

CHAPTER 4: REPORTING ON THE RESULTS OF THE STUDY

CHAPTER 4 AT A GLANCE.....	161
4.1 INTRODUCTION.....	161
4.2 COURSE AND PHASES OF THE FIELD WORK	162
4.2.1 Phase 1: Exploring general perceptions related to HIV&AIDS	163
4.2.1.1 Objectives for phase one.....	164
4.2.1.2 Processes involved during phase one.....	164
4.2.1.3 Outcomes of phase one	164
4.2.2 Phase 2: Mapping the community	167
4.2.2.1 Objectives for phase two	167
4.2.2.2 Processes involved during phase two	167
4.2.2.3 Outcomes of phase two.....	169
4.2.3 Phase 3: Identifying challenges, assets and potential assets in the community.....	170
4.2.3.1 Objectives for phase three	170
4.2.3.2 Processes involved during phase three.....	171
4.2.3.3 Outcomes of phase three	172
4.2.4 Phase 4: Raising awareness of asset-based trends in coping	174
4.2.5 Phase 5: Exploring the community’s way of coping with HIV&AIDS.....	176
4.2.5.1 Objectives for phase five	176
4.2.5.2 Processes involved during phase five	176
4.2.5.3 Outcomes of phase five.....	177
4.2.6 Phase 6: Mobilising potential assets in order to enhance the community’s coping with HIV&AIDS.....	179
4.2.7 Phase 7: Supporting educators in fulfilling their pastoral role, within the context of coping with HIV&AIDS	183

4.3	RESULTS OF MY STUDY	185
4.3.1	Theme 1: Challenges and stressors within the context of HIV&AIDS...	187
4.3.1.1	Sub-theme 1.1: Vulnerability of people who are infected with HIV or living with AIDS	187
4.3.1.1.1	Personal vulnerability.....	187
4.3.1.1.2	Physical vulnerability.....	188
4.3.1.1.3	Social vulnerability	189
4.3.1.1.4	Cultural vulnerability.....	195
4.3.1.2	Sub-theme 1.2: Challenge of supporting people living with HIV&AIDS	197
4.3.1.3	Sub-theme 1.3: Community challenges.....	199
4.3.1.3.1	General challenges	199
4.3.1.3.2	Challenges relating to HIV&AIDS	202
4.3.2	Theme 2: Assets identified in a community coping with HIV&AIDS.....	203
4.3.2.1	Sub-theme 2.1: Assets and strengths of individuals.....	203
4.3.2.1.1	Assets and strengths of community members	203
4.3.2.1.2	Skills related to networking and negotiation.....	205
4.3.2.2	Sub-theme 2.2: Institutions and organisations as assets	205
4.3.2.2.1	Community care centre.....	206
4.3.2.2.2	Educational institutions	207
4.3.2.2.3	Assets related to political organisations	208
4.3.2.2.4	Non-governmental organisations (NGOs).....	209
4.3.2.2.5	Assets related to health	211
4.3.2.2.6	Faith-based organisations and churches	212
4.3.2.3	Sub-theme 2.3: The asset of government initiatives.....	215
4.3.2.4	Sub-theme 2.4: Cross-cutting systemic assets	216
4.3.2.4.1	Financial assets	216
4.3.2.4.2	Other assets	217
4.3.3	Theme 3: Community coping with HIV&AIDS: Existing strategies.....	218
4.3.3.1	Sub-theme 3.1: Community-based coping strategies.....	218

4.3.3.2	Sub-theme 3.2: Coping with being infected with HIV or living with AIDS.....	220
4.3.3.3	Sub-theme 3.3: Coping strategies related to care and support	221
4.3.3.4	Sub-theme 3.4: Coping strategies for children orphaned due to HIV&AIDS	224
4.3.4	Theme 4: Outcomes of activist intervention research in relation to applying the asset-based approach in coping with HIV&AIDS	226
4.3.4.1	Sub-theme 4.1: Coping trends that stayed the same during the course of my study	227
4.3.4.2	Sub-theme 4.2: Changes in coping strategies during the course of my study.....	228
4.3.4.2.1	Increased levels of self-awareness and self-confidence, resulting in feelings of empowerment.....	228
4.3.4.2.2	Increased levels of support for community members living with HIV&AIDS	231
4.3.4.2.3	Becoming actively involved in community development	232
4.3.4.2.4	Extending changes to the wider community.....	234
4.4	CONCLUSION	235

CHAPTER 4 AT A GLANCE

RESEARCH QUESTIONS:

- ⌘ *How is a South African informal settlement community coping with HIV&AIDS, by relying on existing assets and local resources?* (Descriptive research question)
- ⌘ *How can an activist intervention approach to research facilitate change in a South African informal settlement community coping with HIV&AIDS?* (Intervention-related research question)

DATA COLLECTION
Field work
Nov 2003 to Oct 2005
Phases 1-7

RAW DATA:
Transcripts
Field journal
Visual data

DATA ANALYSIS
Thematic analysis

CATEGORIES
EMERGING THEMES
SUB-THEMES

4.1 INTRODUCTION

In chapter three I described the empirical part of my study, conducted over a period of two years in an informal settlement community in the Eastern Cape. My selected research design as well as other methodological choices were justified in terms of my research questions and the purpose of my study, as formulated in chapter one.

In this chapter, I report on the results of my study. As my study progressed, a few research questions emerged that related to my study, yet addressed separate issues. As a result, four other researchers became part of the intervention research, conducting forth-flowing intervention sessions (under joint supervision of myself and my supervisor), building on the results of my study. In order to provide a holistic view of the results of my study, I include brief discussions and the results obtained from these forth-flowing interventions. During the intervention sessions that were facilitated by these four researchers, I fulfilled the role of field worker, in addition to my role as researcher.

I commence the chapter by describing the objectives, processes and outcomes of the various phases of my field work. This is followed by a discussion of the themes that emerged during thematic analysis of the raw data (transcripts, visual data and my field journal). Verbatim responses and visual images are used to enrich my discussions. In chapter five I relate the emerged themes to existing literature.

4.2 COURSE AND PHASES OF THE FIELD WORK

I conducted nine field visits during the period November 2003 to October 2005 (refer to Table 3.4). These visits included various intervention sessions (consisting of focus groups and/or workshops) with educator-participants, as well as numerous informal conversational interactive interviews and *ad hoc conversations* with stakeholders and members of the selected community. To supplement my contact with participants, I made video-recordings, audio-recordings and took photographs of interactions, as

well as of the community. The field work that I conducted can be divided into seven phases, focusing on distinguishable yet interrelated aspects. The various phases are summarised in Figure 4.1, followed by discussions thereof.

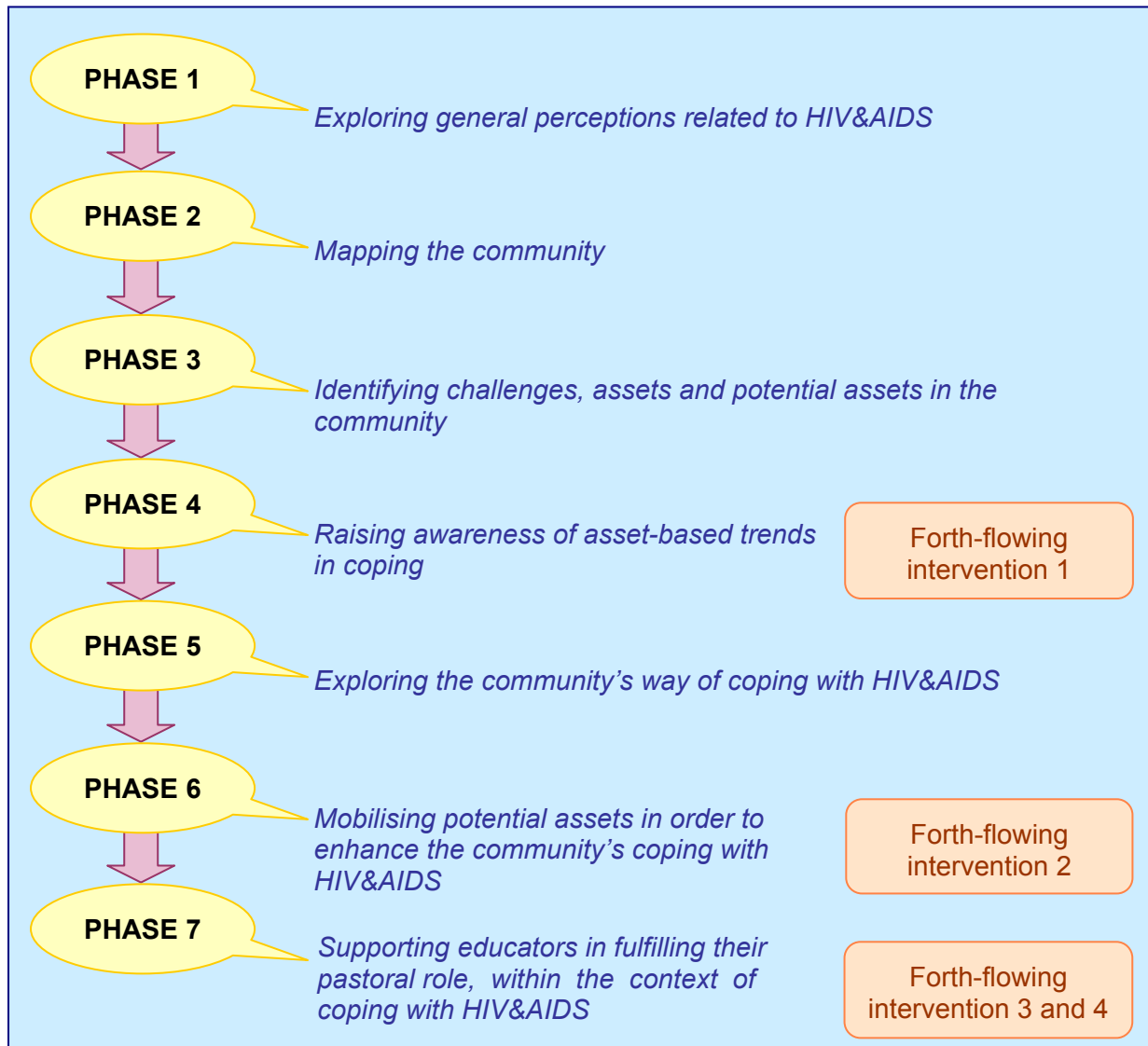


FIGURE 4.1: PHASES OF MY STUDY¹⁰

4.2.1 PHASE 1: EXPLORING GENERAL PERCEPTIONS RELATED TO HIV&AIDS

During phase one I was guided by the following questions:

¹⁰ Data collected during phases 1, 2 and 5, as well as my pilot study (refer to section 1.1.1) constitute baseline data, according to which I could later monitor change (or the absence thereof), subsequent to the intervention phases.

- ⌘ *How do community members perceive HIV&AIDS and the challenges related to the pandemic?*
- ⌘ *How does the community cope with HIV&AIDS? (also part of phase five)*

4.2.1.1 Objectives for phase one

As background to my study, I firstly aimed to explore the general ideas, concerns and perceptions that the educator-participants (as representatives of the wider community) held with regard to HIV&AIDS. In addition, I aimed to explore the community's way of coping with HIV&AIDS and the challenges implied by the pandemic. In line with the basic principles of PRA, I constantly had to remind myself that I had to be flexible and guided by the participants in the processes planned, as well as during the progress of the field work.

4.2.1.2 Processes involved during phase one

Phase one was (mainly) completed on the first day of my first visit. After initial introductions and an explanation for our presence and proposed future involvement in the community, eleven educator-participants were involved in a focus group discussion and workshop activities. The first part of the session entailed a one hour **focus group discussion**, exploring the participants' opinions, views and general concerns relating to HIV&AIDS, as well as the community's current way of coping with the challenge. The focus group discussion was supplemented by **observation**, **photographs**, **audio-recordings** and **field notes**.

4.2.1.3 Outcomes of phase one

Educator-participants initially appeared to be sceptical about our presence and the reason for us being there. However, they became more relaxed after I had explained the purpose of our presence and involvement, and participated well during the initial discussion on HIV&AIDS, in reply to the question on *their perceptions regarding*

HIV&AIDS and how the community was coping with the challenge at that time. As a result, I¹¹ was able to reach the objectives that I had formulated for this phase.

Most of the participants contributed and displayed a willingness to share their views with us, despite a few dominators and a small number of silent participants. I did, however, constantly strive towards involving all participants in the discussions. The participants' relatively extensive responses may possibly be ascribed to sound rapport, established during lunch time, prior to the focus group/workshop activities. During lunch, and the introductory part of the session, I (and my co-researcher) consciously focused on establishing relationships of trust, in order to enable us to facilitate an open and lively discussion on a sensitive topic. The transcribed focus group discussion is included in Appendix B.

¹¹ *In the following two chapters, 'I' implies 'I, in conjunction with the participants', as the participants actively participated and co-created knowledge, in accordance with PRA principles. In the same manner, 'my' results and 'my' findings imply the results and findings that I obtained based on the collaborative efforts of the participants and myself (as well as my co-researchers).*

¹² *My reflections include personal reflections, reflections on my applied methodology and reflections regarding theoretical hypothesis and preliminary findings. These aspects might be reflected upon separately or in an integrated manner.*

On phase one – excerpt taken from my field journal¹² ...

On our way to the community I experienced feelings of excitement but also uncertainty. Although I had planned the session and felt that I was ready to enter the field, I speculated as to whether or not my ideas would work out, to what extent we would be accepted by the participants, whether or not they would all turn up and be willing to participate, whether or not I would succeed as facilitator within a group of people who in so many ways differ from us ...

These feelings of uncertainty and hesitation were soon replaced by excitement and amazement, with me feeling overwhelmed. All participants turned up (in fact, one more joined), they participated in all activities (yet initially with suspicion) and shared their amazing stories. Yet on the down side, many (but not all) of the participants appeared to be there primarily due to the fact that they are going to be reimbursed for their time.

The lengthy lunch and socialising component was successful in establishing rapport and paved the way for a rich discussion on HIV&AIDS. However, it emphasised the fact that I will have to be flexible and be guided by the pace of the participants – which seems to be much slower than the one I had planned.

After our first meeting and discussion with the educators I was left speechless by my experience. In the heart of this poverty-stricken community with seemingly limited external help and resources lies a school with amazing educators and so much potential – indeed a huge asset to the community! Yet they don't seem to believe in themselves and the role that they are already playing ... I feel humble.

I am happy that my selected methods worked well today. I believe that the focus group discussion allowed all participants to make contributions, within the safe environment of a group. Participants could also support one another and elaborate where they wanted to add information or differ from someone else.

Although it is still early days (literally), I get the idea that this community (more specifically the participants) might (from a PRA perspective) benefit from the research. They have so much to offer and possess such a wealth of skills and compassion – yet they seemingly do not believe in their own abilities. This could be mobilised! The participants seem to be convinced that outside resources can assist the community in facing the challenge of HIV&AIDS and that we might be of valuable assistance to them. However, and in this regard, a distinct need to be informed on HIV&AIDS related issues seems to exist.

4.2.2 PHASE 2: MAPPING THE COMMUNITY

During phase two I was guided by the following questions:

- ⌘ *What does the selected informal settlement community 'look' like?*
- ⌘ *Which resources and potential resources are present in the community? (also part of phase three)*

4.2.2.1 Objectives for phase two

During the second phase of the field work I aimed to obtain an overview of the community, in terms of existing structures, resources and facilities. I attempted to facilitate the educator-participants' awareness of available and potential resources, based on them constructing an overview of the community. This process of compiling a *community map/social map* (PRA terminology) was completed by the educator-participants during my first visit to the community.

4.2.2.2 Processes involved during phase two

I (supported by my supervisor fulfilling the role of co-researcher) conducted two ***intervention sessions*** (combining a focus group discussion and workshop activities) with the eleven educator-participants for this phase of the study. During the second half of the first session of field visit one (on a Friday), the participants were provided with stationery (namely cardboard, coloured pens, scissors, glue and magazines) and requested to divide themselves into two groups. Both groups were asked to compile an outline of the community (in writing and/or in terms of pictures), guided by discussions within the smaller groups. Two facilitators (my supervisor and I) monitored the process. After completion of their maps, both groups displayed their maps and reported back to the bigger group, during which participants were allowed to further elaborate.

At the end of the session, two volunteers were requested to go out into the community the following day (Saturday) and take photographs, in order to elaborate on their *community maps*. I provided them with disposable cameras and met with them on the Saturday to have the photographs developed. During the second intervention session (on the Sunday), the two groups used the photographs to elaborate on their initial maps, providing visual representations of the mapped landmarks in the community. Each group again explained the content of their maps. In addition to the intervention sessions, I relied on **observation**, **visual data** and documentation in my **field journal** to obtain an overview of the community.



FIGURE 4.2: EXAMPLES OF MAPPING ACTIVITIES CONDUCTED DURING PHASE TWO

4.2.2.3 Outcomes of phase two

Two *community maps/social maps* were compiled by each of the two groups – one in writing and one consisting of photographs. Photographs of the compiled maps are included in Appendix C¹³.

