

The experience of implementing a psychology service programme at a  
Paediatric HIV Clinic

by

**OLGA MATHARI MOLEBATSI**

A mini-dissertation submitted in partial fulfilment of the requirements for the degree

MA Counselling Psychology

Department of Psychology

Faculty of Humanities

University of Pretoria

**Supervisor:** Ilse Ruane

May 2013

## ACKNOWLEDGEMENTS

My deepest and sincere gratitude goes to the following:

- My heavenly Father- the completion of this project is a song of worship unto Your name. Once again I utter in praise that : It can only be God. I love You Lord Jesus!
- My supervisor, Ilse Ruane- I am so grateful to you for your efforts and continuous encouragement, so many times this moment as I'm writing this, seemed so far but indeed all things are possible.
- The participants- this would not have been possible without you. You availed yourselves despite your busy schedules and you were eager to be part of this study. You guys are wonderful.
- My editor, Debbie Walton- thank you so much, for the good work you did. Your time and expertise are appreciated.
- My family, mom and dad- I am so thankful that I was born of you. Now that I am parent, I appreciate you even more. You are irreplaceable. Pontsho (my baby-sister) and Ikanyeng (my baby-brother), you two are the most treasured in my heart. I hope you achieve more than I have achieved.
- My friends, oh my God, you guys rock. The concept of friendship is beautiful to me, all because of you. Motlatsi- I just had to single you out my friend. You were around campus for such a time as this. Thank you.
- The Tibane and Tshweu family, you guys are such an inspiration. Thank you for your support, I really appreciate your presence in our lives.
- My son, Otlotlegile- this project was dragging to reach its completion stages, and then you were born my Colourfulness, just the motivation I needed to push through. You are the most wonderful gift I ever held in my hands. Indeed you have brought colour in our lives; and that colour looks bright and beautiful; lively and joyful. I am loving you my Booboo.
- Lastly, my husband (Kagiso), my Hunk- oh my! I've always said that you are too good to be true but now I am finally accepting that being kind and wonderful is in your nature. I have to stop myself from writing an essay here. In short, thank you so much, for your unwavering support, love and encouragement, in all the areas of my life. I am so grateful to have you by my side. I love you my Handsome.

## DECLARATION

I, Olga Molebatsi, hereby declare that the work on which this dissertation is based, is original, except where acknowledgements indicate otherwise, and neither the whole work nor part of it, has been, is being, or is to be submitted for another degree at this or another university or tertiary education institution or examination body.

## ABSTRACT

The psychology service programme was implemented at the Kalafong Paediatric HIV Clinic. The students from the Department of Psychology from the University of Pretoria were involved. The aim of the study was to explore, explain and describe the experiences of the personnel at the Clinic during the implementation of the programme in terms of an interpretive narrative framework.

A qualitative research design was used. The primary source of data collection was through interviews. Interpreting experience took place at Reissman's five levels of representation and Labov's six elements for data reduction and interpretation were used. The emerged interpretive categories were presented as questions.

The study found that the multidisciplinary team identified the need for psychological intervention, more so during the time when some of the adolescent patients had discovered that they were HIV positive. The patients were struggling to cope with the reality of accepting the diagnosis. The study noted the challenges that were experienced during the implementation, as well as the highlights.

Availability of the psychology students seemed to be the greatest challenge as well as the issue of arranging psychological consultations to coincide with the same date for other consultations among other challenges. This study exhibited a mutual feeling that the implementation of the psychology service programme was a good initiative and ought to be continued at the Clinic.

**KEY WORDS:** Experiences, Implementation, Psychology programme, HIV/AIDS,

Adolescents, Paediatrics

## ABBREVIATIONS/ACRONYMS/ KEY TERMS

|             |   |
|-------------|---|
| AB          | - Abstract (As according to Labov)  |
| AIDS        | - Acquired Immune Deficiency Syndrome   |
| ART         | - Anti- Retroviral Therapy  |
| ARVs        | - Antiretrovirals   |
| CA          | - Complicating Action (As according to Labov)   |
| CD4 count   | - HI virus targets and destroys CD4 cells in the immune system. CD4 count is a useful marker in determining the state of the immunity in a person with HIV/AIDS |
| Clinic      | - Kalafong Paediatric HIV Clinic/Also known as Immunology Clinic or ARV Clinic  |
| CO          | - Coda (As according to Labov)  |
| EV          | - Evaluation (As according to Labov)  |
| HIV         | - Human Immuno-deficiency Virus   |
| HIV/AIDS    | - Human Immuno-deficiency Virus/ Acquired Immune Deficiency Syndrome  |
| MA students | - Masters Students in Counselling Psychology (Community programme)  |
| OR          | - Orientation (As according to Labov)   |
| OT          | - Occupational Therapy  |
| RE          | - Resolution (As according to Labov)  |
| TB          | - Tuberculosis  |
| VCT         | - Voluntary Counselling and Testing   |

