

**Engaging the Fertile Silence: Towards a Culturally sensitive  
Model for dealing with the HIV and AIDS Silence.**

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**Thesis Submitted in Fulfilment of the Requirements for the  
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Theology, University of KwaZulu-Natal**

**VOLUME 2**  
**Appendices to Thesis**

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## DECLARATION

I declare that this thesis, unless specifically indicated in the text, is my own original work which has not been submitted in any other University.

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Benson Okyere-Manu

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Date

As the supervisor, I hereby approve this thesis for submission

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Prof. Steve De Gruchy

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Date

University of KwaZulu-Natal

2009

## ABSTRACT

This thesis critically examines one of the major hindrances to dealing adequately with the HIV and AIDS problem facing Africa – the issue of silence. The study has examined the hypothesis that there are cultural factors underlying the silence that surrounds the disease, which when investigated and identified, will provide cues for breaking the silence and a way forward for dealing with the HIV and AIDS epidemic. The study utilises the concept of ‘cultural context’ proposed by Hall and ‘dimensions of culture’ postulated by Hofstede, to investigate the cultural reasons behind the HIV and AIDS silence among the Zulu people in and around Pietermaritzburg in the Kwazulu Natal province of South Africa.

Testing these theories in the field with participants in a community-based HIV and AIDS Project called the Community Care Project (CCP) the study found that cultural contexts strongly influence silence around HIV and AIDS. In terms of dimensions of culture, the area was found to exhibit high power distance, low uncertainty avoidance, high collectivism and is feminine in nature in terms of assertiveness, but having high gender inequality (high masculinity in terms of gender egalitarianism). The analysis of the results of the field research revealed that each of the dimensions of culture contributes in various ways to the silence around HIV and AIDS

The study argues that there are two kinds of silence, namely *barren silence* and *fertile silence*, existing on a continuum. In a low context culture, barren silence is the silence that exists as absence, because when people do not talk about the issue, then there is no communication at all about the issue. In a high context culture, fertile silence is the silence that exists as presence, because when people do not talk about the issue at hand, they may still be communicating about it – either through non-verbal signs, or through coded language.

The concepts of barren and fertile silence provide new insights into the issues of stigma and discrimination. Reasons for the silence included stigma, rejection, gossip, witchcraft,

shame, blame, discrimination, secrecy, judgement, suspicion and taboo. It was found that each of the themes had something to do with stigma and discrimination, and lead to infected persons keeping silent about their HIV and AIDS status.

In the final chapter, the research shows that when an intervention such as CCP takes the question of fertile silence seriously, then it is much easier to break the silence around HIV and AIDS and to deal with stigma and discrimination. The research therefore concludes that the concept of 'Fertile Silence' and 'Barren Silence' has provided us with clues as to how to 'break the silence' around HIV and AIDS in a high context culture such as that of Africa.

## **DEDICATION**

This thesis is dedicated to my father, Benjamin Yaw Okyere, my late mother Abena Nyantakyiwah and my late grandmother, Elizabeth Akua Tonoah, who through hard work and dedication showed me the road to higher heights in education,

AND

to my family:

Beatrice, Ebenezer, Gifty, and Emmanuel,  
for their love, encouragement, care, support and prayer,

AND

to the staff of  
the Newfrontier AID Trust (NAT) and  
the Community Care Project (CCP), all the members  
of the HIV Support Group for their dedication to this research,

May the Almighty God richly bless you all.

## **ACKNOWLEDGEMENT**

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I specifically want to mention my family for their immense contribution to my life and my studies. I thank my wife, Beatrice, for expressing faith in the completion of this study. Once again I thank my three children, Ebenezer, Gifty and Emmanuel, for constantly reminding and encouraging me to finish the work. I thank my father Benjamin and my grandmother Elizabeth, for their financial contribution to my education. Rob and Deborah Ng-Yu-Tin and family, thank you for being friends in difficult times.

My sincerest thanks go to Cynthia Harvey-Williams, for sparing her precious time to edit this work without a charge, may the Lord greatly reward you. I thank the eldership of the Grace Generation Church (GraceGen), Pietermaritzburg, for their prayerful support. I wish to thank Pastor Craig Botha for appropriating his prophetic gift in calling me “Doctor B” long before I registered for the programme. I would like to thank the Ghanaian Prayer Group for their unceasing prayer for this study during times when I wanted to give up.

Finally, the initial financial contribution for this study provided by the Overseas Council through the Evangelical Seminary of Southern Africa (ESSA) is hereby acknowledged and appreciated.

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## **ABBREVIATIONS**

AIDS	Acquired Immune Deficiency Syndrome
ART	Anti-Retroviral Therapy or ARV Treatment
ARV	Anti-Retroviral (drug)
CBO	Community-Based Organization
CBOs	Community Based Organisations
CCC	Christian Community Church
CCP	Community Care Project
CHART	Collaborative for HIV and AIDS, Religion and Theology
ECAP	ESSA Christian AIDS Programme
FBO	Faith-Based Organization
FGD	Focus Group Discussion
Gogo(s)	Grandmother(s)
GoLD	Generation of Leaders Discovered
H-BC	Home-Based Care
HIV	Human Immunodeficiency Virus
HIV/AIDS	HIV and AIDS
NAT	Newfrontier Aid Trust
NGO	Non-Governmental Organisation
NPO	Non- Profit Organisation
OVC	Orphans and Vulnerable Children
PCF	Pietermaritzburg Christian Fellowship
PEPFAR	President's Emergency Plan for AIDS Relief
PG	Project Gateway
PLWHA	Person Living with HIV and AIDS
RSBCS	Rob Smetherham Bereavement Counselling Service for Children.
SABC	South African Broadcasting Corporation
SHAPE	Sachibondu HIV & AIDS Prevention and Education
SIM	Serving in Mission
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TAC	Treatment Action Campaign
TB	Tuberculosis

UN	United Nations
UNAIDS	Joint United Nation's Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Scientific and Cultural Organization
UNICEF	United Nations Children's Fund
UNIFEM	United Nations Development Fund for Women
VCT	Voluntary Counselling and Testing
WCC	World Council of Churches
WHO	World Health Organisation

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### APPENDIX 3A: HOFSTEDE'S SCORES ON FOUR CULTURAL DIMENSIONS FOR FIFTY COUNTRIES AND THREE REGIONS

Country	Power Distance	Uncertainty Avoidance	Individualism	Masculinity
Argentina	49	86	46	56
Australia	36	51	90	61
Austria	11	70	55	79
Belgium	65	94	75	54
Brazil	69	76	38	49
Canada	39	48	80	52
Chile	63	86	23	28
Colombia	67	80	13	64
Costa Rica	35	86	15	21
Denmark	18	23	74	16
Ecuador	78	67	8	63
Finland	33	59	63	26
France	68	86	71	43
Germany (F.R.)	35	65	67	66
Great Britain	35	35	89	66
Greece	60	112	35	57
Guatemala	95	101	6	37
Hong Kong	68	29	25	57
Indonesia	78	48	14	46
India	77	40	48	56
Iran	58	59	41	43
Ireland	28	35	70	68
Israel	13	81	54	47
Italy	50	75	76	70
Jamaica	45	13	39	68
Japan	54	92	46	95
Korea (S)	60	85	18	39
Malaysia	104	36	26	50
Mexico	81	82	30	69
Netherlands	38	53	80	14
Norway	31	50	69	8
New Zealand	22	49	79	58
Pakistan	55	70	14	50
Panama	95	86	11	44
Peru	64	87	16	42
Philippines	94	44	32	64
Portugal	63	104	27	31
South Africa	49	49	65	63
Salvador	66	94	19	40
Singapore	74	8	20	48
Spain	57	86	51	42
Sweden	31	29	71	5
Switzerland	34	58	68	70
Taiwan	58	69	17	45
Thailand	64	64	20	34
Turkey	66	85	37	45
Uruguay	61	100	36	38
United States	40	46	91	62
Venezuela	81	76	12	73
Yugoslavia	76	88	27	21
Regions				
East Africa	64	52	27	41
West Africa	77	54	20	46
Arab Countries	80	68	38	53

Source : Adapted from Hofstede G. & Bond M.H. (1988, pp.12-13)

**APPENDIX 3A1**

Power distance index (PDI) values for 50 countries and 3 regions					
Score rank	Country or region	PDI score	Score rank	Country or region	PDI score
1	Malaysia	104	27/28	South Korea	60
2/3	Guatemala	95	29/30	Iran	58
2/3	Panama	95	29/30	Taiwan	58
4	Philippines	94	31	Spain	57
5/6	Mexico	81	32	Pakistan	55
5/6	Venezuela	81	33	Japan	54
7	Arab countries	80	34	Italy	50
8/9	Ecuador	78	35/36	Argentina	49
8/9	Indonesia	78	35/36	South Africa	49
10/11	India	77	37	Jamaica	45
10/11	West Africa	77	38	OSA	40
12	Yugoslavia	76	39	Canada	39
13	Singapore	74	40	Netherlands	38
14	Brazil	69	41	Australia	36
15/16	France	68	42/44	Costa Rica	35
15/16	Hong Kong	68	42/44	Germany FR	35
17	Colombia	67	42/44	Great Britain	35
18/19	Salvador	66	45	Switzerland	34
18/19	Turkey	66	46	Finland	33
20	Belgium	65	47/48	Norway	31
21/23	East Africa	64	47/48	Sweden	31
21/23	Peru	64	49	Ireland (Republic of)	28
21/23	Thailand	64	50	New Zealand	22
24/25	Chile	63	51	Denmark	18
24/25	Portugal	63	52	Israel	13
26	Uruguay	61	53	Austria	11
27/28	Greece	60			

SOURCE: Hofstede, (1997:26)

**APPENDIX 3A2**

## Uncertainty Avoidance index (UAI) values for 50 countries and 3 regions

Score rank	Country or region	UAI score	Score rank	Country or region	PDI score
1	Greece	112	28	Ecuador	67
2	Portugal	104	29	Germany FR	65
3	Guatemala	101	30	Thailand	64
4	Uruguay	100	31/32	Iran	59
5/6	Belgium	94	31/32	Finland	59
5/6	Salvador	94	33	Switzerland	58
7	Japan	92	34	West Africa	54
8	Yugoslavia	88	35	Netherlands	53
9	Peru	87	36	East Africa	52
10/15	France	86	37	Australia	51
10/15	Chile	86	38	Norway	50
10/15	Spain	86	39/40	South Africa	49
10/15	Costa Rica	86	39/40	New Zealand	49
10/15	Panama	86	41/42	Indonesia	48
10/15	Argentina	86	41/42	Canada	48
16/17	Turkey	85	43	USA	46
16/17	South Korea	85	44	Philippines	44
18	Mexico	82	45	India	40
19	Israel	81	46	Malaysia	36
20	Colombia	80	47/48	Great Britain	35
21/22	Venezuela	76	47/48	Ireland (Republic of)	35
21/22	Brazil	76	49/50	Hong Kong	29
23	Italy	75	49/50	Sweden	29
24/25	Pakistan	70	51	Denmark	23
24/25	Austria	70	52	Jamaica	13
26	Taiwan	69	53	Singapore	8
27	Arab countries	68			

SOURCE: Hofstede, (1997:113)

**APPENDIX 3A3**

Individualism index (IDV) values for 50 countries and 3 regions

Score rank	Country or region	IDV score	Score rank	Country or region	IDV score
1	USA	91	28	Turkey	37
2	Australia	90	29	Uruguay	36
3	Great Britain	89	30	Greece	35
4/5	Canada	80	31	Philippines	32
4/5	Netherlands	80	32	Mexico	30
6	New Zealand	79	33/35	East Africa	27
7	Italy	76	33/35	Yugoslavia	27
8	Belgium	75	33/35	Portugal	27
9	Denmark	74	36	Malaysia	26
10/11	Sweden	71	37	Hong Kong	25
10/11	France	71	38	Chile	23
12	Ireland (Republic of)	70	39/41 39/41	West Africa	20
13	Norway	69	39/41	Singapore	20
14	Switzerland	68	42	Thailand	20
15	Germany F.R.	67	43	Salvador	19
16	South Africa	65	44	South Korea	18
17	Finland	63	45	Taiwan	17
18	Austria	55	46	Peru	16
19	Israel	54	47/48	Costa Rica	15
20	Spain	51	47/48	Pakistan	14
21	India	48	49	Indonesia	14
22/23	Japan	46	50	Colombia	13
22/23	Argentina	46	51	Venezuela	12
24	Iran	41	52	Panama	11
25	Jamaica	39	53	Equador	8
26/27	Brazil	38		Guatemala	6
26/27	Arab countries	38			

SOURCE: Hofstede, (1997:53)

**APPENDIX 3A4**

## Masculinity index (MAS) values for 50 countries and 3 regions

Score rank	Country or region	MAS score	Score rank	Country or region	MAS score
1	Japan	95	28	Singapore	48
2	Austria	79	29	Israel	47
3	Venezuela	73	30/31	Indonesia	46
4/5	Italy	70	30/31	West Africa	46
4/5	Switzerland	70	32/33	Turkey	45
6	Mexico	69	32/33	Taiwan	45
7/8	Ireland	68	34	Panama	44
	(Republic of)		35/36	Iran	43
7/8	Jamaica	68	35/36	France	43
9/10	Great Britain	66	37/38	Spain	42
9/10	Germany FR	66	37/38	Peru	42
11/12	Philippines	64	39	East Africa	41
11/12	Colombia	64	40	Salvador	40
13/14	South Africa	63	41	South Korea	39
13/14	Ecuador	63	42	Uruguay	38
15	USA	62	43	Guatemala	37
16	Australia	61	44	Thailand	34
17	Blew Zealand	58	45	Portugal	31
18/19	Greece	57	46	Chile	28
18/19	Hong Kong	57	47	Finland	26
20/21	Argentina	56	48/49	Yugoslavia	21
20/21	India	56	48/49	Costa Rica	21
22	Belgium	54	50	Denmark	16
23	Arab countries	53	51	Netherlands	14
24	Canada	52	52	Norway	8
25/26	Malaysia	50	53	Sweden	5
25/26	Pakistan	50			
27	Brazil	49			

SOURCE: Hofstede, (1997:84)

**APPENDIX 3B – SUMMARY OF HOFSTEDE'S DIMENSIONS**

Region/County	individualism-Collectivism	Power / Distance	Uncertainty/Avoidance	Masculinity-Femininity
North America (USA)	Individualism	Low	Medium	Masculine
Japan	Collectivism and Individualism	High and Low	High	Masculine/feminine
Europe:	Individualism	Low/medium	Low/medium	Masculine
Anglo	Individualism	Low	Medium/high	Medium/high
Germanic: West Slavic, West Urigic	Individualism	Low	Medium/high	Masculine
Near Eastern: Balkanic	Collectivism	High	High	Medium masculine
Nordic	Medium/high individualism	Low	Low/Medium	Feminine
Latin Europe	Medium/high individualism	High	High	Medium masculine
East Slavic	Collectivism	Low	Medium	Masculine
China	Collectivism	Low	Low	Masculine feminine
Africa	Collectivism	High	High	Feminine
Latin America	Collectivism	High	High	Masculine

Source: Raghu and Kunal (1988: 273).

**APPENDIX 3C: Abbreviations for the countries and regions studied by Hofstede**

Abbreviation	Country or region
ARA	Arab-speaking countries (Egypt, Iraq, Kuwait, Lebanon, Libya, Lebanon, Libya, Saudi Arabia, United Arab Emirates)
ARG	Argentina
AUL	Australia
AUT	Austria
BEL	Belgium
BRA	Brazil
CAN	Canada
CHL	Chile
COL	Colombia
COS	Costa Rica
DEN	Denmark
EAF	East Africa, (Ethiopia, Kenya, Tanzania, Zambia)
EQA	Equador
FIN	Finland
FRA	France
GBR	Great Britain
GER	Germany F.R.
GRE	Greece
GUA	Guatemala
HOK	Hong Kong
IDO	Indonesia
IND	India
IRA	Iran
IRE	Ireland (Republic of)
ISR	Israel
ITA	Italy
JAM	Jamaica
JPN	Japan
KOR	South Korea
MAL	Malaysia
MEX	Mexico
NET	Netherlands
NOR	Norway
NZL	New Zealand
PAK	Pakistan
PAN	Panama

Abbreviation	Country or region
PER	Peru
PHI	Philippines
POR	Portugal
SAF	South Africa
SAL	Salvador
SIN	Singapore
SPA	Spain
SWE	Sweden
SWI	Switzerland
TAI	Taiwan
THA	Thailand
TUR	Turkey
URU	Uruguay
USA	United States
VEN	Venezuela
WAF	West Africa (Ghana, Nigeria, Sierra Leone)
YUG	Yugoslavia

SOURCE: Hofstede, (1997:55)

**APPENDIX 5 SERIES**

**APPENDIX 5A: LETTER OF CONSENT**

Benson Okyere-Manu  
University of Natal  
PIETERMARITZBURG  
11<sup>TH</sup> MAY 2004

LETTER OF CONSENT

This letter serves to obtain consent for your participation in the research I am conducting towards my PhD studies with the University of Natal through the Community Care Project (CCP). I trust that the findings of this research, through your participation in answering series questionnaires, interviews etc, will go a long way to help break the silence around HIV and AIDS.

Thank you very much for your co-operation.

Benson Okyere-Manu

(Project Overseer CCP)

-----  
CCP LINK (GROUP):

I ..... consent to participating in the HIV and AIDS research, aimed at breaking the silence around the disease.

SIGNATURE:

## APPENDIX 5A1: SITUATIONAL ANALYSES

### 1. Situational Analysis for ECAP<sup>101</sup> (1999 – 2000)

- ✘ People lived in denial of the disease, both in the community and in the churches.
- ✘ Ministers expressed the lack of HIV and AIDS awareness and they affirmed that they had inadequate information.
- ✘ Generally, HIV and AIDS was regarded as a curse from God to promiscuous people.
- ✘ Infected individuals were reluctant to express their status in public (they exercise their rights of confidentiality).
- ✘ Ministers were not individually involved in the HIV and AIDS situation but they observed the implications of the disease in the community.
- ✘ Pentecostals and charismatic congregations tended to spiritualise the realities of the disease, as their perception was that 'born again' Christians could not be infected with this virus. (They denied the existence of the disease, in the church).
- ✘ Most ministers in the area had not yet addressed issues of HIV and AIDS in the pulpit due to the fact that people considered the church to be too holy to deal with HIV and AIDS issues.
- ✘ There were a number of myths surrounding the disease. (The worst of these was the one that having intercourse with virgins would stop AIDS. This is one of the reasons for the rampant raping of children in the communities).
- ✘ Ultimately, the importance of awareness and prevention were accepted as the only way of preserving life, though the churches and the communities did not know how to go about it, especially as HIV and AIDS is seen as a sexual disease.
- ✘ It was observed in the communities that since HIV and AIDS are closely related to sex, people do not want to discuss it publicly. This is mainly because it is culturally unacceptable to talk about sex in public.

### 2. Situational Analysis for CCP<sup>102</sup> (2001 - 2003)

- ✘ People still live in denial of the disease, despite the gains of the 2000 Durban World AIDS Conference

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101 The situational analysis for ECAP was published by the researcher in *International Congregational Journal* 2003. *Hope in a time of AIDS*. 3 (2003) 169-183.

102 The situational analysis for CCP formed the baseline survey for CCP's Strategic Plan 2004/2005 and was led by the researcher.

- ✘ With an estimated prevalence rate of 18%, at least 100,000 people are living with AIDS, in and around Pietermaritzburg, HIV and AIDS affects everyone, whether directly, in caring for or losing family or household members, or indirectly through income losses.
- ✘ 250 AIDS or TB-related deaths per month are recorded, mainly in the 20-39 year age group.
- ✘ Families go hungry as breadwinners become sick or die.
- ✘ Many families are disintegrated as a result of stigmatisation, suspicion and poverty.
- ✘ There is an increased need for willing and trained caregivers, since the hospitals are stretched beyond their projected limits (up to 65% of in-patients have an AIDS-related illness) and elderly pensioners are left to care for the sick and orphaned children.
- ✘ The long-established kinship systems that exist in Africa (the extended family), which has traditionally provided a haven for children in distress (in that aunts, uncles and grandparents would take care of children left orphaned when their parents died at a younger age) has become overstretched. Children are now having to bear the burden of heading households. One grandmother-led family has 18 mouths to feed.
- ✘ In some instances, stigmatisation, witchcraft-related suspicion and poverty have led to the extended family not being willing to take on orphans.
- ✘ As a result of the rising death toll in the communities, the little-remaining extended family cushioning does not have any substantial effect.
- ✘ Children are caring for dying adults.
- ✘ 10,000 AIDS orphans live in and around the city.
- ✘ An increase in prostitution has been caused by financial pressure on young people.

The following is relevant to our ministry:

- ✘ Though the HIV and AIDS problem is now known to most church members, most churches do not have programmes to deal with the situation. Despite the clear manifestation of the disease in the communities, the church is generally not handling the problem.

- ✘ Pastors are overwhelmed with funerals. Funerals were usually conducted on Saturdays, but these days are performed every day, including Sundays.
- ✘ There is a stigma against AIDS in the communities. Most of the people we see who are sick say that they are suffering from T.B. If they have been tested, they do not want to know the result. If they have the result, they do not speak about it. Most resist knowing altogether. There is a problem of denial regarding HIV and AIDS. No one admits being HIV-positive.
- ✘ Because of issues of confidentiality, we cannot tell people who we see clinically as having AIDS, that they have the disease, until they themselves tell us that they are HIV-positive. So far, of all the hundreds of clients we work with, less than 10 have ever admitted that they are HIV-positive and most of them only when it is when it is too late to do something about it. For such we can only help them to die with dignity.
- ✘ Education and training are vital in the church and therefore to the community.
- ✘ Because of the non-acceptance of the AIDS epidemic (this being the churches responsibility), churches are not providing resources, which makes the issue further exacerbated by poverty amongst the congregation. As a church-based NPO, our resources are being stretched to cope with the needs of the sick and needy.
- ✘ The government has appointed Community Health Workers, who are not very evident. The ones who do care are those who are coming to CCP for assistance with supplies like food, clothing etc.
- ✘ ESSA's Christian AIDS Programme (ECAP) has been offering educational training to some of the churches in the communities, which are now partnering with us in the struggle against the effects of the disease.

The analysis of the situation shows denial, discrimination and stigma as the main ingredients that feed into the silence surrounding the disease. It was this which drove the research question for this thesis.

## APPENDIX 5B1: CASE 1

### SUPPORT GROUP – 2004-2007 (Case 1)

This case study is centred around a Support Group that was initiated on Thursday 13 May 2004. From the findings of the situational analysis concerning people living with HIV and AIDS, it was clear that people were not ready to disclose their status. However, the literature reviewed indicated that it is through education, relationships and trust that infected people and their families would disclose their HIV situation and status to others. The Support Group was therefore formed to determine whether interventions from CCP with the members, their families and relations, would have the desired aim of building relationships and trust leading to break the HIV and AIDS silence. The report below provides a year-by-year account of the researcher's records.

**2004:** On the first day of the Support Group meeting, only four women of over 397 sick people that CCP has been working with through the Home-Based Care programme responded to the call to attend the HIV Support Group. Of the four, two had previously disclosed to the CCP team that they were HIV-positive and the other two had not. The youngest was 18 years of age and the oldest 54 years. Of those who had disclosed their status, one had been living with the virus for 10 years and the other for two years. They had all been very sick at one time or another and CCP staff had gone to offer Home-Based Care interventions to these people in their homes. The CCP team explained to the group that through these meetings, members would learn more about HIV and AIDS and related illnesses. Through these meetings, members would also be able to help each other and take an HIV test and know their status. Each member gave their testimonies about how their relationship with CCP had helped them and the group agreed to attend a weekly meeting facilitated by the CCP team with the researcher constantly visiting. The researcher explained to them the research he is involved in and the fact that the group as a whole will be a case study in the research. He discussed with them the possibility of studying each of those who attended the first meeting in separate case studies. The teenager and the woman who had lived with the virus for 10 years, agreed to be followed as separate case studies, while the other two objected. The oldest person among them explained her interest in the research but said it would not be possible for her to be

followed in a case study as her circumstances and proximity would not allow for constant interactions. However, she agreed to have an interview(s) any time the researcher wanted her to. The researcher explained a letter of consent in line with the research and they all signed. It was agreed that all who were going to be involved with the research would sign the consent letter.

The next two-and-a-half months saw these four women faithfully attending the weekly Support Group meetings during which, among other things, CCP introduced a 10-week Wellness Course for them. Among themselves, the members discussed issues pertaining to their welfare and health. Through the Course, they began to learn about the basic facts about HIV and AIDS. They understood the need to go for an HIV test and if tested positive, the need to take care of oneself, living positively and hygienically.

By the beginning of August 2004, all of the four women had been encouraged to go for HIV tests and their status were all confirmed as being HIV-positive. On a positive note they had all improved in their health. One of the members invited another lady who tested positive to join the Support Group, bringing the membership to five. During the weekly meetings, a time is set aside for prayer on issues of concern to members. Members found this prayer time very meaningful and the researcher then proposed that the group initiate a monthly prayer meeting where the Churches and pastors that CCP work with would be invited to join us in prayer. This was agreed to, and the first Friday of October was scheduled for the first prayer meeting.

By 1<sup>st</sup> October 2004, which was day for the first prayer meeting, membership of the Support Group had risen to 10 – all females. Most of the members were invited by others in the group. There were over 30 people present, including pastors from CCP-related churches, Caregivers, the youth and CCP staff. The researcher preached on the need to carry each other's burdens, from Galatians 6: 2. There was then prayer for the sick and all Support Group members and other people came forward for prayer. The numbers of the people attending the Support Group began to increase from the meeting following the first monthly prayer meeting. The main discussions in November centred on disclosure. Members saw the usefulness of disclosure and realised that it had to be one of the main

discussions of the group as it is linked with ARVs. The increase in the Support Group membership was evident when many more attended the November 2004 prayer meeting. The woman<sup>103</sup> who had been living with HIV for 10 years felt it was time to reveal her status to her family. She felt that as her four girls were part of the CCP Youth Group<sup>104</sup> and were learning about the pandemic, it would be in the family's best interest for them to know that it was HIV that was often making her sick.

The World AIDS Day of 1<sup>st</sup> December 2004 was significant for the Support Group. The group decided that the monthly prayer meeting should be held on that day and incorporated in a service. The group at this time had 22 people on the register, by now including two men. On this day the Support Group decided to sing a song. Included in the programme was a drama by the Youth Group that CCP works with. The last Support Group meeting on the 16<sup>th</sup> December 2004 saw the largest number of people come for a day of refreshments when 32 people shared cakes, food and received various gifts including food parcels.

**2005:** The year began with a change of meetings from Thursdays to Tuesdays. The first meeting was on 18 January 2005 with 25 people in attendance, of which five were new members. It was discovered that three members of the group has died during the Christmas break and eight had moved out of Pietermaritzburg. The woman who at this stage had lived with the HIV for 11 years had been very ill and her condition was deteriorating. The situation led the researcher to arrange with CCP to take the group through a Bereavement Counselling Course and to repeat the Wellness Course for all members who had not yet done it, with those who had done this as co-facilitators. The course was run concurrently with a Memory Box course and a Bereavement Course for the Youth Group. The reason was that the children of two of the Support Group members who had passed were part of the Youth Group and they were struggling to cope with their circumstances. On the first of February a sick woman was admitted at the

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**103 See Case 3**

**104 The CCP interventions in HIV and AIDS include a youth group comprising of Children and dependants of PLWHAs. Members of this group support each other and have opportunity to learn various skills to help them cope with the consequences of HIV, including memory work, bereavement counseling etc.**

Hospice, where the group together with CCP staff visited her. She was transferred to the government hospital at the end of the month.

The number of people who had been referred to the Support Group and had registered their names had passed the 50 mark in March 2005 with an average of 20 people attending the weekly meetings. Attendance at the monthly prayer meeting held on 4 March was good and five members of the Support Group, including the youngest member, gave their lives to the Lord. However, the disturbing news was of the death of the member admitted to the hospital before she had the opportunity of ARV treatment. All CCP staff and available Support Group members attended her funeral on the 2nd of April, at her home village. The monthly prayer meeting due to be held on that day was cancelled.

The prayer meeting in May was very significant in the life of the Support Group and CCP. With all the discussions about disclosure, VCT and ARVs, the researcher at the prayer meeting on the 6<sup>th</sup> of May 2005 preached from Luke 18:35-43 on "What do you want me to do for you?" Before prayer time he asked the gathering the reasons for the prayer meeting. One of the family members of the deceased was present and responded that they were there to pray, but the youngest Support Group member responded that we were there to pray about HIV and went further to say she was HIV-positive and needed prayer. She came forward for prayer and the researcher asked if there was anyone else who was HIV-positive and who needed prayer. Two more Support Group members, including one man, came forward for prayers. That was the occasion on which people came forward openly for prayer for being HIV-positive, and this marked a significant step forward in breaking the silence. Since that day, in the presence of Pastors, Church members, the youth and community members, a number of members of the Support Group and some of their invited friends openly come forward for prayer.

The first week of the June/July 2005 school holidays was the CCP Community Analysis week. This is usually the time that all stakeholders linked with CCP come together to learn from, and feed back into, the CCP programme. The week was used to educate the stakeholders on the need to break the HIV silence through talking and practically helping

people infected feel encouraged to disclose their status, knowing that they will be helped and not discriminated against. The Support Group played a crucial role in helping to understand what it means to be discriminated against in the church. During the prayer day on 1<sup>st</sup> July 2005, members of the Support Group had an opportunity to share their hearts with those gathered to pray about HIV and AIDS. A member, while sharing, thanked the gathering for giving him back his voice. He pointed out that when he was diagnosed with HIV he lost his voice because he could not tell anyone about his condition, knowing how people react to issues of HIV and AIDS. But by being a member of the Support Group, he had been given the necessary tools needed to stand against any opposition and discrimination about his condition. He also pointed out that normally when one discloses one's status to people, one no longer has a voice to speak because people who come to you are always speaking and have to listen. "But," he said "here I am with people giving me a listening ear. Thank you for giving me back my voice"

From the second half of July to the second half of September was very difficult for the CCP members. In this winter period, a number experienced different ailments and the attendance at meetings became as low as 12 per week. The youngest member of the group was seriously ill and was admitted to a government hospital. Members were concerned about the report that she was not taking her medication properly. During this time discussions centred on positive living and personal wellness. The researcher encouraged members to care for one another wherever possible and to keep themselves warm since the cold winter season is a major contributor to the ill health of members.

However, the Support Group meeting on the 13<sup>th</sup> September 2005 was successful in terms of attendance and of people sharing. The 25 members who met saw the need to investigate what business opportunities there might be for them. Zandla, from the business and marketing wing of Project Gateway, was invited to talk to the group at the following meeting, which attracted 30 people. Issues of starting bead work, gardening, poultry, Spaza shops, sewing, selling vegetables and other business ventures were discussed. Through this some of the ladies who knew about bead work secured employment with Zandla.

It was interesting to see how the members of the Support Group were suddenly full of life and concerned about how to raise funds to support their families. The need to know one's CD4 so as to get onto ARVs also occupies the minds of the members. Another young lady of 19 years joined the group after knowing that she was HIV-positive. The prayer meeting for the month, held on 4 November, 2005 was another mile-stone for the group and the CCP. Thirty individuals made a commitment to Christ when a pastor from one of the CCP-linked Churches in the township preached. Sixteen Support Group members came forward to be prayed for, specifically for their HIV-positive situation.

World AIDS day in 2005 was celebrated in style with nearly 300 people from the community attending, and once again the Support Group played a major role. It was clear on that day that the process of breaking the silence of AIDS and stigma, when in a safe place, was under way. The young girl who joined the group in November and became a member of the Youth Group, shared her HIV-positive status with the crowd, and her belief that there really is hope for the future. She cautioned the young people who are not yet infected to maintain their current status. To those who are already HIV-positive she advised a healthy life-style, and urged those who do not know their status to be tested. The Youth Group then presented a short play about AIDS and the Support Group entertained the crowd with a song. The researcher preached a short message of hope in Christ and over 30 people responded and came for prayer and healing. As usual there was a month's break for the holiday, from 13<sup>th</sup> December until 17<sup>th</sup> January 2006. At this time the membership of the group had risen to 76.

**2006:** The first meeting of the Support Group took place on Tuesday 17<sup>th</sup> January with 16 people attending. CCP staff made it clear to the group that in the year ahead the members would be leading most of the proceedings of the weekly meeting, though the CCP staff would be there. A woman of 35 years was appointed by the group to be the main facilitator. From January through to March the group kept growing with an average of 30 members meeting weekly, including five active male members. The register of the group consisted of 80 people who had attended at least one meeting and their particulars recorded. It was realised that many of the registered members who, when they came in were desperate and sick, soon improved and started to work and so could no longer attend

meetings during working hours. However, the group was not yet ready to meet outside of working hours. The discussions of the group were becoming more and more personal, looking at issues of marriage, families and sex. The major discussion for the group at this point, around which there was some division, was whether or not, in their situation, if they got married - should they or should they not have children. The manner in which the issues were tackled amongst the members, spiced with jokes, showed how the group had become a family. A number of people were eager to be helped to disclose their status to their families.

The researcher informed the group that the meeting after Easter, on the 18<sup>th</sup> April 2006, would be dedicated to discussions on HIV medication and African Culture. The group had watched the film *Yesterday*, and this had provoked reflections on the differences between African medicine and Western medicine.

On the day of discussions, because of the wet and cold weather, only three men and eight women attended the meeting. It came to the attention of these members that the youngest member of the group had been admitted to one of the government hospitals. The discussions of the day centred on the place of HIV and AIDS among the different sicknesses in the African culture. It emerged here that HIV and AIDS belong to a group of incurable diseases that are linked to the spirits. Diseases that come through spirits make a person lose weight and the only help is through the *Sangoma*, who pleads on one's behalf for the ancestors to save one. Members felt that HIV has not yet been given a cultural interpretation, and that traditional healers separate it from spiritual diseases that come through the casting of spells, witchcraft, etc. They think it is because more and more, traditional healers are being educated on the disease and so they understand the medical aspect of it. However, the situation, where HIV is considered in the minds of the people of the community and family members to be a spiritual disease, also contributes to the silence around the pandemic in the sense that spiritual issues should not be discussed by ordinary people. It is the role of the traditional healers to look into such spiritual issues that come about because of curse through witchcraft or breach of a taboo that incur the wrath of the ancestors. All the members present acknowledged having visited a witchdoctor, or two, for relief from their illnesses.

Another perspective that emerged to explain the visits of sick people to traditional doctors is one that is tied to the history of black South Africans. In the past, due to a lack of proper hospitals and clinics, many visited *Sangomas* and, more often than not, were healed. In this way more people, especially those living in the rural areas, have become accustomed to *Sangomas* having cured them of various ailments and so the tendency in an HIV and AIDS situation is for people to visit *Sangomas* – Traditional Healers who people consider to be more effective than modern doctors. In this discussion members came to the conclusion that HIV and AIDS is real and modern and so requires modern and scientific treatment, with prayer.

The month of May was an interesting month for the Support Group members. A member of the group died on the 17<sup>th</sup> and another was sent to the Drop In Centre for care since she had no one at home capable of caring for her. Two of the members who belong to the Treatment Action Campaign (TAC) went for a candle lighting ceremony in Tugela Ferry and were disappointed by a comment made by the KwaZulu-Natal Deputy Minister of Health that people must go back to the traditional healers and forget about ARVs. The two members found the discussions on traditional medicines very informative and helped them to educate other TAC members.

The month of June was used to help members to be compliant with medication, especially ARVs. Discussions revealed that all members whose CD4 counts were below 200 were on ARVs and needed encouragement to remain compliant. The group began to prepare for the HIV Celebration week scheduled for the second week of July, during the CCP Community Analysis week. The week's activities concentrated on HIV disclosure. Family members, Church members, community members, Youth and everyone participating in the week's activities were encouraged to create conditions that will make people who are living with HIV willing and ready to disclose their status to others. This can best be done through learning more about the disease and avoiding any discriminatory and stigmatising tendencies. The Support Group graced the Celebration occasion on the 14<sup>th</sup> July with their beautiful singing.

The winter months between July and September, unlike in the previous year, had more people attending the Support Group meetings, though a number of people were sick. The meetings had an average weekly attendance of 25 people with an increasing number of new members. The group looked at stress management during this time, which members felt was very helpful. Most of the meetings were used for watching relaxing and entertaining movies as it was a very long time since some of them watched a movie. It was a good stress reliever. The youngest member of the group that the researcher had been following was in and out of hospital during this time. She was extremely ill and was admitted to the government hospital on the 3<sup>rd</sup> of September 2006 and, sadly, passed away on the 6<sup>th</sup> of September.

The funeral and burial which took place on the 9<sup>th</sup> September 2006 was another milestone for the Support Group. The researcher conducted the funeral, and the young girl had requested that upon her death she wanted people to understand HIV and AIDS through her funeral. Most of the Support Group members who knew of the death attended the funeral. CCP staff, pastors and many people from the community attended the funeral. The researcher preached a message on HIV and the need for people to help others who are infected (see: Appendix 5B4). People were made aware that the deceased was HIV-positive but that she had been open about it.

