'space' in neighbourhoods may offer less opportunity for the type of supportive casual interchange I observed in Swaziland. It also helps explain the reluctance of bereaved children to be

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

uprooted from their 'place' as it severs many trusted links with supportive adults and peers beyond the immediate family.

My last contribution to the literature of children's geographies is a comment on global restructuring and the discourse and practice of international development. Ansell (2005) reviews the discourse on international development over the past fifty years and its impact on children's lives. She reviews the key development models: from structural adjustment programmes through to private sector initiatives and trade liberalisation. Similarly, I have shown how children in poor urban settings experience 'development'. I have delved into the relationships between local, national and international actors and how these linkages/relationships/power struggles affect the supposed recipients of the development process. In chapter four I explore the power relations that influence children's access to schooling and family access to healthcare. I return to the development theme in chapter seven, where I analyse child-care options, and again later in this chapter where I call for more synergy between governments of both North and South.

With the exception of Brazil¹, children have played little part in drawing up global constructions of childhood, and they took no part in the drawing up of the 1989 United Nation Convention on the Rights of the Child (Boyden, 1997, p. 222). It is perhaps a sign of some progress that Swazi children were present and contributed their views, in Swaziland, in 2003, at a UNICEF-organised National Conference on Orphans and Vulnerable Children. It is also a sign of how children's

¹ Boyden (1997) notes that children were not involved in the drawing up of the 1989 United Nations Convention on the Rights of the Child or consulted on how it should be implemented. However, children were involved with the development of the National Statute on Children and Adolescents in Brazil (p.223)

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

lives are mediated by adults, as, two years later, the *Draft National Policy on Children, Including Orphans and Vulnerable Children in Swaziland 2003*, had still not been presented to the Swazi Parliamentary Cabinet.

8.4 Some suggestions for further research

This work has contributed further insights on the lived experiences of older, mainly urban, children growing up in an AIDS epidemic and adds to the growing interest in the heterogeneous childhoods experienced in different cultural, socio-economic and political settings. Through understanding the lived experience of children's lives, resources and policies may be targeted more effectively. To achieve these outcomes, further participatory research with children experiencing different livelihoods is needed. For example, one pressing area for further research is with children living in residential care. I have discussed my inability to by-pass gatekeepers in this study, but it is an area of participatory research with children that is urgently needed. Comparing experiences of current residential care in different cultures in a longitudinal study through the lens of children would enhance our understanding of how to achieve the most favourable outcomes for their lives. There also needs to be more participatory research with children in non-kin foster care within families in resource-poor settings. This research must consider all the ethical issues surrounding researching with vulnerable children, particularly the cultural context, and the children's needs, rather than those of the researcher, must remain paramount.

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

The child-based part of my fieldwork is essentially with a relatively small group of poor urban children. Research with children in different socio-economic, cultural and spatial settings where AIDS is endemic may produce very different results. Another fascinating line of enquiry would be to investigate the way smaller in-country NGOs are monitored and regulated. There is concern that some of these are little more than money laundering organisations, while others struggle to carry out valuable work with children, but lack the administrative resources to understand application procedures for donor funding. I only began to touch on this issue in my research.

The setting up of National AIDS Committees to receive, distribute and monitor Global Fund Monies has created some tensions with other Government departments in Swaziland that I began to detect in this fieldwork. It would be interesting to research the way these tensions are played out in more detail in different African countries, and whether it is, indeed, the best way to achieve development outcomes in the AIDS epidemic, or whether it has the effect of separating out AIDS as a health issue so that it is somewhat detached from, and therefore a lower priority, on the agendas of individual ministries.

8.5 Some final comments on the development debate

Perhaps one of the most interesting findings of my research is the importance of politics, personalities and trust in achieving development outcomes for children whether at local, national or international level. If development is viewed as a set of scales, then on one side there is the international donor/bank community continuing to pour resources into the poor South, in this case in the context of

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

children made vulnerable by HIV/AIDS, and anxious that this money is judiciously spent to achieve development outcomes. To achieve the latter, despite the rhetoric surrounding Poverty Reduction Strategy Papers and the concept of participation and local ownership, there seems to be much conditionality, as is evident in some of my findings, but in a more subtle form than in structural adjustment days. It seems international donors/banks do not really trust governments of the South, perhaps with much justification in some cases, to spend wisely for poverty reduction and development outcomes.

On the other side of the 'development scales', governments in poorer countries like Swaziland want to ensure donor funding continues. They may not always agree with the conditionalities subtly applied to grants and loans, but they are in a weak position to bargain for their removal (some African leaders are the exception here, such as Museveni in Uganda, who has not generally felt intimidated by western agencies).

Contextually relevant local knowledge and wisdom is often by-passed in favour of that supplied by western consultants, who spend a few weeks in the country producing a report for donors and banks. Yet such reports may omit many of the subtleties of local politics, power relations, personalities and partnerships so critical to achieving positive development outcomes. The project may then fail. No one is held accountable. The next round of government/donor bartering for further donor/bank funding begins, with even tighter controls this time and even less local knowledge input.

Meanwhile, the majority of the vulnerable poor struggle to find their own successful livelihood strategies. Projects and donors come and go, but often they

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

do not impact on their lives in any meaningful way for long. Some of the poor qualify for help, while others do not. The rationale behind these allocations escapes most recipients.

Lockwood (2005) has suggested donors should favour governments who attain development outcomes, but give governments plenty of scope for their own decision-making. This seems a sensible course, but strong political leadership will be needed. For example, I found that where there were talented, well-qualified, local-government employees in place, they often felt frustrated working for low pay in a poorly resourced department where clientelism was rife. One such well-qualified government employee remarked to me that *'it is not so much the brain drain that we have here as the brain in the drain.'* He had many ideas but felt he was unlikely ever to have the position or the resources to carry them out. The causes of such clientelism and waste of human capital needs rooting out.