## TABLE OF CONTENTS

|  |            |
|--|------------|
| <b>Acknowledgements</b>  | <b>ii</b>  |
| <b>Declaration</b>   | <b>iii</b> |
| <b>Abstract</b>  | <b>iv</b>  |
| <b>Key words</b>   | <b>iv</b>  |
| <b>Abbreviations</b>   | <b>v</b>   |
| <b>Table of contents</b>   | <b>vi</b>  |
| <br>   |            |
| <b>CHAPTER 1: ORIENTATION</b>  | <b>1</b>   |
| 1.1 Introduction   | 1          |
| 1.2 Research Problem   | 2          |
| 1.3 Motivation of the study  | 3          |
| 1.4 The aims and objectives of the study                                 | 4          |
| 1.5 Research question and emerging intentions                            | 5          |
| 1.6 Conclusion   | 6          |
| <br>   |            |
| <b>CHAPTER 2: RESEARCH REVIEW</b>  | <b>7</b>   |
| 2.1 Introduction   | 7          |
| 2.2 The impact of HIV/AIDS   | 7          |
| 2.3 Disclosure of the HIV/AIDS status to children and adolescents        | 8          |
| 2.4 Disclosure and stigma  | 10         |
| 2.5 Medication adherence   | 13         |
| 2.5.1 Psychosocial barriers to optimal Anti-Retroviral Therapy adherence | 15         |
| 2.5.1.1 Poverty  | 15         |
| 2.5.1.2 Health literacy  | 16         |
| 2.5.1.3 Perceived social support   | 16         |
|  | vi         |

|   |  |           |
|---|--|-----------|
| 2.5.1.4                                 | Mental health  | 17        |
| 2.6                                     | Bereavement  | 17        |
| 2.7                                     | Interventions towards issues involving HIV/AIDS                | 19        |
| 2.8                                     | Psychology service programme at Kalafong HIV Paediatric Clinic | 21        |
| 2.9                                     | Conclusion   | 24        |
| <b>CHAPTER 3: THEORETICAL FRAMEWORK</b> |  | <b>25</b> |
| 3.1                                     | Introduction   | 25        |
| 3.2                                     | Narrative approach   | 25        |
| 3.2.1                                   | Definition of narratives                                       | 26        |
| 3.2.2                                   | Role of narratives   | 27        |
| 3.2.3                                   | Narratives and experience                                      | 28        |
| 3.2.4                                   | Narratives and culture   | 29        |
| 3.2.5                                   | Narratives and language  | 30        |
| 3.2.6                                   | Role of the researcher   | 31        |
| 3.3                                     | Conclusion   | 32        |
| <b>CHAPTER 4: RESEARCH METHODOLOGY</b>  |  | <b>33</b> |
| 4.1                                     | Introduction   | 33        |
| 4.2                                     | Qualitative research   | 33        |
| 4.3                                     | Research design  | 34        |
| 4.3.1                                   | Sampling   | 34        |
| 4.3.2                                   | Data collection  | 35        |
| 4.3.3                                   | Data analysis  | 37        |
| 4.4                                     | Ethical considerations   | 41        |
| 4.4.1                                   | Informed consent   | 41        |
| 4.4.2                                   | Confidentiality and anonymity                                  | 42        |

|                            |   |           |
|----------------------------|---|-----------|
| 4.4.3                      | Beneficence   | 42        |
| 4.5                        | Conclusion  | 42        |
| <b>CHAPTER 5: FINDINGS</b> |   | <b>43</b> |
| 5.1                        | Introduction  | 43        |
| 5.1.1                      | Participants  | 43        |
| 5.2                        | Emerged interpretive categories   | 45        |
| 5.2.1                      | How did the decision to implement psychological services in the clinic come about?          | 45        |
| 5.2.2                      | What were your expectations from the psychology service programme?                          | 49        |
| 5.2.3                      | What steps were taken to implement the decision regarding the psychology service programme? | 51        |
| 5.2.4                      | What was your role?   | 52        |
| 5.2.5                      | What are psychological services according to you?   | 54        |
| 5.2.6                      | What did the psychology service programme mean to you?                                      | 58        |
| 5.2.7                      | Did you get feedback from the cases you referred and what were the cases about?             | 62        |
| 5.2.8                      | How was your relationship with the psychology students?                                     | 66        |
| 5.2.9                      | Were there any challenges experienced and what were they?                                   | 68        |
| 5.2.10                     | What are your views concerning the establishment of the support groups?                     | 73        |
| 5.2.11                     | Do you think that the psychology service programme met the needs of the Kalafong community? | 76        |
| 5.2.12                     | What are your recommendations?  | 80        |
| 5.3                        | Second Interviews   | 83        |
| 5.4                        | Conclusion  | 84        |



|   |            |
|---|------------|
| <b>CHAPTER 6: DISCUSSION, LIMITATIONS AND RECOMMENDATIONS</b> | <b>85</b>  |
| 6.1 Introduction  | 85         |
| 6.2 Discussion of the findings                                | 85         |
| 6.3 Limitations of the study                                  | 90         |
| 6.3.1 Sampling and inclusion criteria                         | 90         |
| 6.3.2 Duration of the study                                   | 90         |
| 6.3.3 Method of analysis                                      | 91         |
| 6.3.4 Role of the researcher                                  | 91         |
| 6.4 Strengths of the study                                    | 92         |
| 6.5 Recommendations   | 92         |
| 6.6 Conclusion  | 93         |
| <br>  |            |
| <b>List of references</b>                                     | <b>94</b>  |
| <b>List of appendices</b>                                     | <b>102</b> |
| Appendix A (Consent Form)                                     | 102        |
| Appendix B (Interview Guidelines)                             | 106        |
| Appendix C (Permission Letter from the Clinic)                | 110        |
| Appendix D (Permission Letter from Kalafong Hospital)         | 111        |
| Appendix E (Permission Letter from the Ethic Committee)       | 112        |
| Appendix F (Psychologist Letter)                              | 113        |
| Appendix G: Participants' Transcripts                         | 114        |
| Lesego's Transcript   | 114        |
| Lebogang's Transcript   | 120        |
| Lesedi's Transcript   | 130        |
| Letlhogonolo's Transcript                                     | 139        |
| Lerato's Transcript   | 151        |