As a result of this funeral and the support that the family received from the CCP team and the preaching about HIV, the next Support Group meeting on the 12<sup>th</sup> September saw six new people join the group, with a total of 32 people in attendance. Besides, at the end of the meeting, watching an entertaining movie to release tension and stress, the earlier discussions centred on Thuli's funeral, which the majority of those present had attended over the weekend. All of those who were present at the funeral accepted that it was helpful to preach about HIV and AIDS and thought it would also be helpful to preach about the disease whenever anyone died from it. They all recommended and appreciated CCP for all they did to rather make the funeral a celebration of Thuli's life. Each of Support Group members wanted HIV and AIDS to be preached at their funerals and pointed out the following:

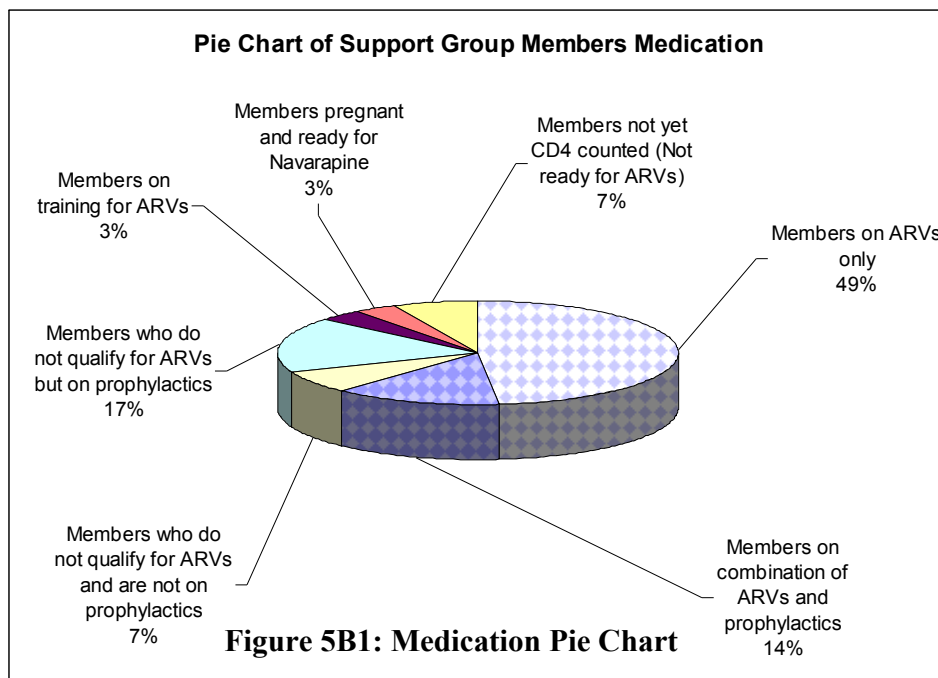
- This will help to make people aware that they did not die of witchcraft, as is normally suggested when one dies of AIDS.
- It is important to find out from the family if they agree with the preaching about HIV and AIDS
- The difficulty will be if family members did not know that their relative had been living with the disease. This is all the more reason why it is important for family members to be made aware that the person is positive, and to be helped to deal with it.
- The preaching should not be conducted, as some pastors do, as an excuse for an attack on people who are HIV-positive
- One of them said “We need to know that, at the funeral, we will not be there to be shamed or discriminated against - we will be dead”

Attendance at the Support Group kept growing week by week and by the end of 2006 it was clear that the group had built a good relationship with CCP staff and stakeholders, which is also evident at the monthly prayer meetings. Members freely gave testimonies about their status, the improvement in their lives and the positive effects of prayer on them as individuals. The 2006 World AIDS Day, with the theme: “*Stop AIDS; Keep the Promise – Accountability*” was celebrated with the Support Group aiming at helping the gathering to fight all forms of prejudice related to HIV and AIDS, to find ways of improving education through all known best practices and also to raise money for fighting this monstrous disease. In doing this the group honoured their promise to be accountable by declaring their HIV status together through singing and dancing. The gathering responded by promising to hold each other accountable before God, our creator and to bring “*A Future Hope*” for the many children and families infected and affected by HIV and AIDS.

The year 2006 ended with the Support Group having a register of 105 people who have attended at least one of the meetings of the group since it started. However, only 10 of these are men.

**2007:** The New Year began with the first meeting held on the 9<sup>th</sup> of January 2007. Only 14 people attended the meeting. Members looked at plans for the year ahead and agreed on ensuring that each member, in the course of the year, would have their CD4 counted and all those who qualify for ARVs would get them. At the next meeting, which saw 36 people in attendance, the researcher informed the Support Group that research on HIV and AIDS silence that has been going on in the past 3 years would be concluded in the coming months. It was agreed with the members to utilise the next few months to interview and administer questionnaires to a selection of members, their families, caregivers, children and others, as the need arose. The first Monthly Prayer meeting of the year was scheduled for 12<sup>th</sup> January 2007, with a not very impressive attendance, because of the holidays.

The Support Group meeting of the 6<sup>th</sup> February 2007 was used to assess the level to which members are heeding the call to seek ARVs or prophylactic medication. From the 29 members who attended the meeting, 18 (62%) were on ARVs and doing very well. Of these 18, four combined their ARVs with other prophylactic medications. 11 (38%) were not yet on ARVs for various reasons. Seven (24%) were not on ARVs because their CD4 counts were more than 200. Five (17%) whose CD4 counts were more than 200 are taking various prophylactic medications. One person was undergoing training to receive ARVs and one person, who was expecting a baby, had been provided with Nevarapine to take when in labour. Two people who had recently joined the group had not yet had their CD4 level assessed.



The meeting of the 20<sup>th</sup> March was very significant as members present saw the need to plan their own lives. The meeting was attended by 42 people, the highest number of people yet attending any meeting. Since the monthly prayer meeting of 2<sup>nd</sup> March, which was well attended, seven newcomers had joined the group. The register of the Support Group then stood at 114. Each of the 42 people present felt that they were doing very well physically and needed to do something that would bring in an income. A number of ideas were raised, including crafts, sewing and other handiwork. Some felt they should be trained to help with HIV and AIDS work in the churches and communities. This was welcomed by the CCP team, and plans were made to have those who had not done the wellness course to do so in May. Discussions were held on the results of the research on ARVs and members were happy that at last they need not be afraid of getting onto ARVs as there had been a lot of myths and confusion<sup>105</sup> around the medication in the past. The suggestion of doing this exercise quarterly came from group members, with the hope that it would encourage members, especially those who were new to the group, to take ARVs and other helpful medication,

<sup>105</sup> See News24. Antiretrovirals 'dramatic': South Africa: AIDS Focus: News24. [www.news24.com/News24/South\\_Africa/AIDS\\_Focus/0,,2-7-659\\_1843092,00.html](http://www.news24.com/News24/South_Africa/AIDS_Focus/0,,2-7-659_1843092,00.html); Adeyemi, Yinka. 2007. Anti-retroviral therapies for HIV and Aid in Africa: Using Advocacy to increase access and deepen impact. [www.uneca.org/mdgs/ARTforHIVinAfrica](http://www.uneca.org/mdgs/ARTforHIVinAfrica); Journ-AIDS: Factsheet - The Politics of HIV and AIDS in South Africa: "AZT Toxicity" (1999/2000). <http://www.journAIDS.org/politicsofhiv.php#azt-toxicity>

With winter approaching, the group dedicated April to look at and discuss how best to care for themselves and for each other. The group had taken stock of the past years and realised that winters have not been very good in terms of the health of the members. The researcher made arrangements with various members of the group, family members, and pastors etc. who agreed to be involved in interviews, questionnaires and focus group discussions. For the Support Group itself, it was agreed that the meeting of the 29<sup>th</sup> May 2007 will be devoted for answering the research questionnaire. Those present were all advised to invite others who were not there to come on that day to be part of the research.

The 29<sup>th</sup> of May 2007 was set aside for answering group-administered questionnaires. 29 members who attended the meeting had an opportunity to answer the questionnaire.<sup>106</sup> All 29 questionnaires were answered willingly by the Support Group and the results are considered in 5G1 below.

The Support Group spent most of the month of June pairing up with each other; those on different forms of treatment to coach and help others who were struggling with accessing or taking medications. This was a form of peer-to- peer assessment, through interviewing and counselling. The process gave members an opportunity to know how each one was doing in terms of their CD4 count, whether they receive grants, TB treatment, ARVs, or they are on prophylaxis. This, again, was to help the group meet each other's physical, educational, spiritual, psycho-social and emotional needs and to help them to begin thinking about initiating support for PLWHAs in their own communities. The national June/July strike by teachers derailed the plans to conclude the research with all the stakeholders of CCP during their community analysis week. The 26<sup>th</sup> June meeting was used to thank the Support Group members and the CCP team for their co-operation and contributions to the research. The researcher made it clear that he will continue to be part of the activities at CCP and the Support Group, although not on the same research, which had then been concluded. The research programme ended with the registry of the Support Group showing 120 people, including 15 men and an average weekly attendance of 40 PLWHAs.

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**106 See Appendix 5E**

## APPENDIX 5B2: CASE 2

### THE YOUNGEST OF THE SUPPORT GROUP (THULI) – 2004-2006 (Case 2)

#### LIFE AND STRUGGLES.

This case study follows up, chronologically, the history of the youngest member of the Support Group at the time it started. The study explores how, through the Support Group, this member dealt with the silence around HIV and AIDS in the midst of dimensions of culture.

**2004:** When the Support Group started on Thursday 13<sup>th</sup> May 2004, Thuli was the youngest among the women who gathered. She was 18 at the time, and had been a client of CCP since 11<sup>th</sup> February 2003, when one of CCP caregivers referred her from one of the



**PHOTO 1: Thuli at the time CCP met her**

townships of Pietermaritzburg. At 17 years of age, when the CCP team first met her, she was really ill, very emaciated and unable to walk. She lived in a mud house with her mother and two other sisters and the environment was hygienically appalling. With the help of the CCP team, through cleaning the house and offering regular food parcels, vitamins, infection control, clothing, and lots of love and prayer, Thuli improved a great deal within only three weeks and again able to walk. She started to walk first with crutches and, later on, unaided. Thuli, in her testimony during the first Support Group meeting, admitted that she was able to go back to school six weeks after interacting with CCP. She said that neighbours and family members had given up hope of her surviving.

Thuli was also a member of the Youth Group that CCP started earlier in the year. When she joined, her major problem was that of her peers knowing that she was a member of the Support Group. At this stage she had not gone for an HIV test and her understanding

was that she had been bewitched and needed the help of others who were as sick as she was.

Discussions in the Support Group began to have a positive effect on Thuli and she began



**PHOTO 2:Thuli abseiling**

to understand HIV and AIDS. The June/July 2004 school holiday was a big step for her when CCP began what they call “community analysis week”. During this week CCP invited the Youth Group to interact with CCP Caregivers and Staff. A number of activities were organised, through which HIV and AIDS education was done. Thuli had the opportunity on the 5<sup>th</sup> July 2004 to abseil on the wall of the old prison in Pietermaritzburg (where Project Gateway is situated) and she was amazed at the courage and strength she had gained since interacting with CCP.

On the weekend of the 6<sup>th</sup> – 8<sup>th</sup> July 2004 the Youth Group visited Sani Pass where they spent time discussing issues pertaining to culture, sexual health, and answering questions that were uppermost in the minds of the youth in relation to HIV and AIDS. It was during this time that Thuli brought to light that, amongst the young people, there is a belief that God has given people each part of their body to be used for certain purposes. They understand that God has given humanity sexual organs for sex and if one does not use them and they die, and God would question why their organs were not used. It was interesting that all the 20 teenagers who were there agreed to this theory. To them, this is one of the reasons why most young people are sexually active. Through theological discussion of human responsibility and doing things at the right time, as well as observing sexual health in the midst of HIV, the youth understood the need to delay sex.

At the beginning of August 2004, as a result of the Sani Pass discussions and the wellness training that took place in the Support Group, Thuli went for an HIV test and found that she was positive. This was a very difficult time for Thuli as she agreed that she had been

sexually active in the past and yet denied being HIV-positive. She was advised to repeat the test in November, whilst the CCP team worked with her to deal with her state of denial. The confirmatory test was done on the 10<sup>th</sup> of November 2004 and her status was confirmed as being positive. At this time a Support Group member who had been living with the disease for 10 years<sup>107</sup>, tried to help Thuli by relating her own struggles with the disease. The older lady revealed to Thuli how she was preparing herself to disclose her HIV status to her four daughters, girls who were Thuli's peers and were also part of the CCP Youth Group. This encounter between the two provided encouragement to Thuli and she accepted that HIV was a reality in her life.

On the 20<sup>th</sup> November 2004, three teenage boys raped Thuli's younger sister and Thuli reported the case to the police and the sister was rushed to a hospital for the administration of ARV and counselling. Thuli took it upon herself to encourage her sister to complete the four-week ARV course. The CCP team helped by removing the sister to a place of safety until the 15<sup>th</sup> December. During the time that she was there, the team continued to counsel her and assigned a specific CCP staff member as Family Worker for the family. The police investigation, which kept Thuli going to the police station to check on every now and then, had not yielded any results by the end of the year.

**2005:** On the 11<sup>th</sup> January 2005 Thuli's sister met one of the rapists, who threatened that they would rape her again and that they would attack Thuli for reporting them to the police. The police had still not apprehended any of the culprits but agreed that the victim's life was still in danger as she stays in the township, and so she was immediately returned to the place of safety.

On the 22<sup>nd</sup> February 2005 the police went to see Thuli and asked her show them the house where the suspects lived. When she showed the police, they went to the wrong house and found people dealing in drugs, who were then chased by the police. The drug dealers in the community somehow got to know that Thuli had directed the police to that house. Some of the drug dealers went to Thuli and threatened to kill her. They told her that they would kill her because had reported them to the police as drug dealers. That

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**107** She is referred to in this study as Mama Zulu.

same day, the alleged rape perpetrators confronted Thuli with physical threats and demanding that she dropped the case with the police. CCP, on learning about this, arranged for the immediate transfer of Thuli also, to the place of safety. This arrangement was helpful for the younger sister who at this stage was seen as a “special needs” child. She was observed as having significantly delayed learning and a low level of functioning. Interviews with her mother confirmed that she had failed to pass each school year since Grade 4. Her progress had however been condoned and so she was in Grade 8 when she got raped and had since been unable to attend school. An arrangement was made for her to be taken to the Natal Children’s Home for placement in a boarding school. In the midst of all this, Thuli continued to attend the Support Group and started taking care of herself and attending school from the place of safety, with CCP paying for her transport.

During the monthly prayer meeting of the 4<sup>th</sup> of March 2005, through preaching by the researcher, Thuli and four members of the Support Group gave their lives to the Lord. She realised that, with so much happening in her life, she needed God and the church to be there for her, and she immediately started membership lessons in the church that she has been attending. It was remarkable that everyone in CCP began to see dramatic improvements in the life of Thuli, despite her being HIV-positive, her sister raped and rapists and drug dealers threatening to kill her. The only worrying news that affected Thuli badly was the passing away of Mama Zulu on the 29<sup>th</sup> March 2005. Mama Zulu had become a good friend and helper to Thuli four months previously, when she was struggling to accept her HIV status. The funeral took place on Saturday, 2<sup>nd</sup> April 2005 and on this day, Thuli was unafraid to sing with both the Support Group and the Youth Group.

The prayer meeting on the 6<sup>th</sup> of May 2005 was the day that Thuli showed how she had made more steps towards breaking the HIV and AIDS silence. After hearing the sermon on the topic: "What do you want me to do for you", from Luke 18:35-43, Thuli became the first ever PWLHA member to respond openly to the call to be prayed for, for being HIV-positive. The researcher who was preaching felt it was time to let people know that the gathering was intended for praying for HIV and AIDS, and not just for the sick as has

been done in the past. And so, when he asked for the reasons for the prayer meeting, Thuli responded that it was to pray for those who are HIV-positive and went forward to admit her status and her need for prayers. Her action encouraged two other Support Group members to come forward and break their HIV silence openly before the gathering of about 120 community members. From that day the nature of the prayer meeting changed from praying generally for the sick to praying specifically for people who are HIV-positive.

Thuli, after finishing her membership lessons, was baptised in her church on the 29<sup>th</sup> May 2005. This brought her family members to the church to witness the baptism. The Youth Group as well as the Support Group members were there to support Thuli. Being the end of May, CCP had to make an arrangement to extend Thuli's stay at the place of safety since the original arrangement was for three months only but the threat to her life was still present. The CCP nurse prescribed *Sutherlandia*, an immune booster, for Thuli, in order to keep her going.

The June/July holiday was the time for the second CCP community analysis week. Within the theme of breaking the HIV and AIDS silence, Thuli, together with another young woman who had recently given birth to a baby and then discovered her HIV status, had an opportunity to disclose their status to the Youth Group. This disclosure led to a deeper discussion among the youth on relationships and HIV and AIDS. The other young woman shared, from her own experience, that teenagers should not involve themselves in serious relationships while they are young and still at school. Thuli made it clear to her peers that they should not close their eyes to the fact that HIV and AIDS is real. It was joy to Thuli that on the 1<sup>st</sup> July 2005, which was the last day of the Analysis Week and prayer and celebration day, she had an opportunity to use the video camera to film the procedure. This was a dream come true for Thuli as she had long desired to be a film maker.

In August of that year, one of the alleged rape perpetrators was arrested and the court proceedings were initiated. By the end of August Thuli felt it was time to go back to the community, no matter what happened to her. When she moved back to the family home things started to go wrong. Her attendance at the Support Group, Youth Group and

Church began to decline. A visit to the family home revealed that sometimes she did not sleep at home, and an older sister suspected that Thuli had a boyfriend. The CCP team tried a number of times to get her to come to the meetings but she would decline the invitations.

On the 13<sup>th</sup> of September 2005, Thuli's sent a message to say that Thuli was very sick. The CCP staff member responsible for that family helped to take her to the government hospital, where a request was made for her to be CD4 counted. Her CD4 was 300 and her mother complained that she was not taking her medication regularly. Thuli could not attend the latter part of the school term and only returned to school in October, the final term. The researcher had an opportunity to have a discussion with Thuli, who admitted to not taking her medication regularly. She also pointed out that she had to discipline herself so much in the place of safety, and since she came back to the community she had been influenced by friends at school, which had affected her lifestyle and health. She promised to put things right and to attend all the meetings that she knew were good for her life.

Thuli's health again improved and she again began to attend the Support Group meetings, Youth meetings and church. Things again came to standstill during the Christmas holidays. Attendance at meetings stopped once more and when anyone visited her home she would not be there.

**2006:** Thuli's life had changed in the sense that the only place one could see her was at school. The first Support Group meeting she attended was on the 8<sup>th</sup> of March 2006. She was surprised to see how the group had grown in terms of numbers. She realised that people in the group were concerned about their own lives and what the future had in store for them. Discussions around marriage and family life, lifestyle and healthy living as well as future careers made her realise that she had been misled in following her peers at school instead of attending these meetings which could improve her life. She told the CCP family worker responsible for her family that she had begun to have diarrhoea and was advised to see the doctor. At the following meeting it was clear that Thuli was losing weight. She was admitted to a government hospital on the 10<sup>th</sup> April 2006, and a visit to her home revealed that it would not be hygienically advisable for her to stay there after

she was discharged. The CCP nurse responsible for the Support Group discussed with Thuli's mother and elder sister of her being taken to a nearby Drop In Centre when she was discharged from the hospital, and they agreed. Thuli spent almost a month at the Drop In Centre before she recovered. Once again it emerged from the Drop In Centre that Thuli was not compliant to medication.

After some time Thuli managed to attend the Support Group meeting on the 13<sup>th</sup> June 2006. She came to the researcher's office and asked whether she could discuss with him some difficulties she was experiencing. She felt that she was losing her strength and needed prayer and advice. She pointed out the fact that she had been misled many times by her peers, into "hanging out" with them and not concentrating on her own health. She said that she did not want become as ill as she was when CCP found her in 2003, and when she had almost died. In a moving way, she told the researcher that she had made a great many mistakes and if she improved again she would let young people and her community know about the seriousness of HIV. Should she die and not have the opportunity to do this before then, she asked that the CCP, through her funeral, inform people on the dangers of HIV.

The researcher enquired from Thuli whether she had informed her family about her status and she said that she had not done so. The reason why she had not disclosed her status to her mother was because she did not want her to faint, since she had high blood pressure and a heart condition. As for her elder sister, Thuli felt that she was not helpful and did not understand HIV and would only make mockery of her if she was told. She could only tell her if she was educated on HIV. For her younger sister, Thuli felt that this would be difficult for her, while she was recovering from her rape crisis and doing well at her Special School. The researcher asked whether Thuli would like the CCP team to help her disclose her status to the family, and she agreed. The suggestion was to do this the following day. The elder sister was only to be told when Thuli was well enough to begin her ARV training so that her sister could become her treatment buddy<sup>108</sup>. Thuli was

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**108 A treatment buddy is a friend or family member that helps support an individual to comply fully with his or her ARV regimen. To ensure adherence to ARVs and complete commitment from PLWHAs, who are expected to take full responsibility for their own health and wellbeing, clinics and health worker rolling out ARVs makes sure that every patient has a "treatment buddy". The buddy**

happy with this idea and confessed that her sister's help would be appreciated because she kept forgetting to take her medication, especially whenever she feeling well and happy. She explained that one of the main reasons that she came to see the researcher was on the issue of compliance to medication that they had once discussed at the Support Group, and which she accepted as being her major shortcoming.

On Wednesday 14<sup>th</sup> June 2006, the researcher went with the CCP Staff worker to visit Thuli's family, and another young male CCP staff member accompanied them to help Thuli disclose her HIV status to her mother. When the researcher and team went to Thuli's home at 3.00 p.m. she was alone with her mother, who was sitting on a mat on the floor while Thuli was lying on a bed. Because of her weight, the mother could only walk with the help of crutches. She welcomed the team, hoping that they had come with food parcels as they had done a number of times. Thuli, somewhat in pain, got up from the bed and brought a small bench for the three visitors to sit on. The researcher began the discussions, with the CCP lady as interpreter. He said that the team was concerned about the health of Thuli. The mother replied that she was equally concerned that her daughter had not been herself lately and was losing a lot of weight. The researcher asked if the mother knew what the problem was with her daughter and she said she suspected that it could be a recurrence of the TB she had three years earlier, when she had almost died. Asked whether she knew of any other diseases that make people lose weight, the mother said they were mostly spiritual diseases, AIDS and bewitchment.

With this answer, the researcher asked if the mother knew what AIDS is and she responded that it is a young people's disease that make them slim and, like T.B., if you have it you need to be on medication for a long time. The researcher then told her that the CCP team had found out from the doctors that AIDS was the disease that her daughter had and that she would need her mother's support. The mother then shook her head and said that she had been thinking about that but when she asked the daughter to go to a doctor to find out what was really wrong with her, she keeps postponing the visit. At this point the daughter said that she had been afraid to tell her mother that she was HIV-

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**attends ARV training with the patient. (See [Http://bbg.org.za/newsletters/24/BGH-HAART.htm](http://bbg.org.za/newsletters/24/BGH-HAART.htm) and Zuber, Deghaye, and Pawinski (2005))**

positive because of her mother's ill health. The CCP team then explained more about the disease to the mother, in Zulu, and gave her the assurance that they would be there for them as a family.

The researcher asked the mother how she was feeling and she replied that she was very relieved to know what was wrong with her daughter. She then added that her daughter was not good at taking her pills regularly. She was also concerned about Thuli's relationship with her elder sister, and felt if they had a better talking relationship, the older daughter could help her sick sister to take her medication. The two CCP team members agreed to work with the older sister to restore their relationship so that Thuli would be able to disclose her status to her sister.

The two CCP team members made appointments with Thuli's elder sister and explained the situation to her, explaining HIV and AIDS clearly and in a way that made her admit that she did not know about the disease. She was prepared to help her sister in any way possible, especially by becoming a buddy for her to receive ARV. Thuli had to be sent to the clinic once or twice every week. Even though her CD4 count was now below 200, she could not be put onto ARVs until she had gone through the training with her sister.

Thuli's condition kept worsening as she spent most of the month of July 2006 in and out of the government hospital and the clinic. On the 31<sup>st</sup> of July 2006, the researcher met with the entire CCP staff, to examine Thuli's situation. Most of the team felt that she had been helped by CCP, the Support Group and the Church. The problem was that she had not been helping herself, and they raised the following concerns:

- She has been in denial and doesn't accept she's really ill.
- Has been sick and got better too many times and so takes her health for granted.
- Does not realise how sick she is.
- She has often been stubborn and difficult.
- The mother is concerned that when she reminds Thuli to take her medicines she does not do so.

- She takes her mother's concern for granted. We need to talk to her mother about the seriousness of Thuli's situation and to encourage her.
- The mother cannot look after Thuli and we have a 2- week rota to visit her and provide care for her. All of us are involved.
- We need to get K and D<sup>109</sup> and other people in the Support Group to talk to her about the seriousness of her illness and taking her medication
- Proper care and a clean environment is needed for her outside of the hospital and her home, as it is now, cannot provide that.
- We need to go and clean her room and the house and let it become a Drop In Centre where for two weeks we visit her to feed her and administer her medication. This will show her mother and family what to do.
- The whole household needs to be empowered
- Thuli needs to be weighed once a week
- Thuli needs to see that there is a future.
- We need to encourage the youth to visit her and give her hope.
- We need to provide spiritual support through prayer and Bible-reading, both for her and the family, at this time.

The CCP team immediately began to implement the suggestions put forward in the 31<sup>st</sup> July meeting. On the 7<sup>th</sup> August 2006 we realised that Thuli's health was deteriorating very rapidly and she was rushed to the government hospital. She was discharged on the 10<sup>th</sup> of August 2006, with a prescription<sup>110</sup> for Home-Based Care. CCP staff visited Thuli in turns, feeding her and ensuring that her medication was taken and helping the mother and sister to observe. On the 21<sup>st</sup> of August, there was some improvement in Thuli's health and her sister was sufficiently confident to administer the medication to her.

On the 24<sup>th</sup> of August 2006, the researcher and a CCP staff member went to visit Thuli in the mid-morning and found that neither she nor her mother were in the house. This was unusual because, if they wanted to go to the clinic, they would usually call on CCP for

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**109 K and D are the first letters of two Support Group ladies who are close to Thuli and can talk to her.**

**110 In a meeting with Doctors at the Government Hospital, they pointed out that Home-Based Care are prescribed to patients if they realized that they the hospital can do little for.**

help. The other children in the house said that the two had left very early in the morning. As the two CCP staff members were leaving the house and were about to enter the main street, they saw Thuli and her mother getting out of a public taxi. The two men turned and offered them a lift home, carrying a container of water and herbs. The researcher asked Thuli where they had been and, with fear in her eyes, she said they had gone to see a traditional doctor. She was instructed to drink certain ‘Muti’ and had brought some home. The two staff members explained the danger of drinking medication that is not hygienically prepared, and told them that even the containers were not clean enough to hold drinking water. A request was made on the 28 August 2006 to one of the clinics for Thuli to be put on urgent ARV training, with her sister as “buddy”.

On the 4<sup>th</sup> of September 2006 Thuli was very ill and was rushed to a different government hospital. The CCP staff visited her in turns at the hospital. She became worse as the days went by. On the morning of the 6<sup>th</sup> September, the researcher went to visit with five other CCP staff and Thuli beckoned him to listen to what she had to say. He held her hand and listened, but nothing she said made sense. They prayed for her and left. It was reported by the nurses on duty that she had died an hour later. This news was devastating to the CCP staff, and led to an extremely difficult time for the staff team and the wider family. Thuli was instrumental in many CCP developments, including the youth programme and the HIV Support Group. One could see that amongst the team members there was a feeling of helplessness and disillusion.

The funeral and burial for Thuli took place on the 9<sup>th</sup> September 2006. The staff of CCP and the various other groups contributed towards a well-organised and -attended funeral. As was personally requested by Thuli, the researcher conducted the funeral and preached a message on HIV, pointing out the need for people to help others who are infected (*see*: Appendix 5B4). Through this sermon people were made aware that Thuli was HIV-positive but that she was open about the disease.

In the meeting with the CCP staff members and a visiting volunteer couple from the U.K., on the 11<sup>th</sup> September 2006, the researcher asked for feedback about Thuli’s funeral. Staff members gave the following responses and comments:

- The message was relevant to the HIV and AIDS situation in our communities
- The funeral was a time of celebration.
- The team was impressed with the youth and how they stood with their colleague in death.
- It was obvious that CCP loved this Thuli and I would want my funeral to be that way if I die in Africa (a reflection by the visitor from England who was present at the funeral)
- Even though the message was intended to help break the silence and stigma that surrounds HIV and AIDS, the team wondered how the family felt (Need for follow-up on this was noted).
- Because the family was poor, there was not much support from the community itself but the CCP contribution showed love and recognition of the image of God in them as a family.
- This funeral has opened a way for us to be open about HIV. Because Thuli was open about her status, it gave us the strength and courage to speak boldly about HIV at the funeral.
- It was good that more time was given to the word of God to encourage people.
- The funeral showed the good relationship within members of CCP
- The major support that the family had was CCP and this was clear to the community.
- It is interesting to note that there were 10 different burials taking place at the same time at the cemetery, even though both on our way to the graveyard and on our return to the city, we bypassed a number of funeral parlour staff members who either had finished burying people or were on their way to bury people
- It was interesting to see that there were people doing business at the graveyard, selling drinks and ice blocks.
- Opposite Thuli's grave was a grave with the script, "Unknown, Ward C bed 23 Edendale hospital on 4<sup>th</sup> September 2006". The caretaker at the grave-yard indicated that the silence around HIV and AIDS has gone as far as people not collecting bodies of those who die from AIDS, and they are therefore being given paupers burials. The number of such burials keeps increasing.

- It was observed that people do not waste time at the graveyard. Unlike the olden days when people spent time mourning for the dead, there is no service or ritual at the actual graveyard. Immediately bodies arrive, they are placed into the graves. Some churches perform the rituals on the way to the grave-yard as they bring the body for burial.
- The funeral honoured Thuli, for being brave and open about her status.
- We hope the message will help the family and community to understand HIV and change their attitudes.
- This is the first time we have seen the message of HIV preached with conviction at a funeral, and at a level that people understand.
- Thuli's aunt was very happy about the support from CCP; she particularly mentioned the donated clothes and food, and then the taking of Thuli to hospital when she was sick. She said she needed to say a lot more but could not express herself.
- A neighbour who spoke at the funeral thanked CCP for the support that was given to the bereaved family. She mentioned that they are a small community, but because of the support from Bethany House, they saw the community as one that changed to being a large community. She had never thought that Thuli's funeral could be so big because they are a small community and she had never thought that there could be White people at the funeral. That was strange to them. She told all Thuli's sisters, especially the older sister that they should repent and release her heart to the Lord, as things happened the way they did because Thuli gave her heart to the Lord.
- All of the mourners were surprised to see Whites, Coloureds, Indians and Blacks in the funeral in the Township. Even people passing in taxis were surprised.
- In a taxi that was boarded at Thuli's house, the passengers were talking and inquiring about how a rich person could die in a poor home. Some said the size of the funeral indicated the death of a rich person, but they did not know any rich person in that family. Or perhaps, they guessed, the person's home was in another province but did not support the family whilst alive. Still others in the taxi said it could be a nurse, or teacher or a Social Worker because they saw many Whites attending the funeral.

### **AFTER THE FUNERAL**

A relationship has been built with Thuli's family and that has not stopped because Thuli is no more. The only difference is that the relationship has changed from intervening in an HIV infected person's life to supporting an HIV-affected family. The mother was offered bereavement counselling to help her deal with the loss. More education was given to everyone in the family, especially the sisters. The issue of the rape was followed up but in early 2007, the judge dismissed the case as the younger sister began to contradict herself in court. Thuli's mother is being assisted to access a disability grant from the government. The younger sister is still part of the CCP Youth Group and visits CCP for counselling and advice.

## **APPENDIX 5B3: CASE 3**

### **THE SUPPORT GROUP MEMBER LIVING LONGEST WITH THE VIRUS AND FAMILY (MAMA ZULU<sup>111</sup>) 2004-2005 (Case 3)**

#### **BACKGROUND INFORMATION**

This case study looks at whether or not the various interventions of CCP with Mama Zulu and her family helped her to deal with her silence around HIV and AIDS in the midst of the dimensions of culture. Within the period of interaction, the case study follows various areas of Mama Zulu's life, not necessarily in chronological order. Mama Zulu was 48-years-old when the Support Group started in May 2004. She had by that time been living with HIV for 10 years. She was one of the very few clients of CCP who disclosed her status to certain staff members. Mama Zulu, with her 10 children, had been on the CCP programme for a little more than a year before the establishment of the Support Group. The five youngest children in particular, ranging from the ages of 9 to 18, mostly received interventions from the CCP programme. The four teenagers are all girls. In terms of Mama Zulu's care and diagnosis she also had multiple other health issues, some real and others psychosomatic, but generally she was in good health. She always appeared to be ill, in the sense of being very wasted and having a constant cough.

Besides the Support Group and CCP, Mama Zulu had a good support base in her church. Because of her health, she did not regularly attend the Support Group, but whenever she was there, all were conscious of her presence as she engaged and interacted with other members to find out how each one of them was doing. Mama Zulu had a heart for the people in the community and so would distribute food donated by the bread factory near where she lived. Sometimes she would also carry some of the foods for the Support Group members.

#### **CHILDCARE**

As CCP became involved in Mama Zulu's life, she would bring out various issues pertaining to her children's lives, so that her own life and needs often came as a

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**111 Mama Zulu is not the real name of this respondent. It is name coined for her to protect her identity as the member of the group living longest with HIV.**

secondary concern. Because of this, CCP involved four of her teenaged children in the Youth Group, and were part of the Group which, in the 2004 Analysis Week, staged a drama and sang during the Friday Prayer meeting on the 9<sup>th</sup> of July 2004. Though Mama Zulu was involved in the Support Group, she had not told any of them about her HIV status. As the researcher and the team interacted with all the children, they suspected that the older children knew about their mother's condition and, because of their own sexual experience, viewed CCP as a threat. One of older children clearly made the team's visit to the family difficult in terms of the comments she made and accusations levelled against the team. However, as relationships were built between the CCP team and the family, it became clear to the team in September 2004 that Mama Zulu's older daughter was pregnant with twins and needed help.

As interaction with the pregnant daughter continued, it became evident that she should have an HIV test. Pre-test counselling was offered to this daughter, to the exclusion of the other family members. Her test proved her to be HIV-positive.

By October 2004, one could see that Mama Zulu's health was deteriorating and that ARVs were needed to help her. Her youngest a boy also concerned the team at this stage. Mama Zulu would complain about his multiple health issues, a bad heart, asthma, and deafness, and as a result she kept him close to herself and not allowing him to go to school.

During a visit on Friday 12<sup>th</sup> November 2004, Mama Zulu complained bitterly about having a hard time at home with the teenagers as they were growing up and not helping their mother in the way she wanted them to. She was also becoming increasingly ill, and she felt the children needed to know what was wrong with her.

Mama Zulu described how the Support Group discussions on disclosure had made her aware that her family, especially the younger ones, needed to know the truth. Also, in helping Thuli to accept her HIV status, she became more aware that her teenage girls could be as sexually active as Thuli and that she might have a lesson to teach them before it was too late. Her biggest problem was that as her four girls were part of the CCP Youth

Group, and learning about the HIV and AIDS, it would be in the family's best interest for them to know that it was HIV that was causing her illness, rather than having them discovering it for themselves and confronting her. After all, the four girls were part of the Youth and knew very well that CCP is an HIV project. Yet the disease was not discussed in their family context. The researcher and the team agreed that the social worker who had been working closely with Mama Zulu through other difficult situations, and who had an excellent relationship her, based more on respect than on a professional client/worker relationship, should facilitate helping her to disclose her status to the five younger children.

The social worker visited Mama Zulu on Monday 15<sup>th</sup> November 2004 to discuss the issue of disclosure to the children. Mama Zulu requested they do it that evening, and asked the social worker to tell her girls about her positive HIV status. She wanted to be in the room but wanted him to tell the girls. She further requested that the CCP youth worker whom the girls also knew very well to be there as well. When the social worker reported to the researcher later, he concluded: "Quite strange, really, to have two men talking to four teenage girls about their mothers HIV-positive status".

### **THE DISCLOSURE – BREAKING THE SILENCE**

Below is the account which the social worker gave on the disclosure event:

When we went it was hot and sunny and we were in the house at about 3 p.m. after the girls had come from school. The youngest boy aged nine was encouraged to play outside whilst we were inside. I sat in the corner next to Mama Zulu, who was lying on the sofa with a hat on and a blanket, as she was feeling cold and not too well. I discussed the role of family with the view to helping each child avoid conflicts about tasks. We then looked at school photos as Mama Zulu was so proud of her children and how well they were all doing. She really had a great work ethic which her children have really adopted.

I started by talking about Mama Zulu's other health issues and how real they were in terms of the surgery she had etc. I spoke about the work I do and

how we had been together working for a while now. I discussed my relationship with Mama Zulu and how all the children had been helped through CCP. I said that Mama Zulu wanted them to know something very important to her so that her children, now almost adults, knew the truth. By this time Mama Zulu was calm but the youngest girl aged 12 put her hands into her face and started crying. Then I said that mum has been HIV-positive for over 11 years and that she knew about her status. She wanted her children to know as well so that they would be patient with her when she was either sick or tired.

All the girls responded in tears but none left their seats and all turned away from each other. I turned to Mama Zulu who was sitting up in the chair, grinning from ear to ear with a huge smile. She looked five inches taller and her face was 10 years younger. None of the kids had any questions but I began by looking at the way forward; what would happen and how we all needed to work for the future.

Mama Zulu then stood up and began to sing a Zulu worship song and she came into the middle of the room. The CCP youth worker and I joined her to sing and give God the Glory. One by one the four teenage girls joined us, all crying but all singing. We all joined arms and hugged as we sang and prayed. We then left them alone.

On Saturday, the next day, the researcher, the social worker and the CCP youth worker went back to the family to give them some encouragement. We made them aware of the fact that what had happened the previous day was an important step in facing the future together with their mother, who for 11 years had walked a lonely journey with a disease that is difficult to manage. In an unexpected way, the 19-year-old daughter said they were sorry that she had to carry that burden alone but that now they were all there for her. The rest of them joined in and assured Mama Zulu of what each one of them would do to make life easier for her. The visitors

also assured all of them that CCP would continue to help, and if any of them wanted to talk, CCP team would be available to be with them at any time.