Finally, if AIDS continues to be treated as a health issue by the G8 countries, as I have indicated earlier, rather than part of the whole development debate, then we have a development process that undermines itself. I have shown throughout this research that AIDS is far more than a health issue, as it interacts across the whole development spectrum. I have shown there are many reasons why the AIDS epidemic is continuing to spread, but poverty features heavily. There is not a simple link between poverty and AIDS as I have discussed, but young people living without a vision of an achievable worthwhile future have less incentive to remain HIV negative. For example, it is surely counter-intuitive to provide money through the United Nations Global Fund to combat HIV/AIDS, while simultaneously creating the trading conditions where jobs are lost (the textile and

CHAPTER 8: Conclusion. Scaling Up Interventions to Support Vulnerable Children in Swaziland in the Context of AIDS: Opportunities and Constraints

sugar industries) and future employment prospects for youth reduced. The vision of that achievable future then perishes.

If the North is genuinely interested in 'equity' (World Bank Report, 2006), and thereby relieving the suffering of children affected by HIV/AIDS, it must be prepared to part with a larger share of the wealth that it currently enjoys, and work towards sustainable global development. Mutual trust and reduction of global inequality will remain elusive, until governments of both North and South recognise it is in both their interests to work towards this end.

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Appendix 1

Community interview guide

Introduction

Babe Gwebu has given us permission to invite you to take part in research about the way family life in Swaziland is changing. We are particularly interested in the way children are cared for. The findings of the survey will be used to help those deciding how best to assist families care for children in these increasingly difficult times.

I am Make Jones from Oxford University in England and this is Sharon Neves a graduate from Rhodes University in South Africa.

When the research is written up your confidentiality will be protected and you will not be mentioned by name. Taking part is voluntary. However we hope you will agree to talk to us.

(show identity card)

1. Demographic data

(fill in enclosed form- appendix 5 and 6)

2. Extended family

1. It is said that the extended family (i.e. other blood relatives not living with you in this house) is no longer as strong as in the past. What is your opinion? (probe for reasons for the view they express)
2. What support do you receive from your extended family?
3. What support do you give to your extended family that do not live in this household?
4. Traditionally, if a father died it was the paternal family's responsibility to care for the children. In your experience, is this still the case? (probe for reasons for the view they express).

3. Fostering

1. Is the head of household looking after any children that were not born to him/her? (these may live in this household or elsewhere)
2. For each child being fostered please explain how and why it was decided the child should live in this household and how long you expect the child to live with the household?
3. Are any of the Head of household's children under 18 being fostered elsewhere? Please explain how and why this decision was made. Does the head of household help towards the upkeep of such children?
4. Is any help received for children fostered here in this household? (probe from family/CBOs/FBOs/NGOs/govt)
5. If you are receiving help for a child, how was this arranged? (how did they learn help was available)?

6. What are the main concerns you have with the children you foster?
7. Have you ever been asked to foster a child and not done so? Give reasons for your decision.
8. Do you know of any child-headed households (i.e. no adult over 18 present in the house to care for them) in Manzana?
9. What do you understand the word orphan to mean?
10. What do you think the community in Manzana could do to help its orphaned children?
11. Do you know of orphaned children who have lost their inheritance? How do you think the property/inheritance of children should be protected?
12. Are there other children that need help besides those who are orphaned? Give reasons why they should be helped?

4. Child care

1. In your opinion, are all the children in this household receiving enough food/clothing/health care?
2. Have any of the children dropped out of school in the past year? Explain why.
3. Where does the money come from to meet all these needs for children? (probe for sources- employment/other relatives/neighbours/NGOs etc).
4. (If there are teenage children) Do you have particular concerns with the teenage children in your household? Explain what these are.
5. With the high rate of HIV/AIDS in the 15 to19 age group, do you try to talk to them about the disease? If not, what do you find difficult?

6. In your opinion, what are the main influences on teenage children you know?

7. Who do you think teenagers respect and listen to?

5. Vulnerability and coping mechanisms

1. In the last year have you had any particular extra hardships to cope with such as unemployment/sickness of a family member/deaths and funerals to pay for/ tenure threats because of lack of rent etc? Please explain.

2. If you have difficulties like these who else can you turn to for help besides your family? (probe- e.g. extended family, church, community leaders, neighbours, employer. If they cannot turn for help outside the family, then why not).

3. If the government through NERCHA had a limited amount of money to spend on families like yours, where would you appreciate the help most?

Thank you for your time. We appreciate your help with the research.

Would you mind us returning to you on another occasion?

Do you have any questions for us?

6. Post interview observations (see environmental quality sheet Appendix 4)

Appendix 2

Example of a completed interview in an informal settlement in Mbabane (Names and other details which might compromise confidentiality have been changed or removed, the respondent's replies are in bold and my additional comments in italics)

Family 6: Head of household (HoH) 69 year old grandmother carer

Respondent: HoH

1. **Demographic sheet (not included for reasons of confidentiality)**

2. **Extended family**

1. It is said that the extended family (i.e. other blood relatives not living with you in this house) is no longer as strong as in the past. What is your opinion? (probe for reasons for the view they express)

We do have strong family ties

2. What support do you receive from your extended family?

My brother who works in Piggs Peak and my son Themba support me. They give me food, money, moral support. I am basically open to them for any help I need, I know I can count on them. My brother does come to check on us, and the cows, occasionally. *(She has several cows and two calves)*

3. What support do you give to your extended family that do not live in this household?

I do the same for my family where I can. For example, if there is a death they know I will go and help with the funeral arrangements.