## CHAPTER 1

### ORIENTATION

#### 1.1 INTRODUCTION

As one of the masters Counselling Psychology students (community programme) involved at Kalafong Hospital Paediatric HIV Clinic from 2009 to 2010, I became interested in conducting a study related to the obstacles and challenges of setting up a counselling programme within a Paediatric HIV Clinic. To give further background, even though it was a paediatric clinic, their patients were aged from birth up until the age of eighteen years old. Our involvement was under the leadership and supervision of the University of Pretoria's Department of Psychology and the Manager of the Kalafong Hospital Paediatric HIV Clinic (hereafter referred to as the Clinic). I, the researcher, and my fellow MA students took part in the psychology service programme at the Clinic.

In this Chapter, I discuss the research problem describing what took place at the Clinic. I then address the motivation of the study and its aims and objectives. Furthermore, research questions as well as the emerging intentions are also presented.

Kalafong Hospital is situated 12 kilometres west of the city centre of Pretoria, near to Atteridgeville. It has a Paediatric HIV Clinic that has been functioning for the past seven years; an adolescent clinic was established in 2007 within the same institution. Other researchers who worked in this Clinic (Vlug, Feucht & Kruger, 2008) identified certain needs that required psychological intervention, thus the Department of Psychology from the researcher's tertiary institution was invited to be part of the multi-disciplinary team.

As part of the practical training, the masters students in Counselling Psychology (community programme), were placed in both institutional and communal environments to gain exposure

to therapy and the world of work of a psychologist. The goal being to equip them as future psychologists who can function in different contexts. The training consists of the academic and professional training programmes that prepared them for work in the service delivery sector (Hecker, Fink, Levasseur & Parker, 1995). At Kalafong Hospital, we were therefore exposed to the experience of counselling within the medical field and working within a multi-disciplinary team.

Practicum experience is an integral component of the training of a psychologist (Hecker et al., 1995). It is also seen as a journey of self-awareness and self-discovery, leading to growth and development. It is a process to clearly define parameters, to explore and realise potential as future psychologists. Training is necessary to familiarise the training professional with the policies and working procedures; and what the goals and structure of the organisation are, including their work culture (Agochiya, 2002).

The following needs were identified (Vlug et al., 2008) in 2008 by the personnel working at the clinic:

- Dealing psychologically with HIV/AIDS and counselling patients regarding the issue of disclosure
- Psychosocial support for patients and their families
- Education on sexuality, HIV prevention and male role models for adolescents

## **1.2 RESEARCH PROBLEM**

As part of the practical training, the University of Pretoria's Department of Psychology was involved in the implementation of the psychology service programme at the Clinic. Both the masters and honours students from the Department of Psychology were participating in the programme in roles prescribed by the core competencies of the two programmes. The masters students were to work with the adolescents and the caregivers in the Clinic, as well as with the children referred by the occupational therapists, while the honours students were to work

with the children seen by the occupational therapists in terms of assisting with the playgroups.

In 2009, we (my fellow students and I) went to the Clinic on Monday afternoons only and in 2010 on Mondays in the morning for six hours. Several meetings were held at the beginning of the year which were necessary for us to get to know the personnel and learn how the Paediatric HIV Clinic operated. We were introduced to the personnel members, who in turn helped us to understand the needs of the Clinic. They also explained the functioning of the Clinic and engaged us in their personnel meetings.

The personnel were also involved in setting up appointments for us (students involved in the psychology service programme), referring clients, making arrangements for support groups and also familiarised us on how the systems worked. For example, the running of the clinic, accessibility of files and setting dates for appointments. In addition, they helped us with the logistics of the programme, for example, office space and recommended which days were suitable for us to be at the Clinic etc.

Once we were introduced to the personnel, much time was spent introducing ourselves to the outpatients and caregivers. This was done in order for them to become aware of our services which was a way of marketing the psychology service programme. Access to the patients who were admitted in the hospital was gained via referrals from the personnel.

Even though much effort was put into implementing the psychology service programme, during feedback meetings with our lecturers there was a common concern among us the students that it seemed our services were not being utilised as we had expected and hoped. We did not have as many clients to see according to the needs that were laid out to us.

### **1.3 MOTIVATION OF THE STUDY**

Our (MA Counselling Psychology students) duties were to offer psychological services, which included individual counselling to both caregivers and adolescents, as well as to the personnel at the Clinic. Moreover, the students were to help establish support groups for

caregivers and adolescents, and to assist adolescents with sexual education, as well as stress management.

Assessing the needs of the patients and the personnel at the Clinic further formed part of the duties allocated to the students. Psychological services were made available to the occupational therapists as well so as to work with the children they were treating. Psychology students were to establish play groups and activities for children waiting in the queue for check-ups, as well as offering therapy to the children. HIV/AIDS has been, and it still is, an epidemic and we were there to help people in dealing with issues pertaining to it.