### **FACING THE FUTURE TOGETHER AND NOT ALONE**

The youngest girl, aged 13, is racially categorised as ‘Coloured’ and had always been teased in the community for not looking like the others. Two weeks after the disclosure, she tried to take her life as she felt she could not cope with her mother’s illness and possible death. The researcher arranged for counselling sessions for her and the counsellor later reported that “Although this girl never said it to me or to the others, I really feel that she felt that her conception was the introduction of the virus to her mother”.

As the days went by, and with the support from CCP, the children began to respond positively to the situation. The Social Worker tried to get the children involved in Youth Group activities during the Christmas holidays through CCP programme.

Shortly after Christmas, Mama Zulu’s condition worsened. During this time her older daughter gave birth to twins but only one survived, as it was a premature birth. Mama Zulu informed the CCP Social Worker that she wanted assistance in making a will and a plan for her children, as she saw her condition to be deteriorating. The CCP team approached the clinic to enrol Mama Zulu for ARV training, with one of her older daughters as “buddy”. The training was arranged to start in the 3<sup>rd</sup> week of January 2005, once a week for four weeks.

On the 10<sup>th</sup> of January 2005, two social workers from the CCP team met with other people involved in Mama Zulu’s family: a White Pastor and his wife from the church she attended, an Indian long-time friend and an old lady from a suburb of Pietermaritzburg, who supports Mama Zulu’s family financially. A similar meeting was organised the following week, in the presence of the children. After attending the 2<sup>nd</sup> training for ARV Mama Zulu became very ill and was unable to attend the third session. Her CD4 count on the 1<sup>st</sup> of February was 10. With her teenagers at school and the older daughter struggling with her own health after delivery, it was arranged for Mama Zulu to be sent to a Hospice

on the 7<sup>th</sup> February 2005. The five youngest children were distributed between two of Mama Zulu's daughters, whom she had identified in her will as being responsible for the younger ones, should she die.

The CCP team motivated for Mama Zulu to be given emergency ARV treatment, especially as CCP had worked with her for more than two years and she had been reliable and compliant in taking prophylactic medication. Through her church she also had a good network of support in her community, and children and other key people who were already supporting her as "buddies". These reasons were acceptable to the Communicable Disease Centre (CDC) clinic for her to be on ARV, in view of the fact that she had already gone through half of the training programme. The only snag at this time was her health. Mama Zulu's health was deteriorating very fast as she had oral and oesophageal thrush, for which she was taking medication. The medication made her lose her appetite and she had sore throat that made it difficult to swallow food, so that she was wasting away even though she remained mobile.

During her stay at the Hospice, which was almost a month, CCP made arrangements for Mama Zulu to do memory work with her younger children. This process helped the children begin to come to terms with the situation they were facing. It was a joy for Mama Zulu to know that she was not alone but had strong support and understanding from her own children.

On Monday 28 February 2005, the Hospice realised that Mama Zulu's condition was serious and so transferred her to the government hospital.

### **MAMA ZULU'S PASSING**

Mama Zulu spent her last month on earth at the government hospital, with difficulty. She was initially discharged with a prescription<sup>112</sup> for Home-Based Care. But the CCP social

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**112 In a meeting with the CCP social worker and one of the senior doctors he knew at the government hospital over the issue, the doctor concurred that prescription for Home-Based Care was merely a script to patients for them to go home and die, as assessing ARVs at this time was very difficult. This situation led to CCP's involvement with this doctor at the government's hospital to channel patients for CCP's family/community based HIV interventions.**

worker contested this, pointing out that the CCP had been providing Home-Based Care for Mama Zulu for a long while and that she now required hospital care. This was an emotional time for everyone as Mama Zulu kept telling people that she would be leaving. The CCP team had to make plans to support the family financially and emotionally. Though the Memory Box work, to a large extent, helped the children to come to terms with the situation, both Mama Zulu and the children needed to be helped to unpack situations as they arose. For this reason the researcher and the CCP team, comprised of the two social workers and the youth worker, had a meeting with the four girls on Tuesday the 8<sup>th</sup> March 2005, to prepare them to accept that their mother might pass away, and to anticipate plans for their future. Behind this move was the request by Mama Zulu that her children sing and dance for her before her passed away. This the children gladly agreed to, except the youngest daughter who said she could not do it.



**PHOTO 3: Daughters of Mama Zulu singing and dancing for her**

The CCP team arranged with the government hospital's administration for this special event to take place on March 10<sup>th</sup> 2005 at 3.00 p.m. in the hospital ward where Mama Zulu lay. This was done amidst friends of the

teenagers, some Youth Group members, Support Group members and CCP staff, in all totalling over 30 people. Some of the hospital beds were removed, with the full agreement of the other patients in the ward. With the music playing very softly, the girls started to move gracefully together in harmony, celebrating the life of their mother. Mama Zulu, weak as she was, cried, but not through sadness but with tears of joy and hope for her children.

From that day, CCP assisted the Children in visiting their mother at the government hospital.

On Sunday 27<sup>th</sup> March 2005 in the morning, Mama Zulu requested her youngest daughter to visit her before going to church. At the same time she requested the researcher to come and pray with her. The researcher, a CCP Youth Worker and the youngest daughter went to see Mama Zulu. When she saw her daughter, though she was weak and frail, she smiled and commented on the beauty of the blue dress that her daughter was wearing.

When the Youth Worker left with the daughter, the researcher prayed with Mama Zulu. An hour later Mama Zulu went to be with the Lord. The young daughter has cherished that final moment with her mother and has kept that blue dress in her memory box as a wonderful memento.



**PHOTO 4: Researcher praying for Mama Zulu before she passed away**

### **THE FUNERAL**

The burial of Mama Zulu took place at her home village, about 40 kilometres away from Pietermaritzburg. The event was attended by the Youth Group, the Support Group, members of the church that Mama Zulu used to attend and CCP staff. At the funeral, once again, the daughters seized the opportunity to sing and dance for their mother for the last time. Mama Zulu was buried at her family home and not in the public cemetery.

On the night following the burial, one of the elders of the family, an uncle of Mama Zulu, organised with certain people that her body be exhumed for certain rituals to be performed, because she had a Coloured child. This, all the daughters stood together and

opposed. They were thankful that the Coloured daughter was not present when this took place as she had often been upset by issues of discrimination and racism.

### **LIFE AFTER THE FUNERAL**

After the funeral the CCP helped the younger children to be absorbed into the older children's homes. Unfortunately the girls, whilst staying with their older siblings, witnessed them being involved in many sexual relationships. With their knowledge of HIV through the CCP, and their own mother's situation and death, it was difficult for them to continue with the arrangement of living with the older siblings. The sister who had given birth to twins, lost the other one and died six months after her mother. She died keeping her sickness silent from the rest of the family. The remaining younger girls felt they would be better off in a home. The CCP social workers managed to help them into a children's home and they are doing very well. The eldest of the teenagers decided to go her own way and now has a 1 ½ year old baby boy. CCP helped her with VCT and she tested negative to HIV. The boy is in school, though at the age of 11 he is in grade 4. The youngest girl, after a long struggle to accept her mother's death, was helped to deal with shock, anger, denial, confusion and fear, and she is now doing well in grade 10. The other two girls will complete grade 12 at the end of the year (2007). One has applied to the University and the other has been accepted into a Fashion School, to start in 2008, meaning that she can stay on in the home and receive a foster care grant as she will be engaged in full-time education.

## **APPENDIX 5B4: THULI'S FUNERAL SERMON**

### **The Lord Welcomes His Own Home**

Ps 116:15 – Precious in the sight of the LORD is the death of his saints.

Death is one appointment that we all have with our creator; an appointment that we cannot postpone to a later date.

Hebrews 9: 27 – “It is appointed unto men once to die, but after this the judgment:

Normally when you have an appointment with someone and something else crops up, you just send a message to the other person to say “I am sorry I am sick and I cannot make the appointment” and that is it. You don't wait for the other person to say “No, you have to come” – you decide I cannot make it and you cancel it. BUT FOR DEATH IT IS AN APPOINTMENT WITH YOUR CREATOR, THAT YOU CANNOT CANCEL WITHOUT HIS APPROVAL.

#### **HE IS THE ONE WHO HAS THE POWER TO POSTPONE**

II Kings 20:1-6 – In those days Hezekiah became ill and was at the point of death. The prophet Isaiah son of Amoz went to him and said, "This is what the LORD says: Put your house in order, because you are going to die; you will not recover." v. 2: Hezekiah turned his face to the wall and prayed to the LORD, v. 3: "Remember, O LORD, how I have walked before you faithfully and with wholehearted devotion and have done what is good in your eyes." And Hezekiah wept bitterly. v. 4: Before Isaiah had left the middle court, the word of the LORD came to him: v. 5: "Go back and tell Hezekiah, the leader of my people, 'This is what the LORD, the God of your father David, says: I have heard your prayer and seen your tears; I will heal you. On the third day from now you will go up to the temple of the LORD. v. 6: I will add fifteen years to your life. And I will deliver you and this city from the hand of the king of Assyria. I will defend this city for my sake and for the sake of my servant David.'"

**DEATH COMES WHEN WE LEAST EXPECT IT, AND ARE LEAST PREPARED FOR IT.** But it is an appointment with GOD our Creator to give an account of our lives.

**BUT THE TRUTH IS THAT IF WE PLACE OUR LIVES IN THE HANDS OF GOD, THEN WHEN WE DIE IT IS PRECIOUS TO GOD BECAUSE HE WILL WELCOME US HOME -** Precious in the sight of the LORD is the death of his saints

**DEATH COMES IN MANY WAYS – MURDERS, SUICIDES, DROWNINGS, ABUSES, DIFFERENT SICKNESS AND LACK OF CARE FOR HUMANKIND.**

**ONE OF THE MAJOR CAUSES OF DEATH IN OUR LAND TODAY IS THROUGH A MONSTER CALLED HIV OR AIDS.**

This is the disease that has taken our sister away from us and she was not afraid to talk about and it was her wish that everyone gets to know about the disease and helps others who may have it. Through this disease, THULI has touched and changed many lives.

EMAIL FROM NEIL:

Benson,

This is sad news regarding sister Thuli. She was talked about many times after my return to Guernsey, and indeed her picture and story has influenced many, not least in Guernsey. She has touched the hearts of many, internationally, through her courage. Please pass on my condolences to all who will be at the funeral. She was a real heroine.

Neil

THIS IS A DISEASE THAT WE HAVE MADE TO BE A MONSTER THAT IS TAKING MANY PEOPLE AWAY. But the President of UGANA, President Museveni, the one President in the whole world who has shown leadership in the fight against HIV and AIDS, says “This disease is one that is very considerate”.

- It is disease that can be transmitted through blood and fluids inside our bodies and not outside the body or through the air. It is not like flu that you can catch because somebody sneezed or coughed.
- It is one disease that when you have it, you can be active for 10 or more years

THE PROBLEM IS THAT WE IN AFRICA IN PARTICULAR HAVE MADE IT A MONSTER AND A BIG KILLER BY KEEPING SILENT ABOUT IT.

We think we know about the disease and yet we know nothing; we do not take the time to learn and teach our family members about the disease.

THE BIBLE IN HOSEA,

Hosea 4:6a “My people are destroyed from lack of knowledge”.

Many people don't know about the disease. Some don't want to hear about it. BUT WE ARE LOSING A LOT OF PEOPLE. WE ARE LOSING THOSE WHO ARE SUPPOSED TO TAKE CARE OF US WHEN WE ARE OLD.

About five years ago I attended a funeral somewhere in Taylors Halt, and one Old Mama was crying and I said to her it is OK. She said “My son, it is not OK when all the young people who are suppose to be burying me are dying. Who will bury me when I die?”

WE HAVE GIVEN IT DIFFERENT NAMES AND LOOK DOWN ON PEOPLE WHO HAVE THE DISEASE SO THAT WE CAN KEEP AWAY FROM HELPING PEOPLE.

IF SOMEONE HAS THE DISEASE, WE CONSIDER THAT ONE TO BE EVIL. But most people have different diseases, some of which are very dangerous. Today in Tugela Ferry, there is a kind of TB where it has been found that once you become victim to it, you will die within 30 days.

IN THE MAIL AND GUARDIAN NEWSPAPER

“A particularly drug-resistant tuberculosis discovered in eastern South Africa is likely to have spread beyond the rural area where 52 of the 53 people first diagnosed with the new strain have died”, the doctor who discovered the super-bug said.

But I want to challenge every one of us who think we do not have HIV that we had better be careful; we cannot say we do not have the disease until we have done the test. ALL OF US, WHETHER PASTORS, TEACHERS, LAWYERS or DOCTORS, have done things that can cause us to be HIV-positive.

INSTEAD OF LOOKING DOWN ON PEOPLE WHO HAVE THE DISEASE AND KEEPING SILENT, THOSE WHO THINK THEY DON'T HAVE THE DISEASE SHOULD BE A MAJOR SUPPORT TO THOSE WHO HAVE.

IN COUNTRIES ABROAD, BECAUSE OF SUPPORT AND ARV DRUGS, PEOPLE ARE NOT DYING FROM THIS DISEASE. WE NEED TO ASSIST THE INFECTED PEOPLE TO TAKE THEIR DRUGS PROPERLY; WE NEED TO REMIND THEM TO TAKE THE DRUGS – THEY ARE OUR FAMILY – THULI SAW ME AS A FATHER – On Fathers Day, she came to church and gave a Father's Day card, which I will always keep in my Bible.

ON HER DYING BED, SHE HELD MY HAND AND WHISPERED IN MY EAR WORDS THAT I DID NOT UNDERSTAND.

WE HAVE TO BE THERE FOR THE SUFFERING AND THE SICK.

Matt 25:31-46 "When the Son of Man comes in his glory, and all the angels with him, he will sit on his throne in heavenly glory. v. 32: All the nations will be gathered before him, and he will separate the people one from another as a shepherd separates the sheep from the goats. v. 33. He will put the sheep on his right and the goats on his left. v. 34: "Then the King will say to those on his right, 'Come, you who are blessed by my Father; take your inheritance, the kingdom prepared for you since the creation of the world. v. 35: For I was hungry and you gave me something to eat, I was thirsty and you gave me something to drink, I was a stranger and you invited me in, v. 36: I needed clothes and you clothed me, I was sick and you looked after me, I was in prison and you came to visit me.' v. 37: "Then the righteous will answer him, 'Lord, when did we see you hungry and feed you, or thirsty and give you something to drink? v.38: When did we see you a stranger and invite you in, or needing clothes and clothe you? v. 39: When did we see you sick or in prison and go to visit you?' v. 40: "The King will reply, 'I tell you the truth, whatever you did for one of the least of these brothers of mine, you did for me.' v. 41: "Then he will say to those on his left, 'Depart from me, you who are cursed, into the eternal fire prepared for the devil and his angels. v. 42: For I was hungry and you gave me nothing to eat, I was thirsty and you gave me nothing to drink. v. 43: I was a stranger and you did not invite me in, I needed clothes and you did not clothe me, I was sick and in prison and you did not look after me.' v. 44: "They also will answer, 'Lord, when did we see you hungry or thirsty or a stranger or needing clothes or sick or in prison, and did not help you?' v. 45: "He will reply, 'I tell you the truth, whatever you did not do for one of the least of these, you did not do for me.'

v. 46: "Then they will go away to eternal punishment, but the righteous to eternal life."

Ps 116:15 – Precious in the sight of the LORD is the death of his saints

THULI'S DEATH IS PRECIOUS IN THE SIGHT OF THE LORD BECAUSE SHE GAVE HER LIFE TO THE LORD. HAVE YOU DONE THAT?

IS YOUR DEATH GOING TO BE PRECIOUS IN THE SIGHT OF THE LORD? I AM SURE THULI'S DEATH WAS PRECIOUS IN THE SIGHT OF THE LORD BECAUSE SHE GAVE HER LIFE TO THE LORD.

## **APPENDIX 5C1: INTERVIEW WITH MALE SUPPORT GROUP MEMBER**

### **Interview with Male Support Group Member**

The respondent, after introducing himself, explained that he is HIV-positive and was on ARVs. He was 39 years old and from a family of five. He had three children who did not live with him. His girlfriend had passed away a month before our interview (in April 2007) as a result of an HIV-related illness. Their daughter, less than a year old, was alive and HIV-negative. The respondent was not a church-goer. He was uncertain as to how long he had lived with the virus and only became aware of his status in 2006 when his girl-friend, who was pregnant at the time, went to the clinic for testing and was found to be HIV-positive. He was shocked at the news, but the way the lady explained it made him calm down and he decided to be tested as well. When he went to the clinic he explained his situation and told them that he had been vomiting blood. They performed the test and found that he had TB as well as HIV. When they realised that they were both positive, the couple went for CD4 count. The respondent's count was 117 and the girl friend's was 330. These results led to many arguments between them. The woman arguing that because the man's CD4 was very low, it was he who had infected her with HIV and so he would die first. While the respondent was being taken through the various learning and assistance programmes of the Support Group, clinics and friends, the girl-friend decided to go to the traditional doctors and use their 'Muti'. The respondent tried as best he could to convince her that the Support Group would help her but she refused. Her condition deteriorated and she passed way.

It took our respondent a year before he could confide in his sister about all of this, but he did not tell anyone else. At home he was taking Bactrim and ARVs. He did not tell his family because they looked down on people with HIV and did not expect any member of their family to ever be HIV-positive. He only told his sister because she was more educated in the matter. She then went for HIV testing and came back to tell him that she was negative. This encouraged him. Most people reject those with HIV because this is regarded as a disgusting disease, and when they become aware that you are HIV-positive they gossip amongst themselves about you. This is one of the main reasons why people who are HIV-positive will not tell anyone of their condition. The community can be

helped through educating pupils in schools and churches, and through people who belong to various other organisations. If you attempt to arrange a community meeting you find that nobody will attend, so the help must come from elsewhere.

The above-mentioned respondent is now doing well, after joining the Support Group and taking ARVs.

This man has been taking care of his life ever since he was told that he was HIV-positive: he has stopped drinking and he is trying his best to stop smoking. He used to have sex with women without using a condom but now he always uses a condom. He does not, however, go to church because he wants to attend church only as a committed person, which at present he is not. However he does attend the monthly HIV prayer meetings as he finds them to be meaningful, and enjoys the time when people lay hands on him and pray for him.

This man has now been in the Support Group for a year. He was introduced to the group by an HIV-positive lady at the TB clinic, who saw how desperate he was and suggested that he approach the group, where he would receive guidance and support. The Support Group has helped him deal with the many stresses in his life which has occurred due to his HIV status. With them he can open his heart freely and, through their guidance he is now able to share his problems with others. He has learned more about the disease and knows his rights as an HIV-positive person. The part of the Support Group that he enjoys the most is where he contributes to the work of CCP from his journey with HIV and where he in turn receives input from the CCP through their interventions with the Support Group. He enjoys the exchange of knowledge that takes place in the Support Group.

The respondent understands how the Zulu culture has contributed much to the current HIV situation. A number of practices and rituals expose people to the virus, and they become infected and are thereby led to a life of shame, and are unwilling to discuss their status with others. An example of this is an event that had recently taken place at his own

home. The family decided to perform a ritual called ‘Ukuqiniswa’<sup>113</sup> where incisions are made into the skin of each family member, by a traditional doctor using a razor blade. When the respondent saw this, and knowing very well that he was HIV-positive, and that through this procedure could be responsible for infecting another member of the family, he took the razor blades and broke them into pieces, giving each member a piece for their own usage only. He also advised them to throw the razor blades away after they have been used to cut them. This raised an uproar within the family and everyone criticised him for what he had done, apart from his sister who was aware of his status.

If it was not for his knowledge of the disease, many people would have been infected that day. He now considers that such cultural practices are exposing a great many people to the HIV infection. The respondent believes that the aspect of the Zulu or African tradition, where blood is extracted from people, is the most dangerous aspect of the culture in relation to HIV infection. This also applies to such practices as ‘Umeqo’<sup>114</sup>, where the traditional doctor uses a porcupine spine to poke the swollen feet of a sick person. The belief here is that the leg is swollen because the person has stepped on a bad track. From the respondent’s own experience with people who are suffering from HIV, most of them develop swollen feet, which are then poked with the same spine as those who might have a swollen foot because of other diseases.

In terms of whether or not the Zulu culture contributes to the silence around HIV and AIDS, the respondent at first hesitated to comment, but said that the answer is both yes and no. The reason for this is that an infected person will always pour out his or her heart to a traditional doctor, but will keep silent before family members and even people who can offer true HIV and AIDS help. This scenario is created by the culture in the sense that the traditional doctor is placed in a sacred situation where he is not expected to

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**113 This is a ritual that literally means “Making you strong or Strengthening you”. It is done for entire families or communities to protect them or make them strong against any disease, accidents, bad omen or spiritual attack. In this ritual, a traditional doctor is called into the family and he cuts every member and applies the medicine for protection in the wound. Usually the traditional doctor uses razor blade in making incisions on people and one razor blade is used on many people. See Moore and Sanders (2001:213).**

**114 All diseases contracted by stepping over something dangerous to health are known as umeqo, regardless of their symptoms (History of Medicine: Zulu Medicine. <http://www.classics.und.ac.za/ngubane.htm> )**

discuss your condition, whereas the ordinary family member can gossip about you, and so an HIV-positive person will not simply discuss his condition with anyone. In this way, the way in which the culture looks at certain aspects of life promotes silence. Issues of sex always promote silence and if you have any disease related to sex, such as an STI, you keep this to yourself and make plans to go to a clinic where nobody who knows you will see you. This becomes more imperative when it comes to HIV and AIDS.

The respondent also agrees that the hierarchical and unequal relations between men and women contribute to the HIV silence in that women cannot easily approach men and inform them that they are HIV-positive, for fear that the man would accuse the woman of having introduced it - even in situations where the man has history of womanising. Because of this a woman would remain silent about her status. The respondent said that: “In my case, my girl-friend told me I had always been complaining about my health and saying that I wished somebody could tell me what was really wrong with me. She told me that she knew what wrong with me. This is the reason why when my CD4 was found to be lower than hers, she concluded I am the one who gave her HIV”.

The respondent also felt that the unequal distribution of power, supported by the culture, contributes to the HIV silence when those who are subordinates find it difficult to tell those in power that they are HIV-positive. The major contributor to the HIV silence in terms of the African community nature, according to this respondent, is the fact that this aspect of culture is motivated by rumour-mongering and gossiping, which lead to stigmatisation and discrimination. As a result, people remain silent about their status.

### **Researcher’s Personal Observation and Reflections**

The interview took place at the researcher’s office on Tuesday the 8<sup>th</sup> May 2007 at 3.30 p.m. immediately after a Support Group meeting. It was conducted in Zulu with a male CCP staff member as an interpreter. The office was quiet and there were no interruptions. Before the interview began the researcher provided the respondent with the letter of consent and explained it to him. He agreed to this and signed it. The respondent was very emotional as he spoke about his girlfriend passing away before agreeing to seek help through the Support Group, clinics and others.

## **APPENDIX 5C2: INTERVIEW WITH FEMALE SUPPORT GROUP MEMBER**

### **Interview with Female Support Group Member**

The respondent here was a 39-year-old female Support Group member who has a daughter aged 22 years, who was born when she was in High School. The respondent's last CD4 count had been 430 and she was therefore not on ARV treatment. She had known her HIV status for seven years, discovering this when she gave birth to a second child who was sickly and it was suggested that she and her baby have an HIV test, to which she agreed. Both tested positive, but by then it was too late to do anything about her little daughter and she passed away. The respondent felt that her baby had died because of her own ignorance of the disease. Until she joined the Support Group, the respondent said she had lived in fear and denial but joining the group had made it possible for her to disclose to her mother that she is HIV-positive. When she told her the news her mother was disturbed, and cried as if the respondent was also already dead. On the fateful day of the disclosure, the respondent was afraid at one point that her mother would have a heart attack, as she had a heart problem. She is always thankful that they were alone in the house when she told her, as, if others had heard her grief, they would have come to help, thinking something terrible had happened.

When asked what it means for someone to be silent about his or her HIV status, the respondent said that in the first place, people don't talk about the disease at all, so as to avoid saying something that could be seen to suggest that they had a personal reason for their interest in the subject. Besides not talking about it, the infected person, in order to avoid suspicion, does other things to conceal his or her status, such as hiding from familiar people or avoiding public places when one is ill. The respondent related that when she was very sick at one stage, she left town to stay with her mother in the location and her mother, who by then knew of her status, hid her there for two months. If the family knows that you are HIV-positive, they help you keep it a secret so that others in the extended family is not aware that you are infected. "This is because", she said, "in our culture a lot of people link AIDS with a curse. If you are cursed, even family members see you as an enemy or a disgrace".

In terms of attending Church, the respondent said that she goes to the Apostolic Church whenever she is well enough. In her church no one knows that she is HIV-positive. She said that it is known amongst most people living with the disease that the church is a place where HIV-infected persons are judged as being naughty or sleeping around. Because of this she is afraid to tell any one of her status. She believes the church should be a place where HIV is not talked about in a judgemental way. She wished the situation in the church was like the way it is with the monthly prayer meeting, where HIV and AIDS are preached about and people openly admit to their status and can be prayed for. The respondent further said that, during the monthly prayer meetings, she feels as though she has never been sick and would often want the meeting to go on for longer. Asked what makes the monthly prayer meeting different from that in her church, the respondent said, “The difference lies in relationships and education. All the people who come to the prayer meeting, Pastors, Church elders, Preachers, Caregivers, family members, Support Group members and even the youth who used to laugh at us before, come there to pray that God will heal those of us with HIV. In my church, however, I don’t think my pastor understands HIV and AIDS. If I should go forward one Sunday to be prayed for, as having HIV that will be my end”. She feels it is time for CCP to help the pastor to preach about HIV and to do something about it.

When asked about how she had joined the Support Group, the respondent revealed that her boss heard about the good work which CCP was doing and referred her there, but unfortunately this same person found a way to get rid of her. However, Group members make her feel human again and she is able to reveal her secrets and constantly learns new facts about the disease that almost killed her. She particularly likes the sharing of ideas and the input from CCP.

This respondent also considers that the Zulu culture contributes a lot to the silence around HIV and AIDS. The worst silence, in her view, is in the lack of discussion around issues relating to sex. If the elders hear girls talking about sex, they regard them with suspicion and so people fail to talk about sexual diseases. Looking at the various dimensions of culture, the respondent felt they are all responsible for the HIV silence. For her, because of hierarchical traditions, it is difficult to approach uncles and elders, who hold power in

the family, with even simple issues. It is even more difficult, or impossible, to tell an uncle that one is HIV-positive.

Perhaps the poverty that has existed amongst black people for a long time, encourages people to risk their lives. People in the African culture are not accustomed to seeking medical help in good time because they do not have enough money to pay the bills. Instead of telling others about a problem such as HIV, and seeking help, people know that no help will come, from anywhere. Even when the government says they will help you, one waits a long time and then still nothing happens.

In terms of the community nature of the African culture i.e. collectivistic nature, the respondent had the following to say: “It makes it easy for people to interact with you and listen to what you have to say, and they go and share with others and before you know, everyone is pointing a finger at you. Because of this you keep silent on issues relating to your HIV”. She felt that the biggest problem of the African culture that contributes to the HIV and AIDS silence, particularly within relationships, is the inequality between men and women. Because men are ‘in charge’ they always see the woman as having introduced HIV into the home. She pointed that the most difficult thing she ever had to do was to tell her boyfriend that she was HIV-positive. She was told to her face that it was because of her that they had lost their baby, and that she was the one who had brought HIV into the relationship. However, because she knew that his former girl-friend had passed away, she was able to argue that he was HIV-positive before they got together. This argument led to the break-up of their relationship, at a time when she needed him so much. When people are caring for you and you tell them of your status, and when they are not fully educated about HIV, they end up discriminating against you – and so you don’t tell anyone.

**Researcher’s Personal Observation and Reflections:**

The respondent preferred an interview in Zulu with an interpreter in her own home in one of the Townships. The interview therefore took place on the Thursday 17<sup>th</sup> May 2007 at 10.00 a.m. with one lady staff member of CCP as interpreter. As the interview began the researcher explained the letter of consent that the respondent needed to sign and she

agreed to it and signed. The respondent was so tearful when she pointed out that if she had understood the management of HIV earlier, her baby would not have died. At this time, the researcher offered her a tissue to wipe her tears. At one point when the respondent was talking about how she had to leave town and go into hiding to avoid being spotted by friends and relatives who would possibly conclude that she is HIV-positive, she shook her head and her face looked sad, as she wondered why that should happen.

## **APPENDIX 5C3: INTERVIEW WITH A YOUNG SUPPORT GROUP MEMBER**

### **Interview with a Young Support Group Member**

The respondent was a 21-year-old male who had been a member of the Support Group for a year and three months. He became aware of his HIV status four years previously, when he was diagnosed with TB in Grade 11. This resulted in his not finishing High School. For six months he was on TB medication and was too depressed to go back to school. The respondent attends a church in one of the locations in Pietermaritzburg, every Sunday unless he is sick or has been away somewhere, but has not yet seen the need to disclose his HIV status to anyone in the church. This is because the respondent feels strongly that members of the church are not yet educated to handle people who are HIV-positive.

The grandmother of this respondent was the only family member who knew his HIV status. Being a member of the Support Group had helped the disclosure about eight months before. He realised that his grandmother loved him and could see that she was concerned about his health and one day when she showed genuine concern for his health; the respondent told her that the doctors had discovered him to be HIV-positive. She was shocked about the news, and started crying. Though the respondent tried to compose himself, he too began to cry. The respondent explained to the researcher that he had no problem disclosing his status but was unwilling to do until he had first built a relationship and trust with that person. He was still young, with many friends and shied away from possible stigmatisation and rejection by his peer group. He was afraid, if he simply and openly disclosed his status, people, would reject and stigmatise him, while he was still building a relationship with them.

When asked what he understands by an HIV infected person keeping silent about his or her status, the respondent indicated that it meant carrying a big burden of secrets. One had to make sure that the people closer to one did not have any cause to suspect him or her. The medication one is taking, documentation from clinics and the clinics that one attends must not be seen by those who are closer. The respondent believed that the family of the infected person, if they know one is infected, as in the case of his grandmother,

would not want one to tell anyone else of one's condition. Family members would do anything possible to keep the disease a secret. Even when the one was sick and in the bedroom, they would tell people that the sick person is away elsewhere.

In terms of the CCP intervention, the respondent found the monthly prayer meeting for HIV and AIDS to be very helpful. He testified that it had helped him to be open about his HIV status to most people linked to CCP. In his own words he said "During prayer meeting when the pastors lay their hands on me, I feel free in my spirit and my life". Through the weekly discussions and input from CCP in the Support Group meetings, the respondent felt that he had been helped in learning more about the disease and how to overcome his fears of it. He had also learned to be confident and to love those who were also sick. The fact that whatever one says freely at the Support Group meeting stays within the group, including his secret, makes the members enjoy good relationships with each other and with CCP staff.

The respondent was certain that the Zulu culture is the underlying factor pushing people into silence on HIV and AIDS, especially in that the culture does not expect people to express their feelings, and is even more secretive when it comes to sex. He confessed that it was because of what he learnt from his peers, and from the TV, about sex, which no one in the family had properly explained to him, that he became sexually active at an early age. The hierarchical nature of the culture makes those who are more powerful use their power to stigmatise any person who is infected and so, to avoid stigmatisation, one would maintain one's silence. "In our African Tradition young people have a lot to inquire about, but no one is ready to answer them." He feels that the leaders and elders would always want to suppress those beneath them, and when someone is HIV-positive, and those in power know it, they use it as a weapon against you.

In terms of risk, the respondent thought that, these days, everyone took risks and as anything to do with sex is risky; people from all cultures risk their lives. When people take risks and it backfires on them, then they are silent, for fear of being ridiculed. The respondent lamented that the community nature of the African culture makes people willing to help a person when s/he is sick because they know that when it is their turn to

get sick that person will be there for them. Now, when they find out that a person is HIV-positive or has AIDS, they know that the person is dying and will have nothing to contribute back in the lives of others, except to transmit HIV to them, and so they stigmatise the infected person. The respondent felt that all of this was caused through ignorance.

The respondent reckoned that *ubuntu* is good but also makes people eager to know more about the lives of others. So far as the inequality between men and women in our traditions are concerned, this respondent did not see this as contributing to the HIV, silence, as, in his own view, men and women are seen to be the same and equal. The respondent however thinks that the caring nature of the Zulu culture makes people so anxious to know every small detail about what is wrong with people. If what is wrong with someone is a sickness such as diabetics or flu, people will take care of that sick person. In the event of people knowing someone to be HIV-positive, however, they at once want to take you to a traditional healer to be cleansed, or to pacify the ancestors for the wrong-doing resulting in the incurable disease. There is immediate stigma which removes any desire to care. It is only when people are properly educated about HIV and know that the one who is sick is not been cursed, or has not offended the ancestors, that the sick person will receive care.

### **Researcher's Personal Observation and Reflections**

On the day on the interview, 12-06-2007, the respondent arrived at the CCP Youth Centre at 1.00 p.m. The interview was conducted in English and the respondent was comfortable. The researcher explained the letter of consent and it was signed.

As the respondent was narrating about how he disclosed his status to his grandmother, his voice changed and he paused for some seconds and said he was relieved when his grandmother assured him that she loved him and would not reject him because he is still her grandchild.

## **APPENDIX 5C4: INTERVIEW WITH THE OLDEST SUPPORT GROUP MEMBER**

### **Interview with the Oldest Support Group Member**

This respondent was 57 years old and the oldest member of the Support Group, whom the researcher had wanted to follow as a case study. However, an arrangement for an interview was made instead of a full case study when she objected on the grounds of staying far away and was not sure whether she was relocating to another place or not. She did not know she had HIV until her husband died in 2002. When the husband died after a long illness, neighbours began to gossip that the man had died of AIDS although she knew nothing about that. However, a bold neighbour whispered to her that she had been told that her husband had died of AIDS. In the midst of this, a cousin who worked at the clinic came to the respondent and said she had heard her husband had died of AIDS, and that she would go with her to be tested at the clinic. The respondent at first refused and said this was not possible because her husband was old, with grey hair, and in her understanding, it is impossible for such a man to die of a disease that everyone in the community regarded as young people's disease. What made her eventually decide to go for the test was when her cousin told her that if she went, and was proved positive, she would get a government grant and pension. She had no food or money, and finally went for the test in 2003, which duly confirmed her HIV status. The respondent gave testimony that she had joined the Support Group at a time that she was very sick and almost dying, but her life had changed because of love from CCP and the Support Group.

This woman pointed out that when she got to know of her status, and joined the Support Group, she was surprised to notice that the dislike she had felt for people who were gossiping about her had stopped. This change on her part is because she realised that she was HIV-positive and did not know. If people did not gossip about her, she would not have been angry and gone for the test and would have eventually died of the disease without knowing of her condition.

In terms of disclosure of her HIV status, she pointed out that she immediately told her sisters about her status, but could not tell everyone else. It took almost two years, through

the help of the Support Group, for her to be able to tell everyone in the family, including her children, about her status. Her son, who was working at a government clinic, was very helpful to her. She found herself fortunate to have had people around her, and who knew about the disease, and encouraged her to be open.

Generally speaking, people remain quiet about their status because most think that if you have HIV then you have been immoral. There is also a stigma attached to the disease in that people consider you disgusting if they know you to be infected. Apart from not talking to anyone about the disease, the respondent feels there are other things that people do, to keep silent about the disease. One of the main examples of what infected persons do to maintain silence is by not attending clinics or hospitals close to them. If one lives in a township one would attend a clinic far away from one's home, which one knows that a community member from one's own area would not normally attend. In this way no one will see which medication you receive or even be so inquisitive as to ask you leading questions.

Asked how people who are living with the disease manage to keep it from the family they stay with, the respondent said she has had a different experience of not hiding her status from the beginning, and as such she found it difficult to know how people do keep their status from the family. However, the respondent was aware that when one's family is aware of one's status, the family contribute to the one keeping the disease silent by preventing other families from knowing. When you are very sick, they keep you away from others by hiding you. To break the silence on the disease, the respondent feels that infected people must be loved and helped and that will help them to open up. Most infected people need education on the disease, as do the other people in the community. We need to know and accept that until now, people in the community have had a weird understanding of the disease. But relationship-building is crucial in helping people to open up about the disease.

The respondent was a church-goer and acknowledged that some of the members knew of her status. The reason why she told these church members about her status is the fact that,

in their church, people are expected to cleanse themselves using the “enema<sup>115</sup>” process and she stopped doing that when she realised her status. The doctor told her not to use any “muti”, nor to introduce any un-prescribed materials into her body. When she stopped doing this people kept asking her for a reason, and she would explain, but more and more people kept asking and so, one day, she stood before the congregation and explained to everyone present that she was HIV-positive and her doctor had requested her not to introduce foreign materials into her body and that is why she no longer uses the enema.

Asked if there are other people who are HIV-positive in their Church, the respondent said there were others who were positive, but who had not declared their status to others in the church, as she had done. She got to know them when they attended the clinics for medication. She had approached a number of them and asked why they still persisted with the enema and they replied that it is their spiritual practice that cleanses them and so they cannot stop what has made them well, even though they are on ARVs. The respondent thinks that even the church people would not want them to declare their HIV-positive status because people will consider those who reveal this status as being immoral and having many boy/girl-friends. To help break the silence the respondent feels that HIV workers and activists should visit the churches and train people in issues pertaining to HIV and AIDS.