4. Traditionally, if a father died it was the paternal family's responsibility to care for the children. In your experience, is this still the case? (probe for reasons for the view they express).

In Swazi culture a wife is a wife. They should stay in their in-laws home until they die: but now, they are often not married and therefore not entitled to remain with their in-laws after death (*Sharon thinks this is because men are not able to pay the lobola*)

3. Fostering

1. Is the head of household looking after any children that were not born to him/her? (These may live in this household or elsewhere)

Yes, two children

2. For each child being fostered please explain how and why it was decided the child should live in this household and how long you expect the child to live with the household?

Eldest fostered girl, 18: The father had never looked after the child. They were just girlfriend and boyfriend. The mother went off to get a job abroad and she is now not in contact with us. She helped us at first but not now. My son

Themba thinks this is unfair especially now the school fees and exam fees are due and they are expensive.

Younger fostered girl 11: Her parents are dead and I'm the (maternal) grandmother.

(Didn't say why she was looking after the younger grandchild rather than the paternal Gogo).

3. Are any of the Head of household's children under 18 being fostered elsewhere? Please explain how and why this decision was made. Does the head of household help towards the upkeep of such children?

No

4. Is any help received for children fostered here in this household? (probe from family/CBOs/FBOs/NGOs/govt)

The youngest grandchild gets a Red Cross food parcel every three months. I've had three so far this year. (Family help from her son Themba and her brother, already mentioned, to pay for school fees, food and clothing).

5. If you are receiving help for a child, how was this arranged? (how did they learn help was available)?

The RHM came round

6. What are the main concerns you have with the children you foster?

My main concern is their welfare in the future. I am old and do not have many days left. I pray to God that after I am gone my son lives long and can look after them.

7. Have you ever been asked to foster a child and not done so? Give reasons for your decision.

No

8. Do you know of any child-headed households (i.e. no adult over 18 present in the house to care for them) in Manzana?

No

9. What do you understand the word orphan to mean?

I take an orphan to be a child who has no relatives. In Swazi culture any child who has a relative is not an orphan. That is why we don't have orphans in Swaziland.

10. What do you think the community could do to help its orphaned children?

There is nothing happening at the moment. I would be happy if there was a meeting so we could discuss the issue.

11. Do you know of orphaned children who have lost their inheritance? How do you think the property/inheritance of children should be protected?

Our culture is based on sharing so I cannot say I have experienced children who have lost their inheritance but I could say I have seen children who are being neglected after their parents have passed on. I could suggest we have a system where children are checked on after their parents have died. Often children drop out of school and are forced to work harder than other children.

12. Are there other children that need help besides those who are orphaned? Give reasons why they should be helped?

It would be unfair to separate the help given to orphan and other children. If they are needy they are needy. There are parents who are alive who cannot help their children so they are as poor as orphaned children.

4. Child care

1. In your opinion, are all the children in this household receiving enough food/clothing/health care?

I really have a problem looking after these children. I don't have enough money for their food healthcare and clothes. It ends up being my son's responsibility, which is a bit too much for him *(he has his own wife and children)*

2. Have any of the children dropped out of school in the past year? Explain why.

No

3. Where does the money come from to meet all these needs for children?
(probe for sources- employment/other relatives/neighbours/NGOs etc).

(see above- her brother and son and Red Cross food parcel for one child)

4. (If there are teenage children) Do you have particular concerns with the teenage children in your household? Explain what these are.

I have not had any problems with my teenage granddaughter.

5. With the high rate of HIV/AIDS in the 15 to19 age group, do you try to talk to them about the disease? If not, what do you find difficult?

I have been very open with her and I talk about a lot of things and so does my son.

6. In your opinion, what are the main influences on teenage children you know?

In my opinion, their friends and peers influence them a lot and are the main influence on their lives.

7. Who do you think teenagers respect and listen to?

I think they listen to their girlfriends and boyfriends and we come second as parents.

5. Vulnerability and coping mechanisms

1. In the last year have you had any particular extra hardships to cope with such as unemployment/sickness of a family member/deaths and funerals to pay for/ tenure threats because of lack of rent etcetera. Please explain.

I have had two hardships:

I have had real difficulty getting the exam fees (*over 2000E*)

The younger grandchild was sick and had a lung problem and was in the government hospital for a week.

2. If you have difficulties like these who else can you turn to for help besides your family? (Probe e.g. extended family, church, community leaders, neighbours, employer. If they cannot turn for help outside the family, then why not).

Besides my family, my brother and son, I would talk to my church. The only other person I would run to is my neighbour. She always tries to help me where she can. (*Her neighbour is a great grandmother carer*)

3. If the government through NERCHA had a limited amount of money to spend on families like yours, where would you appreciate the help most?

I think the government should help the elderly by giving them a monthly grant so they can survive. They also need to help the needy children with food clothes and school fees. They need to make sure there is work for those who are fit. This would reduce a lot of the problems.

I am old and I would like to rest. I hope some help does come so my grandchildren are looked after.

Appendix 3

Sample of all responses to one part of a question and compiled into one document ready for coding. (Some families did not consider they had hardships in the last twelve months to report). Preliminary coding scheme is shown in red.