At the end of 2009, students were to write a report detailing their training at the Clinic and for me, as a masters student, my report was filled mostly with frustrations regarding the process of programme implementation. When the programme began there seemed to be a need for the aforementioned psychological services, but the programme took longer than anticipated to get off the ground. What went wrong? What were the obstacles? What could have been done differently and how could one implement improvement as a team? These were the questions that I asked myself, which in turn lead to the proposed research. During this time of questioning and reflection, the topic of this research study came into being.

#### **1.4 THE AIMS AND OBJECTIVES OF THE STUDY**

The study intends to explore, explain and describe the experiences of the personnel at the Paediatric HIV Clinic during the implementation of the psychology service programme in terms of an interpretive narrative framework. Freedman and Combs (1996) described that each remembered event constitutes a story. Thus the study will allow the Clinic personnel's stories concerning the implementation of the psychology service programme to be told and the meanings attributed to the programme to unfold.

The study may be of value to the tertiary institution's lecturers who are involved with training of the students in clinical settings. The Psychology Department from the hospital or other hospitals, which may want to implement a psychology service programme, may also benefit from the study.

Future psychology trainees at the Clinic or other hospitals may also have a point of reference, to guide and help them, in awareness of the challenges that may arise during the implementation of the psychology service programme in other communities or situations.

It should be noted that the aim of this study is not to evaluate the psychology service programme at the Clinic but to describe the personnels' experiences of the implementation of the programme. In other words, the study aims to tell a story about where the programme has been, where it is now and the direction its future shall take. The interpretive narrative inquiry was decided by the researcher as best suited for this study.

## **1.5 RESEARCH QUESTION AND EMERGING INTENTIONS**

This study intends to research and reveal the views, perceptions and the experience of the personnel. Therefore research questions such as how the programme has been at the clinic; and whether there is a need to adapt any changes within the psychology service programme according to the personnel's experience.

Chapter One outlines the research problem, motivation, aims and objectives of the study. Furthermore, the research question is discussed.

Chapter Two focuses on literature review of HIV/AIDS focusing on issues of stigma, disclosure and medical adherence since those were major challenges at the Clinic.

Chapter Three explains the theoretical approach which is the Narrative framework.

Chapter Four provides the definition of the qualitative research and the overview of the research design is deliberated. This includes sampling, data collection and the method that was applied for data analysis. Furthermore, ethical considerations were explained.

Chapter Five details the findings of the analysis.

Chapter Six concludes with the discussion of the findings, the limitations of the study and the recommendations.

## **1.6 CONCLUSION**

A broad orientation of the study has been discussed in Chapter One which included the research problem, motivation of the study, the aims and objectives. Lastly the research question and emerging intentions of the study were presented.

## CHAPTER 2

### RESEARCH REVIEW

#### 2.1 INTRODUCTION

This Chapter details the literature review on HIV/AIDS specifically to factors that were significant and of relevance to the Clinic. It begins by describing the impact of HIV/AIDS, proceeds to discuss the disclosure of the HIV/AIDS status to children as well as adolescents, disclosure and stigma, medication adherence as well as psychosocial barriers to optimal Anti-Retroviral Therapy adherence. Furthermore, bereavement, as well as interventions towards issues involving HIV/AIDS disease was discussed. Lastly, the researcher explained what the psychology service programme at the Clinic was about, including what it entailed.

#### 2.2 THE IMPACT OF HIV/AIDS

HIV/AIDS has been a challenge in all the world's societies for almost two decades. The disease has been particularly devastating to the African continent. It has been reported that South Africa has the highest number of people living with HIV/AIDS (WHO, 2008). "Issues that contribute to the challenge of dealing with this disease include among others, high level of poverty, low-level of education attainment, inadequate or lack of public health services, inadequate personnel in health services fields, apathy, myths and misconceptions about HIV/AIDS" (Umerah-Udezulu & Williams, 2002, p. 35).

According to Hosek, Harper and Domanico (2000), women and people aged between thirteen and twenty- four are being infected at increasingly higher rates. It is presumed that young adults, who are between the ages of twenty and twenty- nine, were initially infected during adolescence. Factors such as gender, religion, low socio-economic status, lack of sexual education and culture, contributes in placing people at a high risk for HIV (Heam & Jackson, 2002; Hoffman, 1996).



HIV infected individuals often face stressors such as the disclosure of the HIV infection, social ostracism, fears of death, and family conflict. In addition, they also encounter problems in obtaining adequate health care services, medication, transportation, clothing, recreation, housing and counselling (Brown, Lourie & Pao, 2000).

At the Clinic, the challenges that they were faced with in regards to HIV/AIDS were: telling the children or adolescents that they were HIV positive, as most of their paediatric patients had contracted the disease through mother-to-child transmission. Other challenges included issues of disclosure and stigma, medical adherence, loss and bereavement. These factors needed to be dealt with as they had a tremendous impact on one's social, medical, psychological functioning. Furthermore it also has a great impact on the spiritual, educational and economic aspects. I will therefore discuss these issues in this Chapter.

## **2.3 DISCLOSURE OF THE HIV/AIDS STATUS TO CHILDREN AND ADOLESCENTS**

There is no single or easy guide to deciding when and how to disclose an individual's HIV status, especially when it comes to children and adolescents. At the Clinic, most children were told of their status at the age of eleven by either their caregivers or the health professional worker or both (2010). Van Dyk (2005) believes that there is no right or wrong time to tell a child that he or she is HIV positive. The timing does however depends on the parent, the child and the family circumstances.