The educator-participants explained the lay-out of the community by referring to existing infrastructure, landmarks and facilities, such as the national road, salt lake adjoining the community, schools and churches in the community, the fire station, shops, street vendors, brick houses and shacks. By the end of this phase, I had obtained an overview of the community, as perceived by the participants – thereby achieving the formulated objectives for phase two.

On phase two – excerpt taken from my field journal ...

One of the biggest highlights of my first field visit was to see how PRA (which I had thoroughly studied in theory) could be put into practice. Involving the educator-participants in visual concrete activities worked so well! Not only did it result in the planned outcomes for the visit, it also led to lively discussions, energy and excitement amongst all present. I am convinced that a mere discussion on the lay-out of the community would not have resulted in the rich information co-generated by using mapping activities, as proposed by PRA. I am therefore satisfied that I employed a suitable approach and methods.

However, I did not only experience the positive outcomes of employing PRA principles in practice. The potential hurdles of PRA that I read about prior to my field work also became a reality. I had to constantly remind myself that the participants were to determine the process, agenda and the pace of activities. Although a flexible approach during sessions came easily, it took me a while to accept the idea that we were not going to be able to finish all the activities planned for the first visit. We in fact only managed to address half of my ideas ... thus reflecting the golden rule of "The participants determining the process..."

At the end of our first visit to the community, after four days of hard work, I am

¹³ Please note that the pictures of cows, calves and snakes included on the maps in Appendix C did not form part of phase two of the study and do therefore not reflect the community maps in their original format.

exhausted, yet overwhelmed by the great response I received. I am excited about my study and happy about the way that I facilitated activities over the past few days. I am already looking forward to the next visit. Although the participants still seem to be cautious when discussing HIV&AIDS related issues, they are progressively becoming more open and appear willing to share their perceptions with us. Some of them, however, indicated the stigma attached to the pandemic within the community, constantly refraining from using the term HIV&AIDS.

Based on the participants' contributions and my own observations of the community, I want to predict that the asset-based approach may be suitable as theoretical framework in analysing this community's way of coping with HIV&AIDS. The school, principal and participants themselves are great assets to the community, although they do not seem to be aware of the fact yet. In addition, we identified various resources and potential resources in the community, some of which were also mapped by the participants as part of the mapping activity.

4.2.3 PHASE 3: IDENTIFYING CHALLENGES, ASSETS AND POTENTIAL ASSETS IN THE COMMUNITY

During phase three I was guided by the following questions:

- ⌘ What are the main challenges (by implication needs) experienced by the community?*
- ⌘ Which assets and potential assets can be identified in the community?*
- ⌘ How might the identified challenges be addressed by relying on available and potential assets and resources?*
- ⌘ How might HIV&AIDS-related challenges be coped with by relying on existing assets in the community?*

4.2.3.1 Objectives for phase three

Phase three was guided by the objectives of identifying the challenges faced by the community (at the time of the study), as well as the assets and potential assets available in the community. Furthermore, this phase aimed at identifying possible ways of coping with identified challenges (such as HIV&AIDS). This process of

identifying challenges and *assets* (asset-based approach) was initiated during my first field visit and concluded during the second visit.

4.2.3.2 Processes involved during phase three

Phase three once again involved **mapping activities** and entailed the creation of *resource maps* (PRA), in other words *asset-mapping* (asset-based approach). Educator-participants were guided to focus on the positive aspects in their community and within themselves, the rationale being that an awareness of assets might guide the way in which community members (participants) cope with or address challenges. The process of creating *resource/asset maps* was integrated with the production of *mobility maps*, where the utilisation and optimal use of people and other resources and potential resources in the community was highlighted.

After completing the *community maps/social maps* during the second session of my first visit, the participants were requested to categorise the various components of their community maps as challenges, resources (*assets*) or potential resources (*assets available but not yet mobilised*). For this purpose, they had to paste pictures on their maps, namely snakes next to the challenges, cows next to the resources and calves at potential resources. I selected these symbols as I regarded them as traditional and familiar to the indigenous culture of the participants. Participants related to the symbols quite easily.

My second field visit flowed from this session. Educator-participants had to work from their initial maps and list the challenges the community faced (again using the snake as symbol) on a separate poster. Secondly, they had to identify ways of addressing these challenges, by focusing on the resources (*assets* and *potential assets*) available in the community. For this purpose, the symbol of a *knobkierie*¹⁴ was used, to '*kill the snakes*'. Participants again worked in two groups, made use of discussions in their small groups to guide their mapping activities and provided feedback to the bigger group after the separate activities had been completed.

¹⁴ *Club/knobstick*



FIGURE 4.3: EXAMPLES OF ACTIVITIES CONDUCTED DURING PHASE THREE

In addition to the data generated during *intervention sessions* (focus groups and workshop activities), *informal conversational interactive interviews* with other participants (refer to Table 3.3) provided data on the challenges, resources and potential resources (*assets*) as experienced by the community. Although individual interviews did not always necessarily and primarily focus on *challenges*, *assets* and *potential assets*, these topics often did form part of the discussions that transpired. In addition, we (the research team) constantly *observed* (and *visually captured*) the community and identified challenges, assets and potential assets, relying on the asset-based approach as theoretical background. My *field journal* supplemented these data collection activities.

4.2.3.3 Outcomes of phase three

The educator-participants were able to categorise the various components included on their initial community maps as challenges, resources or potential resources. During my second field visit, the initial maps served as the basis to facilitate follow-up discussions, during which the educator-participants summarised the challenges, as well as ways to address them, by relying on resources and potential resources (*assets*) in the community. Against the background of the specific context and nature of my study it is noteworthy that educator-participants did not identify HIV&AIDS *per se* as a challenge faced by the community, but indirectly in terms of several HIV&AIDS-related issues (such as poverty, a high incidence of tuberculosis, children orphaned by HIV&AIDS and at-risk sexual behaviour) that emerged.

Refer to Appendix C for the relevant posters compiled and to Appendix D for photographs of assets (both utilised and those not yet mobilised), taken during field visits. The challenges, assets and potential assets identified during individual interviews are reflected in the transcribed interviews (Appendix E). Based on the raw data generated during the described data collection activities, I can conclude that my objectives for this phase were successfully addressed.

On phase three – excerpt taken from my field journal ...

On our way to the school, I wondered whether or not all of the educator-participants would turn up, as two months had passed since our first visit. As with our first visit, I was a bit anxious and uncertain about the activities I had planned, and whether or not they would be appropriate and suitable to generate the raw data I aimed to obtain.

Once again, I was astonished at how well the activities worked out. Participants easily identified with the symbols I selected, enjoyed the sessions, participated with enthusiasm and created rich and extensive raw data. Nine of the eleven educators that participated during our first visit turned up, with one withdrawing from the study and one becoming involved in extra-mural activities, sending a replacement. In addition, a new participant joined us, once again resulting in eleven participants. All of the educators were glad to see us and visibly more relaxed with us being there than during our first visit.

The willingness of the participants to be part of the study and – even more important – make a difference in the community is truly remarkable. However, in spite of their enthusiasm and motivation to make a difference, they initially still tended to focus on the problems of the community and external support addressing them. During our facilitation we had to constantly redirect participants to the resources and potential resources as ways for the community to solve problems and face challenges. In response to our attempts (towards the end of the visit), participants demonstrated insight into the basic principles of the asset-based approach. Based on the assets and available, but not yet utilised, resources that the participants identified, I can reach the preliminary conclusion that the community is indeed relying on some assets available to them in order to cope with the challenges they face, including HIV&AIDS. However, several assets do not seem to be utilised – maybe necessitating the process of asset mobilisation?

We returned from the community, satisfied with our efforts, filled with admiration and exhausted after the facilitation of energy-laden sessions. I am thankful for the participants' contributions, energy and positive attitudes, making field visits such wonderful and fulfilling personal experiences!

4.2.4 PHASE 4: RAISING AWARENESS OF ASSET-BASED TRENDS IN COPING (FORTH-FLOWING INTERVENTION 1 – IN PROGRESS)

During the intervention sessions and informal conversations that transpired during the first two field visits, the educator-participants revealed a distinct need for basic knowledge regarding HIV&AIDS. At that stage they seemed willing to assist community members and the learners in their school, but voiced their concern of not possessing the necessary knowledge to answer HIV&AIDS-related questions and indicated that they would like to be informed and knowledgeable on the topic. The only two educators that seemingly displayed confidence in their existing knowledge on the topic were the Life Skills educators, who had attended HIV&AIDS workshops presented by the Department of Education.

As a result, a Masters student¹⁵ accompanied me for two field visits, during which she conducted *individual interviews* with six educators (in order to determine their specific needs), upon which she planned and presented an *intervention* for ten educator-participants. This part of the intervention study took the form of *workshops*, focusing on facilitating an awareness amongst the educators of the existing asset-based trends in their current manner of coping. In addition, basic information related to HIV&AIDS was discussed and action plans formulated by the participants, focusing on aspects such as dealing with AIDS-related conditions; nutrition; emotionally supporting a person living with HIV&AIDS; and dealing with a parent and/or a learner infected with HIV (both in general and in the classroom).

After completion of the intervention, Viona and I facilitated a *focus group*, during which the educator-participants indicated that they felt enabled and better equipped to cope with the challenge of HIV&AIDS. Apart from displaying increased confidence with regard to answering HIV&AIDS-related questions when approached by family members, learners or other community members, they also displayed confidence that they would be capable to better support community members infected and affected by HIV&AIDS.

¹⁵ Ms Viona Odendaal, MEd (Educational Psychology).

On phase four – excerpt taken from my field journal ...

Viona accompanied me during the third and fourth field visits. I wondered how her presence might impact on the educator-participants and the dynamics of the group – she being a new face and yet another outsider entering a semi-closed circle ... I was happy when the educator-participants accepted her in the same manner which they accepted Liesel and me up until now. I do, however, partially ascribe the ease with which Viona established rapport with the participants to the firm relationships of trust that had been established already. During field visit four, I faced the challenge of telling the educator-participants that they would not be receiving reimbursements from visit five onwards, as the funds were exhausted. Despite my anticipation that they would show resistance, the participants accepted this fact fairly easily, indicating that they were there to make a difference in the community, and that it was no longer about the money.

I experienced Viona's intervention as beneficial part of the participatory intervention initiated by my study. Viona's intervention afforded me the opportunity of spending more time in the field and in the presence of the educator-participants, strengthening relationships and constantly learning more while in the field. I could sense that the participants appreciated the fact that I kept on returning – honouring my commitment of being involved in the community for a lengthy period of time and adhering to the basic principles of PRA. As such, I got the idea that I lived up to their expectations and that they in turn respected my commitment, once again strengthening our relationships of trust even further. During the individual interviews that I conducted, I appreciated Viona's support as field worker. In the same manner, I benefited from fulfilling the role of field worker whilst she conducted her individual interviews – elaborating on my existing base of raw data.

On the other hand, I did initially experience concern with regard to the potential (negative) impact that Viona's intervention might have on the future progress of my study. I could not be sure whether her intervention would support or compromise my project, as her intervention aimed at raising an awareness of coping within the educator-participants. I speculated about the possible impact that such an awareness might have on future coping strategies, as employed by the participants... Upon reflecting on my concerns I, however, soon realised that Viona's intervention is a piece in the participation and intervention puzzle that will contribute to the final end-product, as she focused on addressing a need identified by the participants during the first phases of my study. As such, Viona's intervention supplemented mine, thereby adding to the bigger participatory picture.

4.2.5 PHASE 5: EXPLORING THE COMMUNITY'S WAY OF COPING WITH HIV&AIDS

During phase five I was guided by the following questions:

- ⌘ *How is the community currently coping with HIV&AIDS and the challenges implied by the pandemic?*
- ⌘ *To what extent do community members rely on existing assets and local resources (asset-based approach) in coping with HIV&AIDS?*

4.2.5.1 Objectives for phase five

Phase five aimed at exploring the selected community's way of coping with HIV&AIDS. As such, I explored the community's coping with the challenges implied by HIV&AIDS, for example coping with being infected with HIV, coping with a family member infected with HIV or who has AIDS, and caring for children orphaned due to HIV&AIDS. My basic assumption was that the community was coping by relying on the resources, structures, beliefs and practices already available and embedded in the community. As a result, I focused on exploring the manner in which the community was coping with that which already existed, thereby relying on the basic principles of the asset-based approach. As the participants, as well as my (and my co-researchers') personal observations could provide insight into this area of investigation, this particular phase of my study took place over the entire course of the study, although it was the primary focus of field visits three and four.

4.2.5.2 Processes involved during phase five

I conducted twelve planned *informal conversational interactive interviews* (refer to Table 3.3) to explore how the community was coping with HIV&AIDS at the time when I conducted my field work. I relied on my own networking abilities, interviews with stakeholders who could refer me to other possible interviewees and the educator-participants to identify suitable people to interview. I strived to involve stakeholders at the various levels and conducted interviews with educators, the principal of the school through which I gained access to the community, social workers (employed by the Department of Health, Department of Social Development,

NGOs and faith-based organisations), the HIV&AIDS co-ordinator in the area (employed by the Department of Social Development), health workers (at the provincial hospital and clinics), employees of NGOs, a church minister, community members taking care of children orphaned due to HIV&AIDS, community members who were infected with HIV or those who had AIDS at the time of my field work, as well as those with a family member infected with HIV or diagnosed with full-blown AIDS. I also attended an awareness campaign of a mental health organisation and visited clinics, the provincial hospital, a community care centre and local hospice for children who have AIDS. Two of the interviews were conducted in Xhosa, resulting in me relying on an interpreter¹⁶.

Besides formally planned informal conversational interactive interviews, I further gained information during ***ad hoc conversations*** with community members and stakeholders, for example, during lunch times or when encountering community members. In addition, ***discussions during intervention sessions, observation, my field journal and visual data collection*** added to the raw data I obtained.

4.2.5.3 Outcomes of phase five

Conducting individual interviews, having informal conversations, constantly observing the community and interactions taking place, documenting my observations in my field journal, and gathering visual data, provided me with a view of the community's way of coping with HIV&AIDS (addressing my objective). Besides gaining insight into the way that HIV positive community members are facing the challenge of their illness, I obtained an understanding of how community members deal with family members or friends who are infected or ill, as well as how they accommodate children orphaned due to HIV&AIDS. Phase five can be related to phase three of the study, which focused on assets (both utilised and those not yet mobilised), as the community relied on such assets to cope with the HIV&AIDS challenge. In addition to the maps and visual data included in Appendices C and D, the transcribed interviews (main source of raw data for this phase) are included in Appendix E.

¹⁶ *One of the educator-participants, able to communicate fluently in both English and Xhosa, acted as interpreter. Prior to the first interview, I briefed her on issues of confidentiality, as well as her responsibility to merely interpret what I and the interviewees said and not to add her own nuances or omit any detail. I am comfortable with the way in which she acted as interpreter, although I am cognisant of the possible loss in meaning and nuances that usually accompany language barriers.*

On phase five – excerpt taken from my field journal ...

I gathered extensive information from the individual interviews I conducted. Despite my initial concerns pertaining to whom to involve and how to gain access to them, I was able to schedule and conduct numerous interviews without too much difficulty. One interview led to another and towards the end of my field work, I had to force myself from making more and more appointments, meeting more and more people. To be quite frank, I even believe that the last few interviews were probably not necessary at all, as data saturation had probably been reached by the end of the fifth field visit. However, I was already so involved in the community and my process of investigating various possible resources at that stage, that I simply continued exploring. I relate this to the fact that I experienced some difficulty to negotiate my roles as researcher and interventionist, constantly having to remind myself that I entered the community as researcher and therefore had to remain focused on fulfilling that role.

I found it easy to conduct the individual interviews. I relied on the interviewing skills that I possess and established sound rapport without difficulty during all the interviews. With the exception of one, all interviewees were willing to contribute after I had explained the purpose of my study and the principles of confidentiality and anonymity to them. Based on my experience in the field and the rich data that I obtained, I regard my choice of informal conversational interactive interviews as appropriate for exploring ways of coping with HIV&AIDS, as employed by the community.

At the end of this phase, I was also able to identify asset-based trends (such as community members' reliance on aspects like faith, inner strength, family and friends when faced with challenges) in the data I had obtained on the community's way of coping with HIV&AIDS. These trends suggested that the community members may be relying on the asset-based approach in coping with the pandemic.

The interviews with the caregivers of the orphaned children (HIV infected), as well as those conducted with participants who were infected with HIV and the family members of infected individuals, were difficult. Visiting the homes of infected community members and their families and seeing the children living with AIDS was emotionally laden and painful. One of the lowest lows of my field work was most definitely the death of one of the children whom I met during a visit when conducting an interview with her aunt, who was taking care of her at that stage. Also, observing the fear, bewilderment and confusion in the eyes of the persons living with AIDS, as well as in the eyes of their loved ones, brought a lump to my throat. I am so grateful that I always had a co-researcher by my side, to debrief with after an emotionally difficult interview!