5 Coping mechanisms

2. How have you coped with these hardships? Where have you turned to for help?

No one helps. We have to take out loans at work to cater for the expenses L

He was bewitched by someone at work. We went to several inyanga (*traditional healer*) **and that solved it.** T

I go to my friends who I know from home (*Mozambique*) **or work** Fw

Besides my family, my brother and son, I would talk to my church. I'm Catholic. The only other person I would run to is my neighbour. She always tries to help me where she can. (*Her neighbour is a great grandmother carer*)

Ch, N

There is no one else we have only ourselves. O

I have a relative in SA helping the daughter in hospital there. R

When I have difficulties there is absolutely no one I can turn to. I used to ask for help from neighbours but they never helped with anything so I don't go anymore. O

Church members helped uplift my spirits. My children and extended family helped a lot during this time. We are here to help each other as neighbours (*but*) we all have our own problems so can't help materially. Everyone struggles too much in this community so we can only help emotionally. Ch, N, R

I do run to neighbours like in a crisis like the deaths of my children. They help me but not financially. My relatives and church come to help me emotionally but that is as far as it goes. Ch, R, N

There's no one else I can turn to besides my daughter. Everyone is needy in this community. R

We just sit in this home. There is suspicion between neighbours (*to do with witchcraft*) and the zone leaders don't care about people. O

We have no one to turn to besides my mother. Our neighbours are as needy as we are. I guess we can just go there for moral support.

We did try church and community leaders. I would say SOS too. Not our neighbours- we all mind our own business. Ch, C, Ng, R

SOS family carer has been very helpful and I can talk to her. Ng

Besides family, we have support from my mother's work friends, church friends and neighbours. Ch, Fw, N, R

It's a personal problem. I find it hard to share my problems with my neighbours or church members. I do go to church. I do have a relationship with the women I sell with and we talk about things. Fw

I go down to Durban on the bus and buy clothes, hats, accessories, blankets and then sell them around the offices. My husband isn't working. I can borrow money from the women I work with. We try to help each other as sisters. We have formed an organisation between ourselves to give each other loans. We have registered as an organisation. We started 3 years ago and there is a membership fee. I'm not sure what happens if you don't pay back a loan. They look at how long you have been a member and at your credibility.

Now this child is grown (*the baby is 4 weeks old*), I hope to go back to my business. Fw, L

I've no one to run to except my boyfriend. F

I used to talk to my father before he died. I do talk to my mother but she can't help me. I did talk to my boyfriend (*father of her child*) but now we have split up. **R**

My employer. I wouldn't want to be a burden at church or with my neighbours. They (*neighbours*) don't sympathise because I'm employed. The neighbours turn to me instead. **L**

| | | | |
|--------------------|---|------------------|---|
| Loans at work | 3 | Relatives | 7 |
| Friends at work | 4 | No one | 3 |
| Friends | 1 | Community Leader | 1 |
| Traditional healer | 1 | | |
| Church | 5 | | |
| NGO | 2 | | |
| Neighbours | 4 | | |

Appendix 4

Environment Index sample sheet

Plot number:
Date: 30-10-03

Location:

Head of Household:

| | | | | | | | |
|-------------|------------------------|----------------------------------|------------------------|---------------------------------|----------------------------------|-------------------------|--|
| walls | Block | <i>mud-and-stick</i> X | good conditn | cracked X | holed X | leaning <i>a bit</i> | collapsing <i>mud screed is falling off</i> |
| Roof | corrugated X | thatch | other | good condtn X | holed/leaking <i>odd hole</i> | | |
| services | electric <i>no</i> | tap water inside | tap water outside | other source: river X | toilet inside | pit latrine X | no sanitatn |
| garden plot | cultivated | uncultivated X | too small to cultivate | | | | |

General comments on material condition of interior

Very poor. Just bed with holed blankets, clothes on hanger on string on wall. Lots of carrier bags with possessions in –mainly clothing? Bible on chair. Windows- no glass just two wattle sticks across. Grass mat, no other belongings in room

General comments on health and well being of children /adults present

Gogo's feet swollen and hurting and can't walk. She looks thin and unwell. Asked for painkillers. She is sitting on bed weaving mat made of plastic rubbish. She ties the plastic bits together to make a rope first then weaves it.

Two small children playing on floor- look quite well fed and clothed. Older girl on floor is weaving grass mat. Looks well.

Appendix 5

Sample of demographic sheets used in family interviews

Demographic data sheet

Location..... Date.....

Owner of plot..... Plot no.Head of household.....

Home owned or rented. Length of stay of HoH.....

Reason for HoH coming to live here:

Original home area of HoH.....Grid refs.....

Adults in the household

| | Name | F/M | Age | Relationship to Head of Household | Employed/un employed/self-employed (E/U/SE) |
|--|------|-----|-----|-----------------------------------|---|
| | | | | | |
| | | | | | |
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| | | | | | |
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| | | | | | |

Appendix 6

Demographic base sheet for children under 18 years old

| | Names of children under 18 | f/m | age | relationship to head of household (patrilineal ... matrilineal) | in sch? Y/N | grade | mother/father on page 1? M= give no. F= give no. | If not resident here, reasons for absence of mother and/or father | Locatn of other siblings if not resident here |
|---|----------------------------|-----|-----|---|-------------|-------|--|---|---|
| 1 | | | | | | | | | |
| 2 | | | | | | | | | |
| 3 | | | | | | | | | |
| 4 | | | | | | | | | |
| 5 | | | | | | | | | |

Appendix 7a

Research with children

Informed consent: letter given to children attending formal school

Teenagers talk back

Dear Learner,

My name is Make Jones from Oxford University in England and I am researching how young people in Swaziland feel about their friends, family life and the communities where they live. The HIV/AIDS epidemic has brought about many changes and stresses. Family members are dying; children have to move to live with other relatives and are sometimes split up from their brothers and sisters.