In terms of the monthly HIV and AIDS prayer meetings, the respondent confessed that these had been a major source of help to her. She cited the prayer meeting held immediately prior to the interview as having been the best, in her view. She noted the word of God that was preached and how comforting and relevant it was to her situation and that it gave her hope for the future; as well as the prayer meeting where pastors and leaders touched her body made her feel that she is not disgusting, as some think, but a person loved by God. She felt in conversations with others after the prayer meeting, that

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**115 According to Wikipedia, an enema (plural enemata or enemas) is the procedure of introducing liquids into the rectum and colon via the anus. Enemas can be carried out for medical reasons (as a treatment for constipation), as a remedy for encopresis, as part of alternative health therapies (See <http://en.wikipedia.org/wiki/Enema>). In this church people will carry bottles full of water to church and the pastor will bless the water and individuals will go to the toilet in turns to do the enema.**

those infected with HIV really benefited from the meetings. They keep reminding each other about the word of God that is shared and how to hold on to it.

This respondent was one of the founding members of the Support Group and had been a member since its inception. She had been cared for by the caregivers of CCP since 2003 and so when the Support Group started she was among the only four people who attended the first meeting. She acknowledged that the Support Group had been the greatest source of help to her as, just before she joined the group, she was giving up on life. She was so distressed that she stopped building her house and asked her children what the point was of building a house when you knew that you were dying. However, the encouragement from group members, and the discussions and food parcels provided over the years has resulted in her turning her situation around. The respondent says that when she begins to think about Tuesday, and the Support Group meeting that lies ahead, she is filled with some inexplicable joy, to the point that if she is not able to make the meeting she feels guilty. Being part of the Support Group and knowing her status has brought hope into her life and she is happier than before joining the group. “The group has helped me forget about all my troubles”. The time of prayer in the group, and the relationships that members have built among themselves and the CCP, had been a source of strength to her, and being the most senior member of the group had also brought her joy.

The respondent was another person who felt that culture contributes to the silence around HIV and AIDS, but said that we should not allow our cultures to get in the way as we deal with the HIV situation. Hierarchical relationships do get in the way but we have to deal with them. She had been open to her children about HIV and she kept challenging one of her children, who was often ill, to go for an HIV test. But her daughter keeps telling her that because she had been tested and she knows her status did not mean that everyone should do the same. But, putting behind her the culture of the old people holding power over the young, she listened to her children and found ways to help them. If the elders do not come to the level of the young people and build good relationships with them, the young people will remain silent about their HIV status. Even with this power difference, the elders would not be free to discuss and reveal their own HIV status to the younger ones. She could not see how issues relating to risk contribute to the HIV and AIDS silence.

The respondent affirmed that the gender inequality in her culture accounts for the HIV silence in marriages. A woman would find it very difficult to tell her husband that she had tested positive to HIV. The man would also find it more difficult to tell his wife if he tested positive. She could not tell whether her husband had a test before dying, but even if he did he would not have told her as he would have felt demeaned. “This is something our culture does not expect a man to do but in a time of HIV and AIDS we need to put this aside and be open to our spouses”, she lamented.

The respondent also agreed that our collective culture contributes to the HIV silence in the sense that people in the community enjoy gossiping and when they hear anything nasty about you, they are happy to go and tell others. As a result, when one is HIV-positive and people begin to ask pointed questions about HIV one would find a way to avoid them, unless there is a good relationship and the person is trustworthy. Our respondent here pointed out an example in her own life, when she began attending the clinic and her viral load was so high. A neighbour once saw her going to the clinic, so she stopped attending the clinic, in case the same neighbour saw her going there again, and would tell everyone that she was HIV-positive. If it had not been for the Support Group and the education she received from CCP, she would have stopped attending any clinic, which would have jeopardised her life.

**Researcher’s Personal Observation and Reflections:**

After three unsuccessful attempts to hold the interview at the respondent’s residence, it finally took place at the researcher’s office on Tuesday 26<sup>th</sup> June 2007 at 3.15 p.m. when the respondent had finished attending the day’s Support Group meeting. The respondent opted for an interview in Zulu and so a female member of the researcher’s team was there as an interpreter. The researcher reminded the respondent about the letter of consent she had signed when the Support Group began and asked her if she still wanted to continue with the research. Apart from one telephone interruption, the interview progressed smoothly. The respondent was passionate about the Support Group and how it is of help to members.

## **APPENDIX 5C5: INTERVIEW WITH A FEMALE PLWHA (NON SUPPORT GROUP MEMBER)**

### **Interview with a Female PLWHA (Non Support Group Member)**

This respondent was a 28-year-old single mother who had been living with HIV for the past five years. She was referred to the researcher by a member of the Support Group, who had known her for about three-and-a-half years and had attended the same church with her during this period. The respondent recounted that her contracting the virus came with the pregnancy of her now four-year-old daughter. She blamed poverty and lack of opportunity in life for her predicament. After finishing her diploma in Community Development the respondent went to work in a rural area under very trying circumstances. She realised that her monthly salary was not enough to cover her living expenses. This situation contributed to her giving in to advances from a local businessman who was ready to foot all her bills. She moved into his house and lived with him.

The respondent mentioned that she gave birth to a sickly daughter and discovered a few months later that both she and the baby were HIV-positive. The respondent was too scared to tell the man about the situation. She was afraid that if she told him she would be accused of first having the disease. She was aware that while she had been with this man, he was often sick and was once admitted to hospital for almost a week. It was not long after she discovered that she was HIV-positive that the man once again became ill and she mustered her courage to suggest that he went for an HIV test. She used a lesson she had learned from colleagues at work, explaining that she has learned about the need to do regular HIV tests as a routine, so as to be able to stop the virus at an early stage. The man was very angry and accused her of being suspicious of him.

As a result of the unpleasant situation the woman left the rural area and returned to Pietermaritzburg to seek medical care for the baby and herself. When she arrived in the city she was fortunate in joining a church that had a programme on HIV, and so was able to confide in a counsellor who was a great help to her. It was not easy for her to deal with her status. One day, she got so angry about the situation that she wrote a letter to the boyfriend thanking him for all the financial and material help he offered her, as well as

for the baby and HIV. She also explained in the letter that she had discovered that both she and the baby were HIV-positive. She didn't hear from the man until months later, when he wrote back to say he was sorry and had not known that he was carrying the virus.

Asked whether the respondent had disclosed her status publicly, she said a lot of people knew that she was HIV-positive, but that she had not had an opportunity to stand on a platform to declare her status to everyone. She said the first person she disclosed her status to was the Support Group member who referred her to the researcher. The lady had given a testimony at church about how an HIV counsellor from that church had assisted her to overcome her fear and anxiety when she was told she was HIV-positive. At the time, she admired the way the testimony was conducted and how people in the church responded to show love to this lady. Through this Support Group member, she was introduced to the HIV counsellor in the church, who had been of a great help to her. The respondent also mentioned that circumstances arose in her life that forced her to disclose to some of the church elders that she was HIV-positive. At one time her daughter was very ill and was admitted to hospital. This was at a time when she had just started work in a new job, and at a time when she needed all kinds of help. All she wanted was for her baby to get well and forgot what people would say about her if she told them about her HIV status. She went through a tough time, in and out of hospitals.

According to the respondent, one day she was at the hospital and the baby was dying, gasping for breath and the nurses looking helpless. She called for an elder of the church and disclosed to him her status and also that of the baby. The elder prayed and prophesied that the child would not die but be healed. She agreed to his suggestion for the whole church to pray for her, although they would then all know that she and her baby were HIV-positive. She also agreed that other elders of the church be told about her situation so that they could all pray for her daughter. To her surprise, her baby recovered and was put onto ARV. The baby was, by then, healthy and doing very well. To her, God has provided everything.

When the respondent was asked if there are people she found it difficult to disclose her status to, she mentioned her employer. She was not sure how much he knew about HIV and since she enjoyed her work and it was her only source financial remuneration, she didn't want to jeopardise it. When asked why she was not part of the Support Group, since her friend was a member and found it helpful, the respondent said it was because of the meeting times which coincide with her working hours. Aside from that, she had attended some of the World AIDS Day programmes and the monthly Prayer Meetings attended by the Support Group. She felt that the Support Group was a good initiative that helped people infected and living with HIV. Through friends she had benefited from the programmes of the group.

On the issue of culture and HIV silence, the respondent concurred that the former contributed much to the latter. To the respondent, the inability of the Zulu culture to deal adequately with questions raised about sex is the first cultural issue that contributes to the HIV and AIDS silence. The strong hierarchical relations in the culture contribute to what she called 'intergenerational silence' where, within one generation group, they are able to discuss sexual issues which but one generation group cannot discuss with the other. The worst scenario would be for a person from a younger generation to discuss sex with someone from an older generation. This is the result of higher hierarchical relations. In terms of gender inequality, the respondent pointed out that, from her own experience, she knew that this it contributes to the HIV and AIDS silence. She believed that that as long as men have both financial and social power over women, there will continue to be silence from both men and women. Males will maintain silence about their HIV status for fear of losing their power and pride, as by disclosing their status, they will be blamed and stigmatised. The women will continue to keep silence on their status for fear of being blamed and rejected for spreading HIV, as they are accused of sleeping with men for financial gain. The communal nature of the culture leads to a lot of community gossip and this in turn leads to stigmatisation and so those who are HIV-positive would not reveal their status even if people showed their *ubuntu* and caring natures.

### **Researcher's Personal Observation and Reflections**

The interview took place on Sunday 15<sup>th</sup> April 2007 at the respondent's church premises after the service at 11.30 a.m. An elder in the church who has been of great help to the respondent in her struggle with HIV arranged for the interview to take place in the Mother's Room. At the start of the interview the researcher explained the letter of consent that the respondent needed to sign and she agreed to this and signed. The interview was conducted in English. The daughter of the respondent was playing with toys in the corner of the room, which prevented any interference from her.

It was clear throughout the interview that the respondent has suffered a lot through her HIV experience. She was so grateful to her church, especially to the elder who has been helping her, for the support she has received. She was full of praise for the work of the Support Group and could have easily become a member, as she knows most of the members, but that is not possible because of her work schedule.

## **APPENDIX 5C6: INTERVIEW WITH A MALE PLWHA (NON SUPPORT GROUP MEMBER)**

### **Interview with a Male PLWHA (Non Support Group Member)**

The respondent here was a 41-year-old male who had known of his HIV-positive status since 2002, but did not reveal this until the beginning of 2007. He said that when his wife was delivering their second child, there were complications and they lost the baby. After that the wife became extremely ill and she passed away two months after delivery. The respondent did not know much about HIV at this stage. He then became sick and had shingles. His employer, knowing his history with the death of his baby and wife, encouraged him to go for an HIV test in late 2002, which the company paid for. The results proved him to be HIV-positive.

He then lived in denial for a year and kept getting sick every now and then. Because of the frequency of his illness, he lost his job. The respondent said he became broken-hearted and told himself that he would not let anyone know his status. In 2004 he moved back from Durban to his home in Pietermaritzburg. The respondent confessed: “the HIV and AIDS journey is a lonely and a burdensome one. When one has this ailment there is much one would want to share with people, but cannot do so for fear of rejection. One cautiously keeps a door open for interaction to build relationship and trust with someone to share the burden with”.

Asked as to how he managed to remain silent about his HIV status for five years, the respondent said that keeping silent on one’s HIV status, especially from family members and relatives, is not easy. It is best to avoid any discussion on the issue as this prompts one to be defensive and sometimes unreasonable, which makes people suspicious. One tries to avoid people who you know are inquisitive. In situations where one so often becomes ill, one would make sure to attend clinics which are not close to where one resides. Especially in situations where one is on ARV medication, one has to get this from clinics that are far from home. According to the respondent, families initially stigmatise an infected member, but they are quick to help one to remain silent about one’s

status. They find it shameful that a family member has the disease, to the extent of locking sick people inside rooms to avoid them being seen by other people.

The respondent attributes the declaring of his HIV status to a family member to the help he received from one Support Group member who has always shared the things he learns from the group with him since this friend joined the group in mid-2006. This friend convinced him of the importance of disclosing one's HIV status to trusted and reliable people who understand the disease. He further pointed out that disclosure helps people to be more compliant with ARV and other medication, as these people become "buddies". This friend had taken it upon himself to disclose his own HIV status to the respondent's nephew, who lives with the respondent. In January 2007, the friend helped the respondent to disclose his status to his nephew in order for him to become his buddy for ARV training. The respondent confessed that he had seen the usefulness of Support Group and would have joined had it not been for his current employment which clashed with the time at which the meetings took place.

The respondent admitted that he did not attend any church. However, he pointed out that he had accompanied his friend to the monthly prayer meetings on two occasions when he was not working, although he could not come forward to be prayed for as he did not want anyone to know his HIV status. The respondent promised the researcher that the next time he attended a prayer meeting he would come forward for prayer as he believed that he would be touched by God.

The respondent agrees that the Zulu culture encourages people who are HIV positive to remain silent on their status. The reason for this is that the culture has so many false beliefs which help people to justify everything they do. Most sicknesses are attributed to witchcraft and no one can talk about it as this is the realm of the traditional doctors and the ancestors. In terms of how the high unequal distribution of power within the culture contributes to the HIV and AIDS silence, the respondent said that the young people fear the elders and those in power. This then creates silence between elders or those in power, and the subordinates and the younger ones. Any mention of HIV would cause the elders to think that the younger generation have been immoral. As a result of this fear, the

younger ones would not dare to tell their elders that they are HIV-positive, as they would use this information to the detriment of the subordinate. This is what happened to the respondent at his place of employment in Durban.

In terms of risk-taking and uncertainty avoidance, the respondent was not sure if that is attributed to the African culture or the South African history. For him, people are generally prone to risky behaviour because Apartheid has made the African people think that one could soon die for any number of reasons and so one more risk is not relevant. This attitude makes infected people slow to tell anyone about their status.

He also felt that, in the African culture, gender inequality has always been there. The only reason why there is silence between partners is that each one fears that the other one would leave if they revealed their HIV-positive status.

The respondent says that to break one's silence on HIV requires a lot of help and encouragement from friends and people who understand the disease. It needs determination to break traditions and culture. One needs to come to the understanding that some cultural dimensions are not helpful in the era of HIV and AIDS.

**Researcher's Personal Observation and Reflections:**

The interview took place at the respondent's home on Wednesday 25<sup>th</sup> April 2007 at 1.00 p.m. It was conducted in English without any problems and interference. The respondent signed a consent letter before the interview began. The respondent was embittered about the way he was treated by his former employer but was full of praise for his Support Group friend through whose efforts he is on ARVs. Through attending some of the monthly prayer meetings the respondent has seen the potential of a church that understands HIV.

## **APPENDIX 5C7: INTERVIEW WITH A PASTOR**

### **Interview with a Pastor**

The respondent was a 45-year-old woman. She was the Assistant Pastor of her Church and had been in the ministry for four years after completing her theological training. She was compassionate about development work, especially HIV and AIDS issues. She had nursed over 20 people who were infected with HIV and once nursed people without using gloves, in an emergency situation. For this reason, she went for an HIV test, in case she had been infected.

The respondent considered that HIV poses a threat to the nation as a whole, and to the church, and that the disease has not been given the attention it deserves. Within her church, she feels she is a lone voice. She was in charge of HIV and AIDS work in her local church, but the work was not progressing. People paid lip service to the church HIV and Aids work, because when they had been sent for training, then they would use their certificates to get jobs in the government, where they were not in touch with the sick people they had been trained to help. Most people in the church still linked HIV to immoral behaviour, which caused infected people to be stigmatised and discriminated against.

The message of “grace”, according to the Assistant Pastor, should be preached so that church members understand that we are all, forgiven by, Christ, and should have grace for other people. They need to know that it is not sex alone that causes HIV. She used her experience of nursing people without the necessary gloves as an example of how she could have contracted HIV without sex. There are also married individuals who are faithful while their partners are not, and when they contract HIV because of the unfaithfulness of their spouses, one should never stigmatise them. The pastor felt there was a need for a conscious effort by the church to educate people to understand the realities of HIV. She felt that the church had not taken the disease as a ‘preachable’ subject. Overcoming this would help the church move beyond merely pitying people to helping them, and their families, to manage the effects of the disease. If everyone in the church could go for HIV testing, that experience alone – the counselling, the testing and

the procedures – would change people’s mindset to an attitude of sympathy, and not scorn, for infected victims.

Asked for her opinion as to why people who are HIV-positive find it difficult to tell others freely of their condition, the pastor thought it was the fear of being stigmatised and judged by others because when people in the community know that a person is infected, he or she is automatically considered to be immoral. She also said that when someone in the community is known to be HIV-positive, the people, from ignorance on the subject, would shun the victim and even confront them with sarcastic comments. For this reason people would rather remain silent about their status, telling themselves that if they were to reveal their status they would still be silenced by the consequent behaviour of the community, and so why open up? When asked how infected people manage to keep their status silent, she said that sick people try by all possible means to conceal their condition. Unlike in the past where people used to lie in bed sick, and everyone knew that they were ill, in these days, when people are sick, they go to clinics well-removed from where they live so that nobody close to them will see them obtaining HIV medication.

These days when people are sick, they keep changing jobs, and moving from place to place. When one is bed-ridden, he or she will go, to be nursed by relatives in rural areas whom they trust. More often than not, they confide in the person they trust, who will then hide them from the public eye. If anyone accidentally notices the sick person or if it becomes obvious that he or she cannot be hidden, the family will provide different reasons for their ill-health to suspicious neighbours. The major reason often cited is that their child has been bewitched, or that the child is being called by the ancestors to become a *Sangoma*, and hence the apparent sickness.

Concerning the aspects of the Zulu culture which contribute to the HIV and AIDS silence, the respondent thought it was simply the nature of the culture not to be open. She felt that the culture had a number of taboos that made people feel obliged not to discuss certain issues. She said that until you are grown and mature, which is mostly after marriage, one cannot freely speak one’s mind. One has to be mindful of what one says lest one incurs the wrath of the elders for saying anything that brings shame on the

family. The major area of silence is to do with sexual issues, and since HIV is a venereal disease, it is even more shameful to talk about this. The respondent therefore linked the silence to the hierarchical nature of the African culture. This culture demands that children listen to their elders but may not say anything. In this practice, children may not even complain when they are ill, but keep silent and suffer. When suffering from HIV or a related illness, one would not discuss it even with one's friends for fear that the elders could hear about it. Now, with HIV known in the community as the "young people's disease", as their culture has trained them, no one wants to discuss the subject.

When it comes to the low uncertainty avoidance nature of the culture, which contributes to risk-taking, the respondent says that when people have taken risks and things do not go well, they are ashamed to expose their folly. Even though they are not very well educated on HIV and AIDS issues, people are aware of the dangers of incurring the disease and yet, because they live in a state of perpetual poverty they will do anything for money. Even when this includes risking their lives, they persist with any money-generating activities. Then, when they contract HIV through these activities, they do not want anyone to know the negative results of the risks they have taken, and are ashamed of themselves.

With regard to how the collectivistic nature of the culture contributes to the HIV silence, the respondent agreed that this aspect of the African culture brings out the caring and humane nature of the people towards those who are and suffering. However, the same aspect of the culture affords people the opportunity to discover the nature of the ailment. In the case of people infected with HIV, and through a lack of education on the subject, people become apprehensive and reveal the situation to others, leading to stigmatisation of the victim. For this reason, infected people are unwilling to reveal their status to those who come to help them.

In the area of gender inequality, the respondent said that women in the African culture are usually silenced in a number of different ways, and so when they become HIV-positive, even if they want to talk about it, circumstances surrounding them, such as intimidation by partners and the apportioning of blame, make it impossible to discuss the issue.

**Researcher's Personal Observation and Reflections:**

The interview was conducted on Wednesday 11<sup>th</sup> April 2007 at 12.30 p.m. in the pastor's own home. The interview was conducted in English in a relaxed atmosphere. The pastor signed the consent letter before the interview began. There were a few interruptions, comprised of two telephone calls and a visitor who came to see the pastor, but these did not affect the interview. The pastor was very passionate about getting church members to offer their all in dealing with the HIV issue. She felt desperate that her church was not doing enough. When she spoke about the many taboos that the culture has, one could see the concern she has about that.

## **APPENDIX 5C8: INTERVIEW WITH CAREGIVER**

### **Interview with Caregiver**

The respondent preferred that the interview be conducted in Zulu and the researcher provided a lady interpreter at this interview, held on Thursday 17<sup>th</sup> May 2007 at 12.30 p.m.

The respondent was a 23-year-old woman who had great sympathy for people infected and affected by HIV. When she was asked why, as a very young person, she had chosen to be a caregiver, she pointed out that she had always wanted to be a nurse but for two years she had been trying unsuccessfully to be accepted into a training hospital. Then, when the researcher came to her church to preach about the responsibility of the church to be involved in the work of HIV, she realised that she could help others by joining the care-giving team in her church. The training she went through opened her eyes to the realities of the disease, and increased her desire to help sick people. Since she had offered herself to do this work, a number of young girls in the community had come to her for counselling on HIV issues. She had already introduced over ten young people to join the HIV Support Group in CCP. Working with people living with HIV made her realise the need to repeatedly be tested for HIV.

By interacting with her peers and working with people infected with the virus, the respondent realised that people who are HIV-positive would not talk freely with others about their status, unless they had an established relationship with these people and were convinced that they are informed and educated about the disease and ready to offer help. She considered that many who are HIV-positive are not educated about the disease and so do not seek help where it is available.

The respondent believed that the Zulu culture contributes in many ways to the silence around HIV. For her, the culture has too many taboos, especially those which children and young people must observe. She says that, for example, one cannot ask questions about sex at home; one can only do this with your friends and during lessons at school. In terms of power distance, she said the culture does not allow children to raise their

opinion and knowledge, which renders them silent, even if something is bothering them about HIV. In the home, parents do not want to listen to their children, and therefore, as a child, one has no say. The young lady also pointed out that the unequal distribution of power within the culture exacerbates the risk-taking behaviour of people, especially the youth. The lack of fluid relationships between parents and children makes young people daring to go and try anything, especially sex. Then, when they have engaged in risky behaviour and they contract HIV, they are too ashamed and too afraid to tell anyone.

On the issue of how the community nature of the Zulu culture contributes to the HIV silence, the respondent said that the nature of the culture has within it what she calls “inquisitiveness and gossip”, especially on the subject of HIV. This is something that HIV-positive people are aware of and so they consciously avoid disclosing their status to people who approach them with the aim of caring for them or sympathising with their ill-health. A number of HIV-positive people in the community have been stigmatised in this way.

In the area of gender inequality, the young lady related her own experience within her family and said the abuse of power by men brings silence and fear in the family. In the area of HIV, the respondent had encountered a number of young girls who are HIV-positive but who cannot tell their boyfriends because of the way they have been abused in the past.

### **Researcher’s Personal Observation and Reflections**

This interview took place on Thursday 17<sup>th</sup> May 2007 at 12.30 p.m. at the respondent’s church office for HIV work. The office was neat and conducive for the interview. The caregiver read and signed the letter of consent that the researcher explained to her. The interview was conducted in English. The respondent is enthusiastic about her work and has the desire to help young people to avoid the disease and to help those who have encountered it. When the respondent was relating her experience on gender inequality when growing up in her home, one could see fear in her eyes. She froze when she said, “As children we had to take care what we said to our father, lest it brought problems to Mum or ourselves later. My father blamed my mother for anything”.

## APPENDIX 5C9: INTERVIEW WITH A CCP STAFF MEMBER

### Interview with a CCP Staff Member

The respondent here was a 70-year-old Zulu woman who joined CCP in August 2002. Being a nurse she enjoyed working in the Home-Based care, helping sick people in her community. Working with CCP was a new experience for her as she worked as a nurse in the Government hospital and had not been involved with the community. Working in the community opened her eyes to how people are suffering, and the poverty they live in, and where you find desperately ill people living in muddy shacks. She worked with the Support Group since its inception, and because of her involvement with infected people, she often had herself tested. She attends church and leads the church's HIV group.

The respondent pointed out that, over the years, and in response to the changing nature of the disease, her role in the CCP had changed and she had become involved in family interventions dealing with adult health. She conducted training according to the CCP's principle<sup>116</sup> of conveying what one does at the project to others in the community. She was in charge of the Support Group and facilitated and taught them wellness so that they fully understood HIV and AIDS and could take care of themselves. She also assisted with the training of volunteers to take care of HIV-infected people in their communities.

According to the respondent, she enjoyed working with the Support Group people. When it started, she did not know how to run the group and there were only three or four people who attended the meetings. Today an average of about 35 to 40 people attend the meetings. Each of the members has disclosed his or her status to other people besides the group members. This is as a result of the disclosure work that has been done with them as well as the interventions into their families.

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<sup>116</sup> CCP uses NAT's 2X2X2 **principle stems from the Bible in 2 Timothy 2: 2**, which says whatever good things you have learned, entrust to or teach reliable people until they too (become like you, having the same knowledge that you have) and so are qualified to teach others (until these others become like them and also like you are), qualified to teach new people. The process then continues. See section 6.2.1 for details.

In terms of the silence around HIV and AIDS, this respondent thinks there has been a change in the sense that people now talk about the disease. Some now openly mention that they are infected. However, some families in the communities remain silent on the subject, as there is still a stigma associated with the disease. Within the churches, the respondent feels most, especially the younger people; are silent on the subject because they are afraid of being discriminated against by their peers. Given the teachings in the church about immorality, together with the fact that HIV in Africa is mostly a sexually transmitted disease, when one declares one's status in the church, people immediately see one as not being morally upright. For this reason people do not want to declare their HIV-positive status. The same is also true in the community where one is considered immoral if considered to be sexually active outside of marriage.

The respondent said that when an infected person is keeping silent about their HIV or AIDS status it means that they don't disclose this to their family members. This is dangerous, because they look after this person without knowing that he or she is suffering from such infections and dangerous disease. From this staff member's experience, when people tell their family members that they are HIV-positive, the family will support them, and have their own means of keeping silent about the disease. There are families who, when a member is HIV-positive, even lock that person alone in the house to prevent people from knowing that this member of the family is HIV-positive. This, according to the respondent, is a sign that the family lacks education on the subject.

The respondent firmly believes that the Zulu culture has a lot to do with the HIV and AIDS silence, as it has issues that are not to be discussed in public. There are also taboos that create silence around the disease. A number of other matters are considered as being purely family matters. An issue such as sex is one of those considered taboo to be talked about in public. Since everyone in the community considers HIV and AIDS as a sexually transmitted disease, this means that it cannot be discussed publicly. Nor may one publicly discuss witchcraft and this is also linked with the disease.

In terms of what we have noted as the power-distance dimension of culture, the respondent believes that the hierarchical nature of the culture contributes to the HIV

silence in the sense that if one has anything to discuss within the family, one must carefully think about how he or she is going to say it and who will be told. Not giving information to the correct person, especially if it is to do with a well-known and dangerous disease such as HIV, may cause serious problems within the family. People are therefore careful about what they disclose to family members, and for this reason people remain silent about their HIV status within the family environment, even though they disclose their condition to people outside of the family.

When asked about whether or not gender (or what we have noted as the masculinity in terms of gender egalitarianity) contributes to the HIV and AIDS silence, the respondent agreed that it does contribute. She related the silence on HIV and AIDS to the practice within families in the African culture where, when things go wrong, the female is invariably blamed. For example, a woman could be blamed for a child being HIV-positive, in the sense that she was not strict enough. The apportioning of blame on the females in the family, cultivates secrecy and silence on issues such as HIV occurring in the family.

On the issue of risk-taking, in terms of what we have noted as 'uncertainty avoidance' as being part of the African Culture, the respondent agreed that the people of the culture are high risk-takers and this also contributes to the silence around HIV. This, in the first place, according to her, contributes to the higher rate of infection as people do not stop to consider the risks that their behaviour brings to them. She believes that most people have heard about HIV from different sources, and yet they have unprotected sex and contract HIV, thereby risking their own lives. She says they gamble with their own lives. Even when it comes to the silence on the disease, both the infected and most families take risks by remaining silent when they know there is help available to them. They allow what they call 'family pride' to take preference over the lives of people.

The respondent hailed the ubuntu and caring nature of the African culture which, she regretted to say is gradually fading away, although within this spirit of helping others, people are inquisitive and eager to know what is wrong with them. As for HIV, the respondent said that people of the communities do know the seriousness of the disease.

However, because of the lack of proper education within the African culture, when people, through the practice of ubuntu, learn that one is HIV-positive, they gossip about it to others. For this reason infected people are not willing to disclose their status until they are confident that the person who is told will not stigmatise, discriminate or gossip about them. Most people these days, with the shift to modernisation, do not have the real ubuntu spirit of genuinely wanting to care for sick people, though it is in their blood to help. Because the real ubuntu is not there, gossip easily overcomes that innate desire to help a sick person.

In all of this the respondent felt that, from her own experience, the way to break the HIV and AIDS silence hinges on education in the community; education that is based on good relationships. A great many people find it difficult to change their behaviour and adhere to the old ways of doing things. We need to be patient with them and win their confidence through relationship-building and trust. She considered it unfortunate that, these days, there are no *Indunas and iNkosis*<sup>117</sup>, who used to have authority to organise meetings for the people and were good educators, to help people change their attitudes. We therefore must do it ourselves by setting a good example.

In her opinion, the HIV silence has been broken through the way the CCP has trained a good number of volunteers in the community in the best approach to deal with the disease. She is happy about the way these volunteers approach people who show clinical signs of the disease, by creating a relationship with them and constantly visiting them. These visits create opportunities for the volunteers to suggest to these people that they go for a VCT and when they know their status the volunteers will provide any help that is needed. These volunteers are able to educate the communities and care for those infected

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<sup>117</sup> During colonial times, indigenous people were ruled by a King (who inherited their authority), iNkosis (or chiefs) and iNdunas (or headmen). [www.ukzn.ac.za/heard/research/ResearchReports/2005/Environment%20Report/Sec%20B\\_intro.pdf](http://www.ukzn.ac.za/heard/research/ResearchReports/2005/Environment%20Report/Sec%20B_intro.pdf). Inkosis or fumes (chiefs) are other lords with fewer vassals. <http://www.1911encyclopedia.org/Monomotapa>. InDuna (plural: izinDuna) is a Zulu title meaning advisor, great leader, ambassador, headman, or commander of group of warriors. It can also mean spokesperson or mediator as the izinDuna often acted as a bridge between the people and the king. The title was reserved for senior officials appointed by the king or chief, and was awarded to individuals held in high esteem for their qualities of leadership, bravery or service to the community. The izinDuna would regularly gather for an indaba to discuss important issues. <http://en.wikipedia.org/wiki/InDuna>

and/or affected by the disease. The respondent cited her own experience of the first person she helped. After building up a relationship with her, she suggested that the client go for an HIV test. This person was happy to do so and said, “Thank you very much for helping me. I know that this thing has been eating me inside and I just tell myself that maybe I am HIV-positive. I wished there was somebody who could talk to me about this HIV more”. She pointed out that after this encounter the person went for an HIV test and was shown to be positive, but accepted the situation by knowing that there was somebody to help her.

To this respondent, the area of CCP’s intervention which shows more evidence of breaking the HIV silence is the Support Group which she has been working with since its inception. She knew that not all of the members had broken the silence, as some were new and in their neighbourhood no one talked about HIV or AIDS. Some of them too did not discuss issues of HIV and AIDS within their families, and so when they came to the Support Group their friends gave them some ideas which helped them deal with the problem. Apart from these few, the rest are not ashamed to talk about, and to deal with, their status, whether or not they were stigmatised or discriminated against. The prayer meeting is very important to them as she saw them wishing to be healed, and most of them trusting that as there is no cure for the disease, God is supreme and will heal them.

At the moment they all know what they need to know about HIV and they trust that at the right time God is able to heal them. This is the reason why the number of HIV-positive people attending the monthly prayer meeting continues to grow. The respondent pointed out that the joy she experienced in doing the HIV work, and especially in working with the Support Group, is from seeing people who are sick, down-hearted and depressed when you meet them the first time, but when you next meet them in the group they are more cheerful. They feel supported by each other and feel they are not alone in this journey.

On the issue of preaching about HIV when Thuli passed away, the respondent felt that this was very helpful to the Support Group and more so to the deceased family. This is because even though they knew that Thuli was HIV-positive, they had continued to live

in denial, and when CCP members visited their home, they would keep asking what was wrong with her. However, when it was preached about during the funeral service, this helped the whole family to come to terms with the reality of HIV.

### **Researcher's Personal Observation and Reflections**

The interview was conducted at the researcher's office on Friday 29<sup>th</sup> June 2007 at 11.00 a.m. The medium of communication was English. The respondent had signed the consent letter at the beginning of the Support Group. The respondent pointed out at the start of the interview that she was nervous as a result of some good news she had received just before coming for the appointment. However she felt that it was not going to affect the interview. She was passionate about the need to mobilise the traditional leaders to help reduce the silence of HIV caused by cultural factors.

## **APPENDIX 5C10: INTERVIEW WITH A PLWHA'S FAMILY MEMBER.**

### **Interview with a PLWHA's Family Member.**

The respondent is a 68-year-old woman. She is the mother of Thuli and has worked with CCP since 11<sup>th</sup> February 2003, the very day that the organisation started intervening in Thuli's health. She has participated in many of CCP's Community Analysis weekly programmes and attended the last few monthly prayer meetings before her daughter died. She has been attending PCF, the church that initiated CCP. The interview was to help the researcher understand how the CCP interventions has helped the family deal with the effects of AIDS and to understand the extent to which the family has broken the silence on HIV and AIDS.

*The researcher asked the respondent to explain how her family has benefited from the work that CCP is doing in the HIV situation the family finds itself in.* The respondent mentioned that she was so grateful to CCP and all the people who work there, and to the caregivers who have been trained in the community; for all that they have done for her family and herself. She recalled that when CCP came to her house three years before, it was because her daughter was dying of TB and could not walk at the time. But CCP made her daughter well and brought back joy into her life. Through CCP food was in the house and her children were educated when Bethany House paid the school fees. Even when her younger daughter was raped and the boys threatened to kill her, CCP arranged for her to be taken away to hide her from these boys and later arranged for a boarding school. CCP did the same for Thuli and hid her from the rapists and drug dealers. The respondent recounted that in all these, CCP provided for her as well. She mentioned that she was grateful to Bethany House for all of this, and especially for the funeral of Thuli, which will remain with them for a long time. She said it will be difficult to remember everything that has been done for the family by CCP. Through CCP everyone in the family and even the surrounding community now understand HIV.

*Asked how the respondent was feeling after the funeral her daughter,* she responded that all the people who came to the funeral are gone and she was feeling a bit confused

but she was 'alright'. She felt she needed more prayer to help her deal with the pain of losing Thuli. *When asked if there was anything about the funeral that encouraged her about her daughter*, she responded that since her daughter began going to church, she saw a big change in her and she started having friends who were helpful to her. All these people were at the funeral and everybody in the community was surprised about the kind of funeral they had.

*In terms of the openness of Thuli about her sickness*, the mother felt that her daughter did not hide her sickness, but told everyone about it. She felt Thuli was bold and she admires her for that. The researcher then said it was because of Thuli's boldness and openness that at the funeral we were able to break the silence and talk openly about the disease. However, he wanted to know *how she felt as a mother about this openness and about preaching on HIV and AIDS at the funeral*. Thuli's mother pointed out that she wasn't at all hurt about the openness about HIV at the funeral as she knew it was a big help for the young people who were there. She said that this is because people in the community know the disease to be young people's disease. Her problem was why Thuli did not tell her for such a long time and wondered why she did not personally come forward to tell her that she had the disease. The researcher then reminded the respondent that when the team came to help, Thuli had in fact disclosed her HIV status to her, Thuli told her that she did not want her to have heart attack. She then remembered and agreed that her daughter said she did not want her to have heart attack if she told her alone.

The mother said perhaps Thuli had wanted to find a way to tell her, except that she was afraid. Her daughter kept saying that she had TB and one day told her mother that a lady in their neighbourhood had AIDS and when she told her family members, she was rejected and sent away from the family. The mother said maybe her daughter felt she would be rejected and that is why she did not tell her. The mother recalled that Thuli often told her about anything she saw about the disease on TV.

*When asked, with all that has happened, how the family now understands HIV and AIDS*, the respondent said that she has never understood the disease. She felt that the disease is explained differently by different people. She said this is the reason why she

and her daughter had tried with the *Sangomas*. She overheard people say that the *Sangomas* have medication for the disease. She pointed out that one day at the clinic, they were talking about condoms as the “thing” you need to prevent the disease, “We were asked to take some for my children, but I did not take any.” She said this is because they used to distribute condoms inside the Echo Newspaper and when she asked Thuli what they were she could not tell her. She has seen children playing with these same condoms and filling them with tap water. She wondered in which way this could prevent such a deadly disease. She felt that the HIV and AIDS information comes in bits and pieces. She said her elder daughter had mentioned to her that she did not understand HIV until she went for the ARV training two weeks before with Thuli when she was alive. But from the training her elder daughter explained to her that she (i.e. the daughter) has come to know that HIV is a serious disease that affects all people and people have to love people with HIV or AIDS. Her daughter also explained to her that the condom is used when one is sleeping with another person and then it prevents the one from getting HIV. She is happy that now the family knows more about the disease. She sees no reason to go for an HIV test at her age, especially as she is not sick and not suspicious of having been infected by her daughter.

*When the respondent was asked if the personal experience of HIV and AIDS has changed any of their cultural beliefs and practices*, she said that now, as a family, especially between her elder daughter and her, there is the ability to talk freely about any issue, especially issues to do with sex, which they could never before discuss because of cultural beliefs. She also felt that the gap that used to be there between her and the children has been closed. She noted that previously she and her daughter had never talked about anything to do with sex but now they all discuss it. She even made reference to the fact that the researcher as a man could come to her home with another young woman and speak to her, a “Gogo<sup>118</sup>” on issues of HIV and sex. She mentioned that would never have happened in her home for cultural reasons, but it is happening because of the HIV situation that they are in.

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118 “Gogo” is a Zulu word for an old lady or grandmother.