4.2.6 PHASE 6: MOBILISING POTENTIAL ASSETS IN ORDER TO ENHANCE THE COMMUNITY'S COPING WITH HIV&AIDS (FORTH-FLOWING INTERVENTION 2)

The identification of latent but seemingly not yet mobilised assets in the community (phase three) necessitated intervention from a PRA perspective, in order to facilitate the educator-participants to mobilise and access such assets. I am of the view that it would have been unethical to withdraw from the community without facilitating the process of asset mobilisation.

As my study primarily focused on the exploration of the community's way of coping with HIV&AIDS, a Masters student¹⁷ became involved in the participatory intervention to address the question as to *how educator-participants could utilise their knowledge of assets in terms of the community's coping with HIV&AIDS* (Loots, 2005). She participated during the fourth and fifth field visits, conducting three **intervention sessions** (consisting of **focus group** discussions and **workshop** activities) with the educator-participants, aiming to explore educator-participants' *asset mobilisation* (asset-based approach), in coping with HIV&AIDS. In addition, I facilitated a follow-up discussion during an **intervention session** during the sixth field visit, in order to monitor the progress of the three projects that the educator-participants initiated during this phase, thereby monitoring their mobilisation of assets. As during the other phases, we also relied on **observation**, **field journals** and **visual data collection techniques** in collecting and documenting raw data.



FIGURE 4.4: EXAMPLES OF ACTIVITIES CONDUCTED DURING PHASE SIX

¹⁷ Ms Mathilda C. Loots, MEd (Educational Psychology). Study completed in 2005 (please refer to list of references).

Following from Loots' (2005) part of the intervention, the educator-participants initiated three projects in the community. After identifying the proposed projects and potential assets to be mobilised, they formulated action plans and strategies to reach their goals. The educators divided into three task teams, each team focusing on a separate project. They were responsible for putting the planned strategies into action between field visits, reporting on and mapping their progress during follow-up sessions. As an outcome, a school-based *vegetable garden*, *support group* and *information centre* for HIV&AIDS infected and affected members of the community, were initiated and established by the educator-participants at the school.

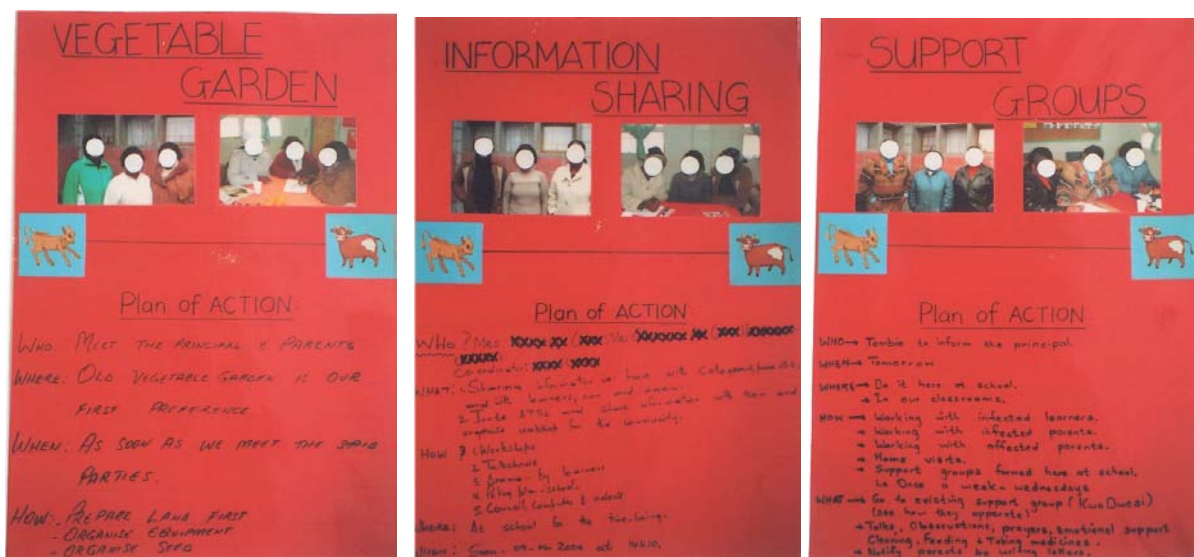


FIGURE 4.5: POSTERS ON THE PROGRESS AND FURTHER ACTION PLANS FOR THE THREE SCHOOL-BASED INITIATIVES

The three projects further resulted in certain secondary outcomes. The *information sharing task team* (supported by Loots and myself), for example, developed a draft HIV&AIDS policy document for the school. In addition, each educator-participant formulated a personal *declaration of commitment* during the initial stages of planning the projects. Educators involved in the project selected a name for themselves as a team (namely *Masizakheni*, meaning *Let us build together*) and (upon their request) nametags stating their names next to an HIV symbol were made for them. Educators proudly wore these identifying nametags for the rest of the duration of my study, possibly indicating pride and ownership in terms of their participation.



FIGURE 4.6: EXAMPLES OF THE OUTCOMES OF PHASE SIX

Findings from Loots' (2005) section of the intervention research study indicate that, apart from the educator-participants mobilising potential assets in the community, the educators experienced feelings of empowerment and accomplishment after planning and successfully initiating the projects. They also showed insight with regard to the asset-based approach. As a result of their initiatives in the community, parents became more involved at the school (both men and women, not only maintaining the vegetable garden but, for example, also volunteering to assist in cleaning the school), and community members seemed to become more willing to disclose their status to selected staff members (mainly the *support team*).

This enabled the educators who participated in my study (and inevitably also other community members they encountered) to better support community members living with HIV&AIDS. Educators supported community members emotionally (by regularly visiting them), spiritually (by praying for and with them), materially (by providing vegetables, food parcels and clothing to those in need), socially (in terms of contact and visits) and on an informative level (by providing basic information on HIV&AIDS-related issues). In this manner, Loots' (2005) intervention (as participatory extension of this PRA intervention research) facilitated the empowerment of not only individuals but also of the school where she (I) conducted her (my) study, as well as the wider community in coping with HIV&AIDS.

On phase six – excerpt taken from my field journal ...

Tilda's part of the intervention formed part of the broader participatory work that I had been doing over the past few months. I was excited to see whether or not the educator-participants would be able to apply the knowledge that they had obtained on asset-based principles. Up till now, they displayed potential skills as well as the motivation to utilise their skills in making a difference in the community, yet they seemed to lack the confidence to take action.

The outcome of Tilda's section of the intervention research study was truly amazing. Although participants displayed motivation and energy to put their plans into action after the first intervention session, I pondered on how much would have been accomplished during our next field visit ...

Standing next to of a large vegetable garden (on the school premises) upon our return, left me feeling humble and ashamed. How could I ever have doubted the participants' motivation to make a difference and set the wheels rolling? – in fact doubting my own theoretical assumptions regarding coping, agency and the asset-based approach! Their feelings of joy, pride and accomplishment cannot be expressed in words! The three identified projects in an attempt to mobilise potential, but not yet utilised, resources demonstrated a success in terms of participatory research!

Tilda's intervention enabled me to distinctly link the theory of the asset-based approach to the community's coping with HIV&AIDS. After identifying assets and potential assets in the previous phases of the study, the educator-participants were facilitated into action. They applied their knowledge of potential resources, as well as the knowledge obtained on asset-based principles, in putting their plans into action. By doing this, they were not only empowered themselves – they also seemed to have empowered other community members in coping with HIV&AIDS and its related challenges.

In addition to the work prior to her intervention, I relate the research outcomes of Tilda's intervention to the methodology she employed. Building on my previous field visits and relying on symbols and methods which the participants were familiar with, proved to be successful. Relying on group activities where participants were not provided with the answers but facilitated to come up with solutions themselves, further contributed to the research outcomes.

4.2.7 PHASE 7: SUPPORTING EDUCATORS IN FULFILLING THEIR PASTORAL ROLE, WITHIN THE CONTEXT OF COPING WITH HIV&AIDS (FORTH-FLOWING INTERVENTIONS 3 AND 4 – IN PROGRESS)

As my study progressed, and during later stages, educator-participants expressed the wish to acquire skills that might be employed to support or counsel people psychosocially. Memory box making and body-mapping were identified as two potential skills that might be utilised and assist educators when supporting people psychosocially. As a result, two Masters students facilitated intervention sessions in this regard, addressing questions on *the possible use of memory box making in supporting vulnerable learners*¹⁸, and *educators' use of body-mapping in fulfilling their pastoral role*¹⁹. They accompanied us (my supervisor and myself) during the seventh and ninth field visits, during which they conducted three **intervention sessions (focus group/workshop combination)** with the educators who were involved in the project.

The first session entailed an introduction to the techniques of memory box making and body-mapping, and a discussion of the basic principles thereof, after which the educator-participants had to implement the techniques with learners (or any other community members) before our next field visit. During follow-up sessions we conducted *focus groups*, exploring the educators' experiences in applying the techniques, the outcome of their intervention in terms of the learners' (community members') reactions and application possibilities of the two techniques, in fulfilling their (the educators') pastoral role. Besides the intervention sessions, we relied on **visual data collection strategies, observation and field journals**.

Preliminary findings of these two forth-flowing interventions indicate that the educator-participants experienced both the techniques favourably and as being suitable to incorporate into formal classroom activities. Apart from the techniques contributing to a warm classroom climate, they enabled educator-participants to establish closer relationships of trust with learners, providing them with more insight

¹⁸ Maria Mnguni, MEd (Educational Psychology).

¹⁹ Malize McCallaghan, MEd (Educational Psychology).

into the life-worlds of learners. However, educator-participants found it challenging to employ the techniques with very young learners (Ebersöhn & Ferreira, 2006).

Furthermore, the techniques occasionally resulted in learners displaying intense emotions, which the educators experienced as overwhelming and difficult to deal with. Therefore, although memory box making and body-mapping might be used by educators as first level intervention skills during fulfilment of their pastoral role, the techniques do not seem to provide educators with the necessary skills to deal with intense emotions (Ebersöhn & Ferreira, 2006).



FIGURE 4.7: EXAMPLES OF ACTIVITIES CONDUCTED DURING PHASE SEVEN

On phase seven – excerpt taken from my field journal ...

Maria and Malize's interventions maybe constitute some of the last pieces of my puzzle. It aimed to address the needs of the participants, paying honour to them determining the process and agenda. This is PRA in action! As always, the educator-participants contributed and shared their experiences openly during the sessions. By now, they were acquainted with the basic principles applied by PRA and the methods we rely on.

During this phase of the study, the already present assets of the educator-participants were expanded on further. Based on their willingness to make a difference and their motivation to help people in need of support, their skills were built on. In empowering them, the underlying principles of both PRA and the asset-based approach were adhered to – all adding to the community's way of coping with HIV&AIDS.

We are on our way to the community – possibly for the last time during this study. I am quiet ... reflective. The past two years have been enriching and fulfilling in many ways – both professionally and on a personal level. Conducting research in the field with people who experience the challenge of HIV&AIDS on a daily basis, whilst employing PRA principles, broadened my skills as a researcher.

Despite the challenges I faced, I had the opportunity to learn and in the process gain invaluable experience, insight into my area of interest and confidence as a researcher. As I strongly believe that I still have much to learn from this community, I am already contemplating the feasibility of a follow-up study in the near future

4.3 RESULTS OF MY STUDY

In the next section I present the results of my study, as derived from the themes that emerged during data analysis, but also keeping in mind the categories proposed by the various phases of my study. Results are presented in terms of the main themes that emerged, each consisting of several sub-themes. Discussions are enhanced by verbatim responses where relevant. As an introduction to my discussion, the results that I obtained are summarised in Figure 4.8.

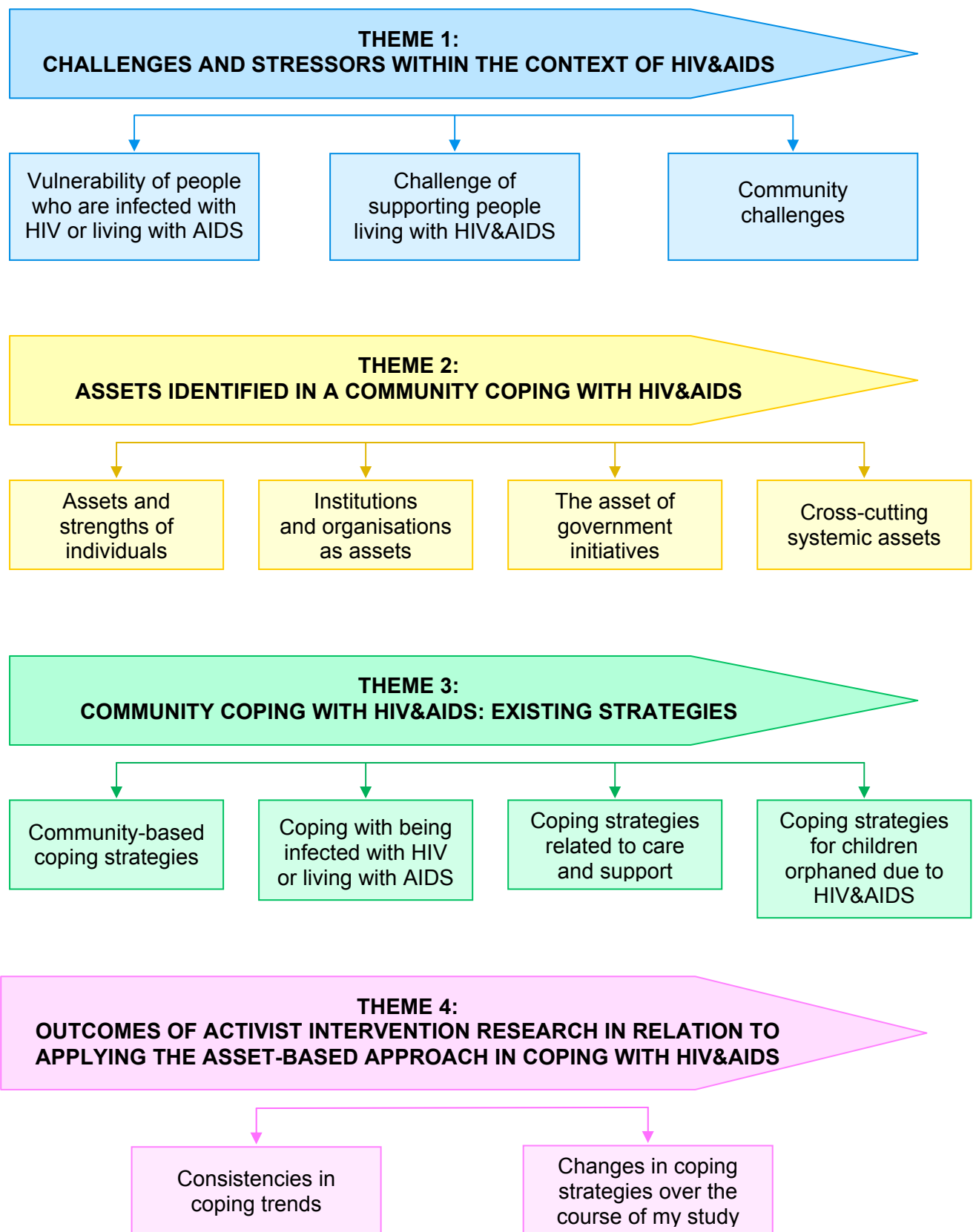


FIGURE 4.8: OVERVIEW OF THE RESULTS OF THE STUDY

4.3.1 THEME 1: CHALLENGES AND STRESSORS WITHIN THE CONTEXT OF HIV&AIDS

I henceforth report on the results relating to challenges and stressors within the context of HIV&AIDS. I structure the section according to the following emerged sub-themes: vulnerability of people who are infected with HIV or living with AIDS; challenges associated with supporting people who are infected with HIV or living with AIDS; and community challenges within the context of HIV&AIDS.

4.3.1.1 Sub-theme 1.1: Vulnerability of people who are infected with HIV or living with AIDS

I report on the vulnerability of people who are infected with HIV or living with AIDS in terms of the emerged categories. The categories are personal vulnerability, physical vulnerability, social vulnerability and cultural vulnerability.

4.3.1.1.1 Personal vulnerability

Apart from regarding the general community as being *traumatized* by the pandemic, participants focused on the *vulnerability of individuals* (community members) who are infected with HIV and those who have AIDS. Awaiting the results of an HIV blood test awakened feelings like: *I was shivering, I was laughing of fear - because the way I was scared to hear the results. I was shivering because I thought the results are going to be positive* (visit 1, educator 1 during focus group 1, p16).