According to Vaz, Eng, Maman, Tshikandu and Behets (2010) in clinical settings, health care providers play a huge role in initiating disclosure with children. At times they are the ones telling parents/caregivers that it is time that the child should be told. Parents/caregivers usually want to be involved in the decisions and the processes revolving around disclosure, but they also want support from health care providers.

Vaz et al., (2010, p. 254) reported that “HIV infected caregivers are reluctant to disclose HIV status to infected children as it means disclosing their own status, subjecting them to both guilt as well as blame for the child’s status”. In Vreeman et al., (2010) and Van Dyk (2005), caregivers raised concerns about disclosure to a child, that it may psychologically harm the child. Other reasons for not disclosing to children included concerns that the child was too young and that the child could not keep a secret. In addition, other parents were afraid of being blamed and hated by their children (Vreeman et al., 2010; Van Dyk, 2005).

The silence around HIV/AIDS may cause harm to children, since some may have known for a while that they are HIV positive and may feel angry, hurt and confused by the time their parents officially disclose to them. Silence can therefore be seen as a message for them to be worried and ashamed. These can create feelings of guilt and isolation (Van Dyk, 2005).

Vaz et al., (2010) explained Vygotsky’s theory which states that “interpersonal processes gradually become intrapersonal ones, and that interaction between individuals structures cognition; interactions between people therefore shape individuals’ understanding of themselves and their environment. Within this context, how caregivers and service providers interact with adolescents and communicate information about health status - either verbally or nonverbally - could theoretically have a strong influence on the adolescents’ understanding of their health and well-being”. Therefore, the potential benefits of disclosure must be weighed against possible negative consequences, before a decision is made to inform the child of his/her diagnosis, and adequate support must be put in place for the period following disclosure status (Vaz et al., 2010, p. 253).

Furthermore, disclosure may cause stress and anxiety (Brown et al., 2000). Therefore, the HIV/AIDS status of children or adolescents is often withheld from them, because parents and guardians fear that such information may cause depression and a decline in their health. However, for some children whose HIV/AIDS infection is not known outside the family, the burden of secrecy may promote feelings of isolation and healthy development may be hindered (Brown et al., 2000).

The literature on chronic illnesses suggests that disclosure of the appropriate facts about illness improves the child's psychological adaptation (Brown et al., 2000). For example, when dealing with a disease such as cancer, disclosure has been found to reduce the child's

feelings of distrust, isolation, confusion, and depression. Finally, cultural differences may influence motivations for disclosure and secrecy (Brown et al., 2000).

When children or adolescents are told about their infection, they commonly ask questions such as “am I gonna die? and why me?” (Brown et al., 2000, p. 89). Children, in particular, may feel that they did something dreadful to deserve HIV and thus may develop severe feelings of guilt. Literature reports negative reactions among adolescents, upon learning about their HIV status, ranging from sadness to hurt and worry (Brown et al., 2000).

Vaz et al., (2010) explained that in other cases, the adolescents indicated a sense of relief in finally knowing the source of their suffering. In addition, children’s awareness of their HIV status has been associated with the quality of adherence to Antiretroviral Therapy (Vreeman et al., 2010). There is not much information documented in the literature about the adolescents experiences after being informed of their HIV status (Vaz et al., 2010).

## **2.4 DISCLOSURE AND STIGMA**

HIV infected individuals were most likely to reveal to significant others and sexual partners once the rewards for disclosing outweighed the associated costs (Kang, Rapkin & DeAlmeida, 2006; Yang et al., 2006). Decisions regarding disclosure of one’s status may be influenced by concerns over possible negative consequences which may be coming from the HIV related knowledge and stigma. Disclosure often involved risk, particularly when the information revealed was potentially embarrassing, negative or emotionally intense (Kang et al., 2006; Yang et al., 2006; Hoffman, 1996).

Other literature in South Africa (Dlamini et al., 2007) reported types of abuse ranging from name-calling in the community and being called “Satan’s people” by church members, to physical abuse against women by their intimate partners. Aggleton and Parker (2002) as cited in Dlamini et al., (2007) described a case of a woman who was stoned and beaten to death for disclosing her status in public.

It is usually a difficult decision to make for an HIV infected individual, whether to disclose or not (Van Dyk, 2005). This is due to the fact that such a decision may have major and life changing consequences. The infected individual should decide if they want a full disclosure (i.e. revealing their status publicly) or partial disclosure (i.e. disclosing only to certain individuals such as a partner, spouse, friend, child or parent). The benefits of disclosure are:

- It can help the HIV infected individual accept their status and reduce the stress of coping on their own (Van Dyk, 2005).
- It can ease access to medical services, care, and support (Van Dyk, 2005). At this present time in South Africa, the requirement is that in order to be eligible for Anti-Retroviral Therapy, patients must have disclosed their HIV status to at least one other person (Kagee, 2008).
- It can help people protect themselves and others. Openness about HIV disease may increase negotiations of safer sex practices (Van Dyk, 2005).
- It may help reducing the stigma, discrimination and denial surrounding HIV/AIDS (Van Dyk, 2005).
- It promotes responsibility. It may also encourage the infected individual's family to plan for future (Van Dyk, 2005).

Negative consequences of disclosure that may be experienced by the HIV infected individuals can be rejection, discrimination and violence. Furthermore, they may experience the conviction that they are constantly judged and may experience problems in relationships (e.g. with sexual partners, employers, colleagues, family, friends and community member) due to stigma (Van Dyk, 2005; Kagee, 2008).