I have already been talking to parents about these issues and I'm now interested to hear your views. Sharon Neves, a psychologist and graduate from Rhodes University will be helping me. I would like some of you to take part in a discussion group and others to write about how you feel. If you volunteer to take part, you will be needed for about half an hour.

Important points!

- Taking part is absolutely voluntary. You can change your mind at any time and cease taking part. You do not have to say or write anything. You can answer some questions where you have an opinion and leave out other questions.
- If you have lost someone close to you in the last few months it may be best to give this a miss as we do not want to upset you by asking questions about your family situation.
- There is no need to tell us your name. What you say or write will be referred to in what I write in reports but you will not be identified personally. We will not show your teachers or anyone else your hand-written accounts
- By participating in this research I am seeking your own view and opinion, there are no right or wrong answers.

What is this information for?

- I will use it for writing research papers and for a chapter in my doctoral thesis.
- I will also write a report for NERCHA, Amicaall and UNICEF here in Swaziland so that it may help towards forming the new "Child Policy" for Swaziland.

I look forward to working with some of you on this important work next week.

Yours sincerely,

Appendix 7b

Stimulus material on HIV/AIDS used with children in formal school

Teenagers talk back



Your age..... (in years) male... female... (Tick one)

Where do you live?.....(e.g. Corporation)

Who is your main adult carer (or carers) where you live?
(e.g. Gogo, mother, father, aunt).....

Some parents' views on teenagers and HIV/AIDS:

"The statistics show a lot of teenagers are dying of AIDS but the teenagers are only listening to each other. When you do things as a group you tend not to listen to your parents and elders"

"I have been very open with my son and I do talk about HIV/AIDS. We have had cases in our family so he has seen it. I think he is sensible about these things."

"I think poverty is a real problem. Girls have sex with older men who promise them things and they see it as a way out of poverty."

"I think boys manipulate girls into having sex with them to prove their love in a relationship"

Who do you think influences teenagers? What is your view on why the

ABC message doesn't seem to be taken seriously by some teenagers?

A (abstinence), B (be faithful), C (condomise)

Appendix 7c: Stimulus material on care of vulnerable children

Teenagers talk back



Your age..... (In years) male... female..... (Tick one)

Where do you live?.....(e.g.Sidwashini)

Who is your main adult carer (or carers) where you live?
(e.g. Gogo, mother, father, aunt).....

Some adults' views on orphans and vulnerable children:

“There are children whose parents have died, there are children whose parents have abandoned them and there are children whose parents have no jobs and can't afford to keep them. They are all needy children. We shouldn't separate out orphaned children for special help.”

“I think children whose parents have died should get special help as they are more stranded”

“There should be structures in place which tell children what to do when a parent dies. My aunt has died and her children don't know how to collect her pension.”

“I think children whose parents have died suffer lots of setbacks as they often have to move to another relative, change schools or drop out of school altogether. They even get separated from their brothers and sisters as families can't always take all of the children.”

“Our community isn't doing anything to help needy children at the moment. I think we could do things to help like vegetable gardens and keeping chickens. We need the youth to help us too”

What are your views on the difficulties faced by orphans and vulnerable children?

How could young people help needy children in your community?

Appendix 7d

Focus Group Guide used with children in formal school

Focus group questions: Urban schools Mbabane 1-12-03

Ethics:

Please check that children know:

1. Taking part is voluntary
2. You can withdraw and go back to class at any time
3. No one who has lost a close relative in recent months should take part, as we don't want to upset you in anyway.
4. You do not have to comment on every question
5. There are no right or wrong answers
6. Everyone's view is equally important
7. The information will be written up for research purposes but no one will be identified personally

Introduction

When you were born the HIV/AIDS epidemic was only just starting. Now 38.6% of adults in Swaziland are infected so you are the first generation to grow up affected by the epidemic. These questions are about how HIV/AIDS has affected your life and that of your family and friends.

Communicating.....

1. Do you find yourself worrying about HIV/AIDS very much?
2. What sort of things cross your mind? (probe- worry about catching it, or that parents/relatives might have it....)
3. Who do you talk to about these thoughts?
4. Are you able to discuss HIV/AIDS worries with your adult relatives?
5. Are there adults, other than members of your family, with whom you discuss HIV/AIDS related worries?

Affect of HIV/AIDS on family life

6. How many funerals do you think you have attended in your lifetime?
7. With deaths in the community now happening so often do you think your attitude to life has changed? If so, please explain how.
8. You may have personal experience or know of close friends whose parent or parents have died. What are the main changes that happen in the home lives of such children?
9. If children have to go to live with other relatives are they consulted about whom they would like to live with?
10. In Swazi culture males are not really expected to cry but to be strong. Do you think it is harder for teenage boys to come to terms with the death of a close relative? Please explain.
11. If you have had other children join your family because a relative has died, has it changed family life for you in any way? Please explain.
12. What sort of support do you think teenagers need most to help them rebuild their lives after parents die?
13. Finally, what do you like doing in your free time to take your mind off things like HIV/AIDS?

Thank you for taking part!

Appendix 7e

Focus Group Guide used with children not in formal school but attending Sebenta literacy classes

Sebenta Focus Groups

Introduction

Please remind them it is voluntary and they may withdraw and return to class at any time.

There are no right or wrong answers. Each persons view is important.

They will not be referred to by name in the written report or in any discussions.

Warm up!

1. How did you get to attend classes at Sebenta? How did you get to know about the classes?
2. How do you think these classes will help you? What do you hope to do in the future?