Participants identified *shock*, *denial* and *anger* as typical *initial reactions* upon receiving the news of being HIV positive or having AIDS. Participants noted that people infected with HIV often *avoid discussing* their disease or *resist support* from others. One of the participants summarised the tendency to deny and avoid discussions on an HIV positive status as follows: *Even if your brother becomes angry at you and say: "Leave me alone", that's also a form of denial...* (visit 1, educator 2 during focus group 1, p9), whilst another participant stated: *It's a symptom of denial that aggressiveness...* (visit 1, educator 3 during focus group 1, p13). In addition to feelings such as shock, denial and anger, participants revealed that people

sometimes *lose hope* during the initial phases of their illness: ... *because that person has lost hope...* (visit 2, educator 6 during focus group 2, p22).

4.3.1.1.2 Physical vulnerability

According to the participants, community members infected with HIV are often **vulnerable due to the conditions they live in**. Social phenomena like *unemployment* and *poverty* seemed to be significant challenges faced by the community at the time of my study, leaving community members living with HIV&AIDS in *need of nutritious food, medical care and treatment*, but not always in the position to afford it, as summarised: *And that medication is damn expensive and the unemployment rate is too high – they cannot afford it* (visit 1, educator 5 during focus group 1, p11). With regard to this statement, it needs to be noted that anti-retroviral treatment was not offered to people infected with HIV free of charge at the time of the focus group discussion. As treatment is provided free of charge at present (although not in all areas yet), this statement might no longer be applicable.

Participants noted the possibility that people with AIDS (in the later stages of their illness) may apply for a **disability grant**. Although the participants regarded the disability grant as a *financial resource (asset)*, they also attached negative connotations to the grant, thereby regarding the disability grant as a *potential social challenge*. Participants reported that people receiving the grant sometimes seem to *abuse the grant*, by spending the money on, for instance, liquor instead of utilising the money to provide in their basic needs, such as healthy food: ... *and they will abuse that money...* (visit 1, educator 9 during focus group 1, p6) and another response: ... *with that money, they don't buy uh... food or education. They just enjoy themselves with that money* (visit 2, educator 3 during focus group 2, p18). As a possible solution, some participants suggested that the South African government rather provide food parcels instead of money. However, other participants were of the opinion that the people who intended to abuse the grant would continue doing so, by selling the food parcels, in order to obtain money for items like alcohol.

Another negative connotation linked to the disability grant by participants lies in the tendency of community members trying to *access the grant, in order to receive an*

income. Two significant trends were identified by the participants. Firstly, participants held the perception that some community members would deliberately have sexual intercourse with a person infected with HIV, in order to *be infected* and eventually qualify for the grant. The following response explains this possibility: *They want this money, they don't care. They want it [it referring to the HI virus] 'cause they are going to get money now, you see. They are going to get it* (visit 2, educator 1 during focus group 2, p17).

Secondly, participants indicated the perception that community members who do qualify for the disability grant would *provide others with their own blood samples*, in order that they may also apply for the grant. This was due to the application procedures not being adhered to optimally during the initial phases of my study (*The clinics are not following the procedures correct* – visit 1, educator 10 during focus group 1, p7). Participants were of the opinion that the *statistics of HIV infected* cases were not correct: *And then someday somehow the government will get confused because of the statistics* (visit 1, educator 11 during focus group 1, p7). It should, however, be noted that this perception might have changed towards the end of my study, as the procedures in applying for the grant were reported to be more strictly monitored at that time. The following response (taken from a discussion during one of the last field visits) emphasises the possibility of application procedures being monitored more closely: *... because of the abuse of the grant, the disability grant, the government is very strict now* (visit 6, educator 9 during focus group 3, p13).

4.3.1.1.3 Social vulnerability

Categories that emerged under this sub-theme are stigma, disclosure and at-risk sexual behaviour. In the following sections I discuss how these categories and sub-theme are present in the raw data I obtained.

(a) Stigma

According to the participants, the selected community seemed to *stigmatise* HIV&AIDS to a *great extent*. Besides *avoiding discussions of the topic*, participants noted that community members also *refrained from admitting* that people are dying of

AIDS. One participant declared: *They will just say it was something from TB or something else... It is not easy to talk about this, to say this* (visit 1, educator 1 during focus group 1, p9). Due to the apparent stigma attached to HIV&AIDS and community members seemingly denying the possibility of being infected, they tended to *avoid testing their status*, as stated by a participant: *... they don't want to go and take the tests* (visit 1, educator 7 during focus group 1, p10). Another participant related this aspect to her own feelings: *So now, if you are taking that life cover... I don't want to go and do that blood test, I'll rather leave that life cover. I don't want to do the blood test. For the time being now, I'm still fresh... [fresh referring to being healthy]* and later: *No, no, no! I don't want to go for testing. I don't want to know my status* (both contributions visit 1, educator 9 during focus group 1, p16).

It is worthy to note that even the participants, who seemed prepared to discuss the sensitive issue of HIV&AIDS, indicated the stigma attached to the pandemic, merely in the manner in which they provided responses. During individual interviews, participants would often *avoid using the terminology HIV&AIDS*, as illustrated by the following response: *... because everybody is coming there, you see, even those that are not living with the, with the ... this disease* (visit 3, ex-employee of the South African Police Department during individual interview 8, p5). Even during some of the very last intervention sessions, one of the educator-participants still refrained from using the words *HIV&AIDS*: *Like I was angry at first with this disease ...* (visit 6, educator 9 during focus group 3, p31-32). This educator's hesitancy to use the term might, however, probably be ascribed to the fact that her brother had been diagnosed with AIDS. However, the hesitancy of this particular educator did not represent that of the entire group of educator-participants, as several of them became comfortable with using HIV&AIDS-related terminology as the study progressed, for example making contributions like: *And they know that these vegetable we are going to take it to those houses that have a HIV and AIDS people who are suffering* (visit 6, educator 7 during focus group 3, p4).

(b) Disclosure

Issues relating to the *disclosure* of being HIV positive or having AIDS are presented in terms of a general lack of disclosure, reasons for not disclosing, consequences of

not disclosing and reasons for disclosing. Participants reported that community members who are infected with HIV seemed to **avoid disclosure** of their status, as emphasised by responses such as: *I think in our community it's not easy for the people to come out and say in the public: "I'm HIV positive"* (visit 3, church minister during individual interview 1, p1). This tendency seems to apply to the different levels of people in the community: *You see, how can we blame others, as even the professionals they don't want to disclose* (visit 2, educator 9 during focus group 2, p25). However, participants repeatedly indicated their *ability to identify people with AIDS* in the community, as illustrated by responses like: *... and you could see the parent is very sick, the symptoms...* (visit 1, educator 3 during focus group 1, p5).

In the case of community members who did decide to disclose their status, participants were of the opinion that such disclosure was only done within the circle of a *selected audience*, mostly family members. Participants mentioned a few rare cases, where individuals apparently preferred to refrain from disclosing to their family members and rather disclosed to their friends (who might support them), due to them not wanting to cause sadness amongst their family members. One participant (a lady diagnosed with AIDS) reported on her decision not to disclose to her family:

Researcher: *May I ask you why did you decide to keep it a secret from your family but disclose it to your friends?*

Participant: *Because they are so weak you know. I'm the last born at home and they put all their hope in me, you know. And I've got this little child, so I was unable to tell them at the time I was diagnosed because I knew that they were going to feel pity for me and get lots of worries, you know. But at the end I did tell them.*

Researcher: *So you were actually being strong for them?*

Participant: *Yes* (visit 4, community member infected with HIV during individual interview 11, p4).

Participants often related **reasons for** people infected with HIV or who have AIDS **not disclosing** their status to *feelings of fear*: *The only thing that I would suspect why people are hiding this is because they are probably afraid, some individuals interpret to be positive as you are positive because you are corrupt, maybe you are linked with a prostitute or maybe you've been going with truck drivers* (visit 3, school

principal during individual interview 3, p10). Participants further identified the *stigma* apparently attached to the disease within the community as a potential cause for community members who did indeed disclose their status being *subjected to rejection and isolation*. Responses such as the following serve as examples:

- ⌘ *... because we have fears that they are going to chase me out, you see... out of their lives* (visit 1, educator 9 during focus group 1, p5).
- ⌘ *... you'll become the laughing stock in the community* (visit 3, church minister during individual interview 1, p10).
- ⌘ *that people are now fearing because you are being isolated immediately you disclose* (visit 3, school principal during individual interview 3, p10).
- ⌘ *... if you ... I hear that you are HIV positive I won't speak to you again!* (visit 3, ex-employee of the South African Police Department during individual interview 8, p4).
- ⌘ *What happened ... when she disclosed her status to her husband, her husband left her* [resulting in a divorce] (visit 3, ex-employee of the South African Police Department during individual interview 8, p5).
- ⌘ *The only thing that I can add is that if you are HIV positive, sometimes your marriage gets broken, relationships, friendship also, but fortunately for me it was only my marriage* (visit 4, community member infected with HIV during individual interview 11, p10).

According to the participants, the tendency to *stigmatise* and *isolate* people infected with HIV or those living with AIDS did not only apply to adults, but included the entire community where I conducted my study – thereby also affecting children, as stated in the following words: *The reason why I don't disclose is even the neighbours will talk. Sometimes the neighbour will be reluctant for her child to play with mine or she want to, to, to send her to somewhere but she won't be able to do that, so that the child can feel that I'm alone and I'm not accepted and that will contribute to her health* (visit 3, caregiver 2 [aunt] during individual interview 2, p12). Participants further mentioned that community members often avoided disclosing the status of a family member who had died of AIDS, due to concern for the family members left behind, as: *the one who stays behind, is going to be labelled by his own people* (visit 1, educator 2 during focus group 1, p14).

Participants indicated the view that community members are often *ignorant* concerning basic information relating to HIV&AIDS, apparently resulting in members of the community *fearing to be infected themselves* when in close contact with an infected person. In addition, participants highlighted the tendency of the community to relate HIV&AIDS to *at-risk sexual behaviour*, evidently resulting in community members judging the people who are infected with HIV or living with AIDS. In this regard, participants indicated that members of the community very seldom disclosed their status to the church. A church minister (participant) replied as follows when asked about possible reasons for people not disclosing their status: *I would say that it's because HIV is always associated to sex. Then if you are HIV positive, it has got that bad flesh, that maybe you didn't behave in a good manner. Eh, you have AIDS because you didn't ever behave, your behaviour was bad* (visit 3, church minister during individual interview 1, p9-10). During an interview with a social worker, discussing the possible role that the church might play in preventing community members from disclosing, she made the following comment: *Then you won't participate in nothing at church. Because if you are HIV positive it's because of your sin, you've sinned in the eyes of the Lord* (visit 4, social worker 2 during individual interview 10, p9). Yet on the other hand, a few (though the minority) participants indicated positive experiences when they did indeed disclose their status to the church, such as: *... so I did tell my priest and the other church group members, and they give a lot of support* (visit 4, community member infected with HIV during individual interview 11, p5).

Furthermore, based on a few early cases (covered in the media), during which people who disclosed were rejected and even harmed, community members infected with HIV reportedly sometimes avoid disclosing their status in *fear of being harmed*. A few participants referred to examples, such as: *If you can notice it, you will remember even in Gauteng, Lulu, that lady who disclosed that, then they stoned her to death*, and also: *Even the other lady, who was the activist, they raped her and killed her because she disclosed her status* (both contributions visit 3, caregiver 1 [aunt] during individual interview 2, p12).

Participants regarded the main **consequence** for community members infected with HIV who did **not disclose** their status, to be that they *prevent* themselves from

receiving *help and support*. One of the participants compared the community members avoiding disclosure to those disclosing their status in the following manner: *Some who didn't come out with this, it is difficult to give them help, but those who talk about it – it's easy for anyone to help* (visit 1, educator 5 during focus group 1, p4). Another participant summarised the effect of not disclosing: *But if you don't have a denial problem, it is easy for the doctor, your own doctor, to help you* (visit 1, educator 3 during focus group 1, p12). In this manner, community members who reportedly needed treatment might have prevented themselves from receiving the necessary medical care: *... they wait until late, because sometimes by denial they wouldn't get those... eh... medicines* (visit 2, educator 9 during focus group 2, p21).

In the minority of reported instances where community members infected with HIV **did indeed decide to disclose** their status, it was only done to a *selected audience*, such as social workers, friends or family – apparently often **for the reason of receiving help**, in the form of *financial support* (from family members and in the form of a disability grant), *emotional support*, as well as *guidance* (from friends and family). One participant stated: *... the reason for the disclosure is because of the money* [quotation taken from a discussion on the disability grant that people with AIDS can apply for] (visit 1, educator 11 during focus group 1, p7). During another interview, the participant responded: *They disclose to the social worker only because eh ... some of them they want a grant. They only disclose to them because there's no way of getting a grant without being recommended by the social worker* (visit 3, church minister during individual interview 1, p6). **Reasons for disclosing** do, however, seemingly also include support on a wider level (and not merely on a financial level), as explained: *There's some ... some of the people are disclosing their status because they need help, they want ... they don't want to die, you see* (visit 3, ex-employee of the South African Police Department during individual interview 8, p4).

According to the participants, community members living with HIV&AIDS who have accepted their status occasionally disclosed with the aim of *being role-models* to other community members, with regard to *accepting their status and living life positively*: *I am somebody who is HIV positive and living with AIDS ... I support people and help them to disclose ... Yes, there's life after HIV* (visit 3, person

infected with HIV [ATICC employee] during individual interview 7, p3). As a result, community members who have disclosed their status sometimes seem to strive towards *educating and informing the general community* about the reality of HIV&AIDS. They apparently display the tendency to attend funerals of people who have died of AIDS and disclose the true reason for death. This does not, however, appear to be the norm, but refers to a minority of the community in which I conducted my field work, as indicated by the participants.

(c) At-risk sexual behaviour

According to the participants, community members infected with HIV or those with AIDS often display at-risk sexual behaviour. The perception exists that they tend *not to practice safe sex: ... then they will tell us that they don't want to use condoms because they must have it flesh to flesh* (visit 4, social worker 1 during individual interview 10, p20). In addition, participants noted that community members infected with HIV sometimes *infect others on purpose: What she was saying is that she is HIV positive and she said she is not going to tell anybody cause she is not going to die alone* (visit 2, educator 6 during focus group 2, p17).

Linked to this idea, a perception emerged that community members who are infected with HIV and those living with AIDS often display a '*don't care*' attitude, not being concerned about their own sexual behaviour or falling pregnant, and, by implication, about the future of more children. One participant summarised this tendency: *... they know about the situation and they know about the status. But they keep on* (visit 2, educator 10 during focus group 2, p16). The following excerpt serves as yet another example: *I have a brother who, who is HIV positive and, and his girlfriend ... his girlfriend is pregnant for the fourth time!* (visit 2, educator 2 during focus group 2, p10).

4.3.1.1.4 Cultural vulnerability

It emerged that the Xhosa culture is perceived to be both a *social asset* and a *social challenge* within the context of my study. As the *core of the community's way of coping* with HIV&AIDS seems to stem from their culture and community members

supporting one another, culture is seen as a significant component of *coping*, as reported by the participants. The *ubuntu*²⁰ principle seemed to be operationalised by community members, in order to support one another during times of difficulty. This strategy is illustrated in the following response: ... *he used to say: “man is my brother not by blood but because we share the same burdens”* (visit 3, school principal during individual interview 3, p12). Refer to section 4.3.3 for further elaboration on the positive connotation to culture.

On the other hand, participants identified several potential challenges relating to HIV&AIDS that are based on their culture and add to the vulnerability of community members infected with HIV or living with AIDS. For example, *multiple female partners* appear to be acceptable within the Xhosa culture, whether the man is married or not. In addition, participants did not seem to regard Xhosa women to be assertive enough to demand that safe sex be practiced within marriage, even in the case of a husband being unfaithful. The phenomenon whereby Xhosa women submit themselves to their husbands was illustrated by a participant in the following words: *If you say to your husband okay, let's use a condom. We always say so, but we are forced not to use it... You are not ready for a fight and you are not ready that your marriage are going to fall apart. You give him what he wants, because he is your husband* (visit 1, educator 9 during focus group 1, p25). With regard to at-risk sexual behaviour (as evident in the selected community), participants identified the *lack of sex education by parents* within their culture as a potential contributing factor to children behaving promiscuously. One of the participants explained: *I can talk with other kids, but not to mine*, and later: *Like we don't talk about these things with our kids – it's not like this with us. Even when we are washing, our kids look away*, and then: *we as blacks...* (visit 1, educator 3 during focus group 1, p29).

Furthermore, some participants related the *hesitancy to disclose* to the African culture. The following fragment serves as illustration of this idea, taken from an interview with an aunt caring for a child infected with HIV and orphaned by AIDS:

Participant: *We as blacks we are not like you, we laugh at each other when you disclose of that. Even the kids next door, if they can, they could know that*

²⁰ *Emphasising the importance of community and collectivism.*

this child is suffering from this thing, they'll laugh at her and insult her about the, the, the HIV status.

Researcher: *Why would they laugh?*

Interpreter: *It's like that to our culture. That's why many people don't disclose.*

(visit 3, caregiver 1 [aunt] during individual interview 2, p11).