### **Researcher's personal observation and reflections.**

This interview followed a different set of questions that concentrated on the third question of the main research question: *Can the interventions provided by the Community Care Project suggest constructive ways of engaging with or breaking the silence around HIV and AIDS in the Pietermaritzburg area?* The interview took place on the 11<sup>th</sup> September 2006 at 15.15 p.m. at the respondent's home. The researcher went for the interview accompanied by one lady CCP staff member. The respondent was sitting on a mat with her elder daughter and a relative who had come for the funeral from the Gauteng Province. The respondent preferred the researcher's questions that were asked in English to be translated into Zulu and so the CCP staff member was the interpreter. Even though the questions were targeted to the mother of Thuli, as the researcher told the other two that the questions were to be answered by the mother, every now and then the older daughter would remind the mother of the things she had forgotten. Also, if a question concerned the older daughter, she would help give the right answers. As the respondent was explaining how her family has benefited from the CCP's work, one could see mixed emotions in the countenance of the respondent. Sometimes one would see smiles on her face and other times a sorrowful face. When asked how she was feeling after the funeral, it was very difficult for her when she said "I feel lonely and I am missing my younger daughter who is at the moment in a boarding school". At this time, tears started coming and the CCP staff gave her some tissue to wipe her tears.

## **APPENDIX 5C11: INTERVIEW WITH A YOUTH.**

### **Interview with a Youth.**

The respondent is a 20-year-old girl who is a member of the CCP Youth Group. She is currently doing grade 10 and pointed out that most of the people she started school with are in the universities. She blames her present situation on the death of her mother three years before, due to HIV, and she having to suspend her schooling to take care of her three younger siblings, the last of which is sickly.

*Asked how the CCP interventions have helped her*, the respondent recounted that until she met with CCP; she was a very angry person and hated the people in her community, especially her neighbours who gossiped about her situation. To earn quick money, she started sleeping with people when her siblings were at school. In early 2006, she met the CCP team who had come to her church and preached about HIV and how people could be helped. She went to see the group and she was invited to go to Bethany House. The respondent said she agreed to the proposal by the CCP social worker to begin attending the Youth Group and to go with him to look for a school for her to attend as the new school year had just began. CCP paid her school fees and she started receiving food parcels for her family. She began the process of applying for a grant, which she got and they are now living on this.

*In terms of being able to talk openly about her HIV situation*, the respondent said it was through the gossip that goes on in the community that she heard that her mother was dying of HIV. Because of this, when her mother died, she was in denial and did not want to have any discussions on the topic. But when she joined the Youth Group, she realised that the group consisted of people who have been affected, and some who are infected, with HIV, who talk freely about the disease. Amongst the CCP team, she started building a relationship with the counsellor who later took her through bereavement counselling. The respondent said the counselling process made her open up and deal with all her fears and she began to have a new outlook on life.

As a result of the counselling and discussions on HIV in the Youth Group, the respondent saw the need to go for an HIV test, mainly because of the sex work she had been involved in. She said that the few minutes of the test for HIV were the most unpredictable moments she has ever been through. She knew she had a good chance of getting HIV, as in the sex work there were times when she did not use protection, because it paid more to go without. She counted herself blessed to be HIV-negative, even after a second test three months later.

When the researcher asked her *why it is difficult to talk about HIV and AIDS even amongst young friends*, the respondent said that most young people are scared to talk about it because of their sexually active life-style and being. The more one talks about the disease the more afraid one becomes if one is sexually active, and therefore young people would rather not discuss it at all. She believes there are other cultural beliefs that prevent people from talking about HIV. The major one being that the *Sangoma* can heal all diseases, including HIV, and so when people get HIV they don't want to tell anyone except the *Sangoma*. Young people especially keep their status from elderly people for fear of embarrassment, as they expect the elderly people to say to the young people 'I told you'.

### **Researcher's Personal Observation and Reflections**

This interview like Appendix 5C10 followed a different set of questions that concentrated on the third question of the main research question: *Can the interventions provided by the Community Care Project suggest constructive ways of engaging with or breaking the silence around HIV and AIDS in the Pietermaritzburg area?*

The interview took place at the CCP Youth Centre on Friday 8<sup>th</sup> June 2007 at 3.00 p.m. The interview was conducted in English. The respondent signed the consent letter before the interview. When the respondent was introducing herself and giving the background to her relationship with CCP, she was full of tears as she remembered the problems they were experiencing since her mother became sick and died. But you could see the expression of joy in her face as she talked about the breakthrough in her life and that of her siblings. She is grateful for the CCP interventions in her life.

**APPENDIX 5D: PASTORS AND CHURCH LEADERS QUESTIONNAIRE**

PASTORS AND CHURCH LEADERS QUESTIONNAIRE – CONFIDENTIAL NO.

Introduction: Thank you for participating in this survey, which is being administered through the Community Care Project to see how best we can deal with the issue of silence around HIV and AIDS. We appreciate your involvement. Please answer the questions as honestly as you can.

PLEASE TICK OR WRITE THE APPROPRIATE CHOICE WITHIN THE BOXES

**YOUR STATUS**

1. How old are you? Years
2. How long are you in ministry? Years
3. What is your Gender? 

Male	Female
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4. Have you done an HIV Test before? Years
5. What made you go for an HIV test? .....
6. Have you personally told anyone your HIV results? 

Yes	No
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  - a) If your answer above is yes, how long after your test did you tell someone? Years
  - b) What relations do you have with this first person you disclosed your status to? (e.g. Father, Mother, Brother, Sister, Husband, Wife, Son Daughter, In Law, Friend etc.)
7. If people are HIV positive, what makes it difficult for them to tell people freely that they are HIV positive? .....
8. When we say people are keeping silent about HIV, apart from not talking about the disease, what do they do to keep the disease a secret? Consider:
  - a) The infected person himself .....
  - b) The family of the infected person, if they know .....
9. Do you know anyone in your congregation who is HIV positive?.....
10. How did you know about their status?.....
11. Why do you think people who are infected keep silent about their status within the church?.....

12. What can the Church in general do for people who are HIV positive for them to be open about their status?.....

COMMUNITIES – DIMENSIONS OF CULTURE

13. Do you think our culture contributes to the HIV and AIDS silence? 

Yes	No
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14. Which aspects of our culture contribute to the HIV and AIDS silence?  
.....

15. Do you think the unequal distribution of power in our culture and the hierarchical order of relationships such uncles and elders having authority to make decisions on behalf of the entire family, etc. contribute to silence on HIV and AIDS.

Yes	No
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16. In which ways does this Power Distance contribute to the HIV and AIDS silence?.....

17. Our culture is seen to make people have no fear for what happens tomorrow and so they are able to take risks. Do you think this behaviour contributes to the HIV and AIDS silence?

Yes	No
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18. In which ways does risk-taking behaviour contribute to the HIV and AIDS silence? .....

19. Our culture is a community-based one, where we nurture each other's interests (Ubuntu). Because of this, people are keen to know what is wrong with me even if I think it is private. Does this behaviour contribute to the HIV and AIDS silence?

Yes	No
-----	----

20. In which ways does our community nature contribute to the HIV and AIDS silence? .....

21. There is a big inequality between men and women in our traditions. Does this contribute to the HIV and AIDS silence? 

Yes	
-----	--

22. In which ways does inequality between men and women contribute to the HIV and AIDS silence? .....

23. Our culture is a caring culture and so people would like to know what is making you sick. Does this behaviour contribute to the silence around HIV and AIDS?

Yes	No
-----	----

24. In which ways does this caring nature contribute to the HIV and AIDS silence?.....

THANK YOU VERY MUCH FOR CONSENTING TO ANSWER THIS QUESTIONNAIRE. PLEASE SIGN

.....

## APPENDIX 5D1: DETAILED RESULTS OF PASTORS' QUESTIONNAIRE

### 1.0 QUESTIONNAIRE FOR PASTORS/LEADERS

Below are the detailed results of the questionnaire (See Appendix 5D) administered on Monday 16<sup>th</sup> of April 2007 to 10 pastors who work closely with the CCP:

#### 1.1 Closed Questions

##### *Question 1: How old are you?*

All ten respondents answered this question.

Age (Years)	Frequency (Number of Pastors/Leaders)	Percent
25-30	1	10.0
31-36	4	40.0
43-48	3	30.0
49-54	2	20.0
Total	10	100.0

**TABLE 5D1.1 – Pastors/Leaders Age**

Results:

The largest number (40%) of the pastors/leaders are in the 31-40 age group followed by 30% from the 43-48 age group.

##### *Question 2: How long have you been in the ministry?*

Response:

All ten respondents answered this question.

Period in ministry		Frequency (Number of Pastors/Leaders)	Percent	Valid Percent	Cumulative Percent
Valid	3 years	1	10.0	10.0	10.0
	4 years	2	20.0	20.0	30.0
	5 years	2	20.0	20.0	50.0
	7 years	1	10.0	10.0	60.0
	10 years	2	20.0	20.0	80.0
	13 years	1	10.0	10.0	90.0
	15 years	1	10.0	10.0	100.0
	Total	10	100.0	100.0	

**TABLE 5D1.2 – Period in ministry**

Results:

30% have less than 5 years' experience in the ministry. 50% have experience in the ministry, ranging between 5 years and 12 years. 20% have more than 12 years experience in ministry. All the pastors/leaders have three or more years experience in ministry and their experience covers the period of the research and the CCP interventions to the Support Group.

***Question 3: What is your Gender?***

Response:

All 10 pastors/leaders answered this question. 8 males and 2 females

Gender	Frequency (No. of pastor/leaders)	Percent
Male	8	80.0
Female	2	20.0
Total	10	100.0

**TABLE 5D1.3 – Pastors/Leaders' Gender**

Results:

80% males are in church leadership and 20% females are in church leadership. It can be noted that the church leadership is mainly male.

***Question 4: Have you done an HIV Test before?***

Response:

All 10 pastors/leaders answered this question.

Tested for HIV before		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	3	30.0	30.0	30.0
	Yes	7	70.0	70.0	100.0
	Total	10	100.0	100.0	

**TABLE 5D1.4 – General response to Pastors/Leaders HIV testing**

Gender respondent			Frequency	Percent	Valid Percent	Cumulative Percent
Male	Valid	No	3	37.5	37.5	37.5
		Yes	5	62.5	62.5	100.0
		Total	8	100.0	100.0	
Female	Valid	Yes	2	100.0	100.0	100.0

**TABLE 5D1.5 – Gender response to Pastors/Leaders HIV testing**

Results:

Five males and two females had done HIV Test before and three men had not.

70% of pastors/leaders had done HIV test before and 30% pastors/leaders had not done HIV test before. Of the male pastors/leaders who responded, 62.5% had been tested before and 37.5% had not had previously had a test done before. 100% of the female pastors/leaders had previously been tested.

***Question 6: Have you personally told anyone about your HIV results?***

Response:

Seven pastors/leaders responded

Results:

All of them told someone about their status (100%)

***Question 6a: How long after your test did you tell someone?***

Response:

Seven pastors/leaders responded

Time taken to disclose		Frequency (No. of pastors/leaders)	Percent	Valid Percent	Cumulative Percent
Valid	Same day	6	60.0	85.7	85.7
	Few days	1	10.0	14.3	100.0
	Total	7	70.0	100.0	
Missing	System	3	30.0		
Total		10	100.0		

**TABLE 5D1.6 – Time taken to disclose**

Results:

85.7% told someone on the same day and 14.3% told someone a few days later.

***Question 6b: What relations do you have with this first person you disclose your status to?***

Response:

Seven pastors/leaders responded

		Frequency	Percent	Valid Percent
Valid	sister	1	10.0	14.3
	husband	1	10.0	14.3
	wife	5	50.0	71.4
	Total	7	70.0	100.0
Missing	System	3	30.0	
Total		10	100.0	

**TABLE 5D1.7 – Person disclosed to**

Results:

85.7% disclosed to their spouses and 14.3% disclosed to a sister.

***Question 9: Do you know anyone in your congregation who is HIV-positive?***

Response:

6 pastors/leaders said Yes and 4 pastors/leaders said No

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	no	4	40.0	40.0	40.0
	yes	6	60.0	60.0	100.0
	Total	10	100.0	100.0	

**TABLE 5D1.8 – Response to knowing HIV-positive person in Church**

Results:

60% know someone who is HIV-positive in their congregation and 40% do not know anyone in their congregations who is positive.

***Question 13: Do you think our culture contributes to the HIV and AIDS silence?***

Response

9 pastors/leaders said Yes and 1 pastor/leader did not answer.

Gender respondent			Frequency	Percent	Valid Percent	Cumulative Percent
male	Valid	yes	7	87.5	100.0	100.0
	Missing	System	1	12.5		
	Total		8	100.0		
female	Valid	yes	2	100.0	100.0	100.0

**TABLE 5D1.9 –Response to culture contributing to HIV silence**

Results:

90% think their culture contributes to the HIV silence and 10% did not answer the question. The reason for not answering the question is not known. All who answered the questions, both males and females, believed that their culture contributes to the HIV silence.

***Question 15: Do you think the unequal distribution of power in our culture and the hierarchical order of relationships such as uncles and elders having authority to make decisions on behalf of the entire family, contributes to silence on HIV and AIDS.***

Response

9 pastors/leaders said Yes and 1 pastor/leader said No.

Gender respondent			Frequency	Percent	Valid Percent	Cumulative Percent
male	Valid	no	1	12.5	12.5	12.5
		yes	7	87.5	87.5	100.0
		Total	8	100.0	100.0	
female	Valid	yes	2	100.0	100.0	100.0

**TABLE 5D1.10 - Response to power distance contributing to HIV silence**

Results:

90% of pastors/leaders think that power distance contributes to the HIV silence and 10% do not think power distance contributes to the HIV silence. Of the males, 87.5% think that power distance contributes to the HIV silence, while 12.5% do not think this behaviour contributes to silence. But all of the women (100%) agree that power distance contributes to silence.

*.Question 17: Our culture is seen to make people have no fear for what happens tomorrow and so they are able to take risks. Do you think this behaviour contributes to the HIV and AIDS silence?*

Response

All 10 pastors/leaders said Yes.

Gender respondent			Frequency	Percent	Valid Percent	Cumulative Percent
Male	Valid	yes	8	100.0	100.0	100.0
Female	Valid	yes	2	100.0	100.0	100.0

**TABLE 5D1.11- Response to uncertainty avoidance contributing to HIV silence**

Results:

100% of pastors/leaders think that the risk-taking tendency in the culture (low uncertainty avoidance) contributes to the HIV silence.

*Question 19: Our culture is a community-based one, where we seek each other's interests (Ubuntu). In this case people are keen to know what is wrong with me even if I think it is private. Does this behaviour contribute to the HIV and AIDS silence?*

Response

All 10 pastors/leaders said Yes.

Gender respondent			Frequency	Percent	Valid Percent	Cumulative Percent
Male	Valid	yes	8	100.0	100.0	100.0
Female	Valid	yes	2	100.0	100.0	100.0

**TABLE 5D1.12 - Response to collectivism contributing to HIV silence**

Results:

100% of pastors/leaders think that the community nature of the culture (collectivism) contributes to the HIV silence.

**Question 21: There is a big inequality between men and women in our traditions. Does this contribute to the HIV and AIDS silence?**

Response

All 10 pastors/leaders

Gender respondent			Frequency	Percent	Valid Percent	Cumulative Percent
male	Valid	yes	8	100.0	100.0	100.0
female	Valid	yes	2	100.0	100.0	100.0

**TABLE 5D1.13 - Response to gender inequality contributing to HIV silence**

Results:

100% of pastors/leaders think that gender inequality contributes to the HIV silence.

**Question 23: Our culture is a caring culture and so people would like to know what is making you sick. Does this behaviour contribute to the silence around HIV and AIDS?**

Response

All 10 pastors/leaders said Yes.

Gender respondent			Frequency	Percent	Valid Percent	Cumulative Percent
male	Valid	no	1	12.5	12.5	12.5
		yes	7	87.5	87.5	100.0
		Total	8	100.0	100.0	
female	Valid	yes	2	100.0	100.0	100.0

**TABLE 5D1.14 - Response to femininity contributing to HIV silence**

Results:

90% of pastors/leaders think the feminine nature of the African culture contributes to the HIV silence, while 10% do not think the feminine nature of the culture contributes to the HIV silence. Of the male pastors/leaders, 87.5% think the feminine nature of the African culture contributes to the HIV silence, while 12.5% do not think this behaviour contributes to silence. But all of the women (100%) agree that the feminine nature of the African culture contributes to silence.

## 1.2 Open-ended Questions

The respondents gave the following responses in their own words, but similar ideas are not repeated:

**Question 5: What made you go for an HIV test?**

- Wanted to know my status.
- For donating blood.

- I hadn't done one before because I needed to buy a house.
- I was very afraid of going for a test then I went because of my funeral policy, but I'm very glad that I went for a test because I now know my status.
- In the first instance, when I was nursing someone without using gloves; I began to suspect that I had it. The second test was voluntary.
- Firstly when I joined the insurance for life cover, secondly when I was getting married and thirdly when we bought a house.

***Question 7: If people are HIV-positive,, what makes it difficult for them to tell people freely of their status?***

- Fear of rejection and stigmatisation.
- At times the persons who are living with HIV are also trying to come to terms with their status and so are not ready to tell.
- It is because people don't want to understand that you are still the same person.
- Not wanting to be treated as if the infected person is dirty.
- Most people are not educated properly about HIV and they tell lies about others they know to be HIV-positive.
- It is because of the stigma, many people are scared of being rejected by someone.
- Fear of stigmatisation and negative reactions from people.
- They fear that everybody will reject them.

***Question 8a: When we say people are keeping silent about HIV, apart from not talking about the disease, what do they do to keep the disease a secret? Consider the infected person himself:***

- When the person becomes sick he/she will say that someone bewitched him/her.
- The person tries to live like an uninfected person and present him/herself as if he/she doesn't have the disease; engaging in relationships and having unprotected sex in order to appear normal.
- The infected person avoids people, especially the neighbours, and also avoids discussing topics relating to HIV.

- The infected person tries to live a normal life as if nothing is wrong and pretends to get medication for other people ,or takes the medication and says it is for another illness.
- The person hides his/her medication.
- The person eats things that will make him/her not lose weight.
- The person may visit a “sangoma” and report that he/she has been bewitched.
- Tell people that they have eaten something poisonous.
- The one can tell the family to be silent if they happen to know.
- The person visits clinics or hospitals that are not in his/her areas of residence.
- The infected person avoids the company of others and avoids conversations that will lead to him/her saying something about HIV.
- The person lies about his/her sickness.

***Question 8b: When we say people are keeping silent about HIV, apart from not talking about the disease, what do they do to keep the disease a secret? Consider the family of the infected person, if they know:***

- The family will tell people that their family is bewitched, and that is why he/she is sick.
- Family members act as though the disease doesn't exist and refer to other diseases as the cause of the illness, just to distract people from associating it with HIV.
- Some family members will hide the sick person during the day but in the night, they will quietly take the sick family member to the traditional doctor.
- They give different reasons to end the suspicions of neighbours; they say that their child has been bewitched or they are called to become *Sangomas* or the sickness is caused by the ancestors.
- The family hides the person and does not tell anyone that the member is sick.
- When others ask what is wrong with the sick person, they blame the neighbours for witchcraft.
- The family tells the sick person to be silent.
- Family members avoid discussions with others about what is wrong with the HIV-positive member.

- The family members always want to answer questions about the sick member's health on behalf of that person. They accuse others of witchcraft.
- They lie to cover up of the sick person's HIV status.

***Question 10: How did you know about their status?***

- They disclosed to me as a minister
- Through the Support Group that we have started in the church
- Since I started been open about HIV in the church, those who are infected are open to me
- When I started showing love towards those in the church who are sick and started continuously praying for sick people after Benson visited the church, then they came and spoke to me.
- After my church members were invited to attend the CCP monthly HIV prayer meeting and these people saw that PLWHAs could come openly in front of the church to be prayed for, then people started coming to me to disclose their status and to ask for prayer.
- They came to speak to me after Pastor Benson and I openly prayed for people in the church.
- A family member in my church who disclosed to the entire family

***Question 11: Why do you think people in the church who are infected keep silent about their status within the church?***

- They are afraid that they will be rejected by the church.
- They think people judge them.
- For fear that other church members will stigmatise against them.
- People in the church are too quick to judge.
- They fear that if they disclose their status, they will lose face in the church for being sexually immoral.
- They fear the loss of friends.
- Because they feel that if they told anyone at all in the church, there is no help put in place in the church for them.
- Afraid of what people will think

***Question 12: What can the Church in general do for people who are HIV-positive for them to be open about their status?***

- The church should encourage members to love people who are HIV-positive and teach members not to be judgmental.
- Pastors must teach about the disease to help people understand it.
- Set up Church programmes to help HIV-infected people.
- Preach about HIV, not in a judgemental manner but showing church members that people with HIV must be made welcome.
- The church should encourage members to reach out to people infected with HIV.
- The church must put in place programmes that educate members about HIV and teach them to be more caring.
- Church programmes must help HIV-infected people to trust the church and to build good relationships with other members.
- Treat HIV-infected people like everyone else

***Question 14: Which aspects of our culture contribute to the HIV Silence?***

- The lack of openness on sexual matters.
- The association of all things relating to an intimate relationship to taboo.
- The consideration of HIV and AIDS as taboo, for which reason people are still refusing to believe that AIDS is real and when they realise that someone has it, they don't want anything to do with that person.
- The culture does not allow young people to talk about everything with the elders.
- Men are allowed to sleep around with as many women as they want.
- When men have sexual diseases it is considered normal but when a girl/woman has any sexual disease, she is considered promiscuous.
- People think HIV and AIDS is for people who are promiscuous, such as prostitutes.
- The culture in itself is a secretive one. It is not open to the sharing of information, especially anything to do with sex.
- There are so many taboos which do not help people to be open.

***Question 16: In which ways does this Power Distance contribute to HIV silence?***

- Young people are restricted by the elders as to how much information one can share, and so when one is HIV-positive one cannot just tell people without the elders knowing, as that would be undermining the authority of the elders.
- When one has been conditioned by the elders, who have the power, not to openly discuss things relating to sex, it is difficult for one to bring out into the open that the one has got a sexual disease called HIV.
- People get kicked out of homes when they are discovered by those in authority in their families to be HIV-positive. This is something that most people who are infected are aware of and so infected people will not disclose their status to their families for fear of being kicked out of the house.
- All children fear the elders as they have said that the children could only listen to them, but not say anything.
- It might bring disgrace in a family. People will not be accepted in their own families.
- The elders and the elderly have more power, so one is afraid to disclose one's status only to be told that they must confess before their entire family and be disgraced.

***Question 18: In which ways does risk-taking behaviour contribute to the HIV and AIDS silence?***

- The risky nature of the culture makes people keep their status to themselves and not to seek help, in the hope that things will change for the better for them.
- Because people in poverty do everything to get money, even if it risks their lives, that does not matter to them.
- Because in our culture people take risks and are not afraid of what will happen tomorrow.
- When people are told that they are HIV-positive, there is a fatalistic attitude of saying 'everyone will die anyway, so what can I do? Let things sort themselves out'.

- When people are accustomed to taking risks, they do not realise there are consequences to decisions they make, and so when people get HIV they do not want to appear as a foolish risk-taker and so they keep silent.
- If a person has been taking risks and does not make plans for his/her life in the areas of insurance, pension and other schemes, and they get HIV, they keep silent lest they are questioned about their plans for their families.

***Question 20: In which ways does the community nature of our culture contribute to the HIV and AIDS silence?***

- The community nature means getting the entire community to know what is going on, and in the case of HIV and AIDS there is fear and a lack of understanding of the disease, and so it makes people gossip and stigmatise the infected person. Because of this nature of the culture, infected people avoid informing others about their status.
- Since there is stigma in our community, it becomes difficult for people to disclose their status to anyone, knowing they will be rejected from the community s/he has been part of.
- Our culture, being community-based in nature, fuels gossip, especially amongst women, and so when one person knows about someone else's status, then the whole community will know about it. This leads to infected people keeping silent over their status.
- Because of improper education on HIV in the community, people end up exaggerating information or give their own incorrect versions of the story to others, and when people are discussing someone's HIV situation it looks bad and hopeless. People who are infected will not want open themselves to such ill-treatment and keep silent.
- They said people need to mind their own business, also because people are not sufficiently educated about HIV.
- The community nature has no room for confidentiality and so for HIV-positive people the only way is to remain silent about their status.

- Our community nature makes people free to approach you for you to tell them your private issues, especially when they are suspicious of your health, and that puts pressure on an HIV-positive person.

***Question 22: In which ways does inequality between men and women contribute to the HIV and AIDS silence?***

- Because of the unequal balance of power between men and women within the African culture, if a husband says to his wife not to tell anyone that she is HIV-positive, the woman will keep silent even if she desires to make her status known.
- Women usually feel threatened to disclose their status for fear of being blamed by men for bringing in the disease.
- Within a marriage situation or in relationships, as a result of the power men have, when women discover they are HIV-positive they are scared to tell their husbands because they could be physically and verbally abused.
- Women in particular are always suspected to be the carriers of the virus and so they keep their status secret in order not to be punished by boyfriends and husbands.

***Question 24: In which ways does the 'caring nature' contribute to the HIV and AIDS silence?***

- One is always certain that once you tell your neighbour, he/she will tell others.
- Because of fear and lack of understanding of HIV, when people are caring for a sick person and they get to know s/he is HIV-positive, the caring nature turns into gossip. In this way it is best that the infected person keeps quiet.
- Although the culture promotes caring for each other, we don't go asking about other peoples business because it affects their pride.
- People, especially family members, would always want to care for anyone who is sick, but because of the stigma attached to HIV, when they know your status, they share the information with others so that they can be careful of associating with you. No one keeps silent.

**APPENDIX 5E: CHURCH TRAINEES/CAREGIVERS QUESTIONNAIRE**

CHURCH TRAINEES/CAREGIVERS QUESTIONNAIRE – CONFIDENTIAL

NO.
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Introduction: Thank you for participating in this survey, which is being administered through the Community Care Project to see how best we can deal with silence around HIV and AIDS. We appreciate your involvement. Please answer the questions as honestly as you can.

PLEASE TICK OR WRITE THE APPROPRIATE CHOICE WITHIN THE BOXES

**YOUR STATUS**

1. What is the name of your Church?
  
2. How old are you?
  
3. What is your Gender? 

Male	Female
------	--------
  
4. Who are you in the Church?
  
5. Have you had an HIV Test before? 

Yes	No
-----	----
  
6. What made you go for an HIV test?.....
  
7. Have you personally told anyone your HIV results? 

Yes	No
-----	----

  - a. If your answer above is yes, how long after your test did you tell someone?
  
  - b. What is your relationship with this first person you disclosed your status to? (e.g. Father, Mother, Brother, Sister, Husband, Wife, Son Daughter, In Law, Friend etc.)
  
  - c. What was this person's reaction?.....
  
  - d. How did you feel?.....
  
8. If people are HIV-positive, what makes it difficult for them to tell people freely? .....
  
9. When we say people are keeping silent about HIV, apart from not talking about the disease, what do they do to keep the disease a secret? Consider:
  - a. The infected person himself .....
  
  - b. The family of the infected person, if they know .....

10. What would change in your life if you were told that you are HIV positive?.....

#### THE CHURCH

11. Does your church have an HIV programme? 

Yes	No
-----	----
- a. Do the Church know which members are HIV positive? 

Yes	No
-----	----
- b. If the Church has an HIV and AIDS programme, what does it do?.....
- c. Why do you think people who are infected in the church keep silent about their status within the church?.....
- d. What can the Church do for people who are HIV-positive for them to be open about their status?.....

#### COMMUNITIES – DIMENSIONS OF CULTURE

12. Do you think culture contributes to the HIV and AIDS silence? 

Yes	No
-----	----
13. Which aspects of our culture contribute to the HIV and AIDS silence?  
.....
14. Do you think the unequal distribution of power in our culture and the hierarchical order of relationships such uncles and elders having authority to make decisions on behalf of the entire family, contribute to silence on HIV and AIDS?  

Yes	No
-----	----
15. In which ways does this Power Distance contribute to HIV and AIDS silence?.....
16. Our culture is seen to make people have no fear for what happens tomorrow and so they are able to take risks. Do you think this behaviour contributes to the HIV and AIDS silence? 

Yes	No
-----	----
17. In which ways does risk-taking behaviour contribute to the HIV and AIDS silence?
18. Our culture is a community-based one, where we nurture each other's interests (Ubuntu). Because of this, people are keen to know what is wrong with me even if I think it is private. Does this behaviour contribute to the HIV and AIDS silence?  

Yes	No
-----	----

19. In which ways does our community nature contribute to the HIV and AIDS silence? .....

20. There is a big inequality between men and women in our traditions. Does this contribute to the HIV and AIDS silence?

Yes	No
-----	----

21. In which ways does inequality between men and women contribute to the HIV and AIDS silence? .....

22. Our culture is a caring culture and so people would like to know what is making you sick. Does this behaviour contribute to the silence around HIV and AIDS?

Yes	No
-----	----

23. In which ways does this caring nature contribute to the HIV and AIDS silence?.....

THANK YOU VERY MUCH FOR CONSENTING TO ANSWER THIS QUESTIONNAIRE. PLEASE SIGN

.....

## APPENDIX 5E1: DETAILED RESULTS OF CHURCH TRAINEES QUESTIONNAIRE

### 1.0 QUESTIONNAIRE FOR CHURCH TRAINEES

Below are the detailed results of the questionnaire (See Appendix 5E) administered to 30 Trainees from 11 churches, who participated in group-administered questionnaires on Friday 11<sup>th</sup> May 2007 at Bethany House:

#### 1.1 Closed Questions

##### *Question 1: What is the name of your Church?*

Response:

30 respondents from 11 congregations

Results:

The churches include: Africa Evangelical Church (AEC), Apostolic Faith Mission (AFM), Bible Baptist Church (BBC) Breakthrough International Church (BIC), Duduza Care Centre (DCC), Entabeni Community Church (ECC), Methodist Church (MC), Pietermaritzburg Christian Fellowship (PCF), Pentecostal Holiness Union (PHU), Maritzburg Christian Church (MCC) and Solid Rock (SR).

##### *Question 2: How old are you?*

Response

All 30 respondents answered this question.

Age of respondent	Gender of respondent				Total		
	Male (No.)	%	Female (No.)	%	No.	%	Cumulative %
19-24	1	12.5	6	27.3	7	23.3	23.3
25-30	1	12.5	10	45.5	11	36.7	60.0
31-36	2	25.0	4	18.2	6	20.0	80.0
37-42	1	12.5	0	0	1	3.3	83.3
43-48	2	25.0	1	4.5	3	10.0	93.3
49-54	0	0	1	4.5	1	3.3	96.7
55-60	1	12.5	0	0	1	3.3	100.0
Total	8	100.0	22	100.0	30	100.0	

**TABLE 5E1.1 – Age of Church Trainees**

Results:

The majority of the Church Trainees (36.7%) were 25- 30 years old, comprising 12.5% of the male Church Trainees and 45.5% of the female Church Trainees. 80% of the Church Trainees were 19-36 years.

**Question 3: What is your Gender?**

Response:

All 30 Church trainees answered this question. 8 males and 22 females

Gender	Frequency (No. of pastor/leaders)	Percent
male	8	26.7
female	22	73.3
Total	30	100.0

**TABLE 5E1.2 – Gender of Church Trainees**

Results:

26.7% of the males and 73.3% of the females were ready to be trained as caregivers . The percentage of males ready to be trained indicates that the CCP awareness messages in the churches are bearing fruit as, usually, only females consider to be trained as caregivers. This is confirmed by the fact that all the caregivers are females (See Appendix 5F1 Question 3).

**Question 4: Who are you in the Church?**

Response:

All 30 Church trainees answered this question, i.e. 5 pastors, 3 other leaders and 22 church members.

Position in church		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	member	21	70.0	70.0	70.0
	elder	2	6.7	6.7	76.7
	pastor	5	16.7	16.7	93.3
	senior leader	1	3.3	3.3	96.7
	youth leader	1	3.3	3.3	100.0
	<b>Total</b>	<b>30</b>	<b>100.0</b>	<b>100.0</b>	

**TABLE 5E1.3 – Position of Church Trainee**

Results:

16.7% of the pastors, 13.3% of other church leaders and 70% of church members were ready to be trained as caregivers. To get 30% of trainees as church leaders willing to be trained as caregivers in the church and community confirms that the CCP awareness messages are bearing fruit.

**Question 5: Have you done an HIV Test before?**

Response:

All 30 Church trainees answered this question. 18 (4 males and 14 females) have had an HIV test before and 12 (4 males and 8 females) had not been tested.

Age of respondent	HIV test done				Total in age group	% age group in training
	No	% No in age group	Yes	% Yes in age Group		
19-24	4	57.1	3	42.9	7	23.3
25-30	3	27.3	8	72.7	11	36.7
31-36	3	50.0	3	50.0	6	20.0
37-42	0	0	1	100	1	3.3
43-48	0	0	3	100	3	10.0
49-54	1	100	0	0	1	3.3
55-60	1	100	0	0	1	3.3
Total	12	40	18	60	30	100.0

**TABLE 5E1.4 – Test in terms of age of respondents**

		HIV test done				Total
		No	% No	Yes	% Yes	
Gender of respondent	Male	4	50	4	50	8
	Female	8	36.4	14	63.6	22
Total		12	40	18	60	30

**TABLE 5E1.5 – Test in terms of gender of respondent**

Results:

Over-all, 60% of respondents had been HIV-tested before and 40% had not been HIV-tested. Of the male church trainees, 50% had an HIV test done before and 50% had not been tested, while 63.6% of the female church trainees had been tested and 36.4% of female church trainees had never been HIV-tested. In terms of age, 100% of the age

group 37-42 years, had been tested. In the age group of 25-30 years, which was the largest number of people being trained (36.7%), 72.7% had undergone an HIV test, followed by the 31-36-year-old group (50%) and in the 43-48 year-old group with 66.7% having undergone the HIV test.

***Question 7: Have you personally told anyone about your HIV results?***

Response:

Eighteen Church trainees who had undergone the HIV test answered this question. Seventeen had disclosed their status to someone and only one had remained silent.

		Frequency	Percent	Valid Percent
Valid	no	1	3.3	5.6
	yes	17	56.7	94.4
	Total	18	60.0	100.0
Missing	System	12	40.0	
Total		30	100.0	

**TABLE 5E1.6 – Response to disclosure**

Results:

94.4% disclosed their HIV status to other people and 5.6% did not disclose their HIV status to anyone.

***Question 7a: How long after your test did you tell someone?***

Response:

16 Church trainees answered this question. 11 told someone on the same day of testing and 5 told someone a few days later.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	same day	11	36.7	68.8	68.8
	few days	5	16.7	31.3	100.0
	Total	16	53.3	100.0	
Missing	System	14	46.7		
Total		30	100.0		

**TABLE 5E1.7 – Period taken to disclose**

Results:

68.8% told someone on the same day and 31.3% told someone a few days later.

***Question 7b: What relations do you have with this first person you disclose your status to?***

Response:

15 Church trainees answered this question.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Sister	4	13.3	26.7	26.7
	Husband	2	6.7	13.3	40.0
	Wife	3	10.0	20.0	60.0
	Boyfriend	1	3.3	6.7	66.7
	Friend	3	10.0	20.0	86.7
	Sister in law	1	3.3	6.7	93.3
	Others	1	3.3	6.7	100.0
	Total	15	50.0	100.0	
Missing	System	15	50.0		
Total		30	100.0		

**TABLE 5E1.8 – Response to relations with person disclosed to**

Results:

33.3% disclosed to their spouses, 26.7% disclosed to their sisters, 20% disclosed to their friends, 6.7% disclosed to their boyfriends, 6.7% disclosed to their sisters-in-law and 6.7% disclosed to others.

***Question 11: Does your church have an HIV programme?***

Response:

All 30 respondents answered this question. Six Church trainees said that their Churches have HIV programmes and 24 Church trainees said their churches do not have HIV programmes

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	24	80.0	80.0	80.0
	Yes	6	20.0	20.0	100.0
	Total	30	100.0	100.0	

**TABLE 5E1.9 – Response to Church having HIV programmes**

Results:

20% of Church trainees said their churches have HIV programmes and 80% said their Churches do not have HIV programmes.

***Question 11a: Does the Church know people which of their members are HIV-positive?***

Response:

Of the Church trainees, 28 answered this question. 9 trainees said that the church knows which of their people are HIV-positive, whilst 19 said their churches do not know which of their members are HIV-positive.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	19	63.3	67.9	67.9
	Yes	9	30.0	32.1	100.0
	Total	28	93.3	100.0	
Missing	System	2	6.7		
Total		30	100.0		

**TABLE 5E1.10 – Response to Church knowing HIV-positive persons in them**

Results:

Of the respondents who answered the question 32.1 % said their churches know those who are HIV-positive, whilst 67.9 % said their churches do not know those who are HIV-positive.

***Question 12: Do you think our culture contributes to the HIV and AIDS silence?***

Response

All 30 respondents answered this question: 21 Church trainees said Yes and 9 said No.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	9	30.0	30.0	30.0
	Yes	21	70.0	70.0	100.0
	Total	30	100.0	100.0	

**TABLE 5E1.11 – Response to culture contributing to HIV silence**

Results:

70% of respondents think their culture contributes to the HIV silence and 30% do not think their culture contributes to the HIV silence.

***Question 14: Do you think the unequal distribution of power in our culture and the hierarchical order of relationships, such uncles and elders having authority to make decisions on behalf of the entire family, contributes to silence on HIV and AIDS?***

Response

28 respondents answered this question. 23 said Yes and 5 said No.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	5	16.7	17.9	17.9
	Yes	23	76.7	82.1	100.0
	Total	28	93.3	100.0	
Missing	System	2	6.7		
Total		30	100.0		

**TABLE 5E1.12 – Response to power distance contributing to HIV silence**

Results:

82.1% think power distance does contribute to the HIV silence and 17.9% consider that it does not contribute to the silence

***Question 16: Our culture is seen to make people have no fear for what happens tomorrow and so they are able to take risks. Do you think this behaviour contributes to the HIV and AIDS silence?***

Response

All 30 Church trainees said Yes.