It is important to note that not only the HIV positive individuals are faced with issues of disclosure and stigma but also the caregivers. According to the personnel at the Clinic, most adolescents/children were orphans and were taken care of by their caregivers. Caregivers included, grandparents, other family members or family friends, etc. These people also often

found themselves in the same position as of those infected by HIV/AIDS regarding issues of disclosure and stigma (Murray, 2010).

Disclosing of one's status was one of the most important aspects that needed to be addressed at the the Clinic because of the stigma attached to the disease in the communities. During the time of our practicals, I discovered that most adolescents found it difficult to disclose to others due to the negative consequences of disclosure that has already been discussed. I also noticed that other patients avoided going to the nearby clinics or hospitals, they would rather travel from afar. This was to be certain that they do not meet up with anyone they knew, thus avoiding to be victims of stigma.

Skinner and Mfecane (2004) reported that stigma and discrimination plays a vital role in developing and maintaining the HIV epidemic. For most individuals who are HIV infected who want to disclose, the anxiety surrounding how the recipient of the news will react can be overwhelming. Stigma promotes emotional distress in people living with HIV/AIDS (Gonzalez, Solomon, Zvolensky & Miller, 2009). Thus if an individual makes a decision to disclose, he or she needs to be comfortable with his or her diagnosis (Van Dyk, 2005).

Deacon, Stepheny and Prosalendis (2005) claim that stigma should be understood as a problem of blame and fear than that of ignorance. It occurs in different ways and differs according to context. In South Africa, AIDS related stigmas are also socially and culturally driven (Kalichman & Simbayi, 2003). It further disrupts the functioning of individuals living with HIV/AIDS within their own communities and complicates HIV's prevention, treatment, care and support (Skinner & Mfecane, 2004; Martinez et al., 2012).

Martinez et al., (2012, p. 109) defined HIV/AIDS related stigma as comprising of "unfavourable attitudes, beliefs and policies directed towards people perceived to have HIV/AIDS as well as towards their loved ones, associates and communities". Literature have established that HIV stigma profoundly affects utilization of medical and mental health care, voluntary HIV counselling and testing, and level of psychological distress among persons living with HIV/AIDS (Kang et al., 2006).

Herek (1990) as cited in Hoffman (1996) explained that stigma represents the intersection of psychological processes with the cultural construction of the HIV disease. Five areas of analysis related to stigma were listed in Hoffman (1996, p. 35) as:

- The biomedical perspective (e.g. lack of information versus accurate and sufficient information, biomedical history of the disease in terms of who are infected and how they became affected).
- The cultural construction of HIV disease and AIDS (e.g. its association with death, marginalized groups, “blamable victims,” association with semen and blood).
- Reactions of the nonstigmatized (e.g. moralism, fear of contamination, attitudes towards gays and other groups disproportionately affected by the disease).
- The experience of AIDS related stigma (effect on the self esteem and self concept of those infected, others’ suspicions and condemnation of private behaviors related to HIV transmission).
- Managing social interactions between those who are infected and nonstigmatized others (e.g. disclosing infection status, social consequences of disclosure).

## **2.5 MEDICATION ADHERENCE**

The issues of adherence to medication need to be taken into consideration during treatment of HIV infected individuals. According to Martinez et al., (2012), it has been shown in other studies that HIV stigma was responsible for poor medication adherence in adolescents. They feared that friends or family members may discover their status and reject them, when witnessing them taking their medication (Martinez et al., 2012).

Strict adherence to Anti-Retroviral Therapy is very important to achieve viral suppression and avoid the risk of mutation, the development of resistant strains and drug failure (Van Dyk, 2005; Purdy et al., 2008; Wood, 2010). Adherence from medication causes drug resistance to develop, failure to attain viral suppression with existing antiretroviral regimes and also can hinder the efficacy of future regimens (Van Dyk, 2005; Purdy et al., 2008; Wood, 2010).

Poverty, alternative disease constructs, stigma, gender, as well as unpredictable drug supply are vital issues influencing adherence (Wilson & Fairall, 2010). There are various categories of adherence. Dose adherence refers to the number and proportion of doses taken, while schedule adherence refers to adherence of doses taken on time and dietary adherence refers to doses taken correctly with food. To achieve optimal results from Anti- Retroviral Therapy (ART), all of these categories of adherence are required (Kagee, 2008).

Non-adherence to ART, therefore includes, not taking the medication at all, taking the medication at the wrong time, taking the wrong dose due to misunderstanding treatment instructions and prematurely terminating the medication without consulting the health provider (Kagee, 2008). Other behaviour patterns indicative of non-adherence include, not filling prescriptions, self-adjusting the treatment to modulate side effects and the incorrect understanding of the doctor's instructions. Common methods used to measure adherence are pill counts, pharmacy refill records, drug level monitoring and CD4 count testing (Kagee, 2008).

Van Dyk (2005, p. 81) listed factors which relate to adherence and the questions that ought to be asked in order to find out whether the patient will adhere to medication. These are:

- The patient: “Is the patient motivated to take ART? Does he or she have a social support system? What does he or she know and believe about sickness in general? What was the patient's previous level of adherence to medications such as TB medication or antibiotic? Does he or she have proper coping skills? What is the level of cognitive ability of the patient?”
- The treatment regime and disease factors: “How many pills will the patient have to take, and how often? What is the size of the pills, what do they taste like, and how easy is it to take them? How must the pill be taken with? What are the side effects and how severe are they? Will there be interactions with other drugs? Does the patient suffer from any other associated conditions, and if so, for how long? ”
- Relationship between the patient and the health worker: “Is there a relationship of trust between the patient and the health worker? Is the health care service consistent?”