4.3.1.2 Sub-theme 1.2: Challenge of supporting people living with HIV&AIDS

Participants indicated the *ability to identify* people in the community suffering from AIDS, despite the hesitancy of such community members to disclose their status. For example, one participant responded: *You could only know when you see that this person is eh ... becoming sick and very thin and then you'd start realising when you see the symptoms, but they won't say that we are HIV positive* (visit 3, church minister during individual interview 1, p5).

According to the participants, supporting people infected with HIV and those with AIDS comprises of a variety of aspects. To them, support firstly seems to imply *acceptance of people who are infected*, thereby not rejecting or isolating them. Secondly, support implies that others support the person living with HIV&AIDS by providing *financial support, food parcels and supplements (... even in the community if you can go to give them food parcel* – visit 1, educator 7 during focus group 1, p2). In addition, *advice* might be given and *recommendations* made with regard to changing the person's lifestyle to a healthy one, illustrated in responses like: *... sometimes they will ask questions and you must know that you are going to answer all those questions* (visit 1, educator 9 during focus group 1, p1). Lastly, others are required to display a *caring attitude* by, amongst other things, regularly visiting individuals infected with HIV and *counselling* them when needed. The following responses illustrate the component of home visits: *... she visits their homes and take them something, whatever she has she gives to them at their houses* (visit 6, educator 1 during focus group 3, p6), and: *But if, even if we can go and visit her, you'll see that at least now she is better* (visit 3, ex-employee of the South African Police Department during individual interview 8, p3).

Although participants appeared to be *willing to support* other community members (or family members) infected with HIV, they often *lacked the confidence* to do so, because of their own perceived *lack of sufficient knowledge*. Furthermore, most of the participants did not appear to perceive themselves as *sufficiently skilled* to provide the necessary emotional support. In the words of one of the participants: *We want to support them, but we don't know the way to support others* (visit 1, educator 9 during focus group 1, p2). As a result, participants indicated a *need to be informed* on aspects such as appropriate diet requirements, food supplements and a healthy lifestyle when diagnosed with AIDS.

Apart from the reported lack of knowledge amongst the community members involved in my study, participants mentioned that many *myths* and *misconceptions* seemed to be believed by community members, occasionally resulting in people being *hesitant to get involved* with or support a person infected with HIV or who has AIDS. This may possibly sometimes lead to community members (even family members) being afraid to assist a person with AIDS, as highlighted by the following response by an educator: *And still they don't believe that you can use the same chair as the infected person and whatever. So someone does not want to be ignored if he's HIV positive, so they still want to keep it from their families, they are afraid of that* (visit 2, educator 1 during focus group 2, p8). In addition to this apparent lack of knowledge and skills, participants' hesitance to support those infected with HIV or diagnosed with AIDS, seems to be linked to the stigma attached to HIV&AIDS. Participants indicated that they often refrain from providing support in order to protect the person, as other community members might observe them providing support and as a result conclude that the person is HIV positive. Statements like the following illustrate this hesitancy to support community members living with HIV&AIDS: *But I can't just give them special food, because there will be stigma. They will ask: "Why are they eating special foods?" We want to give them the support, but how are we going to give them the support?*, (visit 1, educator 9 during focus group 1, p2), and: *And even in the community, even in the community, if you can go to give them food parcel, they ask: "Why those houses?"* (visit 1, educator 7 during focus group 1, p2).

With regard to *professional counselling*, participants indicated that people being tested for HIV do indeed receive *pre- and post-counselling* at the clinic where they

are tested, yet to a limited extent. However, participants mentioned a few examples where the *testing* of community members was *not dealt with sensitively*, resulting in such community members having negative experiences. Participants indicated a definite *need for more extensive counselling* and even psychotherapy. Yet, possibly due to stigma attached to psychological services in South African indigenous cultures, participants noted that counselling services are seldom accessed: *Even with us educated people, we seldom see psychologists – we believe in general practitioners... We don't use psychologists. The only time that they get the counselling, a little bit, is when they are told about the results* (visit 1, educator 5 during focus group 1, p10).

4.3.1.3 Sub-theme 1.3: Community challenges

I discuss community challenges in terms of two emerged categories. The categories are general challenges and challenges specifically related to HIV&AIDS.

4.3.1.3.1 General challenges

Participants identified *poverty* and *unemployment* as central challenges faced by the community, as evident from responses like: *Cause financially, the problem is money...* (visit 2, educator 8 during focus group 2, p6). During an interview with the school principal, he provided some background on the community: *The neighbourhood in the sense that quite more of them are ... those infected or affected families are mostly below the poverty line type of families* (visit 3, school principal during individual interview 3, p1-2). A Catholic sister (nun) at the community care centre supported his view: *In my opinion, one of the biggest problems is poverty* (visit 3, Catholic sister during individual interview 4, p1).

Another distinct challenge identified by the participants relates to *at-risk sexual behaviour*, more specifically to the tendency of children (girls) to become involved in various sexual relationships (often with adult men). Participants related the tendency of young girls to become involved in sexual encounters to poverty, by stating that young girls provide sexual favours in return for payment (thereby becoming involved in *child prostitution*), in an attempt to combat poverty and earn the necessary money

to meet their basic needs. The following response sums it up: *To sleep around is only because they want to get some money* (visit 2, educator 11 during focus group 2, p4), and further on during the discussion: *It's poverty, that's why! ... only because they want money and then they get the, the disease from them. You see! Sugar daddy, sugar daddies!* (visit 2, educator 7 during focus group 2, p4). Another participant spelled it out in clear terms: *They must sell their body in order to get something ...* (visit 2, educator 2 during focus group 2, p6), thereby clearly indicating *child prostitution*, which is also evident from the following response: *So she was sleeping with this guy because this guy was paying the school fees, buying uniform, doing everything for her* (visit 4, social worker 1 during individual interview 10, p13).

A closely related issue revealed by participants pertains to *multiple sex partners* (*And she knew that she's not the only woman for this guy, there are also others* – visit 4, social worker 1 during individual interview 10, p13) and *teenage pregnancies* (*they are 14, 15 and 16 years of age and they are pregnant* – visit 4, social worker 2 during individual interview 10, p8). Other social challenges reportedly faced by the community include *alcoholism* (*most of the parents they are alcoholic* – visit 4, social worker 2 during individual interview 10, p8), *domestic violence* and *child abuse* (*and that boyfriend was beating her* – visit 4, social worker 1 during individual interview 10, p17), and also *And it's because the parents are not really taking good care of the children, most of them they abuse their children* (visit 4, HIV&AIDS co-ordinator at the Department of Social Development during individual interview 12, p12), *child neglect* (*Well that child must maintain her own home because her mother is alcoholic* – visit 4, social worker 1 during individual interview 10, p17), *crime*, *substance abuse* and *early school drop-outs* (*she was supposed to do standard 9 but she dropped out of school two years ago, because she didn't have money and her mother didn't ask her even one single day why she didn't go to school* – visit 4, social worker 1 during individual interview 10, p17).

With regard to the geographical lay-out of the community, participants viewed the *salt lake* adjoining the community as a challenge (problem), as indicated during mapping activities (refer to Appendix C). During discussions of mapping activities, participants ascribed their opinion of the salt lake as being a community challenge to factors like water pollution, illnesses and health problems originating from the lake, children

swimming and dying in the lake, and the lake occasionally flooding the main road of the community.

Participants noted the process of *accessing the resources (assets)* available in the community as yet another challenge that might be related to poverty and the lack of money to pay for transport. Participants (during informal conversations and discussions whilst mapping activities were taking place, as documented in my field journal) reported that community members on occasion die because they are too weak to walk to the nearest hospital or clinic, not having money to travel to the provincial hospital (which is 3½ kilometres from the centre of the community), and due to a *lack of sufficient ambulance services* and community members not having money to make a telephone call in order to summon the services that are indeed available. During an individual interview, a participant for example stated: *The clinic it's very far away ...* (visit 4, social worker 1 during individual interview 10, p6) (with the clinic being 700 meters from the centre of the community). In addition, the *lack of sufficient health and social services, as well as police services* in the immediate community were also mentioned in informal conversations, observed by me (and my co-researchers) and mapped as part of the workshop activities (refer to Appendix C). For instance, despite the fact that social workers was reported to be employed in the area by the Departments of Health and Social Development, as well as three faith-based organisations and NGOs, I could trace only one social worker permanently employed in the community at the time of my study (refer to Appendix E, specifically to the individual interviews with the employee of the ACVV²¹ [visit 4, individual interview 9, p1-2], as well as with the HIV&AIDS co-ordinator at the Department of Social Development [visit 4, individual interview 12, p17-18]). As a result, participants voiced the opinion that the employed social worker was overworked and not able to address each and every family in need of support. In general, the social workers involved in the area appeared to feel overwhelmed with the task at hand, as summarised in the following excerpt: *... because some of the social workers, in fact most of them, say they are overworked* (visit 4, HIV&AIDS co-ordinator at the Department of Social Development during individual interview 12, p1).

²¹ *Afrikaanse Christelike Vroue Vereniging / Afrikaans Christian Women's Association.*

4.3.1.3.2 Challenges relating to HIV&AIDS

Participants identified several challenges relating to HIV&AIDS. Apart from the general *challenge of coping with HIV&AIDS* (and other illnesses such as tuberculosis) in the community, participants indicated the *need for a change in attitude* by community members, as people apparently tended to judge and label other community members living with HIV&AIDS. One of the participants stated: *That means that we must change our community, we must change the communities* (visit 1, educator 10 during focus group 1, p9). Another participant elaborated: *we must as a community educate ourselves about this, then there will be no stigma* (visit 1, educator 1 during focus group 1, p14). The idea of *educating the community* in order to *overcome the stigma* attached to HIV&AIDS is indicated by responses such as: *If we educate a community, then no one will be afraid to be tested* (visit 1, educator 5 during focus group 1, p17). Furthermore, participants recorded the tendency of community members to *deny* and *not disclose* their HIV status as challenges, resulting in the members of the community infected with HIV or living with AIDS *not receiving* the necessary *treatment*.

Taking care of community members infected with HIV or those with AIDS was voiced as yet another challenge. In this regard, a *need for more home-based care services* (external aid) was expressed, as community members do *not seem to know how to support* people with AIDS. Participants indicated community members to occasionally be ignorant or *misinformed*, fearing infection if they were to get involved: *That's a major problem when it comes to bathing, most of the people they don't want to bath them* (visit 4, social worker 2 during individual interview 10, p17). Participants further identified the possible link between *at-risk sexual behaviour* and *ignorance* or *misconceptions* (*And then I found out these girls were confused about the AZT thing because they thought if you are pregnant and HIV positive you are going to get a vaccine to prevent your child to have HIV and whatever. So they thought the AZT is going to protect them, now they can sleep with the boys* – visit 4, social worker 2 during individual interview 10, p10).

Orphaned children, and related to that, *ill and dying parents*, were identified by participants as other challenges faced by the community. During a discussion on the

effect of a HIV&AIDS-related death of a parent on a child, educator-participants indicated the *need for counselling services* for such children (as well as the other members of the community). In response to the limited services that are available in the community, educators explained their role: *We are their counsellors, we are their psychologists you know. And if you are teacher, if you are a teacher, you are supposed to do it all, you see. You're supposed to do it all!* (visit 2, educator 4 during focus group 2, p11). Building on this discussion, participants further indicated the *need for being supported* themselves, due to the effect that dealing with such cases have on them personally (*It affects you as a teacher ...* – visit 2, educator 8 during focus group 2, p12). When in need of support, educators seemed to rely on one another and apparently did not receive any external support at the time of my study.

4.3.2 THEME 2: ASSETS IDENTIFIED IN A COMMUNITY COPING WITH HIV&AIDS

For the purpose of presenting my results on available assets in the community where I conducted my study, I combine the aspects identified as resources with those that emerged as potential but not yet utilised resources. I therefore discuss *assets available* in the community, whether or not they have been utilised optimally by community members. In identifying potential assets, I considered the following comment by one of the participants: *But at the end of the day, make sure that these resources are acceptable to people and that they are accessed, you know, when you talk in terms of accessibility and acceptable by them* (visit 4, HIV&AIDS co-ordinator at the Department of Social Development during individual interview 12, p20).

4.3.2.1 Sub-theme 2.1: Assets and strengths of individuals

I structure my discussion on assets and strengths of individuals in terms of the categories that emerged. The categories are assets and strengths of community members; and skills related to networking and negotiation.

4.3.2.1.1 Assets and strengths of community members

Participants often emphasised the tendency of family members, friends, neighbours and community members to support other community members facing challenges or

being in need of support. Apart from basic support to other community members, participants identified the few *community members owning vehicles* as potential assets during mapping activities, as they could assist others with transport, for example to the hospital or clinic. *Volunteer workers* also seemed to play a significant role in supporting others. In this manner, I conjecture that community members can probably either be regarded as assets (resources) or potential assets (resources). Several of the participants emphasised the importance of not focusing on outside help, but rather getting community members involved in taking the initiative. The following comment by a social worker is significant: *So I'm for job creation, not for hand-out* (visit 3, social worker at provincial hospital during individual interview 6, p4). I wonder if this *attitude* may in itself be regarded as an asset, as it focuses on empowerment.

Support groups were identified as another (potential) asset for community members living with HIV&AIDS. According to the participants, support groups in local communities are usually initiated by volunteers, often by people being infected with the HI virus themselves. During the time of my field work and based on my observation and various inquiries during individual interviews and *ad hoc* conversations with members of the community, I could only trace one operating support group in the selected community, facilitated by a faith-based organisation. Participants reported the closest volunteer-initiated group to be situated in the neighbouring community. According to the participants (specifically those directly affected by HIV&AIDS), support groups meet on a regular basis (usually once a week), in order to provide each other with spiritual and emotional support, as well as to share information on how to deal with the symptoms related to AIDS, what to include in a diet, which medication and food supplements to take, or any other kind of information that they acquire. Members belonging to a support group were also reported to occasionally visit one another at each others' homes (refer to individual interviews and *ad hoc* conversations with community members infected with HIV). As such, they become like a family: *When I'm with them it's like I'm with my family. I get lots of love and I become very happy with them. So when Friday is coming I feel something inside of me, like oh, my "family" is coming, you know and it's hard when you are going to be parted* (visit 4, community member infected with HIV during individual interview 11, p4).

4.3.2.1.2 Skills related to networking and negotiation

I observed that the *principal of the school* where I conducted research displayed good *negotiating skills*. For example, based on his negotiation powers, the school had an agreement with an organisation in the Netherlands at the time of my study, providing support in specific areas of growth. In addition, at the time I interviewed him, he was in negotiation with a NGO to sponsor computer training for the staff of his school,. The principal summarised his attempts: *What I'm trying to say is, there are quite a number of incentives for the teachers in the community, and I am going to keep on trying, I want to go and unlock other opportunities for the community in which I find myself in* (visit 3, school principal during individual interview 3, p11). My supposition is that the principal's negotiating skills be regarded as an important potential asset, which might be utilised to *negotiate for further support* by organisations such as NGOs or faith-based organisations.

In the same way, one of the *social workers* at the provincial hospital described a bead work project that she had initiated, where unemployed women do beadwork which is sold, often to international supporters (refer to Appendix E, individual interview 6, p4). I propose that such initiatives by stakeholders of the community may indicate potential *networking powers* which might be utilised further (potential asset on the macro-level). Other examples of skills relating to networking and negotiation that were evident in the community at the time of my field work include the skills of the *HIV&AIDS co-ordinator* of the region (observed by me and indicated during visit 4, individual interview 12, p12: *... but I provide the NGOs but sometimes I go to them, for instance if I've got a crisis*), as well as employees of the ACVV and NGOs (indicated during individual interview 7, p6 and individual interview 9, p17) who were reported as regularly networking with other organisations (both on government and non-governmental level), in an attempt to negotiate external assistance to community members in need of support.

4.3.2.2 Sub-theme 2.2: Institutions and organisations as assets

Categories that emerged under this sub-theme are: the community care centre, educational institutions, political-related assets, NGOs, assets related to health, and

faith-based organisations. I discuss how this sub-theme and categories are present in the raw data in the following sections.

4.3.2.2.1 Community care centre

During mapping activities (refer to Appendix C), educator-participants identified the community care centre as a potential asset to community members. I further relied on informal inquiry from other participants and community members, observation, visual data in the form of photographs (Appendix D) and an individual interview with the founder of the centre (Appendix E – individual interview 4, Appendix G – documentation on the care centre), in order to explore the facilities the care centre offers. Based on my investigation, I determined that the care centre was initiated close to the community (actually situated in the neighbouring community) by a Catholic sister, and that the centre is run by volunteer workers and with the financial support of external organisations. The centre serves the immediate communities and apparently addresses problems such as illnesses (including HIV&AIDS), poverty, alcohol abuse, substance abuse, malnutrition and people in need of medical care, spiritual guidance or psychosocial care. In addition, services seem to be provided to senior citizens, illiterate adults and pre-primary and primary school children. The centre is said to be operated in accordance with the philosophy that people coming to the centre must not receive *hand-outs* but give something in return, for example collect cans that might be recycled. Community members are apparently also encouraged to become involved in self-help projects.