Results:

100% of the Church trainees think that uncertainty avoidance contributes to the HIV silence.

**Question 18: Our culture is community- based, where we nurture each other's interests (Ubuntu). Because of this, people are keen to know what is wrong with me even if I think it is private. Does this behaviour contribute to the HIV and AIDS silence?**

Response

29 respondents answered this question. 27 respondents said Yes and 2 respondents said No.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	2	6.7	6.9	6.9
	Yes	27	90.0	93.1	100.0
	Total	29	96.7	100.0	
Missing	System	1	3.3		
Total		30	100.0		

**TABLE 5E1.13 – Response to collectivity contributing to HIV silence**

Results:

93.1% agree that collectivism contributes to the HIV silence and 6.9% do not think that this has any bearing.

**Question 20: There is much inequality between men and women in our traditions. Does this contribute to the HIV and AIDS silence?**

Response:

All 30 respondents answered this question. Of the Church trainees 27 said Yes and three said No.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	3	10.0	10.0	10.0
	Yes	27	90.0	90.0	100.0
	Total	30	100.0	100.0	

**TABLE 5E1.14 – Response to gender inequality contributing to HIV silence**

Results:

Amongst these respondents, 90% agree that gender inequality contributes to the HIV silence, but 10% do not agree.

***Question 22: Our culture is a caring culture, and so people would like to know what is making you sick. Does this behaviour contribute to the silence around HIV and AIDS?***

Response:

All 30 respondents answered this question. 24 Church trainees said Yes and 6 said No.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	6	20.0	20.0	20.0
	Yes	24	80.0	80.0	100.0
	Total	30	100.0	100.0	

**TABLE 5E1.15 – Response to Femininity contributing to HIV silence**

Results:

Of the respondents, 80% agree that the feminine nature of the African culture contributes to the HIV silence, and 20% do not agree.

## **1.2 Closed Questions**

The respondents gave the following responses in their own words, but similar ideas are not repeated:

***Question 6: What made you go for an HIV test, or why did you not go?***

- I wanted to know my status because I was very sick and if I died my family would know.
- Out of fear and because I abstain from sex.
- I just wanted to know my status so that I can easily help people by knowing my own status, and as a care-giver I can't tell people to go for a test when I haven't done it myself.
- I was looking after my mother who was very ill because of AIDS; I didn't use gloves to look after her. Most of my family members who died I also cared for without using gloves.
- I wanted to know my status early so that I could manage my life, to be able to plan my life properly and to treat any disease accordingly.
- I was pregnant and wanted to protect my child.

- I wanted to know my status because I was helping my mother without wearing gloves, and then I found out that she was HIV-positive and she later died.
- Before marriage the church would need to know your status so I and my wife both went for a test before our wedding.
- Because I was pregnant I wanted to know my status.
- When I was married for second time, and again when I was pregnant.

***Question 7c: What was this person's reaction?***

- She said I was lying to her so she didn't believe me.
- He was very happy
- He was very supportive and he understood and he told me that we must go for another test in three months.
- She was happy
- He was shocked and asked me many questions, like why I did the test.
- She gave me advice to deal with my status.
- He was very happy because we discussed it before.
- She loved me and gave me good advice. She told me that it was not the end of my life and that I'm still going to survive.
- She was very happy for me and she told me that I had made a good decision. It's better now that I know my status.
- She was so excited because my result was negative.
- Everyone was so happy and said that it was normal for me as a Christian.
- They were happy to be able to go for the test.
- They were so excited to hear about my status because of what is happening around this world we are living in.

***Question 7d: How did you feel?***

- I felt free because at least someone knew my status and what was happening to me.
- I was excited. At first I was scared but then I was happy.
- I felt relieved.

- I was excited.
- Mixture, because they told me about the window period.
- I was so scared, but at the same time I felt relieved.
- I felt bad. I was crying in case I got the news that I'm HIV-positive.
- Very excited, I thanked God for his grace.
- Happy and responsible for my future.
- I felt well, even before the test, but a little bit nervous after the pre-counselling.
- I was very happy; I had to arrange the way of how to behave.
- I am very relieved.
- I am so happy and feel more power in me.

***Question 8: If people are HIV-positive, what makes it difficult for them to freely tell people ?***

- It is because if you tell people that you are HIV-positive they don't like you any more, and they treat you like animal.
- Because they know that if they tell people, they will gossip about them and others will not want associate with them.
- They are afraid of rejection and of people running away from them.
- Because they are afraid of being judged and some are even afraid of being rejected by their families.
- I think it is because of the attitude that the disease is mostly a sexually transmitted one and so in some ways people see the disease as one for promiscuous people.
- People might judge you wrongly, and you could even lose friends and face rejection and not be loved.
- People will gossip about you, and reject and stay away from you, believing that you have a sickness for sexually active people.
- I think it is through the stigma and the fear of the past behaviour of people.
- It is because of people's reactions, and when they laugh at you. This makes people keep their status secret.
- They worry about rejection, stigmatisation and being judged.
- It is because people make their own judgment about the HIV-positive person.

- People around you think that you're a sinner and that you're naughty.
- They are ashamed of being isolated and unloved by people around them; they are also scared to die, because of the long suffering.
- Some of them are afraid of their family and that they will be chased away or the family will end up laughing at them.
- They are afraid of the reaction of people don't know about HIV and only know lies about the disease and don't seek education about the disease.
- The stigma that the community have about people who are HIV-positive, so they don't want to be rejected.
- People with HIV think if you have this virus, you are different from others and they are scared that people will laugh at them and start neglecting them. They don't want to be left out.
- They fear that people may laugh at them and reject them from the society.
- They feel they cannot cope with the additional stress that will come upon them.
- They think they will become a laughing stock and people will not accept them, nor talk to them but talk about them.

***Question 9a: When we say people are keeping silent about HIV, apart from not talking about the disease, what do they do to keep the disease a secret? Consider the infected person himself:***

- They work hard and get disciplined, so that they don't fall seriously sick to make the disease obvious, by going to the gym, eating a balanced diet and taking medication regularly.
- The people try healthy living and live positively by learning to accept their condition.
- I take care of myself; eat balanced food, and take my medication timely so that I don't lose weight.
- People do not go to the clinics in their communities for check ups, medication, or ARVs , because in these clinics, there are many people who they know and may be asking leading questions and suspect they are HIV-positive.
- They go to private doctors and not public clinics.

- Some do not leave their homes and keep themselves locked in.
- They pretend everything is normal and keep on doing things as they always do that affect their health, e.g. sleeping around, drinking alcohol, using drugs etc.
- They try hard to live a normal life, just as they did before they found out their status and they believe that they are normal people, like everyone else.
- They go to the clinic and take their medication at the right time.
- They try to hide behind other opportunistic diseases and when they have a serious illness that they cannot hide, then they accuse people of bewitching them and lie about their status.
- He or she will continue having sexual relationships with his or her partner without using a condom in order not to be suspected.
- It is shameful and the sickness will multiply.

***Question 9b: When we say people are keeping silent about HIV, apart from not talking about the disease, what do they do to keep the disease a secret? Consider the family of the infected person, if they know:***

- If the sick person has got children they look after them carefully and warn them, if they already know the parent is sick, not to talk about their parent's sickness to anyone.
- They don't tell anyone out side of the family about the disease and try to protect the sick person from being seen by other people and provide care for the sick person.
- They will not tell anyone even the children in their own homes.
- They will make sure that they keep the sick person in the house and not let anyone come and see him or her.
- The family don't talk about your status and even if you tell them that you want to go public about your status they tell you not to do that and remind you that you will put the family's name to shame.
- If the family has medical aid, they allow the sick person to use private hospitals where very few people from their community may attend and cannot ask questions if they do visit the sick person there.

- They do not allow him or her to go out and tell them that it is bad to tell the community.
- They look after that person by providing him with balanced food and also making sure he's always clean. If he takes medication they make sure he takes it according to the doctor's instruction.
- They will just say that the infected person is suffering from something else rather than mentioning HIV and with the backing of the African culture say that the infected one has been bewitched.
- When the sick person gets seriously sick that will make people suspect HIV, and they withdraw the sick person from the community and send the person to a relative or family member or a *Sangoma*, away from home, from the eyes of other people.
- Initially family members get angry with the person but later accept the situation and hide the person through many ways such as locking up the person, sending the person away to the village, etc.
- Some families even tell HIV-positive persons not to tell anyone about their status because having HIV is a disgrace and they are afraid of what the community will say about the family. In this way they force the sick person to be silent.

***Question 10: What would change in your life if you were told that you are HIV-positive?***

- I would look after myself better and take my medication regularly as instructed by the doctors.
- I will not sleep around and abstain from sex.
- I will look after my children better.
- My attitudes will change, more especially towards those who are HIV-positive.
- I will make sure that I protect my family to prevent them from becoming HIV-positive as well.
- I would change the way I do things, like sleeping around, my attitude to other people, the way I eat, will all change.
- I would change my lifestyle and live positively.

- The way I used to live would change – I would practice self-control, take precautions about prescriptions I have been given etc.
- I will try to eat and live healthily and do some exercise.
- I will try to have more knowledge about the virus and the disease and change my sex life.
- I will think about the people who need me and love me and have a good relationship with them.
- I would change my way of eating and believe in myself.
- My lifestyle – the way I am living and handling myself.
- Accept and forgive myself and not judge people.
- I will change my attitude of blaming other people and begin to take responsibility.
- My sexual life and my attitude towards life will change.
- I would have to readjust my life-style, plan for the future and get a Support Group to help me cope with life.
- I will change my life and take HIV seriously and begin to share the HIV and AIDS information with others.
- My way of living or my lifestyle, the way I worship GOD, sit back and plan for the years that I have still to live on earth.
- Almost everything would change because I would have to make sure I do not infect anyone with HIV and I will have to eat healthy food to keep me at the same stage.
- My life will change. I will not be happy and I will think about death.
- I will practice positive living every day but I would let everyone know.
- My attitude towards death will change and begin to understand that death is near and not too far away.
- The way I manage myself will change in terms of physical exercise, control of my nutrition etc.

***Question 11b: If the Church has an HIV and AIDS programme, what does it do?***

- It gives people food and hope.
- The church is helping to train its members in HIV so that they can help others and teach them about the virus and disease.

- It takes care of HIV-positive persons.
- The church has started a Support Group for HIV-positive people to share and advise each other about their problems.
- We visit, counsel, bath, pray, send food parcels and feed those who are sick as a result of HIV.
- The people who are HIV -positive and are part of our Support Group, are normally asked to come to the front of church and they testify how they are feeling and how people are helping them. They encourage others that are HIV-positive but still remain silent to come out and join them and to know that there is hope for them.
- Training and caring for HIV-positive people, orphans etc
- The Church has a programme through which we do counselling and help those who are affected with HIV and AIDS.

***Question 11c: Why do you think people in the church who are infected keep silent about their status within the church?***

- Because they are afraid of being judged as sinners.
- It is because if they come out they will not feel loved by the others.
- It is because the church is not well taught about HIV and AIDS. So people in the church are just the same as people in the community with a lot of stigma inside the church.
- I think the church has pride of not associating with sinners and so if someone is HIV-positive, that person is seen as a sinner and does not deserve to be in a holy church.
- They think the church will make them feel they deserve their condition because of their sins.
- People keep silent because most of the times the church does not speak openly about being HIV-positive
- They are afraid that they are going to be treated badly with people avoiding them or stop loving them anymore.

- It is because once you tell people about your status you will face loneliness and rejection and no one wants to be with you in the church.
- They are scared that they won't be accepted by the church as they are now infected and yet they do not want to lose their church.
- They are afraid that people will reject them.
- They are scared of the stigma and judgment attached to the disease, which is also in the church.
- It is because of the mentality that those who are infected are sinners and therefore discriminated against in the church.
- They are scared of being seen as sinners, they are scared of being isolated and discriminated by the church.
- It can be that they do not trust the other people in the church.
- It is because there is no platform created in the church for them to have a chance to talk about it.
- It is because there is a lot of rejection in the community, which they see and feel, and they do not want to experience the same in the church when people realise they are HIV-positive.
- They are afraid that people will be angry with them and hate them.
- Fear of rejection from church, fear of being considered as a sinner.
- People are ashamed of HIV-positive people as people living in sin, and they believe that when we are coming to church we become new creatures, all the sins are gone.
- People will start gossiping about you as HIV-positive and are scared to touch you and find it shameful to associate with you.
- People will force you to come forward for prayer as they believe that in church you could be healed.

***Question 11d: What can the Church do for people who are HIV-positive for them to be open about their status?***

- Have HIV programmes that teach people to understand HIV and AIDS.
- Members of the church must have more knowledge and skills on HIV so that they can teach others to be considerate to people infected.

- Encouraging infected people they know, help them spiritually, pray for them and love them so that others will see and long to be treated in a similar way.
- I think every Sunday there must be time to talk about HIV openly to everyone.
- Teach members and tell them the truth about HIV so that they know it's not the end of their lives to have HIV.
- The church must talk about HIV and AIDS so that people must be open about it.
- They have to encourage people by telling them that there is hope.
- The church must teach those who are not infected not to judge those who are, to make them feel comfortable and welcome.
- Members must be taught to give love to those infected.
- It should encourage people to go for HIV testing, as the process is able to change people's attitude towards the disease.
- The church should show love as well as caring, it is also important to avoid judgments.
- It must show the genuine love and to be ready to help HIV-positive people.
- The church must behave different from what happens in the community and take care for those who are infected and feel rejected and discriminated by their families and communities.
- The church can try to educate members about the importance of taking care of HIV-positive people in church and outside the church.
- The church should talk or preach about HIV in the church and encourage the people to go for testing.
- Initiate workshops where people will learn and discuss about HIV freely and openly and raise people who can teach about HIV.
- There must be a counselling team in the church and Support Group.
- The church can help them, they can pray for them not to be scared. They can give hope to them.
- The church should organise HIV programmes to give HIV people hope that HIV is not a matter of death but they can manage it by having a healthy balanced diet and taking medication.

- There should be education in the church about HIV and AIDS so that it will remove fear from members, which makes them ill-treat and mishandle HIV-positive people, and so that members will not be afraid.
- To educate church members and to organise conferences about HIV and AIDS so that fighting the disease in all forms becomes the fibre of the church.

***Question 13: Which aspects of our culture contribute to the HIV Silence?***

- For example in Xhosa culture for circumcision they usually use one sharp object without sterilising. If people get HIV through this process, they cannot tell anyone.
- In our culture there are certain things you do that put shame on the people in your family and HIV is seen as one of them. Therefore, if you are HIV-positive at times it looks like you have put shame on your family.
- Our culture does not allow us to talk about [disclose] everything with our elders or publicly, especially issues with sex. Since HIV is more to do with sex, Africans feel ashamed to talk about it.
- In our culture, your parents choose who they want you to marry without pushing that person to have an HIV test.
- People are judgmental and unsupportive and so if one is infected, one stays silent.
- The old cultural tendency of the elders in choosing our husbands is still at work and yet they fail to encourage people to go for HIV testing because of lack of education on one side and fear of shame on the other.
- The culture does not allow women to speak in public without men's permission. Because men rarely give permission, there is always silence from women even when dying of HIV.
- Women have no say in the house even when the men come late or sleep around, it is a taboo to talk to him about where he has been.
- Our culture always looks for the bad people to reject and isolate them. Unfortunately when HIV came; infected people were grouped into this bad side and face rejection and isolation from the community and people.

- Our culture always groups people with STIs as prostitutes and so when you are HIV-positive people think of you as a prostitute, which carries a bad connotation of shame and filth.
- In our culture any incurable disease is linked with a curse and punishment from the ancestors and if you have such a disease, people will not associate with you and you become lonely. This is how the culture sees HIV until it becomes curable.

***Question 15: In which ways does this Power Distance contribute to HIV silence?***

- Some children are scared of their mothers about HIV and AIDS because our culture does not allow children to discuss issues such as sex and for that matter HIV with parents.
- The ignorance of HIV and AIDS amongst our community leaders who exercise power, as well as the lack of education about HIV and AIDS in the community as a whole, scares HIV-positive people and contributes to silence on the disease.
- The elders do not talk about HIV because they relate it to promiscuity which the culture forbids. In this case infected people will not want to be seen as promiscuous so they keep silent as the elders will reprimand them.
- All children fear to talk as in the culture it is only the elders that have the right to say something.
- The hierarchical nature of our culture does not encourage young people to be open to their parents or elders in the family and so when one is infected with HIV, especially the youth, one finds it very difficult to talk to the parents or elders about it.
- Normally because in our communities HIV has shame to it, infected people cannot just talk about their status until authority is sought from those with power in the family.
- Whatever decision that is made by the uncles or elders is final and cannot be challenged. Usually when people are infected and it is known in the family, uncles and elders decide what has to be done about the situation but public disclosure is out of the question. Rather decisions are made to refer the HIV-positive person to the traditional doctor.

- The way people have to respect the elders by following their choices and decisions rather than following individual people's choices and decisions.
- Because your parents have the authority and power to say you must keep quiet you don't have any choice but to respect them and keep silent about your HIV-positive status.
- Elders have the authority to punish people when they think you disrespect them or disobey them, and punishment from the elders and uncles brings disgrace to individuals and families and so for this reason people who are HIV-positive will always keep silent in the family.
- I am dependent on my family and under their authority. If I speak to them about my status, they will reject me and stay away from me for bringing shame to undermine the family.

***Question 17: In which ways does risk-taking behaviour contribute to the HIV and AIDS silence?***

- Risk-taking is part of our culture and it makes people think that situations will come and go naturally and in this case making people not taking precautions. When people get infected, even when they can get help, they keep silent about their status thinking the problem will go away, until the sickness overwhelms them and they are ashamed to tell anyone.
- People don't care about what is happening in their lives and take risks and so they don't go for VCT even when they know they are at risk. They are forced by the sickness to go for the test when nothing can be done about their situation. This is when they look stupid in their own eyes and ashamed to tell anyone about their situation.
- Poverty mentality also leads people to take risks in their lives and they end up infecting themselves with HIV and when they realise their life is at stake, then they keep silent and avoid anything that will make people question them about their lifestyle.
- Our people believe that you live for money and they are willing to do anything to get it and they risk becoming HIV-positive and when they realise that the money

- they got through sex work cannot cure them, they become ashamed and hide from friends and families, keeping silent on their HIV status.
- The risky nature of our culture makes infected people not to plan for their life and the future, once they know their status, by seeking help from others.
  - Families also take risks by keeping silent about the status of their HIV-positive members and not seeking proper help such as how to care properly for the sick member and they end up infecting each other.
  - Our culture is more oriented towards today than tomorrow and people don't think about tomorrow, they only think about what they can enjoy today. This means enjoying anything that come into people's lives including unprotected sex. It is when people are tested positive that they realise, they have fooled themselves and so become ashamed to expose their ignorance and wrong decisions.

***Question 19: In which ways does the community nature of our culture contribute to the HIV and AIDS silence?***

- People are always eager to help a person who is sick but because our community does not have enough skills and materials to cope with HIV issues, when people realise that your sickness is due to HIV, they consider you dead and are afraid to catch the sickness themselves. So they begin to isolate you and gossip about you. For this reason people who are HIV-positive will keep silent about their status.
- People are usually surprised to see others getting wasted because of sickness, as is the case of AIDS. This situation attracts more people coming to the sick person and showing care. But this situation makes the sick person become suspicious and does everything that will make people not confirm one's HIV status, such hiding medications, lying about what the doctors are saying and accusing others of witchcraft.
- In our community the only thing those elders know about HIV and AIDS is that you get it through indiscriminate sexual encounters, and so if you tell them you are positive they see you as an outcast who does not deserve to stay in the family and you will be chased. Some are even killed for their status.

***Question 21: In which ways does inequality between men and women contribute to the HIV and AIDS silence?***

- Men, because of this inequality, usually blame women as those who bring HIV into the relationship and so women keep silent about their status to avoid unnecessary punishment.
- Men keep silent about their status because they are the ones who use their power and masculinity to blame women all the time, for bringing HIV into the relationship. So they are afraid and ashamed to be told by their female partners that they have brought HIV into the relationship.
- In our culture, men are allowed to have more than one sexual partner, as a result of inequality, and they do it secretly and so when they become HIV-positive, they keep silent about and keep it secret as well from all the women they are in relationships with.
- In marriage situations, wives are scared of their husbands and every time a problem arises a wife is the one blamed. So even if the wife knows she is HIV-positive she will keep silent about it just to protect herself.
- It's because we always listen to our men but they treat us like children, they don't give us the opportunity to talk or listen to what the woman has to say and so we don't have any opportunity as women to disclose our HIV status.
- Women are powerless in their homes because of our culture; we believe that it is our husband who always must be respected and they keep a lot of secrets from us including their HIV status.
- Men who lead the family in our culture do not want to talk about the virus and that makes women scared to bring it up.
- Inequality in our culture between men and women makes women afraid of opening up about HIV, because men abuse them and beat them, and chase them out of the home when women disclose their HIV-positive status.
- The fear of rejection by men makes women keep silent as well as the fear of being accused to be the one who brought the disease.
- Only men have the authority to marry more than one wife. This causes the silence to women because they fear to be divorced because of disclosing.

- Normally men believe that they have more power than women and they own them so they have the right to do whatever they want to women. For example having sex with women at will is not a big deal for them. This behaviour of men makes them keep silent about their status when they are HIV-positive.
- Due to the inequality between men and women within marriage, the man keeps silent about his HIV status for fear of losing respect in the marriage and also in the community. The women also keep silent about their status for fear of being rejected by her husband for another woman

***Question 23: In which ways does this caring nature contribute to the HIV and AIDS silence?***

- The caring nature of the African culture makes people ready to offer care for the sick but in the process when they get to know that the sick person is HIV-positive, then they tell the whole community.
- So far as HIV is concerned, the caring nature of the community does not go with desire to learn more about the disease. In this case when people are caring for the infected person they do so ignorantly until they get to know that the person is infected with HIV and then because of lack of education, the person begins to talk to others seeking education and gossip begins. Knowing this, infected people would not want disclose their status.
- Our culture makes people have desire to help sick people and that desire also makes people compare diseases and talk to others to inquire about a *Sangoma* or a herbalist who has a cure for the disease that the person might be suffering from. It is this process of genuinely looking for help on behalf of the sick person that begins gossip especially if they know it is HIV.
- Unless people know right from the beginning that the patient they are helping is HIV-positive, people feel cheated when they learn that the patient they have been caring for is HIV-positive. They feel they are in danger of infection then they begin to withdraw, gossip, reject etc.
- In our culture HIV is considered shameful and a punishment from ancestors as it has no cure. Only diseases relating to curses do not have a cure and so the

moment people hear that you have an incurable disease, people begin to avoid you, even though the desire to care for you is in them. Until HIV has a cure, it will be related to diseases originating from curse. Until TB had a cure it was seen as a curse and people were isolated and discriminated against for having the disease.

## APPENDIX 5F1: DETAILED RESULTS OF CAREGIVERS QUESTIONNAIRE

### 1.0 QUESTIONNAIRE FOR CAREGIVERS

Below are the detailed results of the questionnaire (See Appendix 5E) administered to 12 Caregivers who were invited for training at Bethany House on Friday 25<sup>th</sup> May 2007 and participated in a group-administered questionnaire:

#### 1.1 Closed Questions

##### *Question 1: What is the name of your Church?*

Response:

12 respondents from 7 congregations

Results:

The churches include: Africa Evangelical Church (AEC), Duduza Care Centre (DCC), Full Gospel (FG), International Christian Brethren Church – Bethel (ICBC), Methodist Church (MC), Roman Catholic (RC) and Welcome Christian Fellowship (WCF)

##### *Question 2: How old are you?*

Response

All 12 respondents answered this question.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	19-24	3	25.0	25.0	25.0
	25-30	3	25.0	25.0	50.0
	31-36	2	16.7	16.7	66.7
	37-42	1	8.3	8.3	75.0
	43-48	1	8.3	8.3	83.3
	49-54	1	8.3	8.3	91.7
	61-66	1	8.3	8.3	100.0
	Total	12	100.0	100.0	

**TABLE 5F1.1 – Ages of Caregivers**

Results:

Of the Caregivers 25% were 19-24 years old, 25% were 25-30 years, 16.7% were 31-36 years, 8.3% were 37-42 years, 8.3% were 43-48 years, 8.3% were 49-54 years and 8.3% of Caregivers were between 61 and 66 years old.

**Question 3: What is your Gender?**

Response:

All 12 Caregivers answered this question. All caregivers were females

Results:

Caregivers active and working are all females.

**Question 4: Who are you in the Church?**

Response:

All 12 Caregivers answered this question: one elder and 11 church members.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Member	11	91.7	91.7	91.7
	Elder	1	8.3	8.3	100.0
	Total	12	100.0	100.0	

**TABLE 5F1.2 – Position of Caregiver in Church**

Results:

Only 8.3% of leaders work as Caregivers and 91.7% are church members who work as caregivers.

**Question 5: Have you done an HIV Test before?**

Response:

All 12 Caregivers answered this question. 8 respondents had been HIV-tested before and 4 had never been tested.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	4	33.3	33.3	33.3
	Yes	8	66.7	66.7	100.0
	Total	12	100.0	100.0	

**TABLE 5F1.3 – Respond to HIV Testing**

Results:

66.7 % of respondents had been tested before and 33.3 %of respondents had never been tested.

***Question 7: Have you personally told anyone about your HIV results?***

Response:

7 Caregivers answered this question. 6 had disclosed their status to someone and one had not.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	1	8.3	14.3	14.3
	Yes	6	50.0	85.7	100.0
	Total	7	58.3	100.0	
Missing	System	5	41.7		
Total		12	100.0		

**TABLE 5F1.4 – Respond to HIV test disclosure**

Results:

Of those who tested, 85.7% disclosed their HIV status to other people and 14.3% did not disclose their HIV status to anyone.

***Question 7a: How long after your test did you tell someone?***

Response:

6 Caregivers answered this question. 5 told someone on the same day of testing and one told someone a week later.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Same day	5	41.7	83.3	83.3
	Few days	1	8.3	16.7	100.0
	Total	6	50.0	100.0	
Missing	System	6	50.0		
Total		12	100.0		

**TABLE 5F1.5 – Period before disclosure**

Results:

83.3% told someone on the same day and 16.7% told someone a few days later.

**Question 7b: What relations do you have with the first person you disclosed your status to?**

Response:

6 Caregivers answered this question.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Sister	2	16.7	33.3	33.3
	Husband	1	8.3	16.7	50.0
	Boyfriend	1	8.3	16.7	66.7
	Friend	1	8.3	16.7	83.3
	Sister in law	1	8.3	16.7	100.0
	Total	6	50.0	100.0	
Missing	System	6	50.0		
Total		12	100.0		

**TABLE 5F1.6 – Relationship with Person disclosed to**

Results:

33.3% disclosed to their sisters, 16.7% disclosed to their husbands, 16.7% to their friends, 16.7% to their boyfriends and 16.6% disclosed to their sisters in-law.

**Question 11: Does your church have an HIV programme?**

Response:

10 respondents answered this question. 9 Caregivers said their Churches have HIV programmes and one Caregiver said her church does not conduct HIV programmes.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	1	8.3	10.0	10.0
	Yes	9	75.0	90.0	100.0
	Total	10	83.3	100.0	
Missing	System	2	16.7		
Total		12	100.0		

**TABLE 5F1.7 – Response to church having HIV programme**

Results:

Of the Caregivers, 90% said their churches have HIV programmes and 10% said their Churches do not have HIV programmes. It is important to note that most of the caregivers have HIV programmes in their churches. This is an important support to the caregivers.

***Question 11a: Does the Church know which people in their congregation are HIV-positive?***

Response:

11 Caregivers answered this question. 8 Caregivers said the church know which people are HIV-positive, whilst 3 said their churches do not know those who are HIV-positive amongst their congregationist.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	no	3	25.0	27.3	27.3
	yes	8	66.7	72.7	100.0
	Total	11	91.7	100.0	
Missing	System	1	8.3		
Total		12	100.0		

**TABLE 5F1.8 – Response to the church knowing PLWAs in them**

Results:

72.7% say their churches know those who are HIV-positive whilst 27.3% say their churches do not know those who are HIV-positive.

***Question 12: Do you think our culture contributes to the HIV and AIDS silence?***

Response

11 respondents answered this question. Nine Caregivers answered Yes and two answered No.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	2	16.7	18.2	18.2
	Yes	9	75.0	81.8	100.0
	Total	11	91.7	100.0	
Missing	System	1	8.3		
Total		12	100.0		

**TABLE 5F1.9 – Response to culture contributing to HIV and AIDS silence**

Results:

81.8% of respondents think their culture contributes to the HIV silence and 18.2% do not think their culture contributes to the HIV silence.

***Question 14: Do you think the unequal distribution of power in our culture and the hierarchical order of relationships, with people such as as uncles and elders having authority to make decisions on behalf of the entire family contribute to silence on HIV and AIDS.***

Response

11 respondents answered this question. and all said Yes.

Results:

100% think that power distance contributes to the HIV silence

***Question 16: Our culture is seen to make people have no fear for what happens tomorrow and so they are able to take risks. Do you think this behaviour contributes to the HIV and AIDS silence?***

Response

All 12 Caregivers answered this question. 11 answered Yes and one answered No.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	1	8.3	8.3	8.3
	Yes	11	91.7	91.7	100.0
	Total	12	100.0	100.0	

**TABLE 5F1.10 – Response to uncertainty avoidance contributing to HIV and AIDS silence**

Results:

91.7% of the Caregivers think that uncertainty avoidance contributes to the HIV silence and 8.3% think that uncertainty avoidance does not contribute to HIV silence.

***Question 18: Our culture is a community-based one, where we nurture each other's interests (Ubuntu). In this case people are keen to know what is wrong with me even if I think it is private. Does this behaviour contribute to the HIV and AIDS silence?***

Response

All 12 respondents answered this question. 10 respondents said Yes and 2 respondents said No.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	no	2	16.7	16.7	16.7
	yes	10	83.3	83.3	100.0
	Total	12	100.0	100.0	

**TABLE 5F1.11 – Response to collectivism contributing to HIV and AIDS silence**

Results:

83.3% think collectivism contributes to the HIV silence and 16.7% do not think that collectivism contributes to the HIV silence

***Question 20: There is strong inequality between men and women in our traditions. Does this contribute to the HIV and AIDS silence?***

Response

11 respondents answered this question. 10 Caregivers said Yes and one said No.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	no	1	8.3	9.1	9.1
	yes	10	83.3	90.9	100.0
	Total	11	91.7	100.0	
Missing	System	1	8.3		
Total		12	100.0		

**TABLE 5F1.12 – Response to gender inequality contributing to HIV and AIDS silence**

Results:

90.9% of respondents consider that gender inequality contributes to the HIV silence and 9.1% do not agree.

***Question 22: Our culture is a caring culture and so people would like to know what is making you sick. Does this behaviour contribute to the silence around HIV and AIDS?***

Response

All 12 respondents answered this question. 8 Caregivers said Yes and 4 said No.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	4	33.3	33.3	33.3
	Yes	8	66.7	66.7	100.0
	Total	12	100.0	100.0	

**TABLE 5F1.13 – Response to femininity contributing to HIV and AIDS silence**

Results:

66.7% respondents think the feminine nature of the African culture contributes to the HIV silence and 33.3% do not think the feminine nature of the African culture contributes to the HIV silence.

## **1.2 Open-ended Questions**

The respondents gave the following responses in their own words, but similar ideas are not repeated:

### ***Question 6: What made you go for an HIV test?***

- I wanted to know my status.
- I was very sick and I was wishing to know about what happening to my life.
- To know my status in order to help people who are sick.
- Because we look after children so it is wise to check yourself.

### ***Questions 7c: What was this person's reaction?***

- The person gave me some advice and was proud of me for doing the test.
- The person did not say much but wanted to know more about HIV and AIDS.
- The person did not believe me.
- The person was shocked and asked why I went for a test and asked many other questions.
- The person was very happy and also went for the test.

### ***Question 7d: How did you feel?***

- I felt brave because it was not easy going through the process of counselling, the test, and receiving the results.
- I felt great.
- I felt hopeless as I read the results. I did not know much about HIV and thought I was going to die.
- I was very happy and the stress that had built up in me for along time came out.
- I felt relieved that my suspicion was proved wrong.
- I was thankful to the one who encouraged me to go for the test.

***Question 8: If people are HIV-positive, what makes it difficult for them to tell people freely that they are HIV-positive?***

- It is because this disease is associated with sexual promiscuity and one does not know how to tell people.
- It is because if you tell anyone that you are HIV-positive it is translated as being sexually active or unfaithful to your partner.
- I think it is because they are afraid that people would judge them if they are HIV-positive.
- People are afraid of being stigmatised.
- It is because the infected people know that they are gossiped about when people know their status.
- They are afraid of being rejected by other people.
- They think you are going to tell other people about their status.

***Question 9a: When we say people are keeping silent about HIV, apart from not talking about the disease, what do they do to keep the disease a secret? Consider the infected person himself:***

- Because of the queues at the Clinics for CD4 counts and other HIV-related services, HIV-positive people do not attend the clinics closer to them. They rather attend clinics far away in other communities to maintain their silence on the disease.
- They hide medication and other documentation that makes reference to the disease.
- Those in the city run to the villages or locations when they get sick to avoid being questioned by the regular people who know them. When in the village they blame witchcraft for their situation.
- When they need help, they ask questions as if they are acting on behalf of others.

***Question 9b: When we say people are keeping silent about HIV, apart from not talking about the disease, what do they do to keep the disease a secret? Consider the family of the infected person, if they know:***

- The family tries hard to hide the patient and to some extent lock them away when the sick person is left alone in the house.

- The members of the family cover up by blaming neighbours or workmates for using black magic or witchcraft on the sick person.
- They become spokespersons for the sick to avoid the sick person saying things that would show the sickness is HIV.
- To protect the name of the family from shame and ridicule, the family initiate attendance at traditional doctors at nights and very early mornings instead of attendance at public clinics and hospitals.

***Questions 10: What would change in your life if you were told that you are HIV-positive?***

- I tried to change the way I eat, the way I think about the disease.
- My whole life was changed, my life style was totally changed, I look after myself.
- I was very happy and I felt free within my self.
- I feel relieved.
- Nothing can change if you know about HIV and AIDS.
- I was very happy.

***Question 11b: If the Church has an HIV and AIDS programme, what does it do?***

- It offers prayer and food support to infected families.
- It is involved in training the church members in HIV and AIDS issues and for them to be involved in the care of infected people and affected families.
- The members of the church visit people infected with HIV and give them support and hope and pray with them and their families.
- It has many volunteers who offer home-based care for the sick infected people and encourage the families.
- It teaches people about HIV and AIDS in order to be aware about the disease and stop discrimination and stigmatising.
- It runs a Support Group for the infected people to help them to be open about their situation and seek help and encourage one another.
- It helps and cares for orphans and vulnerable children in the communities.

- It has a homework club to support orphans and vulnerable children with their school work.

***Question 11c: Why do you think people in the church who are infected keep silent about their status within the church?***

- They are worried that if one person knows then the whole church will know and gossip about the person.
- Because most church members are not well educated about HIV.
- A number of people in the church think being HIV-positive is a disgrace because it is related to sexual immorality and so people who are infected do not want to be seen this way.
- There is a lot of discrimination in the church because of a lack of education which makes people to think that shaking peoples hands can bring infection.
- Infected people are afraid that people will say they have prostituted themselves and now they are worse sinners if they tell them they are HIV-positive.
- They do not trust people because they know them and think they will talk about their status to other people.

***Questions 11d: What can the Church in general do for people who are HIV-positive for them to be open about their status?***

- The Church should talk and be open about HIV and build the confidence of infected people.
- The church must teach people about HIV and AIDS so that people can understand the disease more and stop discriminating against infected people then they will open up.
- The church must be open about this disease and teach more about it.
- From my own experience, the idea of a Support Group works in helping infected people open up about their HIV-positive status and so if every church can initiate a Support Group that will help.
- Help the infected people get a voice with which to speak by the church preaching on positively on HIV.
- By encouraging church members to be supportive to infected people and their families.

***Question 13: Which aspects of our culture contribute to the HIV Silence?***

- The aspect of the culture that does not allow children to ask the father or uncles questions especially if it is to do with sex. This makes it difficult for young people to talk about HIV which people see as relating to sex.
- The cultural practice of making incisions on people when they are sick and are not allowed talking about it.
- The embarrassment that is associated discussions on sex, that makes it taboo to talk to elders about the subject creates silence around HIV which is considered a sexual sickness.
- Our culture does not allow children to raise their opinion and knowledge on the so-called taboo subjects such as sex. This makes young people silent about sex and HIV issues.
- Some of the rituals and undertakings contribute to HIV infections and make people keep silent about their status because the way they get infected makes them look ridiculous. For example when performing their rituals, people use the same blade, and when the children fight, they have been told to drink each other's blood so that they can get along. If someone get infected through drinking an infected blood, it is ridiculous.

***Question 15: In which ways does this Power Distance contribute to HIV silence?***

- It is not that easy to talk about anything, because we believe that one's opinions on issues such as HIV must pass through the head of the home, an elder or husband or an uncle.
- The uncles who have power in the family can chase infected people away from home thinking that they are dirty and cursed with an incurable disease from the ancestors because of immoral behaviour.
- The elders who make decisions and hold power are still not fully educated on HIV and think that if you are HIV-positive it means that you are a person who has been misbehaving sexually and it is time to shame you for your behaviour.
- People who are infected keep silent about their HIV status because they know that if they open up, the elders in the family and leaders will conclude that because the sickness is a sexually transmitted disease, the infected person is bringing disgrace into the family. And the sick person, being a subordinate, will not have the chance to explain what has happened in his or her life.