Does the health care worker offer support and service? Does he or she give clear explanations, and explain the possibility and symptoms of side effects?”

- Environment: Are health care services easily accessible? Does the patient have a broad scope of services? Does he or she have transport to clinics? Will the patient have enough pills at all times? Does the person have enough food if the pills have to be taken with food?”

## **2.5.1 Psychosocial barriers to optimal Antiretroviral Therapy Adherence**

### **2.5.1.1 Poverty**

Literature suggests that social and economic factors yield poor adherence outcomes (Kagee, 2008). Poverty affects adherence, as funds for travelling to the ART clinic may not be available, child care may not be readily accessible for parents who attend clinic visits, and transport problems may be experienced as well as the need to take time off work without pay to attend clinic appointments (Kagee, 2008).

Kagee (2008) explained that the competing demands of several responsibilities such as work and family life, along with the stresses associated with poverty and difficult life circumstances such as unemployment, may remove an acknowledgement of the importance of complying with treatment regimens. In addition, food required to be taken alongside medication may not be easily affordable and money for external prompts such as alarms and diaries may not be available (Kagee, 2008). Due to the abovementioned information, I believe it is important for a psychologist, during counselling to have an understanding of client’s economic background since that will also affect the client’s attendance to therapy.



### **2.5.1.2 Health literacy**

Health literacy involves, among others, an awareness of the importance of adherence despite the absence of actual symptoms (Kagee, 2008). Most medical patients only consider medication as a tertiary measure following the onset of symptoms, rather than as a prophylactic intervention. However, the long-term health consequences of non-adherence may be severe, as symptoms will certainly develop and the disease will progress unchecked. Health literacy is related to educational level therefore it was found to be a concern in poor communities in South Africa since they are characterised by limited educational opportunities (Kagee, 2008).

Closely tied to health literacy concerning ART is HIV related knowledge, which has been shown to be associated with ART adherence (Kagee, 2008). It is recommended that health providers should include questions focused on knowledge of HIV in their assessments of medication readiness and the need for adherence support. Poor literacy has been associated with low levels of understanding of medical instructions and adherence to ART (Kagee, 2008).

### **2.5.1.3 Perceived social support**

Perceived social support is shown to be a strong predictor of medical adherence (Kagee, 2008). Social support for adherence is defined as encouragement from family and friends. This will assist the patient to cooperate with the recommendations and prescriptions of a health professional. “The expression of concern and encouragement from others to engage in health promoting behaviours, including medication adherence, may combine with social desirability needs on the part of the patient to yield higher rates of medical cooperation” (Kagee, 2008, p. 417).

While the health worker- patient relationship does seem to set up an example of social support, it also extends beyond this (Kagee, 2008). The health worker is usually perceived as a person in authority, in possession of specific expertise, and in whom the patient invests

hope for help and support in the recovery process. On the other hand it has been shown that well-intentioned efforts by medical providers to emphasise the importance of adherence may actually undermine adherence. Apprehension about failing to adhere perfectly led some of the patients to stop taking ART (Kagee, 2008).

#### **2.5.1.4 Mental health**

There is consistent evidence that mental status, specifically depressive illness, plays a role in adherence to medication. Mental health problems such as depression, hopelessness, anxiety, avoidance, substance abuse, and other psychological problems were identified as the most common barriers to treatment adherence (Kagee, 2008).

Symptoms of depression have been shown to be associated with lower CD4 counts. Depressed patients may be too unmotivated or fatigued to attend clinic appointments and may be overwhelmed by helplessness and hopelessness to the extent that they may question the purpose of optimal adherence. A diminished ability to concentrate may negatively influence their memory to take their medication on time (Kagee, 2008).

## **2.6 BEREAVEMENT**

AIDS has been the leading cause of death in South Africa (Demmer, 2007). The experiences and needs of those grieving AIDS related deaths are different from the rest of the world due to factors such as pervasive poverty, limited access to ARV treatment, scarce mental health resources, and high levels of AIDS related stigma, gender inequality, high levels of unemployment as well as crime and violence. These factors increase the vulnerability of South Africans who have experienced AIDS related deaths (Demmer, 2007).

AIDS related bereavement ought to be understood in terms of the social, political, cultural, and economic context inherent in South African society (Demmer, 2007; Hardy-Bougere,

2008). The high levels of stigma, silence, and denial towards AIDS, makes the bereavement experiences of individuals considerably more difficult. Those who have lost loved ones to AIDS are destined to remain “hidden grievers” due to the stigma and the silence in the country (Demmer, 2007, p. 827).

Demmer (2007) explains that individuals coping with AIDS related loss in South Africa are most likely to report feeling overwhelmed and powerless as a result of ongoing loss and needing to keep their feelings and grief to themselves. The need to repress one’s emotions among South Africans may transpire for several reasons: to avoid dealing with the pain that comes with a loss of a loved one, due to a perceived lack of social support (formal and informal) as well as, the need to focus on the daily struggle to survive because this sort of behaviour is not encouraged (Demmer, 2007). According to Thupayagale-Tshweneagae and Benedict (2011), grieving process is made worse by having to maintain the secrecy of the cause of the loved one’s death.