With regard to the potential value of the community care centre as an asset to community members of the informal settlement community where I conducted my study, I wonder whether or not community members will indeed access the services offered by the centre. As the centre is situated in the neighbouring community (yet close [approximately 1 kilometre] to the centre of the community where I conducted my study), I propose that community members might not perceive the centre as an asset in their immediate environment. I raise these questions based on my data collection activities, during which it seemed evident that institutions and professionally employed participants were mainly aware of the centre and the

services it provides, as opposed to community members at ground level who did not regularly identify the centre as an asset.

4.3.2.2 Educational institutions

Being central institutions in the community, the *schools* (namely two primary schools, two high schools and several crèches), *school principals* and *educators* were identified as important assets by the participants in my study. The potential role that schools and educators might play in guiding other community members is summarised in the following contribution: *I think that we as a school, as teachers, it is our responsibility to call the community to train the people* (visit 1, educator 4 during focus group 1, p12). With regard to the *parents of the school*, participants viewed only some of the parents as assets, as illustrated by responses such as: *We didn't say they're coming to school all of them. No, they're coming to school some of them, you see* (visit 2, educator 9 during focus group 2, p21). In addition to the identification of schools, the *university* close to the community was also indicated as a potential asset by the participants and observed by us (my co-researchers and I).

Based on my observations, *ad hoc* informal conversations, planned data collection activities and, I suppose, also the outcomes of my research, the school where I conducted field work emerged as an institution fulfilling a significant role in meeting the needs of community members infected with and affected by HIV&AIDS. The school principal, for example, summarised the school's involvement and commitment to support the community in the following manner: *And this year we have declared that we are going to make a difference, and not in the classroom alone, but the communities. In the next five to ten years they must always remember that there have been the teachers in the year 2004 that have been very concerned with the plight of the communities in which we find ourselves in* (visit 3, school principal during individual interview 3, p8).

With regard to the learners, the school seemed to fulfil the role of identifying vulnerable learners (those with a dying parent, orphaned by AIDS or infected with HIV themselves) and taking care of them, for example by providing food and support: *What the teacher did is she gave him a bread, a loaf of bread everyday* (visit 2,

educator 2 during focus group 2, p12). Although the following contribution was made by the principal only after I've been involved in the community for three months, it emphasises the school's efforts to support the community: *we are starting to get hold of the NGOs so that they can be given some clothes and the meals and with the meal again it can make a difference to one's life* (visit 3, school principal during individual interview 3, p2). Furthermore, educators-participants reported that HIV&AIDS was included as a topic of discussion at meetings (with staff but also with parents) more regularly towards the end of my field work. In addition, the school apparently invited social workers and others to address such meetings from time to time.

I regard the *knowledge* and *positive attitudes* of both the educators and the school principal (that were reported on, observed and noted in my field journal) as a key asset in supporting the community. The following excerpt serves as evidence: *You want to give help, you want to give help, because you could see this person has no one to help her. Even if it's financial, just a little bit. Not that much solution, you see, just to like buy food parcel or give her something, like fruit* (visit 2, educator 6 during focus group 2, p24). Another participant emphasised the school's and educators' *willingness* to make a difference: *But we want to do more, we want to do more. Like we said last time, that we wish to have a garden here in our school* (visit 2, educator 3 during focus group 2, p28). However, in dealing with learners whose parents had died, educators reported on their own experiences of difficulty and the need for support. Educators apparently had to rely solely on themselves, their knowledge (yet another asset) and the resources available amongst themselves in supporting vulnerable children: *I will go to my colleague and eh..., trying to help this child and afterwards I will see this is how we helped each other. And we are giving care to each other* (visit 2, educator 1 during focus group 2, p12).

4.3.2.2.3 Assets related to political organisations

Participants identified *meetings by political parties*, as well as *unions* (such as the Union of South African Provincial Teachers or Women's unions) as assets. Some participants suggested that such meetings might serve as *information sessions*, during which community members might receive basic information on issues like

HIV&AIDS: ... *particularly it's predominantly African National Congress area and in a number of meetings that I have attended, they will always speak about the sketch of the HIV AIDS* (visit 3, school principal during individual interview 3, p3). In addition, participants indicated (and I observed) that the *African National Congress* has an *office* situated in the community, which, I propose, could be utilised as an asset.

4.3.2.2.4 Non-governmental organisations (NGOs)

Participants identified several NGOs as potential resources during intervention sessions, individual interviews and *ad hoc* informal conversations, for example the Ubuntu Education Fund, Barnabas Trust, LAMULA and the AIDS Training, Information and Counselling Centre (ATICC). Even though participants seemed to be aware of the potential services that might have been provided by NGOs, participants were of the opinion that such services were not utilised to their full potential at the time of my field work. My investigation revealed ATICC to be the most prominent NGO in the community where I conducted my study and, at certain levels, involved in the community. Participants, for example, reported that ATICC materially supported selected families in need and presented workshops in the area that might be attended by community members. The following excerpt was taken from my interview with the school principal, reporting on the potential role of ATICC: *They conduct workshops. They make pre- and post-counselling. They also provide clothing and food, especially for the families that have need, that's what they do* (visit 3, school principal during individual interview 3, p6).

Several participants (employed by NGOs and the Department of Social Development) remarked that the particular (selected) *community had been neglected* by external service providers in the past and that outside agencies could become more involved in supporting the community: *Yes, when you mention that area ... there's always something that I've neglected with that area* (visit 3, ATICC employee during individual interview 7, p1), and: *You know that area is a little bit neglected, because our social workers are working there but as I say they are not really doing what they are supposed do* (visit 4, HIV&AIDS co-ordinator at the Department of Social Development during individual interview 12, p5). I conjecture that NGOs may have the potential to offer valuable assistance to the community where I conducted

my study (as in other geographical areas), but they seemingly still need to be mobilised. According to the participants, the potential value of NGOs can firstly be ascribed to the *training and workshops* they might present in the community. Secondly, NGOs are regarded as a *potential financial asset*, as participants appeared to perceive NGOs as a source of funding or other related initiatives to support community members infected with HIV or those who have AIDS.

As mentioned, participants identified ATICC as a *prominent (potential) asset* in the community. Participants indicated awareness of the services offered by ATICC, but indicated that such services were not fully utilised in the community at the time of my study. Based on the contributions by educator-participants during intervention sessions, as well as individual interviews with stakeholders, community members and an employee at ATICC (refer to Appendix E – Individual interview 7; Appendix F – Documentation on ATICC), it became evident that this NGO provides services such as *training, information and counselling services* to community members at a variety of levels. ATICC appeared to present *workshops* on HIV&AIDS, both on introductory and advanced levels, to professionals (such as nurses, educators and business people), community members, significant groups in the community (like traditional healers) and lay-workers. With regard to traditional healers, the ATICC employee whom I interviewed, stated that workshops focus on aspects like sterilisation of instruments and hygienic measures when treating patients, treating symptoms related to AIDS in traditional ways, as well as educating traditional healers regarding the fact that AIDS cannot be cured. Community-based workshops apparently focus on educating community members in terms of basic HIV&AIDS-related information, where to obtain medication in case of being HIV positive, supporting a person living with HIV, sexually responsible behaviour and living positively with AIDS. For this purpose, peer educators are trained and employed, emphasising one of the basic principles of ATICC (as reported by the ATICC employee), namely *training the trainers*. In addition, ATICC organises and facilitates *health forums* at clinics in communities (targeting areas with a high infection rate), where volunteer community members were indicated to be involved in training other community members, paying *home visits* to people infected with HIV or living with AIDS, and assisting in areas like gardening. Services such as home-based care training are also offered.

According to the ATICC employee I interviewed, ATICC *facilitates sectoral forums and council meetings* on a broader level, involving other NGOs, the South African government, schools, clinics, tertiary institutions, representatives of particular groups in the community (for example traditional healers), businesses and local companies, in order to discuss the initiatives employed in the community and to prevent duplication. ATICC seem to also focus on *marketing and fundraising campaigns, networking* with partners such as the South African Broadcasting Corporation (that I propose to be yet another asset) in order to support orphaned and vulnerable children and families in the form of food parcels, clothing, counselling and support. On an international level, ATICC is reportedly also supported financially by companies abroad.

4.3.2.2.5 Assets related to health

I relied on observation, as well as intervention sessions, interviews and *ad hoc* conversations in identifying *clinics, hospitals* (one provincial hospital and one treating tuberculosis patients), *doctors, nurses* and *social workers* as important (potential) assets, specifically within the context of supporting community members infected with HIV or having full-blown AIDS. Despite my observations and reports by participants indicating that these facilities and services were limited and not situated within the community itself at the time of my field work, participants appeared to recognise the potential of such facilities. Responses such as the following illustrate this idea: *... the clinic, that's where they're going to get help* (visit 2, educator 9 during focus group 2, p23).

Participants alluded to the following possible services which might be provided by these facilities and people: *medication (treatment)*, the *provision of information* and *pre- and post-counselling* (both on mental health issues and aspects like nutrition). Based on interview data and my observations, I ascertained that pre- and post-counselling were provided to community members being tested for HIV, yet to a limited extent. Participants suggested that this service could be developed further in order to address the need for counselling, not only of community members with AIDS but also of their family members. The possible role that *ministers* may play in *counselling* community members was also mentioned by participants. Furthermore,

in informally conversing with stakeholders and community members I determined the existence of a *hospice* situated in the area, which I visited and observed. I regard the hospice (approximately ten kilometres from the centre of the community) as a potential asset that might support community members living with HIV&AIDS, despite the fact of it being situated relatively far from the centre of the community.

4.3.2.2.6 Faith-based organisations and churches

Participants' identification of churches, ministers and church workers as (potential) assets are supported by my observations, despite the seemingly negative connotation to churches stigmatising and being judgemental of people living with AIDS. However, in the case of community members disclosing to the church, participants regarded this institution as an asset, as illustrated in the following excerpt: ... *so I did tell my priest and the other church group members, and they give a lot of support. They give advice, emotional support ...* (visit 4, community member infected with HIV during individual interview 11, p5). Participants indicated that churches, ministers and church workers might assist community members with *household chores* (like cleaning), *visit them at home*, *support them emotionally* (support groups, the church-based social worker or auxiliary worker), *support them spiritually* (prayer group) or *financially* by providing money or food. With regard to potential assistance to church members, the church minister with whom I conducted an interview (Appendix E – individual interview 1, p14) regarded his (the *minister's*) *knowledge* of the churchgoers and their needs as an asset, possibly as a means to identify needs and organise assistance.

Concerning *traditional healers*, participants acknowledged traditional healers as a *potential asset* to community members. However, participants often appeared to experience traditional healers in a *negative manner*. Although community members infected with HIV reportedly tend to initially visit traditional healers (*So since they didn't come back with a tangible reason, they thought the white people cannot see the cause of her illness. So she said, let me use the black thing – let's take it to the traditional healer. She knew that she's HIV positive but she was not ready to tell them* – visit 4, social worker 1 during individual interview 10, p12), the outcome of such visits seems to often be regarded in a negative manner (*So if you drink a*

traditional healers' medication and you are already infected with HIV, it can make you more sick because they are very strong – visit 4, social worker 2 during individual interview 10, p11).

Participants (supplemented by my own investigation, observation and field notes) also identified the ACVV (Afrikaanse Christelike Vroue Vereniging/Afrikaans Christian Women's Association), a faith-based organisation, as an *important potential asset* for the community. I visited and observed the organisation's regional offices to be situated approximately five kilometres from the community. Based on my observation and reports by the participants (refer to Appendix E – individual interviews 9 and 10 with employee's of the ACVV), supplemented by documentation on the organisation (Appendix G), the ACVV appeared to be involved in supporting the community at the time of my field work. Involvement in the community included the *services of a social worker*, operating from a school in the community. As reported by an employee of the organisation (Appendix E – individual interview 9), the social worker however appeared to be overworked and not able to deal with the full range of cases, as a result mainly focusing on child neglect and abuse in the community. Other services offered by the organisation at the time of my study included a *weekly youth group* (focusing on discussions and offering annual camps) and *women's groups* (where women receive support, education and acquire skills, in order to generate income) (refer to Appendix E – individual interview 9 and Appendix G – documentation pertaining to the organisation). In order to be able to facilitate such groups in the community, the ACVV reportedly initiated *fundraising projects* and mobilised a physical resource in the community, namely a local church, where they could conduct meetings (*Since we don't have a community hall, we are using that church* – visit 4, social worker 1 during individual interview 10, p4). During meetings, the organisation apparently provided attendees with food/refreshments, in my view *addressing* community members' *basic needs*. In response to the lack of sufficient facilities, members of the organisation indicated that they were planning on building a *community centre* in the community (after obtaining money from the *national lottery*). Participants voiced their opinion that the community centre could offer them with their own premises in future, from where they held the prospect of empowering community members, to be able to help themselves. The following statement illustrates the potential value of the planned community centre (translated from Afrikaans): *And we*

are very excited about this new service centre and everything that we are going to build, because if you can change that into a one stop service centre – a welfare centre ... (visit 4, ACVV employee during individual interview 9, p17).

Both my interview and observational data indicated the ACVV's involvement on an individual level in the community as being supportive by nature, for example, by providing *food parcels* to families in need. Furthermore, the organisation started a *crèche* for needy children in the community, in my view providing in their basic physiological needs on a daily basis. Employees of the organisation reported that the organisation initiated and maintained a few *food gardens in the community*, apparently providing seed (when available or received from a sponsor), guidance and support.

Within the context of HIV&AIDS, the social workers situated at the ACVV offices (therefore not the one already mentioned as being situated at the school) reportedly facilitated a *support group* in the community where I conducted my study on a weekly basis (*yes, we do have a support group but it's a new thing* – visit 4, social worker 1 during individual interview 10, p3). During weekly meetings, guidance was reportedly provided on nutrition, treatment and a healthy lifestyle (of people living with HIV&AIDS or in support of others), how to live positively with HIV&AIDS and supporting people living with HIV&AIDS emotionally. In addition, *home-based care* seemed to be provided by the social workers and home visits paid to community members preferring not to attend the support group. Furthermore, social workers reported that they assisted community members in *applying for financial grants* (such as the disability grant) in cases where individuals were eligible to qualify for such a grant (*Then, if we find that this one can qualify for a grant then we go, we just tell her: "You do qualify for a grant, this type of a grant, you can go to hospital D." Then we write a letter and ask hospital D to help us with this person* – visit 4, social worker 1 during individual interview 10, p17). The social workers also indicated their involvement at schools, in *giving talks* to learners at the schools in the area when requested to do so, on topics related to life skills, including HIV&AIDS (*... it was Mrs M, that approached me to come to school Z, to help her with the life orientation* – visit 4, social worker 1 during individual interview 10, p5). Lastly, the ACVV was reported

to regularly *network* with other NGOs in support of communities in the area, in the form of workshops, providing in basic needs or providing counselling services.

4.3.2.3 Sub-theme 2.3: The asset of government initiatives

Participants identified *government grants* as a potential financial asset to community members (also refer to the discussion in section 4.3.1.1.2). At the time of my field work, many community members were reportedly receiving financial support in the form of a foster care grant, disability grant or child support grant. I view these grants as assets to selected community members. However, I also propose that the government grants were potential assets to other community members at the time of my study, as the participants reported that some members of the community (also those living with HIV&AIDS or taking care of a child orphaned due to HIV&AIDS) were apparently still in the process of applying for, or even ignorant about such grants.

Based on the interview data I obtained (refer to Appendix E – various individual interviews with stakeholders and community members), the *Departments of Education, Health and Social Development* were identified as assets/potential assets for the community. The Department of Social Development was reported to collaborate with the Departments of Education and Health, in order to provide *training, workshops and basic treatment, care and support services* to the community, focusing on aspects such as life skills. In addition, the HIV&AIDS co-ordinator of the Department of Social Development (Appendix E – individual interview 12, p26) reported that she co-ordinated volunteers and caregivers involved in home-based care, providing them with *training and guidance*, in collaboration with NGOs. The Department further focused on *facilitating support groups* in the community (for men, women, people living with AIDS, orphans and child-headed households). Other mentioned *programmes co-ordinated* by the Department of Social Development and facilitated in the communities (yet not in the community where I conducted field work) include programmes on victim empowerment, child protection services, substance abuse and HIV&AIDS (Appendix E – individual interview 12, p26).

Both the Departments of Health and of Social Development employed *social workers* during the time of my study, which, I propose, might serve the community. Despite some of the social workers being situated at the provincial hospital (not paying home visits) and the social workers allocated to the community (one per district) apparently not being able to address existing needs and at times not doing the work they are supposed to do (based on interview and observational data), I propose that available social workers be regarded as potential assets. Furthermore, during the individual interview I conducted with the HIV&AIDS co-ordinator of the Department of Social Development, she mentioned that the Department of Social Development provided support to community members in the form of *food parcels*. In addition to this, I regard the fact that the Department has an *HIV&AIDS co-ordinator* situated in the region (approximately 8 kilometres from the selected community) as an asset, as she might, apart from providing individual support to community members in need of support, facilitate government HIV&AIDS initiatives such as the *National Action on Children that are Affected by HIV and AIDS* (NACA), as reported on during our individual interview (Appendix E – individual interview 12). I propose this lady to be an important (potential) asset, as I observed her as being dedicated to her work and committed to helping people in need. She represented the Department on an inter-sectoral forum and in the local AIDS council at the time of my field work, taking on individual cases to attend to. As such, she could reportedly provide *support* by *placing children* in foster care, *providing food and food supplements*, as well as *assisting families with grant applications*.