Reasons for not being in formal schooling

1. Did you ever go to Primary school?
2. What caused you to drop out/or not attend in the first place?

Effect of not being in formal school

1. What have been the most difficult problems caused by you not attending school?
2. Do you have friends who are in school?
3. Do you get teased because you are not in Primary school?

4. How do you spend your day when you are not here at Sebenta? What sort of things/chores do you do at home?

Family situation

1. Who is the main adult carer for you now at home?
2. Do you eat everyday?
3. Do you go to the clinic when you are very sick?
4. What tips/advice could you give to someone who has just lost his or her parents?

Conclude

Thank you for taking part.

If there is anything you are worried about and you would like us to speak to you on your own, please see us after your sandwich and we will come back another day.

Appendix 8a

List of key informants

(The following key informants were willing to be named but not everyone wished to be directly quoted. There were a few informants who did not wish to be named or quoted. Some key informants were interviewed more than once.)

| NAME | ORGANISATION | POSITION |
|-------------------------|---|---|
| Dr. Alan Brody | UNICEF | Country Resident Representative |
| Pelucy Ntambirweki | UNICEF | Project Officer Social Policy |
| Thinie Dlamini | UNICEF | Assistant Project Officer |
| Gcebile Ndlovu | International Community of Women living with HIV/AIDS | Southern Africa Regional Coordinator |
| Nomzamo Dlamini | Save the Children Fund | Child Protection Manager |
| Dumsani Mnisi | Save the Children Fund | Director |
| Brigitte Imperial | Joint United Nations Programme on HIV/AIDS | UNAIDS Country Coordinator |
| Dr. Derek von Wissel | National Emergency Response Committee on HIV/AIDS (NERCHA) | Director |

| NAME | ORGANISATION | POSITION |
|-----------------------|---|---|
| Sibusiso Dlamini | NERCHA | National Coordinator Care and Support |
| Thandi Shongwe | NERCHA | National Coordinator Impact Mitigation |
| Rudolph Maziya | Association of Mayor's Initiative for Community Action on AIDS at the Local Level in Swaziland (AMICAALL) | Director |
| Bongani Motsa | AMICAALL | Finance and Administration Manager |
| Sebenzile Ginindza | AMICAALL | Local Coordinator (Mbabane) |
| Tessa Rintale | World Food Programme | Reports Officer |
| Khanya Mabuza | Baphalali Swaziland Red Cross Society | Director |
| Aloys Lorkeers | European Union | Resident Adviser |
| Jabu Dlamini | Deputy Prime Ministers Office | Officer for Care and Support of OVC |
| Lungile Dlamini | Mbabane City Council | Planning Officer |
| Gcinile Buthelezi | Mbabane City Council | Public Health and Social Welfare Unit Head |

| NAME | ORGANISATION | POSITION |
|---------------------------|--|---|
| Amy Whalley | Office of the Prime Minister | Public Policy Officer |
| Jabulani Tsabedze | British High Commission | Development Manager |
| John Lowsby | World Bank | Consultant (Mbabane informal housing upgrade project) |
| Hugh James | Swazi Sugar Association | Executive Officer |
| Michael Dlamini | Sebenta | Hhohho region Supervisor |
| Thuli Dladla | Sebenta | National Director |
| Eric Dlamini | Sebenta | Finance Director |
| Dudu Dlamini | Herman Gmeiner SOS orphanage | Director |
| Mary Jean Kopp | New Life Homes (for vulnerable children) | Director |
| Father Larry McDonnell | Manzini Youth Care | Director |
| Mildred Henwood | Eswatini Swazi Kitchen | Project Manager |
| Revd. Wright | Care Nakekela | Director |
| Veli Ndzinisa | National Youth Network | National Coordinator |
| Siphiwe Hlophe | Swaziland Positive Living for Life (SWAPOL) | Director |

Appendix 8b

Sample from fieldwork diary

Saturday 6-9-03

Swazi horse show at Mlilwane

Met Thelma - lived in SD 50 years. Thinks that SD has been independent for 35 years so can no longer blame state of country on Britain's governorship.

Concerned at govt. corruption. Also worried about number of orphans and the prospects for the future if they are not cared for.

Sunday 7-9-03

Met Sibusiso Dlamini, ex Hospice at Home. Now at NERCHA. Arranged to visit tomorrow to set up interviews. V. friendly.

Chatted to Hugh James about the likelihood of SD losing the sugar preferential agreement with EU. Up for renewal in 2006. Other countries now able to start growing sugar due to change in WTO agreements for LDCs (SD is MDC) – Sudan keen to grow sugar and has water from White Nile. Mozambique growing more too. Brazil is the giant (22 million tons pa) and SD couldn't compete if EU subsidy lost as Brazil has the land/water and cheap labour. Hugh concerned, as economy of SD can't afford to lose the sugar export income.

Monday 8-9-03

Arrived at NERCHA office at 9.am. Sibusiso thought I should see the person in charge of children and orphan care. Could hear discussion in next office in siSwati. Began to think she was worried about seeing me. Had given Sibusiso my letter from Oxford. Not sure if that put her off or worry about bosses permission

(DVW). Sibusiso returned to ask me to meet DVW. I felt confident from previous meeting but bit unnerved when he said he would talk and I would listen! However he seemed to soften and gave me several sheets to read of his thoughts on orphan care and said I could give my input. Arranged to meet at 9.30pm tomorrow. (Noted address of Women and Law on way out- the activist group promoting women's rights).

NERCHA seems to be well funded, well organised and active. DVW very much in charge- first impression. May get more depth from informal meeting with Sibusiso. Met Simon Dlamini (union activist) by chance on way across town. Keen to be a translator on Saturdays if necessary.