- Parents do not want to listen to their children because when you are a child you have no say. It is even worse if it is to do with HIV, which is seen as a shameful disease. An infected child cannot say anything, the authority procedures in the culture silences him or her.

***Question 17: In which ways does risk-taking behaviour contribute to the HIV and AIDS silence?***

- The risk-taking behaviour within our culture makes people overlook precautions for pleasure. In HIV most young people are involved in unprotected sex saying that you cannot eat a sweet in a wrapper, meaning that sex is not the same with condoms on. When people behave this way and they get infected, then they are afraid to tell anyone they are infected because they look stupid in their own eyes.
- A lack of concern about the future makes people take risks that lead to HIV infections. These people are only concerned about the now and become fatalistic and say that death can come any time and anywhere through any means and as such are not concerned about HIV. And since these people are vocal about their stance, when they get infected they keep it a secret.
- When people visit traditional doctors, they take risks by allowing themselves to be cut with the same blade thinking that the traditional doctor has power over sicknesses and so they will not get HIV. Then if one is infected through these cuts in the body, they become ashamed to tell anyone about their situation.
- It is common for people to take risk in our culture for economic reason because of apartheid. When risk-taking people get infected, they are afraid to disclose because they know that they have been reckless and are afraid to be told so.

***Question 19: In which ways does the community nature of our culture contribute to the HIV and AIDS silence?***

- Because many people are ready to help and begin to ask infected people about what exactly is wrong with them, infected people become overwhelmed and see the possibility of gossip if they disclose their status.
- Many people out of our community nature come to a sick person to offer help but this same person will go and tell others about the situation of the sick person and when they are told it is HIV then people begin to stigmatise the sick person.

- These days, people come to help you when they already know rumour around that you are infected and they come to you to confirm through helping you and so HIV- infected people know this and keep silent about their status.

***Question 21: In which ways does inequality between men and women contribute to the HIV and AIDS silence?***

- Men like to rule all the time and that makes women the oppressed partner. As a result of the stigma attached to HIV, when they become aware that they are infected, women cannot disclose to their partners for fear of being more oppressed.
- Woman are always scared of being beaten up or chased away by the husband or boyfriend if they disclose their HIV-positive status.
- As result of the unequal power-sharing in marriages, most of women do not speak about their HIV status in the family because they will be blamed by their husbands for bringing the sickness into the family.
- In most cases men think that women are the ones who bring sickness. That is why if a woman finds out she is HIV-positive she keeps quiet because he will say she was cheating.

***Question 23: In which ways does this caring nature contribute to the HIV and AIDS silence?***

- The desire of our people to care if not done with an understanding and education of HIV, leads to fear as people know that HIV has no cure. For this reason HIV-positive people keep their status to themselves.
- It all boils down to the way people who are offering care understand HIV themselves. If they see the disease as a disgrace to the family then once they know the person they are caring for is HIV, they begin to reject the person and gossip about this person.
- The caring nature of the people is genuine until they realise that the person they are looking after suffers from what in their understanding is a shameful disease. People who are caring then begin to spread rumours for people to be careful about the sick person, leading to stigmatisation.

**APPENDIX 5G: SUPPORT GROUP QUESTIONNAIRE**

NO.

**SUPPORT GROUP QUESTIONNAIRE – CONFIDENTIAL**

Introduction: Thank you for participating in this survey, which is being administered through the Community Care Project to see how best we can deal with silence around HIV and AIDS. We appreciate your involvement. Please answer the questions as honestly as you can.

PLEASE TICK OR WRITE THE APPROPRIATE CHOICE WITHIN THE  
YOUR STATUS

- 1. How old are you?
- 2. What is your Gender? 

Male	Female
------	--------
- 3. For how long have you been diagnosed HIV-positive?  Years
- 4. What made you go for an HIV test? .....
- 5. Have you personally told anyone else, (apart from the Support Group members) that you are HIV positive? 

Yes	No
-----	----

  - 1. If your answer above is yes, how long after you were diagnosed HIV positive did you tell someone that you are HIV positive?
  - 2. What relations do you have with this first person you disclosed your status to? (e.g. Father, Mother, Brother, Sister, Husband, Wife, Son Daughter, In Law, Friend etc.)
  - 3. What was this person's reaction?.....
  - 4. How did you feel? .....
- 6. What has been the greatest difficulty for you to tell people freely that you are HIV positive?.....
- 7. When we say people are keeping silent about HIV, apart from not talking about the disease, what do they do to keep the disease a secret? Consider:
  - a. The infected person himself .....
  - b. The family of the infected person, if they know .....

8. What has changed in your life since you were told that you are HIV positive? .....

THE CHURCH

9. Do you go to church?

Yes	No
-----	----

a. If you go to Church, does the Church know that you are HIV positive?

Yes	No
-----	----

b. Who in the Church know that you are HIV positive?

All Leaders	Some Leaders
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Some Church Members	A Group in the Church	All Church Members
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c. If you don't go to Church, can you tell us why? .....

d. What makes infected people in the church keep silent about their status, within the church? .....

5. What can the Church in general do for people who are HIV-positive for them to be open about their status?.....

HIV PRAYER MEETINGS

10. Is our Monthly Prayer Meeting for HIV and AIDS helpful to

Yes	No
-----	----

11. In which way(s) has the Monthly Prayer Meeting been helpful to you?.....

SUPPORT GROUP

12. For how long have you been a member of the Support Group?

--

13. How did you join the group (How did you hear about it)?.....

14. In which ways has the Support Group been beneficial to you?.....

15. What do you like most about the Support Group?.....

COMMUNITIES – DIMENSIONS OF CULTURE

16. Do you think our culture contributes to the HIV and AIDS silence?

Yes	No
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17. Which aspects of our culture contribute to the HIV and AIDS silence? .....

18. Do you think the unequal distribution of power in our culture and the hierarchical order of relationships such uncles and elders having authority to make decisions on behalf of the entire family, etc. contribute to silence on HIV and AIDS.

Yes	No
-----	----

19. In which ways does this Power Distance contribute to HIV and AIDS silence?.....

20. Our culture is seen to make people have no fear for what happens tomorrow and so they are able to take risks. Do you think this behaviour contributes to the HIV and AIDS silence?

Yes	No
-----	----

21. In which ways does risk-taking behaviour contribute to the HIV and AIDS silence?

22. Our culture is community-based, where we seek each other's interests (Ubuntu). In this case people are keen to know what is wrong with me even if I think it is a private matter. Does this behaviour contribute to the HIV and AIDS silence?

Yes	No
-----	----

23. In which ways does our community nature contribute to the HIV and AIDS silence? .....

24. In our tradition there is a strong inequality between men and women. Does this contribute to the HIV and AIDS silence?

Yes	No
-----	----

25. In which ways does inequality between men and women contribute to the HIV and AIDS silence? .....

26. Our culture is a caring culture and so people would like to know what is making you sick. Does this behaviour contribute to the silence around HIV and AIDS?

Yes	No
-----	----

27. In which ways does this caring nature contribute to the HIV and AIDS silence?.....

THANK YOU VERY MUCH FOR CONSENTING TO ANSWER THIS QUESTIONNAIRE. PLEASE SIGN

.....

IMIBUZO YE SUPPORT GROUP – LOKHU KUYIMFIHLO

NO.

Isibingelelo: Siyabonga ukuthi nawe ube yingxenywe yaloluphenyo olwenziya yi Community Care Project, ukuthi iyiphi indlela engcono ekulengiseni inkinga yokuthi abantu abafuni ukukhuluma nge HIV and AIDS. Kuyasithokozisa ukuthi ube nathi. Sicela uphendule lemibuzo futhi uzame ukuthembeka ekuphenduleni kwakho.

LAPHO KUNAMABHOKISI KHONA FAKA INKOMBA ESHOYO UKUTHI UKHETHA KUPHI.

ISIMO OKUSONA

1. Uneminyaka emingaki? 

Iminyaka
----------
2. Ubulili bakho? 

Owesilisa	Owesifazane
-----------	-------------
3. Usuneminyaka emingaki unaleligciwane iHIV
4. Yini eyenze ukuthi uhambe uyohlolwa?.....
5. Ukhona yini umuntu osuke wamutshela (ngaphandle kwethu iSupport Group) ukuthi wena uHIV positive. 

Yebo	Cha
------	-----

  - a. Uma umbuzo ongasenhla uwuphendule ngokuthi yebo. Kwase kunesikhathi esingakanani usunaso lesifo ngesikhathi umtshela lowomuntu?
  - b. Uhlobene kanjani nalomuntu omtshela isimo sakho? (isibonelo, ubaba, umama, ubhuti, umkhwenyana, umakoti, njalonjalo).
  - c. Wathini uma umtshela?.....
  - d. Wena waphetha kanjani?.....
6. Yini eyenze ukuthi kube nzima kakhulu ukutshela umuntu ngokukhululeka ukuthi wena unalesifo iHIV?.....
7. Uma sithi abantu abakhulumi ngeHIV, ngaphandle kokukhuluma ngesifo, benza kanjani ukugcina isifo siyimfihlo? Ucabangelel umuntu:
  - a. Umuntu osengenwe yisona lesifo?.....
  - b. Umndeni walomuntu onalesifo uma kuwukuthi sebeyazi?.....
8. Yini esishintshile empilweni yakho kusekela ngesikhathi utsheliwe ukuthi unalesifo iHIV?.....

IBANDLA/ ISONTO

9. Ingabe uyaya yini esontweni?

Yebo	Cha
------	-----

a. Uma uya esontweni, bayazi yini ebandleni lakho ukuthi uHIV positive?

Yebo	Cha
------	-----

b. Ubani esontweni lakho owaziyo ukuthi uHIV positive?

Bonke abaholi	Ingxenywe
---------------	-----------

Ingxenywe yabazalwane	Iqembu elithize ebandleni	Bonke
-----------------------	---------------------------	-------

c. Uma kuwukuthi alikho ibandla/isonto okhonza kulo, sicela usitshela ukuthi yingani ungakhonzi?.....

d. Yini eyenza ukuthi abantu abasontayo bengakhulumi ngokuthi banalesifo esontweni?.....

e. Uma ucabanga nje yini ibandla/isonto into elingayenzela abantu aba HIV positive ukuze bavele obala ngesimo abakusona?.....

HIV PRAYER MEETING

10. Ingabe lemihlangano yokuthandazela iHIV iyakusiza?

Yebo	Cha
------	-----

11. Ingabe ikusiza ngayiphi indlela lemithandazo yeHIV? .....

IQEMBU LABASIZANAYO

12. Usuneskhathi esingakanani ulilunga lale Support Group?

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13. Ubekanjani yilunga laleliqembu (Uzwe kanjani ngalo)?.....

14. Leliqembu libe wusizo ngaziphi izindlela empilweni yakho?.....

15. Yini oyithanda kakhulu ngaleliqembu?.....

UMPHAKATHI – AMASIKO AHLUKAHLUKENE.

16. Ucabanga ukuthi amasiko ethu anomthelela ngokungakhulumi AIDS?

Yebo	Cha
------	-----

17. Uma ucabanga ingabe amasiko ethu ayanezezela yini ekwenzeni ukuthi abantu bengafuni ukukhuluma ngeHIV?.....

18. Uma ucabanga ingaba ukungalingani ngesikhundla nokunika abantu abadala njengomalume kanje, igunya lokwenzela umndeni izinqumo, lokho kuwumbandela wokuthi abantu bengathandi ukukhuluma nge HIV ne AIDS?

Yebo

Cha

19. Ingabe lolugebe lamandla anikwa abadala lunezezela kanjani ekuthuleni kungakhulunywa nge HIV ne AIDS?.....

20. Usiko libonakala sengathi asesabi ukuthi kuzokwenzekani kusasa, ngakhoke sithatha iriski. Ingabe uma ucabanga lento ayinezezeli yini ekutheni kungakhulunywa nge HIV ne AIDS?

Yebo

Cha

21. Yiziphi izindawo lapho ukuthatha iriskikunganezezela ekungakhulumini nge HIV ne AIDS?.....

22. Ibandla lethu lithanda ukusebenza nomphakathi, lapho sifuna khona ukwazi ngabanye abantu (Ubuntu). Ngenxa yalokho abantu bafuna ukwazi ukuthi kwenzakala ngami noma kimi, yize noma kwesinye ngike ngicabange ukuthi kuyimfihlo yami ngedwa. Ingabe lokhu kuyanezezela yini okuthuleni kwabantu bengakhulumi nge HIV ne AIDS?

Yebo

Cha

23. Iyiphi indlela umphakathi oziphatha ngayo eyenza ukuthi abantu bengathandi ukukhuluma nge HIV ne AIDS?.....

24. Kukhona ukungalingani okukhulu phakathi kwabantu besilisa nabesifazane. Ingabe lokho kuyabanga yini ukuthi abantu bengakhulumi nge HIV ne AIDS?

Yebo

Cha

25. Ukungalingani phakathi kwabantu besilisa nabesifazane kukubanga kanjani ukuthi kungakhulwa nge HIV ne AIDS?.....

26. Usiko lwethu lunabantu abanothando ngakhoke bayathanda ukwazi ukuthi uguliswa yini. Ingabe lokhu kuyanezelea yini ekutheni umuntu akhulume nge HIV ne AIDS.

Yebo

Cha

27. Ingabe lolothando noma ukunakekela kunezezela kanjani ekutheni umuntu angathandi ukukhuluma nge HIV ne AIDS?.....

SIYABONGA KAKHULU UKUTHI UVUME UKUPHENDULA LEMIBUZO.  
SICELA USAYINE NGEZANSI

.....

## APPENDIX 5G1: DETAILED RESULTS OF SUPPORT GROUP QUESTIONNAIRE

### 1.0 QUESTIONNAIRE FOR SUPPORT GROUP

Below are the detailed results of the questionnaire (See Appendix 5G) administered to 29 Support Group members who attended the meeting of Tuesday, 29<sup>th</sup> May 2007 at Bethany House that was devoted to group-administered questionnaires for members who were willing to participate:

#### 1.1 Closed Questions

##### *Question 1: How old are you?*

Response

All 29 respondents answered this question.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	19-24	4	13.8	13.8	13.8
	25-30	4	13.8	13.8	27.6
	31-36	13	44.8	44.8	72.4
	37-42	5	17.2	17.2	89.7
	43-48	1	3.4	3.4	93.1
	49-54	1	3.4	3.4	96.6
	55-60	1	3.4	3.4	100.0
	Total	29	100.0	100.0	

**TABLE 5G1.1 – Respondent’s Age**

Results:

13.8% of Support Group members were 9-24 years old, 13.8% were 25-30 years, 44.8% were 31-36 years, 17.2% of were 37-42 years, 3.4% were 43-48 years, 3.4% were 49-54 years and another 3.4% of Support Group members were 55-60 years.

##### *Question 2: What is your Gender?*

Response:

All 29 Support Group members answered this question. (10 males and 19 females)

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	10	34.5	34.5	34.5
	Female	19	65.5	65.5	100.0
	Total	29	100.0	100.0	

**TABLE 5G1.2 – Gender of respondent**

Results:

34.5% of males and 65.5% of females are in the Support Group.

***Question 3: For how long have you been diagnosed HIV-positive?***

Response:

All 29 Support Group members answered this question.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	4	13.8	13.8	13.8
	2	2	6.9	6.9	20.7
	3	6	20.7	20.7	41.4
	4	5	17.2	17.2	58.6
	5	4	13.8	13.8	72.4
	6	2	6.9	6.9	79.3
	7	3	10.3	10.3	89.7
	9	2	6.9	6.9	96.6
	11	1	3.4	3.4	100.0
	Total	29	100.0	100.0	

**TABLE 5G1.3 – Period of being diagnosed HIV-positive**

Results:

72.4% of Support Group members have known their HIV-positive status for 5 years or less, 27.6% have known their status for more than 5 years, and 3.4% have known their status for more than 10 years.

***Question 5: Have you personally told anyone else (apart from the Support Group members) that you are HIV-positive?***

Response:

All 29 Support Group members answered this question. All had disclosed their status to someone else apart from Support Group members.

Results:

100% disclosed their HIV status to people other than Support Group members.

***Question 5a: How long after you were diagnosed did you tell someone that you are HIV-positive?***

Response:

All Support Group members answered this question

Period taken to disclose		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Same day	3	10.3	10.3	10.3
	Few days	5	17.2	17.2	27.6
	Weeks	2	6.9	6.9	34.5
	Months	1	3.4	3.4	37.9
	1 year	2	6.9	6.9	44.8
	2 years	4	13.8	13.8	58.6
	3 years	4	13.8	13.8	72.4
	4 years	2	6.9	6.9	79.3
	5 years	1	3.4	3.4	82.8
	6 years	1	3.4	3.4	86.2
	7 years	3	10.3	10.3	96.6
	8 years	1	3.4	3.4	100.0
	Total	29	100.0	100.0	

**TABLE 5G1.4 – Period before disclosure**

Results:

10.3% told someone the same day they tested, 17.2 % told someone a few days after the test, 6.9% told someone between 1-3 weeks, 3.4% took a month, 44.9% took 1 to 5 years, and 17.2% took more than 5 years to tell someone else that they are HIV-positive.

***Question 5b: What relations do you have with this first person you disclosed your status to?***

Response:

All 29 Support Group members answered this question.

		Frequency	Percent	Valid Percent
Valid	Mother	7	24.1	24.1
	Group of people e.g. Family, Children, etc.	4	13.8	13.8
	Father	3	10.3	10.3
	Brother	3	10.3	10.3
	Sister	2	6.9	6.9
	Friend	2	6.9	6.9
	Grandmother	2	6.9	6.9
	Husband	1	3.4	3.4
	Boyfriend	1	3.4	3.4
	Girlfriend	1	3.4	3.4
	Sister in law	1	3.4	3.4
	Auntie	1	3.4	3.4
	Niece	1	3.4	3.4
	Total	29	100.0	100.0

**TABLE 5G1.5 – Relationship with the person disclosed to**

Results:

24.1% of the Support Group members disclosed to their mothers, 13.8% disclosed to a group of people, 10.3% to their fathers and 10.3% to brothers. 6.9% Support Group members disclosed to sisters, 6.9% to friends and another 6.9% to grandmothers. Only 3.4% disclosed to their husbands, boyfriends, girlfriends, sisters-in-law, aunts and nieces.

***Question 9: Do you go to church?***

Response:

All 29 respondents answered this question. Of the Support Group, 26 said they attend a Church and 3 said they do not attend church.

Church Attendance	Frequency	Percent	Valid Percent
Valid No	3	10.3	10.3
Yes	26	89.7	89.7
Total	29	100.0	100.0

**TABLE 5G1.6 – Response to church attendance**

Results:

89.7% of Support Group members said they attend church while 10.3% do not attend any church.

***Question 9a: If you go to Church, does the Church know that you are HIV-positive?***

Response:

From the Support Group 26 members answered this question. 15 members said their churches know they are HIV-positive and 11 said their churches do not know they are HIV-positive.

Church know status		Frequency	Percent	Valid Percent
Valid	No	11	37.9	42.3
	Yes	15	51.7	57.7
	Total	26	89.7	100.0
Missing	System	3	10.3	
Total		29	100.0	

**TABLE 5G1.7 – Response to if the church knows respondents status.**

Results:

57.7% say their churches know they are HIV-positive whilst 42.3% say their churches do not know of their status.

***Question 9b: Who in the Church knows that you are HIV-positive?***

Response:

15 Support Group members answered this question.

Church people who know status		Frequency	Percent	Valid Percent
Valid	All leaders	5	17.2	33.3
	Some church leaders	4	13.8	26.7
	Some church members	1	3.4	6.7
	All church members	3	10.3	20.0
	A group in Church	2	6.9	13.3
	Total	15	51.7	100.0
Missing	System	14	48.3	
Total		29	100.0	

**TABLE 5G1.8 – Response to who in church know respondent's status**

Results:

From the Support Group, 33.3% of the members have disclosed to all of their church leaders; 26.7% of Support Group members have disclosed to only some of their leaders, while 6.7% of the members have disclosed to some of their church members, 20% have disclosed to all church members and 13.3% have disclosed to a group in the church.

***Question 10: Is our Monthly Prayer Meeting for HIV helpful to you?***

Response

All 29 Support Group members answered this question, and all said that the HIV Prayer meeting is helpful to them.

Results:

100% of Support Group members find the HIV Monthly Prayer meeting helpful.

***Question 12: For how long have you been a member of the Support Group?***

Response

All 29 Support Group members answered this question.

Period in support group		Frequency	Percent	Valid Percent
Valid	Less than a year	2	6.9	6.9
	1 year	11	37.9	37.9
	More than a year	3	10.3	10.3
	2 years	8	27.6	27.6
	3 years	5	17.2	17.2
	Total	29	100.0	100.0

**TABLE 5G1.9 – Length of being Support Group member**

Results:

6.9% have been less than a year in the Support Group, 37.9% have been members of the Support Group for a year, 10.3% have been members of the Support Group for more than 2 years, 27.6% have been members for two years and 17.2% have been members for three years.

***Question 16: Do you think our culture contributes to the HIV and AIDS silence?***

Response

All 29 respondents answered this question. 23 Support Group members said Yes and 6 said No.

Culture to HIV silence		Frequency	Percent	Valid Percent
Valid	No	6	20.7	20.7
	Yes	23	79.3	79.3
	Total	29	100.0	100.0

**TABLE 5G1.10 – Response to culture contributing to HIV and AIDS silence**

Results:

79.3% respondents think their culture contributes to the HIV silence and 20.7% do not agree that their culture contributes to the HIV silence.

***Question 18: Do you think the unequal distribution of power in our culture and the hierarchical order of relationships such as uncles and elders having authority to make decisions on behalf of the entire family, contribute to silence on HIV and AIDS.***

Response

28 respondents answered this question. 22 respondents said Yes and 6 respondents said No.

Power distance to HIV silence		Frequency	Percent	Valid Percent
Valid	No	6	20.7	21.4
	Yes	22	75.9	78.6
	Total	28	96.6	100.0
Missing	System	1	3.4	
Total		29	100.0	

**TABLE 5G1.11 – Response to Power distance contributing to HIV silence**

Results:

78.6% think that power-distance contributes to the HIV silence and 21.4% do not think power distance contributes to the HIV silence

***Question 20: Our culture is seen to make people have no fear for what happens tomorrow and so they are able to take risks. Do you think this behaviour contributes to the HIV and AIDS silence?***

Response

28 Support Group members answered this question with 21 Support Group members responding Yes and 7 members responding No.

Uncertainty avoidance to HIV silence		Frequency	Percent	Valid Percent
Valid	No	7	24.1	25.0
	Yes	21	72.4	75.0
	Total	28	96.6	100.0
Missing	System	1	3.4	
Total		29	100.0	

**TABLE 5G1.12 – Response to uncertainty avoidance contributing to HIV and AIDS silence**

Results:

75% Support Group members think uncertainty avoidance contributes to the HIV silence while 25% Support Group members do not think uncertainty avoidance contributes to the HIV silence.

***Question 22: Our culture is a community-based one, where we seek each other's interests (Ubuntu). In this case people are keen to know what is wrong with me even if I think it is private. Does this behaviour contribute to the HIV and AIDS silence?***

Response

28 Support Group members answered this question. 25 members said Yes and 3 said No.

Collectivism and HIV silence		Frequency	Percent	Valid Percent
Valid	No	3	10.3	11.1
	Yes	24	82.8	88.9
	Total	27	93.1	100.0
Missing	System	2	6.9	
Total		29	100.0	

**TABLE 5G1.13 – Response to collectivism contributing to HIV and AIDS silence**

Results:

88.9% Support Group members think collectivism contributes to the HIV silence and 11.1% do not think collectivism contributes to the HIV silence

***Question 24: There is a big inequality between men ad women in our traditions. Does this contribute to the HIV and AIDS silence?***

Response

28 respondents answered this question. 23 Support Group members said Yes and five members said No.

Gender inequality		Frequency	Percent	Valid Percent
Valid	No	5	17.2	17.9
	Yes	23	79.3	82.1
	Total	28	96.6	100.0
Missing	System	1	3.4	
Total		29	100.0	

**TABLE 5G1.14 – Response to gender inequality contributing to HIV silence**

Results:

82.1% of respondents think gender inequality contributes to the HIV silence and 17.9% do not think gender inequality contributes to the HIV silence.

***Question 26: Our culture is a caring culture and so people would like to know what is making you sick. Does this behaviour contribute to the silence around HIV and AIDS?***

Response

28 Support Group members answered this question. 25 Support Group members said Yes and 3 Support Group members said No.

Femininity to HIV silence		Frequency	Percent	Valid Percent
Valid	No	3	10.3	10.7
	Yes	25	86.2	89.3
	Total	28	96.6	100.0
Missing	System	1	3.4	
Total		29	100.0	

**TABLE 5G1.15 – Response to femininity contributing to HIV and AIDS silence**

Results:

89.3% of the respondents think the feminine nature of the African culture contributes to the HIV silence and 10.7% do not agree.

## **1.2 Open-ended Questions**

The respondents gave the following responses in their own words, but similar ideas are not repeated:

***Question 4: What made you go for an HIV test?***

- I wanted to know about my status and I needed help
- I was pregnant.
- I found out when I went for a pregnancy test.
- My friend went for a test and he told me about the virus. Since I trusted him, when he told me to go and check I went also.
- I had TB and I was given treatment but it didn't work, so I went for a blood test and I found out I was HIV positive. Now I'm on ARV's.
- My feet [were] giving me problems then one nurse asked me to go for a test but she did not force me.

- My wife and children were sick so I took the children to hospital and I was told that the children are HIV positive. So I also did the test. I was also HIV positive.
- I wanted to know about my health because my spouse went for an HIV test and she was positive.
- I had flu and it was not going away.
- I went for the test because I was pregnant; I was looking forward to seeing my baby living a normal life. Also the sister in the clinic was talking words of encouragement for my soul.
- I was very sick for a very long time without knowing the reason , then I decided to go for the test and this is when I found I was positive.
- I found out through my baby who passed away.
- I wanted to know the secret of my life, voluntary testing.
- My husband passed away and there were some HIV symptoms I saw. I was also on and off being sick and wanted to know my status.
- I knew myself that I needed to be tested.
- I was always feeling sick and my husband got sick and died, so I got worried and then I decided to go for a test.

***Question 5c: What was this person's reaction?***

- The person said I must not worry because all those who have this disease survive and I will survive.
- The person accepted me nicely and did not have any problem
- The person gave me hope.
- The person accepted me and he did not say anything.
- I did not understand the person because she just said 'life on earth'
- The person didn't say anything but confronted me and said I must not worry; I will live only I just need to take care of myself.
- The person accepted me and she is caring for me.
- The person was happy that I came out to the light.
- The person said she accepts me.
- The person accepted me very nicely.
- The person said no problem because HIV is not the end of my life.

- The person advised me a lot, made me to be strong; they preached to me that this is not the end of life.
- The person said I did a good thing and I must not forget to take my medication.
- It was difficult for the person to believe and accept it.
- The person was shocked and in denial
- The person felt very disturbed and hurting.
- The person was terrified.
- The person was embarrassed.
- The person was amazed.
- The person was so embarrassed but she consoled in me and said that there was no problem.
- The person was surprised and asked me why I didn't tell him all the time.
- The person chased me away from home and I left them.
- The person confronted me.
- The person laughed and talked about [me]. They are still carrying on doing this.

***Question 5d: How did you feel?***

- I was sad but I felt free after telling my aunt because she accepted me.
- I felt sad because at the time I did not know much about HIV and so I told myself that I was going to die.
- It was painful
- I just accepted the situation.
- I was sad, especially because I infected my child and wasted his life and he is aware of his status and situation.
- I was worried.
- I felt strong and decided to go for a CD4 count test so I could be on ARVs.
- I felt accepted after telling her my status because she did not reject me when she said "You are still my child".
- I was able to accept my status.
- Shocked and I could not believe it and then there was anger and denial.
- I was sad when I looked at the person crying.
- I couldn't believe it I was crying every day.
- I was hurt and crying.

- I was deeply in pain, I knelt down and prayed.
- I was terrified also.
- I wasn't terrified because I was having different information – explanations on the TV and radio.
- It was hurtful to me.
- I felt okay and I accepted everything and I was happy that my family members understood me and got close to me.
- I was very sad up to a point that I could not even sleep at night.

***Question 6: What has been the difficulty for you to tell people freely that you are HIV-positive?***

- I get worried that people will gossip about me.
- The thought that people will reject me and I will not have a place to stay.
- Feeling scared that I will become a laughing stock and then people will gossip about me and judge me.
- To me it was like you have sinned by having the disease.
- The fact that people haven't been taught properly about this disease and so when they know you are HIV-positive, they immediately shun and reject you.
- The fear of rejection.
- The fear that people will begin to look at me differently and even feel pity for me.
- Fear of being severely stigmatised since already my father and brothers were neglecting me.
- Fear of being exposed sexually the more. When you get infected, you feel like sexually exposed. It is like the way people feel so ashamed when they are caught having sex. This is something that you do not want people to see about you
- The difficulty I had was to cause people who love me and never expected me to be HIV-positive to have a heart attack because of shock.
- It is the fact that people laugh at you when they know you are HIV-positive as a young person.
- Because you don't know how they will treat you.
- The fear that what I have seen happen to my neighbour who is HIV-positive will happen to me. The rejection from people and her own friends when they learnt that she was HIV-positive.

- It is because still HIV-positive people are seen to be shameful.

***Question 7a: When we say people are keeping silent about HIV, apart from not talking about the disease, what do they do to keep the disease a secret? Consider the infected person her/himself:***

- They just carry on with life as if nothing has happened.
- Just be free and carry on with your life like any other person.
- They lock themselves inside the house for people not to see them.
- They mention another diseases but not HIV.
- They tell people they are becoming a *Sangoma* or they are being bewitched.
- By looking after your health and seeing a doctor regularly so that you don't get sick for people to suspect you.
- I look after myself by not having sex.
- By not attending nearby clinics in order to be seen by community members who are stigmatising and are talkative.
- You hide from your neighbours. In the clinic you hide the pills you are using and lie to people and tell them that you are bewitched.
- I hide and not come out in public.
- They wear red dresses and go to the *Sangomas* to become one of them.
- I hide and don't show myself in public.
- I stay in the house alone and do not associate myself with HIV-positive people that people know.
- Lock yourself in the house and go out at night to get some fresh air and also to go to the clinic.

***Question 7b: When we say people are keeping silent about HIV, apart from not talking about the disease, what do they do to keep the disease a secret? Consider the family of the infected person, if they know:***

- They hide the person.
- You can hide the person inside the house and fetch the medication for him/her
- The signs do show that you are sick and so your family say that you are becoming a *Sangoma*.
- When they see someone coming, they say you are asleep or you are not at home.
- Sometimes you are locked alone in the house when they have to go out.
- The family mentions that the sick person is suffering from another disease and they don't mention HIV.
- The family made us leave the place we were living to go to a new place where people did not know us.
- Your family will blame your neighbours for having giving you *muti* or something poisonous through witchcraft.
- They will hide you from people and they don't tell anyone about you.
- They avoid talking to people about the sick person and show love to the affected person.
- They take the person far away from the neighbours blaming them of bewitching a family member and will not bring him or her back until the person gains some weight or recover.

***Question 8: What has changed in your life since you were told that you are HIV-positive?***

- I have stopped smoking and drinking because I was told that it is dangerous.
- I have lost weight
- I lost weight because I was stressed.
- I live my life through prayer.
- I am careful and have to wear a condom when I have sex.
- I follow the doctor's instructions and also practice safe sex.
- Now I have changed, I am no longer that playboy.

- There is nothing except that I look after myself better now.
- I lost hope about life until I joined the Support Group.
- I have began monitoring my CD4 count and learning about HIV.
- I am not scared of infection any more because I have the virus and protect my self from further infection.
- The life I'm living now is positive.
- I'm feeling better now that I accepted that I'm HIV-positive.
- I have accepted that I'm sick.
- I used to smoke but now I have stopped.
- I have stopped drinking and following women.
- Now I am free. I eat and take care of myself because I have accepted my condition.
- I go to church, I gain a lot of weight and I decided to be happy at all times.
- I am free because I know the status of my life.
- I have lost a lot of weight but I go to church and pray.
- I changed my behaviour and I am careful about the food I eat.
- I know how to look after myself, and take the path to positive living and I plan my future.
- I have put my trust in prayer and medication.

***Question 9c: If you don't go to church can you tell us why?***

Many who used to go to church stopped for the following reasons:

- Preaching takes too long and people gossip in the church. Also it is because our pastor criticizes a lot.
- Falling pregnant and could not to go again.
- Because of poverty and hardship one is compelled to work on Sundays and therefore thinking there's no Jesus, because everything bad is happening to one and God is not answering the one's prayers.

***Question 9d: What makes infected people in the church keep silent about their status within the church?***

- I am scared that they will gossip about me
- I'm scared that the pastor will criticise me.
- People at the church are not educated about this disease so people are scared to talk about it because of stigma.
- They are scared of stigmatisation and rejection.
- The church has this belief that if you have got HIV then it is because you have been behaving badly.
- I feel ashamed of myself to talk about it in the church.
- They are scared of discrimination as a result of their status.
- They are scared of stigmatisation.
- It is because of the way some church leaders talk about the disease.
- It is because people in the church gossip, talk and discriminate against infected people.
- Is because of the fear of not knowing the reaction that will come after disclosure.
- I fear that people will laugh at me.
- They fear that the congregation will talk about them.
- For me, it is because I told my brother at home and he went and preached about me in his church.
- They fear that they will become the preaching topic in the church.

***Question 9e: What can the Church in general do for people who are HIV-positive for them to be open about their status?***

- The church should love them just as they are.
- They need to be taught.
- The church needs to support infected people emotionally.
- People at the church itself must be educated to understand HIV from different angles.
- Pastors should preach about the virus at church for everyone to understand the infected person.
- We need to talk about this disease and explain that the disease is transferable only through sex.

- Setting up a prayer meeting for the infected people that come out of love and concern for the sick individual.
- There must be a talk about this disease so that there will be no stigmatisation.
- They are not supposed to stigmatise people; they are supposed to love them.
- They need to teach people how people get infected and how to change the stigmatisation.
- For the church to help infected people spiritually, mentally and physically.
- If the church can talk about HIV and AIDS and urge people to go for the test that will help them understand the stress of being told you are HIV-positive.
- If members of the church can be helped to stop speaking badly about people who are HIV-positive.
- If pastors themselves begin to preach and talk about the disease freely but not judgementally.
- If pastors themselves also go for VCT and come out with their status.
- If members of the church can understand that no one is HIV-negative until they have done an HIV test that will help them understand that they could be HIV-positive while pointing fingers at those who are HIV-positive.
- They need to talk about this disease for every church member to know that this disease exists and it is alive.
- They must preach about it and pray for us.

***Question 11: In which way(s) has the Monthly Prayer Meeting been helpful to you?***

- It lifts up my spirit up and gives life to my soul.
- It helps me forget about what has happened to me and gives me hope
- It makes me feel free within myself and I feel Jesus leading and guiding me.
- I'm free inside and I'm not scared anymore.
- It is nice to meet, even when I've been feeling sick I feel better.
- They comfort me and give me hope.
- It makes me feel free in my spirit and my life.
- The preaching always gives me hope that I will recover from this disease.
- Through them I have hope about my health.

- They revive me.
- They make me feel whole again
- They laying on of hands on me when praying pray for me make me feel loved by God.
- The aspect of calling all of us infected coming together for prayer and not ashamed of our status, uplifts me.
- They make me feel alive and energised.
- They have made me forget about the disease and see myself as a born again person.
- I feel as lively as someone who doesn't have the disease.
- I feel free when they pray for me, I feel like I have no burdens at all.
- The prayers free me from diseases and my soul is free.
- It helps me because now I feel free in my spirit.
- I feel free.
- They help me in many ways, including spiritual upliftment, healing and hope.
- The way HIV and AIDS is freely spoken about and how we, infected people, feel loved and are touched during prayer times.

***Question 13: How did you join the group (How did you hear about it)?***

- I heard from one of the members of the Support Group
- I came on my own and I was welcome by the staff of CCP
- A Support Group member invited me.
- I heard from someone who works at CCP then I joined.
- Because I was tested at CCP and my friend who is a member of the Group told me about the usefulness of the group.
- I was visited by the CCP group who told me that there is a Support Group and other activities.
- My friend told me.
- I was told by the nurse who tested me for HIV at the clinic and she mentioned how some people that she knows have had their lives changed by the group.

- There is a Support Group near my house and CCP also came to do the awareness training for them and the training attracted me.
- I heard one of the ladies talking about the group at the clinic in Edendale.
- Somebody told me about it and invited me.
- I was informed by a friend that I met at the social welfare department.
- A friend brought me.
- I heard from a cousin that was being looked after by The CCP staff.
- I heard about the group from my colleague at work who urged me to come here to the project.
- I was referred the group by my boss who eventually chased me away from her business.
- There is someone who told me about this group and I came and joined them.
- I was invited by someone.
- I was taken by my friend to the talks we have on HIV.
- Someone told me.
- I was very sick and my sister in-law directed me to a staff of CCP who taught the wellness course and invited me to the group.
- My neighbour, who is a member of the group, told me about it.

***Question 14: In which ways has the Support Group been beneficial to you?***

- I feel accepted in this group and I can feel that I am not alone.
- The discussion time and encouragement of one another.
- It makes me feel at home.
- The CCP staff and members advise me and guide me.
- It has given me an opportunity to discuss issues that have been bothering me for all this time with CCP staff without any fear.
- My child and I were very sick when I joined this group, but through advice and encouragement from the group we are now well. I know that without the group we would have died.
- I feel at home when I'm with the group.
- I have access to different forms of counselling.