4.3.2.4 Sub-theme 2.4: Cross-cutting systemic assets

I henceforth present the results of my study relating to cross-cutting systemic assets. I structure the section in terms of the categories financial assets and other assets.

4.3.2.4.1 Financial assets

Participants (supplemented by my own investigation, observations and field notes) identified *several bodies* as potential resources which might provide financial support to the community. On a macro-level, I regard the *pay-out by the national lottery to the ACVV* as a financial asset. Furthermore, participants mentioned that *NGOs*

appear to be *raising money* in order to support the community. In addition, participants identified the *South African government* as a financial asset, providing potential support in the form of *food parcels*, as well as *government grants*.

Based on the data generated by participants during mapping activities, observation and visual data in the form of photographs (refer to Appendix D), *shop-owners in the community* (three shops and one butchery) were identified as potential assets. However, I wonder whether shop owners would indeed assist community members who are in financial need. On the other hand, participants reported that *schools* and *educators* supported community members in material need (*She is getting food here at school ...* – visit 6, educator 3 during focus group 3, p11). On an even closer level (micro-level), participants identified *family members* as regularly providing *money and food* to relatives in need (*... if she has money she must give him* – visit 3, sister of a person living with AIDS during individual interview 5, p11).

4.3.2.4.2 Other assets

By relying on the mapping activities facilitated during intervention sessions, my own observation and visual data, I identified the *availability of electricity and running water* as assets in the community. I observed water to be provided by means of community taps. With regard to *communication networks*, I observed and visually captured (Appendix D) that community members might access the *post office* and *public telephones*. Furthermore, educator-participants identified the *fire station* as well as *bus and taxi facilities* as resources during mapping activities. Participants further mentioned that the *South African police* (situated in a neighbouring community) and *correctional services* could be employed for crime prevention and child protection. At an *agricultural level*, I observed that the community possesses several *open areas*. I wonder what the possibility is for these open areas to be utilised for vegetable garden purposes. On a wider level, participants identified the *media* as a potential asset, as community members often receive information relating to HIV&AIDS *via* television or radio. The school principal summarised the potential role of the media: *The media seems to be playing a predominant role, into spreading the news for the people to understand that HIV AIDS is indeed a reality and that it is among people* (visit 3, school principal during individual interview 3, p2).

At the school where I conducted my study, I observed and visually captured internet facilities and a library (of which I attended the official opening – Appendix D), which I view as additional assets available to the community. I further propose that potential future projects identified by educator-participants be regarded as potential assets (namely soup kitchens, poverty alleviation projects, gardening projects and bead work projects), as educators' motivation and enthusiasm might assist the community in coping with the challenges it faces.

4.3.3 THEME 3: COMMUNITY COPING WITH HIV&AIDS: EXISTING STRATEGIES

The manner in which the selected community was coping with HIV&AIDS at the time of my investigation is presented in terms of the relevant sub-themes. The sub-themes that emerged are community-based coping strategies; coping with being infected with HIV or living with AIDS; coping strategies related to care and support; and lastly coping with children orphaned due to HIV&AIDS.

4.3.3.1 Sub-theme 3.1: Community-based coping strategies

Despite the community experiencing HIV&AIDS in a negative manner (*The community has all been traumatized by this HIV/AIDS*) (visit 2, educator 8 during focus group 2, p8), participants were of the opinion that the community itself needs to *take responsibility* for addressing the challenge of HIV&AIDS and support community members living with AIDS. The following responses summarise this idea: ... *because it's not about helping people at your workplace, help your community, do it for community, you see* (visit 3, ex-employee of the South African Police Department during individual interview 8, p17), and: *We need to call in everybody ... teachers, reverends, NGOs, everybody must be involved, you see. It's not only one body's problem, it's everybody's problem. So to fight this everybody must stand up to help those who can't help themselves, you see* (visit 3, ex-employee of the South African Police Department during individual interview 8, p7).

I view *culture* as a central component within the context of community-based coping. After a lengthy discussion during the third intervention session on the community's way of coping, I summarised my understanding as follows: *Your culture is the*

foundation of your coping, and the participants responded: *Yes! Yes! Yes!* (visit 2, several educators during focus group 2, p30). In line with the traditional African (including the Xhosa) culture, participants (family members) regarded themselves as being part of a unit that supports one another in times of difficulty (for example after the death of a parent due to AIDS), as emphasised by one of the participants: *The reason why I cope, it's because I know that it's my sister's child and my sister's child is my own child. What I want to do is for her not to feel that she has lost her mother, she must know that her mother is still alive, which is myself. So that I can take her as my own child. So that's why I'm coping, I'm taking her as my own child* (visit 3, caregiver 2 [aunt] during individual interview 2, p10). On a wider level (and possibly applying to the community *per se* and not only to the needs of family members), the following response highlights the tendency of community members to support others that need assistance: *... and then they take responsibility to be giving some food into the next door neighbour* (visit 3, school principal during individual interview 3, p1).

Religiosity, in terms of *prayer* and *faith in God*, seems to be another central component in attempts at coping with HIV&AIDS, as identified by the participants and highlighted in responses such as the following: *I do cope because in everything you do you must pray, if you pray and you believe then God will hear you* (visit 3, sister of a person living with AIDS during individual interview 5, p3). Participants frequently emphasised prayer to be one of the first actions to be taken after a person has disclosed a HIV positive status. In the words of one of the participants: *And they prayed and they prayed and they prayed*, and: *And I said to him pray because you have strength and I'm sure you are going to be okay, because I can see that you have faith and you are strong* (both contributions visit 1, educator 5 during focus group 1, p4).

I suggest that faith might be linked to hope, optimism and expectancy (thereby being *positive* about personal *abilities* and the *future*). A participant summarised these important facets of coping by saying: *... because if you don't have faith, nothing will come right - you must believe that. What I believe in is that if you want to live, you will live, if you want to achieve something, you'll achieve that, you see* (visit 3, ex-employee of the South African Police Department during individual interview 8, p15). Participants further elaborated on the importance of a *positive attitude* in overcoming

difficulties in the following manner: *So if you are positive you can be able to do anything, that's true* (visit 3, school principal during individual interview 3, p13). Another participant remarked: *... this is the kind of extra that you can approach life with, they are making the most of what they have in that way* (visit 3, catholic sister during individual interview 4, p1).

With regard to the potential value of *inner strength* and *perseverance* when coping with challenges, a participant remarked: *For those who are strong, the life is still there* (visit 1, educator 9 during focus group 1, p13). In addition, *acceptance* and then *hope* were also voiced as important ways of facing challenges and coping with difficulties: *Ja ... through the hope which we gave them, then they could cope, because we were visiting them now and again, now and again and we explained to them that they mustn't eh ... worry, that they can cope with the situation. But the problem is you have to accept it ... that you are HIV positive and you can also live a longer life if you take, eh use the medication and you take a right diet* (visit 3, church minister during individual interview 1, p2). With regard to *hope* and *acceptance*, the following response is appropriate: *And they don't believe in death and I will definitely say that that is the one thing keeping people together here, saying that it's okay. And they can still laugh and they can still be nice to each other ...* (visit 3, catholic sister during individual interview 4, p1).

4.3.3.2 Sub-theme 3.2: Coping with being infected with HIV or living with AIDS

Participants expressed their view that the first step in coping with being HIV positive or having full-blown AIDS, lies in the *acceptance* of one's condition, as illustrated by the following words: *I said that they must accept it. Eh ... in order for them to be strong, you have to accept that I have the status ... treat it as if you have the diabetes or high blood or something of that nature. Then you can carry on with your life ...* (visit 3, church minister during individual interview 1, p4). Participants further indicated that community members living with AIDS have to rely on their *own abilities* and *inner strength*. Although other members of the community ought to *support* them, they need to fulfil the primary role, as explained by a few participants: *You need to be strong. You, you need to love yourself first you see ... I must help myself first, then the rest will follow*, and: *If you don't fight this disease, who do you think will*

fight it for you? ... God helps those who want to help themselves (both contributions visit 3, ex-employee of the South African Police Department during individual interview 8, p7). Furthermore, participants were of the opinion that people living with HIV&AIDS were required to have *faith* and be open to receive *support*, thereby allowing others to help them cope with the challenge of their illness: *But if you want to I will help you* (visit 3, ex-employee of the South African Police Department during individual interview 8, p7).

According to the participants, coping with HIV&AIDS (being infected) might imply a *change in lifestyle*, in terms of following a healthy diet and taking food supplements as well as medication. Upon being identified as HIV positive or diagnosed with AIDS, participants stated that community members often tended to *collect as much information as possible* on HIV&AIDS. A lady who was living with AIDS at the time of my study summarised her experiences: *But when I was diagnosed that I'm HIV positive, I became to seek knowledge* (visit 4, community member infected with HIV during individual interview 11, p5). Despite the fact that participants reported that the majority of the community tended to avoid disclosure due to denial and stigmatisation, participants also identified a few people infected with HIV who indeed disclosed their status and *lived positively*. Several participants emphasised the following idea, which may be one ideal way of coping with being HIV infected or having AIDS: *And she must know that to be HIV positive doesn't mean that you, you are dying* (visit 3, ex-employee of the South African Police Department during individual interview 8, p2).

4.3.3.3 Sub-theme 3.3: Coping strategies related to care and support

Participants indicated that family members often find it *difficult to cope with relatives being HIV positive*, as stated by the sister of a person with AIDS: *Yes I'm supporting him but even to me it's painful, you see* (visit 3, sister of a person living with AIDS during individual interview 5, p15). Although participants revealed that the family members of people living with HIV&AIDS rely on the basic means of coping, such as *prayer* and trying to *maintain a positive attitude*, such family members initially undergo *phases of shock* and *denial*. Family members were, however, reported to apparently *take responsibility* to look after relatives infected by HIV in most cases:

But we accepted it, we must accept it ... because we are going to look after him (visit 3, mother of a person living with AIDS during individual interview 5, p2).

Within the community where I conducted my study, participants identified family members' *need for information* as a typical immediate reaction to finding out that a member of the family is HIV positive. According to the participants, such a need to be informed can be related to family members' need to be able to guide and support their relatives living with HIV&AIDS. Participants refined this need for information by stating that community members (family members) *require guidance* on aspects such as healthy eating habits or a healthy diet, food supplements, treatment options and ways of supporting a person with full-blown AIDS, both emotionally and with regard to practical issues, like assisting the person to bath. In fulfilling their role as *primary caretakers*, family members reportedly also provide *financial support*, *advise* infected or sick relatives to go to the clinic or hospital and *accompany them* during such visits. They thereby seemingly take responsibility for *identifying and accessing assets* in the community, such as hospitals, doctors, counselling services and a disability grant, as reported by the participants. However, participants further voiced the challenge that members of their community face in, more often than not, having to *deal with infected relatives' feelings* of denial, anger, fears and frustration, as illustrated by responses like: *Now he's acting like a baby, you see. Acting like a baby, who wanted to be cared for*, and also: *He ... usually he has that aggression, gets cross quickly, you see* (both contributions visit 3, sister of a person living with AIDS during individual interview 5, p13, 15).

The *lengths to which family members would go* in order to support an infected relative became clear during my interview with a lady whose sister is living with AIDS. The interviewee related her story by explaining that she was previously employed by the South African Police Department and had a medical fund, whilst her sister was unemployed and could not afford medication at the time her sister discovered that she had AIDS. As a result, the interviewee *was untruthful* about her own HIV status (moving between doctors and clinics to prevent them from finding out the truth). She reportedly informed the doctors she visited that she had been tested and diagnosed with AIDS several years ago, but had not been emotionally ready to take medication during the time of the diagnosis. She then continued by indicating to

the doctors she visited that she would like to obtain medication at that stage (at the time when her sister became ill). According to the interviewee, she for several months obtained medication for her sister *via* her (the interviewee's) medical aid, until the medical aid investigated the matter and apparently discovered the truth. The interviewee reported that she consequently lost her job and had to repay the medical fund for the medication she had obtained. Reporting on the incident, the interviewee stated: *I know that what I did was wrong, but I was trying to help my sister ... I was not worried about myself and that I can go to jail and loose everything for what I've done, I was worried about her* (visit 3, ex-employee of the South African Police Department during individual interview 8, p10).

Although participants identified family members (in general) as the primary source of care and support to other members of the community living with HIV&AIDS, I realised, as my field work progressed, that participants seldom referred to the role that men fulfil. Reports on care and support to others centred around *women* supporting others, for example the *women* supporting her sister (previous paragraph), the *sisters* and *mother* supporting their brother and son who is living with AIDS (referred to in previous paragraphs), the *aunts* with whom I conducted an individual interview looking after relatives' children, the educators becoming involved in my study being *women*, to mention but a few examples. Based on this realisation and my hypothesis that women might be fulfilling the central care and support role within the community where I conducted my study, I made the following comment during an individual interview with family members of a person living with HIV&AIDS: *I'm starting to get the idea that it's all about women. It's the women that pray and it's the women that support. What is the role of the men?* Participants confirmed my hypothesis by stating: *It's like that to, to ... in our culture, you see, the man doesn't want to take responsibility for others* (visit 3, family members of a person living with AIDS during individual interview 5, p14). I further tested my hypothesis during *ad hoc* informal conversations with participants, for example during lunch times, upon which my idea of women fulfilling the primary role in supporting others was confirmed.

Apart from the family supporting other family members, it emerged that close *friends of the family* serve as a *basic support system*, not only to infected/sick individuals but also to the rest of the family. Furthermore, participants indicated that *colleagues of*

family members, as well as *volunteer workers* could offer a supportive role in praying with the family member whose relative has been infected, thereby providing support on a wider level. The following response serves as an example: *I talked to this woman at work, and then we talked and then we prayed* (visit 3, sister of a person living with AIDS during individual interview 5, p15).

4.3.3.4 Sub-theme 3.4: Coping strategies for children orphaned due to HIV&AIDS

Participants reported that *family members* usually take children into their care when they are orphaned due to their parents dying of AIDS: *Usually with us as the black people, the family take the children ... most of the people they, they have families. So when the parents pass away, the family they take the children* (visit 3, church minister during individual interview 1, p8). Grandparents and aunts appeared to be the primary caregivers in the community where I conducted my study, as revealed by responses like: *It's the relatives, maybe the grandmother or maybe the aunt or whatever, the relatives. As I've explained to you, we have very extended families, so there's always someone from the family that is taking care of the child* (visit 4, social worker 1 during individual interview 10, p16), and: *Usually it used to be the grandparents, but sometimes if there are no grandparents the sisters and brothers, they are taking the children* (visit 3, church minister during individual interview 1, p9). Only two participants mentioned the option of *children's homes*, but regarded this option as a last resort and added that children's homes are limited in number in the area and not easily accessible to community members.

Although the idea emerged that the majority of orphaned children are taken in by *extended family members* within the selected community and the context of my study, participants also indicated that *some families* are *not willing* to take care of orphaned children, resulting in *children being left on their own* after the death of a parent. The following answer was provided in response to a question relating to the caregivers of orphaned children: *The grandparents. But in other families they just leave them there. They're left alone* (visit 2, educator 6 during focus group 2, p9). In cases where extended family members do not fulfil the role of caregivers, participants identified *neighbours* as important sources of *assistance and support*.

Participants explained the potential roles that neighbours might fulfil as taking care of orphaned or vulnerable children, or supporting others who are looking after these children. Participants appeared to value help of this nature, as illustrated in the following words: *The neighbour asked can they come to school? And I asked: Are you going to be able to take care of him? She said: Yes! I will be able to, I will do everything for that kid ... And I realise it so much, that neighbour wasn't just a neighbour, he's a real neighbour, because he could see the need of this kid!* (visit 2, educator 4 during focus group 2, p31).

In the case of family members taking care of their relatives' children who had been orphaned, participants indicated the tendency for such family members to *rely on possible resources and services* available to them, such as *government grants*. However, participants voiced the opinion that family members caring for relatives' children might experience *difficulty in applying for and accessing these grants*, due to the apparent lack of knowledge concerning the correct procedures to be followed. Participants further reported that these community members (family members) might, as a result, *rely on the resources that they can indeed access*, such as *doctors, clinics, nurses and social workers*, in order to assist them in the application process. Unfortunately, participants regarded some members of the community to be *ill-informed and ignorant about the resources* that are available. However, participants acknowledged the possibility of community members not having the *financial means* to travel to the nearest clinic or hospital. Medical and social support services were also identified as limited in the community (based on interview data and my observations), resulting in family members supporting the children of relatives *not receiving the potential support* available to them, such as counselling for the children in their care.