Mbabane centre seems affluent going by the vehicles and new shops. Very different from my drive up from Malkerns. Is this wealth just/mainly aid money?

SD Times today- more on sugar and importance of WTO talks in Cancun 10th-14th Sept. Also affects ART arrangements.

Have appts arranged for 9.30pm weds and Thurs now at NERCHA. Need to keep the ball rolling but a lot to take in at the moment. Need to read latest initiatives and try to think how this influences my choice of field sites for family/orphan level. Still thinking that Jane Cox's Moya centre near here sounds promising as the orphans are within the community so other children's' lives can be observed too. Also, Jane has good local knowledge as born in SD. Will see her at w/e as she is working in the week.

Will end the day looking at interview technique in Denzin and Lincoln. Will stick to listening with DVW as he says, until I get more rapport going! I did e-mail him my areas of interest so I hope it will be useful. Not sure how critical I can be of the

papers he gave me to read. Think that the proposals he has are geared to rural areas and broadly sensible but I think a mosaic of solutions tuned to locality may be more realistic. How will the govt control the orphanages springing up (heard of several since arriving)? Is it sensible to target OVC in light of Simon Dhlamini's comments about resentment building up within the community? Thinking of Demonica's paper on the impact of improving basic services to all female children in India, rather than targeting groups, is it divisive to provide help only for OVC? Is it sustainable without careful monitoring? Accountability? How much consultation has there been with local communities? Have children's' views been included? Not sure whether I can raise these thoughts tomorrow. Wonder how close NERCHA is to UNICEF? Are these ideas DVW or Alan Brody at UNICEF or others? The orphan numbers are rather vague too.

What is being done about disinheritance of children? What about the gender aspects? Is the law likely to change? Who controls this? What are the governance issues? Where is the power?

This model may be OK for rural areas but what about peri-urban and urban where land is in short supply? Has the chieftaincy the same importance or has the deagrarianisation and change in family units become too entrenched in peri-urban environments for IF to work? Perhaps other economic activity is possible with the access to markets, and this would allow food sustainability.

Then there is DVW's push for Christian/church angle. Putting all his eggs in one basket? I think the use of religious leaders is sound given the very religious attitude of many Swazis but do the younger generation hold the same views?

Wonder how DVW's message can be packaged to seem like going forward rather

than backward. Are the traditional structures too far gone? May be a rural/peri-urban/urban factor involved. These are things I need to check out with Swazis. How do the other piecemeal activities run by Hope House etc fit into his model? Are they part of it? Will be interesting to see how the other large agencies see things.

Appendix 9a

Family situation of the 42 children whose parents are alive

| Family | Children living with both their parents | Children living with father only within extended family | Children living with mother only within extended family | Number of children living with mother in single female-headed household | |
|--------|---|---|---|---|---|
| 1 | | 0 | 0 | 0 | |
| 2 | | 2 | 0 | 0 | |
| 3 | | 2 | 0 | 0 | |
| 4 | | 4 | 0 | 0 | |
| 5 | | 0 | 0 | 0 | |
| 6 | | 1 | 0 | 0 | |
| 7 | | 0 | 0 | 3 | |
| 8 | | 0 | 0 | 0 | |
| 9 | | 1 | 0 | 2* | |
| 10 | | 1 | 3 | 5 | |
| 11 | | 5 | 0 | 0 | |
| 12 | | 0 | 0 | 0 | |
| 13 | | 1 | 0 | 0 | |
| 14 | | 0 | 0 | 1 | |
| 15 | | 0 | 0 | 0 | 1 |
| 16 | | 0 | 0 | 0 | |
| 17 | | 0 | 0 | 0 | |
| 18 | | 1 | 0 | 1 | |
| 19 | | 0 | 0 | 0 | |
| 20 | | 0 | 0 | 2 | |
| 21 | | 0 | 0 | 0 | |
| 22 | | 0 | 0 | 0 | 5 |
| 23 | | 0 | 0 | 0 | |
| 24 | | 0 | 0 | 0 | 1 |
| 25 | | 0 | 0 | 0 | |
| | 18 | 3 | 14 | 7 | |

Summary

11 women are bringing up 14 children without the support of the father who is believed to be alive. 9 of these women live within the extended family with other adult females (families 7,10,14,18,20).

Lone young females head up only two households (families 15 and 24)

Only 4 children live in a family where there are no orphans or fosters present (family 4)

Appendix 9b

| Family type | adults in formal employment | Family | Notes |
|-----------------------------|-----------------------------|--------|--|
| nuclear+ | 3 | 1 | |
| Nuclear+ | 2 | 2 | |
| nuclear+ | 1 | 3 | Many fostered children |
| Nuclear | 0 | 4 | Lack of employment |
| Extended | 0 | 5 | |
| Extended | 2 | 6 | |
| Extended | 0 | 7 | |
| Extended vulnerable | 0 | 8 | 4 orphans, one 18 year-old orphan and only elderly grandmother employed informally |
| Extended | 3 | 9 | |
| Extended | 4 | 10 | Very over-crowded (26 in the h'hold), 5 orphans |
| Nuclear+ | 1 | 11 | |
| Extended | 2 | 12 | |
| Extended | 1 | 13 | |
| Extended | 1 | 14 | 6 orphans, lack of employment (1 adult employed, plus informal childminding) |
| Single female nuclear | 0 | 15 | partner has died |
| Extended | 0 | 16 | Illness (grandmother and son), 3 orphans. Only 1 fit adult employed informally |
| Extended | 1 | 17 | |
| Extended | 0 | 18 | |
| Adult sibling head of house | 0 | 19 | |
| Extended | 2 | 20 | |
| Single female nuclear | 0 | 21 | partner has died |
| Nuclear, polygamous | 0 | 22 | |
| Nuclear+ | 1 | 23 | |
| Single female nuclear | 0 | 24 | partner has abandoned her |
| Extended | 3 | 25 | |
| | 27 | | |