- The meeting discussions guide me and teach me about change of behaviour.
- Learning about the disease and learning to love those who are sick like me.
- It has helped me realised that I'm not the only one who is infected and there are others.
- I have felt reconciled with God through my faith that has been uplifted.
- I have learnt about positive living and about adherence to my treatment.
- The various training programmes offered by CCP to the group has helped me break my silence.
- The free and open discussions around disclosure have helped me to disclose to my status to my family.
- Talk about our problems and finding solutions together.
- It has helped me to look at my diet and nutrition.
- The group made me feel accepted and cared for.
- The activities of the group help me to release tension.
- This group has helped me deal with loneliness.
- It is through this group that I have found freedom which has helped me to live a better life.
- It takes out my loneliness and stress.
- The group supports me in every way.
- CCP often gives us food parcels and that is so helpful.

***Question 15: What do you like most about the Support Group?***

- I enjoy the discussions about medication
- The care giving
- The singing.
- I like praying with the group.
- The freedom in the group.
- You get help with all your problems because when you come you inform the group about your status.
- Courage.
- Being able to speak freely.

- The transparency within the group and CCP team.
- My secret staying within the group and no one gossiping.
- The fact that I tell my brothers and sisters about the disease and I know that they won't go around talking about me.
- There is no discrimination.
- Times of prayer.
- Receiving of more experience about life in general, besides being able to manage HIV.
- Just seeing or meeting people who are going through the same challenges in life as you face.
- Just to be with people who have the same sickness as me.
- Discussions and guiding one another.
- The counselling we receive from each other and the CCP staff.
- The talk, sharing of ideas and other things that I don't understand.
- The encouragement from each other.
- The times of prayer and singing.
- The way we talk about the HIV disease from different perspectives.
- Being encouraged all the time to take your tablets, to think positively about your life and condition and to know that God has the power to touch and heal you.
- We teach each other about HIV for you stay updated.
- They help me deal with stress

***Question 17: Which aspects of our culture contribute to the HIV Silence?***

- The culture lacks the ability to help tell young people about how they should behave and not fall into the temptation of HIV and AIDS.
- The many myths and false beliefs in the culture and HIV is linked with a number of them and so when you get HIV it makes people laugh at you.
- The way the culture sees HIV and AIDS as a disease linked with witchcraft makes people keep it as a secret as it is expected that it is only the traditional doctor who can help you when you have it.
- The culture allows people to keep secrets

- There is fear for witchcraft in the culture, which intimidates people to keep silent
- The fear of being accused of breaking taboos
- The secrecy about sex in the culture
- The unfamiliar nature of the disease to the culture.
- The culture has false beliefs.
- The inability of uncles and elders to talk and teach people about the truths in the culture to the young ones
- The culture encouraging people to keep deep issues secret to prevent the family from being disgraced.
- The culture's inability to defend the sick (infected people) when people judge and accuse them freely
- The leaders and elders lack of talking openly to the youth
- The culture makes sex shameful
- The inability of the elders to discuss important issues of life such as sex and marriage openly with young people
- The fear of being ashamed in front of people if one reveals secrets
- The shame that is attached to breaking taboos within the culture
- The culture is too secretive
- Within the culture people see AIDS as incurable and death
- The culture restricting girls but allowing boys to do things freely and so girls keep silent about their indulgences
- Young people are not allowed to ask deeper questions
- The culture allowing men to be too powerful and therefore making women fear to be abused when they talk.

***Question 19: In which ways does this Power Distance contribute to HIV silence?***

- The power that the elders and uncles have does not give you any opportunity to express yourself or how you feel therefore and so why say anything?
- Those who have power stigmatise you through their power when they know you are HIV-positive, therefore why expose yourself?

- Those who have power in the family do not allow you to take your own decisions once they know you are infected. They say you will do something that will make everyone know that you have the disease and that will disgrace the family.
- The way this aspect of our culture does not allow a young person to speak freely makes people keep silent when they have HIV.
- This aspect of our culture makes people scared to approach elders and uncles who have power and make decisions in the family. It is because they are scared.
- The rumours that goes on in the families that when there is a HIV-positive person at home, that person is chased away by the elders.
- When those in authority in the family get to know that you are HIV-positive, they consider you as dead and shameful to the family and they begin to exclude you from family discussions and issues.

***Question 21: In which ways does risk-taking behaviour contribute to the HIV and AIDS silence?***

- Because of money people take risk and are involved in unprotected sex and when they get infected they can't talk about their situation to anyone.
- As a result of the risky behaviour we have grown up with, we don't listen especially when we make up our minds that we want some stuff and realise that you will fall into HIV. Then when you get HIV, you feel so defeated that you don't want to talk about your status to any one.
- When you are sexually active you don't mind the risks you take and you have sex for fun and financial gains and because of the money you get you become disrespectful to those who can help you and so when you get HIV, you dare not say anything to anyone.
- It makes the HIV spread to other people; people die without getting treated.

***Question 23: In which ways does the community nature of our culture contribute to the HIV and AIDS silence?***

- The community nature makes everyone in the family ready to help you in one way or another, and yet they go and gossip about you as they see you slim and

- slim and if they confirm that you are HIV that is when they begin to discriminate against you.
- The community nature demands that everybody knows what goes on in your life and you have no secrets. But with HIV this does not work as they want to take you to the traditional doctor and sometimes build a small mud house outside the main house for you to stay in as the *Sangoma* visits. None wants to go through this and so you keep your status a secret.
  - Our culture does not have ways of educating people about HIV effectively and so people have got a wrong understanding of the disease. Once they know you are infected, they spread the information like wild fire and you are stigmatised. The fear of this makes people keep their status to themselves.
  - Our community nature makes it difficult to satisfy too many people who come to you. Some understand the situation, especially those who are educated on HIV issues, and others do not. It is only the elders who are educated about the disease who are able to help you otherwise you don't tell anyone until you have confidence in them.

***Question 25: In which ways does inequality between men and women contribute to the HIV and AIDS silence?***

- The inequalities between men and women lead to distrust of each other and as such in a relationship, each other thinks the other is cheating. And so when there is HIV, the first to disclose is considered as bringing the disease and so each one keeps silent when they know their status.
- Men have more power and so if you disclose your status they use their strength and aggressiveness to punish you.
- Men are have problems in accepting that they are at fault and so they are scared that if they tell their wives or girlfriends that they are HIV-positive, they will be left to die alone.
- Some people are scared to expose their status because they will be blamed that they came with the virus.
- Most times they use their power and say the disease came with the woman.

- Because men are abusers, if you tell them you are HIV-positive they end up rejecting and hating you and discussing you with others when they go to drink with friends.
- If you tell your spouse that you are HIV-positive, because of this inequality situation you will be asked to show immediately where you got it from and so no one wants to say anything about their status.
- The inequality between men and women in our culture leaves room for fewer discussions which leads to misunderstanding on HIV issues. In the end when you mention anything about HIV your partner gets angry. Even when you suggest the use of condoms you are considered a prostitute. Therefore there is silence on HIV.

***Question 27: In which ways does this caring nature contribute to the HIV and AIDS silence?***

- The caring nature makes people sympathise with you as long as they don't know that you are HIV-positive. Once they know your status then they stigmatise you. For this reason you allow people to feel sorry for you but not let them know that you are HIV-positive
- The caring nature of our culture and the lack of education, which makes people cling to their misunderstandings and myths, lead to silence on the disease. This is because as people draw to you to care for you, their lack of education on HIV will make them gossip about you if they know that you are HIV-positive or even turn to drive you out of the house.
- People who are infected know all that happens in the community to infected people. And so the infected person will receive all the care that is given by the family members as he or she is sick, but will not disclose to people who do not have proper HIV education and are trusted, as disclosure changes everything.
- There is a lack of trust in people who care for you, though you need their help. People need to be taught about this disease so that they know how it is transmitted to help them stop judging sick people and stop using their caring to find out whether you HIV or not.

## **APPENDIX 5H: QUESTIONNAIRE FOR NON-SUPPORT GROUP PLWHAS**

### **PLWHAS IN THE COMMUNITY (NON-SUPPORT GROUP MEMBERS) QUESTIONNAIRE - CONFIDENTIAL**

1. What are the difficulties one faces if one was to disclose ones HIV status publicly?
2. Who do you find most difficult to disclose your HIV Status to? Why is it difficult? (Who did you find most difficult to disclose your HIV Status to? Why was it difficult?)
3. In terms of HIV disclosure, what is your view about preaching about HIV and AIDS at a funeral
4. What will make it easy for one to disclose his/her HIV-positive status to the elders in the family or leaders in the community or one's Parents?
5. What makes it difficult to disclose your status to your spouse or boy/girl friend?
6. In our African community, what contributes to the HIV and AIDS silence?
7. What do we need to preach about HIV in our Churches to help break the silence on HIV and AIDS?
8. Please share with us, if you have disclosed your status to others, what was the most helpful event or incident that made you decide to share your HIV-positive status with others? If you have not disclosed to others, what makes it difficult for you?

THANK YOU

## IMIBUZO – LOKHU KUYIMFIHLO

1. Iziphi izinkinga umuntu abhekana nazo uma efuna ukuvela obala ngesimo sakheseHIV
2. Ubani umuntu othola kunzima kakhulu ukuthi uziveze kuye ngesimo sakho se-HIV? Kungani futhi kunzima? (Ubani owathola kunzima kakhulu ukuthi uziveze ukuthi une-HIV? Futhi kungani kwaba nzima?)
3. Ngokombono wakho, ucabangani ngokushumayela nge-HIV NE AIDS emngcwabeni?
4. Yini engenza ukuthi kube lula ukuziveza isimo sakho se-HIV. Kungaba ukuziveza kwabadala bomndeni, noma abaholi bomphakathi wangakini, noma abazali bakho?
5. Yini eyenza kube nzima ukuthi uziveze kuloyo osuke uthandana naye, noma oshade naye kungaba umfazi nendoda noma isoka nentombi?
6. Emphakathini wethu wase-Africa, yini engumthelela wokuthi abantu bathule bangazivezi
7. Yini esifanele ukushumayela ngayo emasontweni mayelana ne-HIV, ukuthi sisize ukuqeda ukuthi abantu bathule bangakhulumi ngayo?
8. Ungasixoxela ukuthi yisiphi isehlakalo esenzeka, esaba wusizo esenza ukuthi ukwazi ukuxoxa nabanye ngesimo sakho se HIV. Mawungakaze uzivezekwabanye yini eyenza kubelukhuni kuwena?

NGIYABONGA

## **APPENDIX 5H1: DETAILED RESULTS OF NON- SUPPORT GROUP PLWHAS QUESTIONNAIRE**

### **1.0 Questionnaire for PLWHAs in the Community (Non-Support Group Members)**

Below are the detailed results of the questionnaire (See Appendix 5H) administered between 29<sup>th</sup> May 2007 and 5<sup>th</sup> of June 2007 to 21 PLWHAs who are not Support Group members:

The respondents gave the following responses in their own words, but similar ideas are not repeated:

### **2.0 What are the difficulties one faces if one was to disclose one's HIV status publicly?**

- Most people are not educated about the disease and do not know their own status and so they discriminate against you
- Once you disclose your status, people begin to gossip about you
- There are a lot of insults against you when you disclose your status.
- In most homes, you are not allowed to use the cooking utensils if you disclose your status.
- HIV-positive people have legal rights that state clearly that you need to get someone's permission in order to tell others; but people assume one is HIV-positive before one discloses one's status.
- Fear of rejection
- Even when people suspect that you are HIV-positive, without having any discussion with you about how life is treating you, they indirectly suggest that you change your behaviour. I ask myself if, without knowing my HIV status, people behave this way towards me, then what will happen if I told them I was HIV-positive? Until I know someone deeply cares about me, I will not declare my HIV status to him/her

- If you to disclose people do not like you and they do not like your company, people make fun of you and you are belittled in the community. That is how people insult you.
- The problem is who to tell first and who to trust.
- It is difficult to disclose especially to your family as they will talk about you and your brothers insult you and your neighbours tell other people that you are HIV-positive, so it is difficult to disclose.
- The moment you start disclosing many people do not accept you, there are only a few who accept you.
- The difficulty is getting your family to accept you first. It becomes easy if your family accepts you first then your neighbours and it becomes easy with the whole community.

### **3.0 Who do you find most difficult to disclose your HIV Status to? Why is it difficult?**

33.3% said Mums – Reasons: They are soft and cannot handle bad news and will see HIV and AIDS as bad news. They easily discuss issues with friends and gossip. Mums are dependant on us for livelihood and may see the disease as a death penalty and get confused

19% said Fathers – Reasons: Mostly not on good terms with fathers and will not dare talk to them. Their expectations are so high and telling them about the disease will be disgraceful and difficult for them.

19% said Brothers and Sisters – Reasons: We do not understand each other and envy each other and so cannot tell them about one's status. They will gossip about you especially when they are drunk and ridicule you.

19% said Others (bosses, friends, colleagues) – Reasons: They see HIV as something bad and so will gossip about you and ridicule you. The relationship may change for worse

9.7% said Children – Reasons: They are too concerned and inquisitive and may tell their friends to find answers. They may not give the same respect they had for us before.

#### **4.0 In terms of HIV disclosure, what is your view about preaching about HIV and AIDS at a funeral**

- There is no need of preaching HIV and AIDS during funerals. What is needed is talking about HIV on daily basis in homes and churches and not just during funerals.
- The church needs to have motivational speakers more often and undertake awareness campaigns to help break the stigma for people to know that the church is concerned about the disease.
- There is the need to teach people about the reality and facts on HIV and AIDS and so if someone dies of the disease, it is very good to preach about it at her funeral to remind people.
- I have no problem preaching about HIV and AIDS when someone has died of the disease as long as it was his wish as the dead person. Since the church is a powerful institution in the community, it is important to preach about HIV and AIDS wherever we are so that everyone will know that the disease is killing too many people.
- It is good to preach at the funeral so that other people can be helped and saved from HIV infection.
- With me it is fine to preach about HIV at my funeral. But it is difficult to speak about other people as I don't know how their family will feel if they did not know that the dead person was HIV-positive.
- The church has no right to preach at the funeral of someone if they were not available to help the person and the person passed away. It will be good if the church is able to tell the help they provided to the diseased through his/her sickness.

#### **5.0 What will make it easy for one to disclose his/her HIV-positive status to the Elders in the family or to leaders in the community or one's Parents?**

- These days family heads do not take their responsibilities and are not reliable and that make it difficult for one to even make an attempt to disclose one's status to them. They need to prove reliable.

- They need to stop discussing infected people outside to other people.
- They need to help organising families and giving leadership.
- They need to know that HIV is not a death sentence. Even if they think the infected person is dying, the infected person needs to be part of the funeral's planning rather than the elders using the funerals of infected persons to make money.
- Disclosure must begin with trusted friends who understand HIV very well. When you tell friends then they can inform the elders.
- It is easier if parents and elders talk more and discuss more about the disease.
- It helps if the elders or parents understand you and are closer to you.
- If there is a way to educate them about HIV and for them to know that HIV is not a death sentence but people can have full life even with HIV.

#### **6.0 What makes it difficult to disclose your status to your spouse or Boy/Girl friend?**

- It is because of abuse in the relationship.
- It is mainly because of abuse in the relationships. It is difficult to disclose your status to a partner when your partner is always suspicious of you and thinks you are unfaithful and so may think you are the one who has brought them the HIV infection.
- It is because of fear of misunderstanding and possible separation.

#### **7.0 In our African community, what contributes to the HIV and AIDS silence?**

- The fact that the disease is a sexually transmitted disease making people to think that if you have it then you have been sexually promiscuous.
- People are more concerned about their social status and do not want to be disgraced with a disease they consider shameful.
- It is a disease that makes people see themselves as sinners and so feel condemned to be exposed.
- People associate AIDS with death and are scared to tell their loved ones that they have the disease and will be dying
- The disease has a negative publicity in our community.

- The disease is almost a taboo sickness because it is linked to sexual misbehaviour and promiscuity.

### **8.0 What do we need to preach about HIV in our Churches to help break the silence on HIV and AIDS?**

- Preach about the fact that sexual sin is not the only sin a person can commit, and that the blood of Christ covers every sin.
- That HIV is not synonymous with sin but a disease like the others, that has the ability to kill people and so must be taken seriously.
- Preach hope to people who have been tested positive.
- We need to preach that HIV is about everyone whether infected or affected and the solution lies with all of us breaking the silence and stopping it.

### **9.0 Please share with us, if you have disclosed your status to others, what was the most helpful event or incident that made you decide to share your HIV-positive status with others? If you have not disclosed to others, what makes it difficult for you?**

- Hearing people give testimonies about their status and sharing their experiences with schools kids challenged me.
- Seeing one lady who is HIV-infected getting married and pointing out that even though she is infected life must continue with everyone around her knowing that she is HIV, changed me and I felt I needed to disclose to my family.
- Accepting one's HIV status
- The presence of an effective nurse at the clinic who made me feel that I am still a human being despite being HIV-positive made it possible for me to disclose my status to her friend at CCP.
- My one and only daughter was sick and I needed help at the time. In this situation I did not care about what people would say about my past. All I wanted was for my daughter to be helped. I went through a tough time in and out of hospitals. I then disclosed my status to a friend and I asked her to tell the Church leadership because I could see my daughter was dying. One elder came to the hospital and

prayed for my daughter. There was a prophecy that the child will be healed and I believed. I knew Christ could even raise the dead. Now my daughter is healthy and has started ARV.

- When I delivered my baby I became ill and I was diagnosed with TB I took my anti-TB treatment and finished it but I was not better until I went for an HIV test and I discovered that I was HIV-positive. I was so desperate that I decided to tell my sister who showed real concerned about my condition and also knows more about HIV. She was there for me through and through and helped me to attend ARV training as my buddy. Now I am well and healthier than some who claim they are HIV negative.
- My two sons died and I did not know what was wrong with them. Somebody else became ill and my neighbour suggested that I go for a HIV test, which I did and was tested positive. What made me go for an HIV test was the death of my sons and sickness. I then accepted my status and disclosed it to my neighbour who works with HIV people who then encouraged me to disclose to my family.
- The reason why I have not disclosed my status to anyone apart from this friend who gave me the questionnaire is because both my family members and the community members do not know much about HIV and so they just gossip and gossip about HIV-positive people.

**APPENDIX 5I: STUDENTS/YOUTH GROUP QUESTIONNAIRE**

STUDENTS/YOUTH GROUP QUESTIONNAIRE – CONFIDENTIAL

Introduction: Thank you for participating in this survey, which is being administered through the Community Care Project to see how best we can deal with silence around HIV and AIDS. We appreciate your involvement. Please answer the questions as honestly as you can.

PLEASE TICK OR WRITE THE APPROPRIATE CHOICE WITHIN THE

**Your Status**

1. What is the name of your School?
2. How old are you?
3. What is your Gender? 

Male	Female
------	--------
4. Which Grade are you in?
5. Have you done an HIV Test before? 

Yes	No
-----	----
6. a) What made you go for HIV testing?.....  
b) If you have not gone for a test before, why haven't you done it yet?.....
7. Why do you think it is difficult to talk about HIV and AIDS even among ourselves as friends?.....
8. What are some of the cultural beliefs that prevent us from talking about the disease?.....
9. What makes it difficult for young people to disclose their HIV status to the older people?.....

THANK YOU VERY MUCH FOR CONSENTING TO ANSWER THIS QUESTIONNAIRE. PLEASE SIGN

.....

## APPENDIX 5I1: DETAILED RESULTS OF YOUTH GROUP QUESTIONNAIRE

### 1.0 QUESTIONNAIRE: YOUTH GROUP

Below are the detailed results of the questionnaire administered to 41 Youth Group members who attended the meeting of Friday, 22<sup>nd</sup> June 2007 at Bethany House, that was devoted to a group-administered questionnaires:

#### 1.1 Closed Questions

##### *Question 1: What is the name of your School?*

Response:

41 respondents from 17 schools

Results:

Alexandra High School, Bondudunga Secondary School, Gobindlovu Comprehensive High School, George Town High School, Ikusaselihle High School, Kwapata High School, Khwezi Primary School, Mthuli High School, Mpumelelo Primary School, Mthethomusha Primary School, Nyanithwele High School, Nomasazi High School, Oxford Matric College, Sqongweni High School, Sobantu Secondary School, Willowfontein Primary School and Zamazulu High School.

##### *Question 2: How old are you?*

Response

All 41 respondents answered this question.

Age (Years)	13	14	15	16	17	18	19	20	21	22
Number of Youth Group	1	5	6	7	11	4	5	0	1	1

**TABLE 5I1.1 – Respondent's age**

Results:

2.4% of the Youth Group were 13 years old, 12.2% were 14 years old, 14.6% were 15 years old, 17.1 % were 16 years old, 26.8% were 17 years old, 9.8% were 18 years old, 12.2% were 19 years old, No one (0%) was 20 years old, 2.4% were 21 years old and 2.4% of the Youth Group were 22 years old

**Question 3: What is your Gender?**

Response:

All 41 Youth Group members (23 males and 18 females) answered this question.

Results:

56.1% of respondents were males and 43.9% were females.

**Question 4: Which grade are you in?**

Response

All 41 respondents answered this question.

Grade	6	7	8	9	10	11	12
Number of Youth Group	1	5	2	5	19	8	1

**TABLE 5I1.2 – Respondents’ grade at school.**

Results:

2.4% of the Youth Group are in Grade 6, 12.2% in Grade 7, 4.9% in Grade 8, 12.2 % of in Grade 9, 46.4% in Grade 10, 19.5% in Grade 11 and 2.4% of the Youth Group are in Grade 12.

**Question 5: Have you done an HIV Test before?**

Response:

2 males and 8 females had done Test before while 21 males and 10 females had not yet done the test.

Results:

24.4% of the Youth Group had done HIV test before and 75.6% of the Youth Group had not done HIV test before. Of the male Youth Group members, only 8.7% had taken the HIV test before and 91.3% had not had an HIV test before. Of the female Youth Group members, 44.4% had taken the HIV test before while 55.6% had not taken an HIV test.

## 1.2 Open-ended Questions

The respondents gave the following responses in their own words, but similar ideas are not repeated:

### ***Question 7: Why do you think it is difficult to talk about HIV and AIDS even among ourselves as friends?***

- When you talk about HIV people may conclude that you are infected and that is why you want to talk about it.
- It is scary to talk about the disease and it makes you feel you are infected.
- It is because it is related to sex.
- People are afraid of this disease because it cannot be cured and that makes them afraid to talk about it.
- It is because some of us there are scared to talk about it.
- It is because one feels shy to ask question around the disease.
- It is difficult because people will say you are rude to talk about it.
- Talking about it makes you feel like you are infected.
- Because some people will think you are suspecting them and that is why you are bringing it up for discussion.
- If you bring up a discussion on the disease, people will gossip about you and judge you so it is better to keep quiet and not talk about it.
- It is because people of today are talking behind the backs of other people.
- It is a topic that does not give freedom and you are not sure about how the people you discuss with take it.
- It is because you never know that your friend is HIV-positive or not and they think that you want to be clever on them by discussing the issues just to catch them. This can affect our relationship.
- It is because friends enjoy talking about other things that they consider cool and not subjects that frighten you.
- It is because some of people can think that you are talking about HIV because you have it or there is someone who has it in your family and that will make them stigmatise you.

- Maybe one of us in the group might have HIV and as you discuss you will hurt that person's feelings.
- Because of our culture, you feel uneasy to talk about anything related to sex on a serious note and not for fun, as it is with discussions on HIV or AIDS.
- Once you initiate discussions on HIV your friends will say you are so boring.
- It is because as people we do not accept HIV and AIDS like other diseases.
- I can say it is because most of us are sexually active and not faithful at all so each of us feels uncomfortable talking about this disease that touches and exposes our behaviour.

***Question 8: What are some of the cultural beliefs that prevent us from talking about the disease?***

- In our Zulu culture it is not allowed for children to be too inquisitive about sexual issues and so you keep silent on such issues.
- The culture does not allow you to get information anyhow on ways to behave sexually; you have to approach the elderly people through schools such as the virginity testing other wise you keep quiet.
- Fathers have more power at home than mothers and they are the ones who give directives. As such mothers keep silent most of the time over many issues including HIV, and yet our fathers are not ready to talk about these things.
- Once you begin talking about a sexually transmitted disease our parents and the uncles will think you consider yourself more mature than they are. Because of this perception, young people keep silent about HIV.
- In the Zulu culture when someone begins to show clinical signs of HIV infection, they say the person is becoming a *Sangoma* and you cannot say anything but to keep quiet about the situation and leave it to the traditional doctors.
- In our culture people believe that experience is the best teacher. As a result people who are old find it difficult to learn from the young ones through discussions. They want to learn from their own experience and silence young people.

- Boys are made to think that they have the power to demand sex from girls and can move from one girl to the other but girls dare not do that.

***Question 9: What makes it difficult for young people to disclose their HIV status to the older people?***

- The fears that the elderly people will think you are a living dead and so discriminate against you.
- It is because adults will shout at you and think you have been prostituting yourself.
- You think that your parents will chase you away and not give you money.
- Parents should not be surprised because they will die at anytime.
- It is because young people are scared of the consequence of telling the elders you are HIV-positive.
- It is because of the thought that they will be treated differently from other people.
- You are afraid that your parents will be ashamed of you in the community.
- It is because most of the elderly people have not done any training on HIV to help them understand the disease.
- It is because culturally young people cannot go to the elderly to disclose sexually transmitted diseases.
- The elderly people will use your disclosure to prove a point of the young person being disobedient or sexually active.

## **APPENDIX 5J1: DETAILED RESULTS OF FOCUS GROUP DISCUSSIONS**

### **1.0 Focus Group discussion 1 (FGD1)**

#### **Question 1: What makes it difficult for women to tell their husbands or boyfriends about their HIV-positive status?**

- The man will kill the woman.
- The woman will be physically abused.
- The woman could be locked outside the house.
- In situations where the woman has been unfaithful before, she will be afraid as she may not know where she got it from and the man will demand to know.
- The man will leave the woman and things may change for the woman and children.
- If the man drinks with his friends, he will start telling others and may be advised by his friends to kill her.

#### **Question 2: What is the role of the infected female in dealing with the HIV Pandemic?**

- Take care of themselves.
- Have safe sex by using condoms
- Have one sexual partner.
- Teach each other to live faithful lives and trust each other.
- Have a faithful partner like oneself then it will be easier to understand each other.
- Encourage one's partner to go to the clinic so that life will proceed smoothly.
- Tell one's partner her secrets and do not tell outsiders.
- Infected women should abstain from sex. It is the best for their lives
- Infected women have the role of letting men who express interest in them know that they are HIV-positive right from the beginning before they become too excited about wanting to befriend them or marry them.
- A case in point is the example of an HIV-positive woman who is on ARV treatment and has befriended a man who has even bought a car for her and yet she has not told him that she is HIV-positive. She says it is too late to tell the man and if she does, she knows that he would kill her.

- By declaring their status to men who approach them, women are stopping HIV from spreading.

**Question 3: What is the role of the infected female in engaging with the HIV silence?**

- Infected women have the role of educating the community about HIV and thereby reducing the stigma which hinders the disclosure.
- They have the role of disclosing their HIV status to their family members and thereby initiating HIV discussions in the family
- Infected women can share their HIV stories with young women and girls and encourage them to ask questions on the disease.
- They have the role of organising Support Groups in the community to encourage other infected people, especially women, to be open about their status.
- They have the role of being open about their status to men who express sexual interest in them

**2.0 Focus group discussion (FGD2)**

**Question 1: What makes it difficult for men to tell their wives or girlfriends about their HIV-positive status?**

- Because of the way men blame their wives or girlfriends for problems in the marriage or relationship, men are afraid to be blamed for bringing HIV into the family.
- Men are afraid that the women would leave them.
- The man may be questioned as to where he got the disease from and be suspected of having a girlfriend somewhere.
- The woman may kill the man or kill herself.
- Things will change at home; the one who reports first is the one who will be considered to have brought in the disease, so the man will wait for the woman to mention her status first. [much laughter]
- The woman will point out past issues to remind the man as to why he is HIV-positive.
- The fear of losing the confidence, respect and the trust that people have in him.
- Fear of rejection.

**Question 2: What is the role of the infected male in dealing with the HIV pandemic?**

- Infected men have the role of encouraging those who have been diagnosed HIV-positive, and are struggling in terms of accepting their own status or that of others who are failing to cope with their HIV situation. Through offering counselling and the sharing of experience, these people will be able to attend clinics regularly to access help.
- Infected men can be an example to people know that HIV is not a death sentence, as is presumed in the communities.
- Personal near-death experiences can be shared with others.
- An infected man needs to accept who he is and to accept his status.
- Normally, men in the home are the key for solutions to most of the problems, because they are seen to have control. In fact, they have the power to determine other people's lives as, when they are HIV-positive and sleep with women they infect them and destroy their lives. Infected men therefore have the role of stopping the spread of the disease.
- Men even have power to change the HIV situation. They are the ones who can boldly tell their partners they are HIV-positive. Women cannot tell their partners that they are HIV-positive for fear that they would be killed.
- Infected men should stop the propaganda of saying that ARVs don't work when in actual fact they are using them and it is working for them.
- Infected men have the role, through proper training, to become HIV counsellors. There are very few male HIV counsellors and so when men get tested they don't receive much-needed help from women counsellors. Infected men can therefore be trained to fulfil this role.
- Traditionally, men find it difficult to be counselled by women. Therefore infected men could be trained as counsellors.
- They have a role to wear condoms whenever they are involved in sex.
- They must learn to be faithful if they are in a relationship, and to disclose their condition to their partners right from the beginning.
- They must not involve themselves in alcohol, drinking or any form of drugs. This will prevent them harmful behaviour to themselves and their partners.

- It is their role to stop all purposeful spread of HIV and AIDS to others, including their partners.
- They have a role to seek more information about HIV and AIDS when they know their status.

**Question 3: What is the role of the infected male in engaging with the HIV silence?**

- Infected men need to be open about their HIV status, especially to younger men. This will help the youths to come to them with their problems.
- Every infected individual, especially men, from the day he is told of his status vows not to disclose to anyone. Not even the girlfriend. There is a lot of shame and stigma around the disease. But as men we know that it is not easy to keep this secret. We always leave room for people to build relationship with us so that we can trust them and share this burden with them. The role of infected men, especially those of us who have learnt ways to engage with others and build relationship with so that we disclose our status to, is to lead the way and teach infected men and women how to build relationship and disclose their status in a meaningful way to trusted people.
- Within families, infected men should share their stories to encourage the others to be open. In our African tradition, people are naturally secretive, especially about HIV, but if the man in the house is open and not ashamed to disclose his status to his own family, he will encourage other family members to also be open. Women in particular will be encouraged, as they are often afraid of their men, even to ask questions relating to men's, or their own, health.
- Using their own experiences, infected men have a role to help others struggling to disclose their status to family members.
- It is difficult to disclose the information to family members who are drunkards, because when they get drunk they gossip about the PLWHA in public, and about their status. Infected men have a role of talking to people who drink about the dangers of HIV and alcohol and to stop them from gossiping.
- Infected men must learn to disclose their status to family members, at least to trusted ones.

- Generally, community members don't have proper education and understanding about HIV. Infected men can help with community HIV and AIDS education and to dispel wrong concepts and to reduce stigma, thereby helping infected people to feel sufficiently secure to disclose their status. As an example, some people still think that a sweat from an infected person can infect others.

### **3.0 Focus group discussion 3 (FGD3)**

#### **Question 1: What aspects of your culture make you keep silence about your status?**

- In the community people talk (gossip) and they stigmatise people who are HIV-positive.
- A young woman is expected to keep her virginity. If she says that she is HIV-positive, it means that she is not a virgin and incurs shame.
- The belief that if someone is sick, with a disease such as HIV, then that person is bewitched and must be taken to the traditional doctor.
- The relationship between the older and younger generations is not smooth, with the elders always being suspicious of the behaviour of the young, and so one is afraid for the elders to know that one is HIV-positive. They will question your sexual behaviour.
- People see HIV as a disease linked to witchcraft.
- The culture lacks perspective and knowledge on HIV and people do not consider it as they do any other disease. It is linked with a group of diseases that only *Sangomas* can deal with.
- Community members, especially the older generation often consider the disease as one that infect people who are immoral and engage in indecent sexual activities and so people who are living with the disease are considered to deserve their fate. The fear of being told in the face that one is promiscuous make infected people keep silence about their status.

**Question 2: Which aspects of the African culture contribute to the HIV and AIDS silence?**

- The inability of the culture to allow discussions on issues of sex with a younger person who is not in one's own age group.
- When one is HIV-positive one cannot disclose this because people will think that that one has been involved in immoral sexual relationships, and will have no way to express himself or herself.
- The inequality between men and women and the blaming of women when things go wrong in the family. That is why, when there is HIV in the family, husbands blame wives or boyfriends blame girlfriends. For fear of blame, women in particular keep their status to themselves.
- As a result of the inequality between men and women, men are afraid to be accused of wrong-doing in bringing HIV to the relationship. In this case, the men are unwilling to talk about their status for fear that their girlfriends might not be HIV-positive; as the women will then know that the men have been involved with other women.
- In our cultures, any disease that is linked with sexual intercourse is stigmatised as a disease that has no cure. Incurable disease is linked with witchcraft, and so when people know you have an incurable disease, they will shun away from you and you will be left alone. Because of this, when one has got HIV or AIDS she or he will not mention it. It is in our culture to 'save the face' of the family and so you will not tell family members for fear the elders will question your behaviour before they can protect or help you.
- The question of protecting sick family members with the view of saving the face of the family as a whole leads to silence. Instead of the family seeking medical help, it seeks traditional help through *Sangomas*. Families believe that incurable diseases can only be cured by traditional doctors. This is because the elderly people in our families are afraid of anything that will disgrace the family and they see HIV as such.
- In our culture, those who lead us and have power are ashamed of people who violate cultural taboos such as those on sexual practices or consulting the

ancestors on your own. If, for example, a family member is proved to be sleeping around or involved in sex work that person will be reprimanded by the elders and if that person is suspected to be sick because of breaking any of the cultural taboos, it is arranged for this person to be taken to a sangoma for spiritual cleansing. This is a shameful ritual involving slaughtering of goats to appease the ancestors who have been offended through one's careless life. This makes people who are HIV-positive keep their status a secret to avoid castigation and blame as a taboo breaker.

- According to our culture, when someone is sick, the parents send that person to the traditional doctor, who always says it is the ancestors sitting on you (maybe because of your behaviour or something you have done against them) and so you need to pacify them with a goat. This is a sacred and a shameful situation that you have to keep secret. The sick person will try by all means to avoid this by keeping his sickness from the entire extended family scrutiny. Even if one goes through this procedure with the *Sangoma*, it is even kept more secret because of the stigma on sacred pacification, with all the slaughtering and rituals that go with it.
- The community nature of our culture helps people to offer help when you need it but, at the same time, our culture does not have a way of teaching people about modern diseases and always links diseases to traditions that expose the sick person to ridicule when he or she is not getting well.
- Unless you have a good relationship and trust for people, it is difficult to disclose your status to them, even though in our culture people are caring they end up gossiping about you.
- The concentrations of power in men, who are considered leaders and elders, allows them to misuse family funds. Sometimes they use the money, including the money that women work hard for, on drink. This brings poverty to the family and children and women (wives or girlfriends) are tempted to look for money from other men.

### **Question 3: What do you see to be the benefits of the CCP Support Group?**

- It has helped more people access ARVs and encouraged people to take them regularly
- It has helped people to disclose their status to their families and to receive help from them.
- The group has helped create a level of boldness about the stigma on the disease. The men of the Support Group confirmed that when they go to the clinics for ARVs they see only women, and see themselves as blessed to be able to go to the clinics boldly for their ARVs. In this way, they are in a position to help other men go to the clinics and access ARVs and help them take them properly.
- In questioning and discussions with other Support Groups in the KZN province, they have realised that there are no Support Groups for men. They see the CCP Support Group as the only one with men attending regularly.
- The group teaches members to be true to themselves and others. One of the men pointed out how at the clinic he used to flirt with a nurse. Then he realised that the nurse was becoming interested in him, and so, one day, he told the nurse that he had come to fetch his ARV medication. The lady was shocked and said, “You are the first man who has ever told me he is here to fetch ARV”
- The Support Group is a source of hope for positive living where people give hope through their own physical strength and testimonies.

### **Researcher’s Personal Observation and Reflections on the Focus Group Discussions.**

The focus group discussions were successful and participants found them very helpful. Having held the female and male group discussions separately, before the combined men’s and women’s group discussion, was helpful, as they prepared the groups for the combined discussion and made it very interesting. It was interesting to note that the participants pointed out their roles in dealing with the HIV silence. Through these discussions one could see how bold the participants had become in freely discussing their own situations and also how they had come to terms with, and achieved an understanding of, the disease that they are living with.

## APPENDIX 6A1: REPORT FROM RUSSELL HIGH SCHOOL ON CCP'S WORK



### RUSSELL HIGH SCHOOL

31 October 2008

To Whom It May Concern:

#### Report on Community Care Project

Beatrice, Patrick and Richard have been actively involved with our learners since 2007. Asanda has joined them in 2008.

I originally formed the AFBF (Aim for a Better Future) committee in 2006 after we had a grade 10 learner losing her life because of HIV and Aids. Benson Okyere-Manu became involved with my committee and introduced us to the 2 x 2 x 2 philosophy.

Since then the girls look forward to their meeting with their co-ordinators every two weeks. The number of learners involved in the group increases each year. The learners enjoy an open rapport, which they would not be able to achieve with their educators about sensitive issues discussed.

The programme followed by Community Care Project has had a significant and positive impact on our learners. The pregnancy rate has definitely decreased. I am hoping that many of them have decided not to get involved in sexual relationships because of the risks involved.

I have enjoyed being part of such a caring and dedicated team of people whose only desire is to make a difference and save lives. I hope that their involvement, and the exceptional work they do with Russell High, will continue in the future.

Thank you once again for the impact you have on the Russell High ladies.

Kind Regards

Padayachee  
**Ms R Padayachee**  
Deputy Principal

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