In addition to families approaching others for help, participants mentioned that family members might be *assisted voluntarily by the community* (such as neighbours) or the *school* (both the *principal* and the *educators*, who appeared to sometimes extend their help on a wider level, by involving *social workers* or *NGOs*). With regard to other community members, *support* was reported to be provided at *various levels*, as illustrated by responses like the following: *I'm getting from the neighbours, they are trying to help me ... Sometimes they give me food so that I can cook for us, they*

would give me flour so that I can make bread for us. Sometimes they'd give me even money so that the child [HIV positive] can buy something here at school to eat. It's with her ... the neighbours are taking good care of her. The neighbours are giving me whatever they've got, food or even they sometimes buy shoes for her (visit 3, caregiver 2 [aunt] during individual interview 2, p7). On the other hand, participants reported on some families supporting orphaned relatives apparently *not receiving support from other community members*, having to primarily *rely upon themselves*, with some help from relatives. During an interview with an aunt of a child infected with HIV who was in her care, she remarked: *No neighbour is helping me. We are helping us by ourselves, by trying by all means to get whatever is good for the child* (visit 3, caregiver 1 [aunt] during individual interview 2, p7).

Participants framed *coping with orphaned children* in their community as involving more than the provision of a home for the children orphaned due to HIV&AIDS. As orphaned children might experience intense emotions in the period before, during and after the death of a parent, participants regarded the provision of *basic support and counselling services* as another component of *coping with orphaned children*. Educators identified feelings and behaviour like fear, sleepiness, concentration problems, a decrease in scholastic performance, loneliness and sadness as typically displayed by children orphaned due to HIV&AIDS. Educators reported on their ability to observe such feelings and behaviour, enabling them to *identify vulnerable children*. As a result, *educators* seem to play a significant role in supporting orphaned and vulnerable children of the community: *We are helping these kids out of our own potential* (visit 2, educator 10 during focus group 2, p15), and another participant's opinion: *I would try and be a parent for that child ... I will try by all my means that, so that she will feel comfortable and she can not feel that my mother is not here ... I'm your mother, if you've got a problem come to me* (visit 2, educator 3 during focus group 2, p15).

4.3.4 THEME 4: OUTCOMES OF ACTIVIST INTERVENTION RESEARCH IN RELATION TO APPLYING THE ASSET-BASED APPROACH IN COPING WITH HIV&AIDS

Two main sub-themes emerged under this theme: coping trends that stayed the same during the course of my study, and changes in coping strategies during the

course of my study. In the following sections, I discuss how this theme and sub-themes are present in the data I collected and analysed.

4.3.4.1 Sub-theme 4.1: Coping trends that stayed the same during the course of my study

By relying on observations, continual reflection, as well as the data obtained during individual interviews and intervention sessions with participants, I was able to identify a few coping trends remaining consistent throughout the course of my study. The importance of relatives and, to a lesser extent, neighbours and other community members was emphasised by numerous participants throughout my study. As such, I identified relatives and other community members as central coping components in the community where I conducted my study. I relate the importance of family and friends to the culture embedded in the selected community, as the culture of participants was highlighted as underlying component to their willingness to assist community members in need, from the very first visit to the last. In addition, participants' emphasis on prayer, faith and religion, as potential ways of coping with challenges, remained constant throughout my study.

With regard to the demographic lay-out of the community and therefore the available local resources that could be relied upon in coping with HIV&AIDS, I did not observe significant changes (refer to Appendix D, which includes visual data on the community – captured over the period of two years). In this manner, I propose that the community where I conducted my study had to rely on similar resources towards the end of my study as at its outset. Outside resources and infrastructure appeared to be limited in the community – both at the start and end of my study, implying that community members had to rely mainly on themselves and the assets in their immediate community in order to cope with the challenge of HIV&AIDS throughout my study. With regard to the community-based resources initially identified by participants during mapping activities (Appendix C), I also did not observe any changes as my study progressed.

Concerning financial resources available to community members, the need for finances and financial assistance was emphasised by participants during the entire

course of my study. I relate this need (as illustrated in the constant referral by participants to accessing government grants) to the fact that poverty prevailed in the community. However, based on stigmatisation and secrecy appearing to remain social challenges within the wider community, community members did not seem to be better equipped to access government grants as my study progressed. Despite the levels of stigmatisation seemingly decreasing amongst the group of educator-participants and selected community members becoming more willing to disclose their HIV status as my study progressed, this tendency cannot be applied to the broader community.

Finally, educator-participants displayed the need to be informed throughout the entire course of my study. During initial phases, they indicated a distinct need to acquire basic HIV&AIDS information, including skills with regard to potential manners in which they could support other people living with HIV&AIDS. As my study progressed and the educator-participants mobilised such HIV&AIDS-related knowledge and skills, they seemed to rely on newly acquired knowledge to identify further areas in which they would like to be knowledgeable and skilled. During the final phases of my study, educator-participants, for example, indicated the need to obtain counselling skills, in order to be able to support community members coping with HIV&AIDS.

4.3.4.2 Sub-theme 4.2: Changes in coping strategies during the course of my study

Four categories emerged under this sub-theme: changed levels of self-awareness and self-confidence which resulted in feelings of empowerment, changed levels of support to community members living with HIV&AIDS, becoming actively involved in community development, and changes in the wider community. I henceforth discuss how this sub-theme and categories (which concern the intervention-related purpose of my study) are present in the data I collected and analysed.

4.3.4.2.1 Increased levels of self-awareness and self-confidence, resulting in feelings of empowerment

During the initial phases of my study (more specifically during our first meeting), participants showed limited awareness of the assets situated within themselves and

their immediate community. Despite my observation of a variety of measures already taken in terms of coping (like providing material support, emotional care and spiritual support to other community members in need), educator-participants displayed the *need for expert advice and training* by outsiders: *We want to receive the workshops first, so that we can give* (visit 1, educator 3 during focus group 1, p16). They indicated their *need to be knowledgeable and informed* on HIV&AIDS-related aspects, in order to be able to support community members (as well as family members) infected with HIV and answer the questions posed to them. Themes that participants identified as areas where they required guidance include aspects such as *dietary requirements* of people living with AIDS, *treatment and supplements* to be taken, the procedures to be followed in *applying for a disability grant*, and *how to provide basic support* to people living with AIDS. Participants further voiced the opinion that *all educators* need to receive basic HIV&AIDS training and that training must therefore not be limited to a few selected educators (reported to usually be the Life Skills educators).

Early in the study – towards the end of the second intervention session (field visit 1, day 3) – educator-participants displayed an *awareness regarding their own abilities* to make a difference, as voiced: *We can do this. We can do this. Like I think we must contact ...* (visit 1, educator 10 during focus group 1, p15). This comment was made by a participant in response to my question as to how educators themselves might assist the community in coping with the challenge of HIV&AIDS. As the study progressed, educators confirmed this awareness in their own abilities: *I didn't know what I'm capable of doing, but you did make sure that I know what I can do ...* (visit 6, educator 9 during focus group 3, p31), as well as *confidence in their efforts*: *At least we are trying our best. We are trying our best, you know* (visit 2, educator 8 during focus group 2, p29), and later: *... but today I can stand here and say school G has progressed on that, and school G is the light of community X, because where parents can get help there is a light* (visit 6, educator 9 during focus group 3, p32). Being seemingly aware of their own existing and potential coping strategies resulted in the participants displaying enthusiasm and motivation to take action, by initiating the three projects mentioned.

Towards the end of the field visits educator-participants distinctly indicated how *proud* they were of what they had accomplished. They talked openly about HIV&AIDS (despite one participant still avoiding the terminology) and wore their HIV&AIDS nametags with pride (*because we were not afraid wearing these nametags* – visit 6, educator 1 during focus group 3, p6), showing the community who to approach for help. The change in educator-participants' *general posture and self-confidence* that took place as my study progressed is highlighted by the photographs included in Appendix D. The *positive experiences of being empowered* voiced by educator-participants are highlighted by the following selected responses, taken from a focus group session conducted towards the end of my field work:

- ⌘ *I've been wanting to help people living with HIV and AIDS but I didn't have a breakthrough. But for me being part of this team, now I got a chance to do whatever I wished for. Inside myself I'm feeling great that there's a lot that I'm doing for the community who are infected or affected with HIV and AIDS, through you* (visit 6, educator 7 during focus group 3, p33).
- ⌘ *You know what, it was something that I was thinking about it, but I didn't know how to start it ... What I was doing for the community, there was nothing I was doing. I want to thank you because now I feel proud that there is something I'm doing for the community. I am the light here in this community now ...* (visit 6, educator 5 during focus group 3, p33).
- ⌘ *Okay when you came here, I, myself was like a stagnant water because I had a vision, but my vision needed somebody to stimulate it to be out. Like I was angry at first with this disease, I didn't want even to talk about it because I was affected because somebody in my house is infected. I didn't want anything to say about this disease. But the second week or third time you visited us, something was taken off my shoulders because I learnt to talk about this. I learnt to see what is happening in the world with a real eye. And as we were always gathering every time, I saw that this one can help me, that one can help me, this is a support group for me, I am counselling myself. Then I said also to myself, this thing is a blessing in disguise to me, because now I can talk to my family about this* (visit 6, educator 4 during focus group 3, p35).
- ⌘ *Yes, I didn't know what I'm capable of doing, but you did make sure that I know what I can do, because if you didn't come, I wouldn't have known that I*

can do something for the community that I'm working for, for the people in my church, and they trust in me ... You've shown us that we are able, we are capable of doing things but we don't use that capability of doing that, but since you came here, look at the garden ... Today we are proud of being teachers that can help our nation (visit 6, educator 9 during focus group 3, p36).

4.3.4.2.2 Increased levels of support for community members living with HIV&AIDS

As an outcome of my study (and its forth-flowing components), the *school* emerged to become an even more *prominent asset* in the community than before, characterised by an increase in referrals of vulnerable children and their families to the school. Educator-participants related the increase in numbers of children and parents approaching the school for support and assistance, to the possible positive message conveyed to the community with regard to the school: *There was a conflict before between us and the parents, but I think now they believe in us, they know that we want to work with them ...* (visit 6, educator 9 during focus group 3, p30). I ponder about a possible link between these increased levels of children and parents approaching the school on the one hand, and reduced levels of fear of discrimination in the case of disclosure, on the other.

Educators, towards the end of my study, seemed to more readily realise their significant role regarding their involvement in learners' well-being, as illustrated by the following response: *And then we promised them we will be their parents, we are going to take care of their children, we will be part of their children* (visit 6, educator 2 during focus group 3, p25), and also: *... if they* [referring to community members – parents as well as children] *are sick they can report at school, we phone ATICC so that he can send a social worker, someone to help them* (visit 6, educator 1 during focus group 3, p3). Within the context of supporting others living with HIV&AIDS, educator-participants displayed decreased levels of stigmatisation towards the end of my study. They wore their nametags with pride, indicating their participation in an HIV&AIDS-related project to people they encountered, as illustrated in the following contribution: *... and they could see that we are wearing this* [indicating nametag], *because we were not afraid wearing these nametags, even anyone who can maybe*

ask, we don't mind, because we know what we are struggling for (visit 6, educator 1 during focus group 3, p6).

Apart from focusing on the learners, educator-participants mentioned that they started *supporting the community on a wider level* as my study progressed. One participant, for example, reported a conversation between her and a community member whom they (the *support team*) had supported: *But what made me so excited is the following day when she came, she didn't even have a tear on her eyes and she said I came here to thank you. I didn't know that I could get help, even the nurses at the hospital prayed for me and said why did you take so long? And I told them it's only when I got information at the school, it's only now that I'm ready. They prepared a grant for her, they gave her a cream...* (visit 6, educator 3 during focus group 3, p11).

As a direct outcome of the second forth-flowing intervention, educator-participants initiated three projects, as already reported on. Apart from the reported *emotional support* and *providing information and advice*, the school's *vegetable garden* appeared to *provide in basic needs* of community members: *... now we haven't got money to buy food, now she's getting food from school, she's getting vegetables. I told her the way to eat you see, and I also told her to ask the clinic nurses to tell her more about what she is suffering from so that they can add more on what we have told her you see* (visit 6, educator 3 during focus group 3, p11). In support of community members living with HIV&AIDS, the support team *obtained donations* from outside agencies, in order to provide such families with *support parcels*, consisting of vegetables (from the community garden), clothes and other food supplements. Members of the HIV&AIDS team (educator-participants) further mentioned that they started *assisting* community members in *applying for the disability grant* as the study progressed by, for example, referring them to the right person or institution where they could apply for the grant.

4.3.4.2.3 Becoming actively involved in community development

Besides initiating change in terms of the three school-based projects, educator-participants were visibly more focused on community development towards the end

of my study. Based on their own feelings of accomplishment, empowerment and agency (as voiced during intervention sessions, observed by me, noted in my field journal and documented as visual data), educator-participants identified *other potential projects* that they would like to initiate in future, expanding on the work that they had already done. They indicated that they were planning to start a *soup kitchen* at school, using vegetables from the garden, thus providing in learners' nutritional needs. They also discussed the possibility of negotiating with outside companies in order to *obtain funding to build a hall*, from which *income generating projects* (such as bead work) might be operated, involving unemployed parents.

Educator-participants' willingness to initiate projects and approach external agencies towards the end of my study highlights the change that occurred, from displaying the need for external assistance (as voiced at the onset of my study) to taking agency and initiating projects of their own volition. Responses like the following serve as illustration: *I thought I was going to learn from you when you first came here* (visit 6, educator 6 during focus group 3, p34), vs. *I phoned a certain guy at the municipality ... And then that man said he's going to send someone here at school ... Then they said I must write a letter then ... I wrote the letter ...* (report on the possibility to expand the vegetable garden) (visit 6, educator 1 during focus group 3, p3). In addition, a change in attitude could be observed with regard to their reasons for participating in the intervention. Whereas they initially appeared to be motivated to participate due to the financial benefit received, they seemed to relate their participation to the desire of making a difference in the community during the later stages of my study.

Educator-participants acknowledged the *potential positive impact* that they might have on the community. Towards the end of the field work, responses such as the following were often provided: *because we know we are helping the entire community* (visit 6, educator 1 during focus group 3, p3). They were also positive about *conveying agency to other members of the community: ... and we wanted them to know that HIV is here to stay so that they can be capacitated too, so that they can know where to get help* (visit 6, educator 4 during focus group 3, p5).

4.3.4.2.4 Extending changes to the wider community

Participants reported that the *school's involvement in the community (we are no longer educators now, we are community workers, because we are here to work in this community* – visit 8, educator 3 during focus group 3, p38) led to the *community responding in a positive manner*. Based on the educators' increased levels of empowerment, other community members seemed also to be empowered. In the participants' view, community members seemingly experienced the school as being *more tolerant with regard to vulnerable community members* and as a *source of information and support*, as the study and the three initiatives established by the educators progressed. In addition, parents' *levels of involvement* were reported to have *increased*, resulting in parents, including men, voluntarily providing their services at school. Educator-participants, towards the end of the study, described their school as a *community school*, summarising the *collaborative approach* as follows: *We are a great team. We didn't know that in a school we can work together, parents and teachers like this* (visit 6, educator 3 during focus group 3, p9).

As a result, participants reported that more children infected with and affected by HIV&AIDS entered the school, partially ascribing this increase in enrolments to the school's involvement in supporting the community in coping with HIV&AIDS. Apart from being more involved, parents also seemed to be *more willing to disclose* their status, yet sometimes only to the *support team*. During visit six, an educator-participant reported on the progress and activities of the support team: *And the parents are coming, are free now to disclose, they come in numbers to come and disclose their status since they have seen that we are, here at school G, there is a group of HIV and AIDS, they come and disclose to us then* (visit 6, educator 3 during focus group 3, p4). In response to a question with regard to the possible reasons for the increase in community members disclosing their status, the following answer was provided by an educator-participant: *Okay, the reason for this is because when the information team tell them about it, when we put them on the programme, we told them that since they know nothing about HIV and AIDS, they can come to school to get help. The only thing that the teachers can give them is to give them help and to show them the right procedures to take and give them the advice, good advice, that's*

what the information team can do because they know nothing about this (visit 6, educator 7 during focus group 3, p23).

4.4 CONCLUSION

In this chapter, I reported the results obtained during my study. In addition, I briefly reported the results of the forth-flowing interventions that emerged, as they add to a holistic view of the results. Results were discussed in terms of the themes that emerged during my thematic analysis of the raw data, namely transcribed interviews and focus group/workshop sessions, my field journal and visual data.

In the following chapter, I interpret the results of my study and present it as findings, thereby firstly exploring the manner in which the selected informal settlement community is coping with HIV&AIDS by relying on existing assets and local resources, and, secondly, by exploring possible changes that might have been facilitated by the intervention research approach I employed. In addition, I relate my findings to existing literature. In case of possible contradictions, I attempt to explain such inconsistencies within the context of my study.