Summary

In terms of living conditions, number of children to care for, number of fit adults able to work, families 8 and 16 are most vulnerable. 28/57 (49%) of orphans live in the [better homes](#) as indicated by block construction or electric or tap water, 18/57 (32%) of orphans live in the [poorest homes](#)

Appendix 9c:

| Family | Length of Residency in years | Number of Generations in Household | Number of Adults in H/hold | Number of Children in the Household | Total Number of Orphans | House walls x=poor condtn b=block m=mud/stick | Corrugated Roof x=holed 0=unholed | Water s=spring r=river t= tap | Electricity connected 1=yes 0=no | Garden crops C=cultivate U=unused X=plot too sn |
|--------|------------------------------|------------------------------------|----------------------------|-------------------------------------|-------------------------|--|---|--|--|--|
| 1 | 18 | 2 | 4 | 0 | 0 | m | 0 | t | 0 | C |
| 2 | 4 | 2 | 2 | 3 | 0 | mx | 0 | r | 0 | X |
| 3 | 5 | 2 | 3 | 6 | 0 | mx | 0 | r | 0 | X |
| 4 | 3 | 2 | 2 | 4 | 0 | mx | x | s | 0 | C |
| 5 | 30 | 2 | 2 | 4 | 4 | b | 0 | s | 0 | C |
| 6 | 30 | 3 | 4 | 2 | 1 | m | 0 | s | 0 | C |
| 7 | 40 | 4 | 5 | 4 | 1 | mx | 0 | r | 0 | U |
| 8 | 33 | 2 | 2 | 4 | 4 | mx | 0 | r | 0 | X |
| 9 | 30 | 4 | 11 | 5 | 1 | b | 0 | t | 1 | C |
| 10 | 35 | 4 | 12 | 14 | 5 | mx | x | r | 0 | X |
| 11 | 10 | 2 | 2 | 6 | 1 | m | 0 | s | 0 | X |
| 12 | 40 | 3 | 7 | 6 | 5 | mx | 0 | t | 1 | C |
| 13 | 40 | 4 | 4 | 3 | 2 | mx | 0 | s | 0 | C |
| 14 | 50 | 4 | 7 | 7 | 6 | mx/b | x | r | 0 | C |
| 15 | 5 | 2 | 1 | 1 | 1 | m | 0 | r | 0 | X |
| 16 | 40 | 3 | 3 | 3 | 3 | mx | x | r | 0 | X |
| 17 | 20 | 3 | 5 | 5 | 5 | mx | x | r | 0 | X |
| 18 | 30 | 4 | 13 | 10 | 8 | b | 0 | t | 1 | X |
| 19 | 20 | 1 | 2 | 3 | 3 | b | 0 | t | 0 | U |
| 20 | 6 | 3 | 5 | 2 | 0 | b | 0 | t | 1 | X |
| 21 | 10 | 2 | 1 | 3 | 3 | m | 0 | t | 1 | X |
| 22 | 0.25 | 2 | 1 | 6 | 1 | b/m | 0 | s | 1 | X |
| 23 | 6 | 2 | 3 | 2 | 2 | m | 0 | s | 0 | C |
| 24 | 30 | 2 | 1 | 1 | 0 | m | 0 | s | 0 | C |
| 25 | 20 | 3 | 3 | 1 | 1 | b | 0 | t | 0 | C |
| | | | 105 | 105 | 57 | Block=7 | Holed=5 | Tap=8 | Electric=6 | Cultivate |
| | | | | | | Partly block=2 | | River=9 | | Unust |
| | | | | | | Mud/stick=16 | | Spring=8 | | Plot too sma |
| | | | | | | Poor condtn=11 | | | | |

Appendix 10

Major NGOs and Donor Organisations actively involved in HIV/AIDS, in Swaziland, at the time of the research

| |
|---|
| Donor Organisations |
| Commission for the European Union |
| Italian Co-operation |
| South African High Commission |
| UNAIDS |
| UNDP |
| UNESCO |
| UNFPA |
| UNICEF |
| USA Embassy |
| WHO |
| Church Based Organisations |
| Bread of Life Ministries |
| Care Nakelela |
| Leadership for Africa |
| Swaziland Conference of Churches |
| Community and Commercial Based Organisations |
| Light House |
| Manzini Youth Care |
| Maphiveni Theatre Arts Performing Organisation |
| Shewula Orphan aid |
| Sidwashini Against HIV and AIDS |
| Swaziland Positive Living For Life |
| Swaziland Youth United Against HIV/AIDS |
| Zondle Women's Organisation |
| Swaziland Business Coalition Against AIDS |
| Swaziland Brewers Ltd. |
| Other Non-Government Organisations (NGOs) |
| Baphalali Swaziland Red Cross Society |
| Caritas |
| Cheshire Homes of Swaziland |
| Coordinating Assembly of NGOs (CANGO) |
| Family Life Association Swaziland (FLAS) |
| Lutsango LwakaNgwane |
| Salvation Army |
| Save the Children Fund Swaziland |
| Sebenta Vocational Centre |
| SOS Swaziland |
| Swaziland Action Group Against Abuse (SWAGAA) |
| Swaziland AIDS Support Organisation (SASO) |
| Swaziland Hospice at Home |
| Women and Law Swaziland |
| World Vision Swaziland |