Moreover, in South Africa, HIV/AIDS mainly affects the poorest and the majority of the poor experience inadequate access to clean water, sanitation and electricity (Demmer, 2007). Poverty dominates the lives of most individuals who have experienced the loss of loved ones to AIDS, to a point that instead of grieving they may focus on finding ways to feed, clothe, and house themselves and their families. “For many South Africans, particularly those living in rural areas where the poorest of the poor live, the death of a loved one to AIDS compounds existing hardship” (Demmer, 2007, p. 835).

The loss of parents to HIV/AIDS has a significant impact on the bereaved children. They miss the opportunity to learn important life skills such as communication and interpersonal skills; decision-making and critical thinking; and coping and self-management that they would have learned from their mothers and fathers (Murray, 2010).

## 2.7 INTERVENTIONS TOWARDS ISSUES INVOLVING HIV/AIDS

To address stigma, there is a need for activating support services and media coverage of compassionate behaviour towards individuals living with HIV/AIDS. Disclosure to others and HIV/AIDS awareness campaigns may help in reducing the level of stigma in our communities (Visser, Makin, Vandormael, Sikkema & Forsyth 2009; Kalichman & Simbayi, 2004).

Concerning disclosure of the HIV/AIDS status to those infected, interventions should consider how communication takes place within families in order to inform the design of interventions to assist families in communicating illness information to children (Vaz et al., 2010). Various forms of support such as psychosocial counselling support groups are necessary. (Kagee, 2008). The objectives of a support group according to Hoffman (1996, p. 71) should include the following:

- An educational component that permits the group to share HIV/AIDS specific information.
- An opportunity to express intense emotions.
- An opportunity to observe how others cope with the predicaments that occur with HIV/AIDS.
- An opportunity to experience the therapeutic value of receiving help from group members and giving help to others.
- An opportunity to discuss how one will disclose his/her diagnosis to others and about other aspects of one's life.
- An opportunity to come to terms with the HIV/AIDS diagnosis.
- An opportunity to discuss terrifying and difficult issues such as anticipatory grief and death.

Interventions should aim at including a component that explores the benefits and consequences of self-disclosure of HIV status (Hosek et al., 2000). In addition, education and training can also be used to address safer sex practices, issues of disclosure and issues pertaining to the legal rights and confidentiality of HIV positive individuals (Hosek et al., 2000). In addition, interventions should be aimed at enhancing treatment literacy among patients in the South Africa. Effective ways that may assist clinic personnel to identify optimal times for intervention are: testing, receipt of a positive diagnosis, and commencement and maintenance of ART. This will be useful as a means of increasing levels of adherence (Kagee, 2008).

Interventions aimed at educating family members and friends of individuals who are HIV infected are also necessary (Hosek et al., 2000). Other important factors to consider among others are: ways of promoting good health and the strengthening of the immune system of the HIV infected individuals. These includes: rest, exercise, and a healthy diet; avoidance of smoking, drug and alcohol abuse, avoidance of contact with infections or other illnesses; routine visits to doctors or clinics; stress management, as well as positive living (Van Dyk, 2005).

As particular interest to this study are the therapeutic services. Therapeutic services should also be offered to individuals living with HIV/AIDS and to their families and friends, whereby issues such as medical adherence, disclosure, grieving process and the possibility of death could be explored. Furthermore, feelings of sadness, stress, depression and anxiety could also be discussed as well as stress management techniques and increasing social and financial support systems (Hosek et al., 2000; Hoffman, 1996; Van Dyk, 2005).

Furthermore, interventions aimed at improving the coping style for people who have been diagnosed with HIV/AIDS are needed (Brown et al., 2000). By identifying distress in HIV infected individuals and implementing early interventions can enhance their coping and it is hoped that their quality of life will thus be improved. It was found that poor coping was associated with psychological stress, repression of anger, external locus of control, and low social support (Brown et al., 2000).

Coping is culture-dependent (Brown et al., 2000). Cultural beliefs impact on how people cope with illness and loss. Cultural attitudes may regulate an individual's behavior and reactions to death, the role of families in medical treatment, and the nature of community support for an

illness. Each of these factors are particularly relevant to individuals infected by HIV/AIDS (Brown et al., 2000). Interventions to increase coping skills may include stress management programs and exercise ( Hoffman, 1996).

Hoffman (1996) stipulates that interventions for those who are infected by the HIV/AIDS disease needs to address the following:

- Emotional adaptation to HIV/AIDS disease
- Cognitive and behavioural adaptation to HIV/AIDS disease
- Health promoting behaviours and attitudes
- Adaptation to changes in life goals and roles
- Exploration of spiritual and religious adaptation to HIV/AIDS disease
- Preparation of death and the dying process.

Lastly, Wilson and Fairall (2010, p. 507) explains that “the ideal community HIV clinic needs to provide: voluntary counselling and testing (VCT); referral to a conveniently located tuberculosis (TB) clinic; information on the benefits of safer sex, prophylaxis, and antiretroviral treatment, a wellness programme, a drop-in clinic; and a well managed antiretroviral programme.”

## **2.8 PSYCHOLOGY SERVICE PROGRAMME AT KALAFONG HIV PAEDIATRIC CLINIC**

The psychology students were responsible for the psychology service programme which was aimed at providing psychological services to the patients at the Clinic. They relied heavily on the personnel to refer patients to them. Most of the adolescent patients, who were referred to

them, were already aware of their HIV status. Moreover, the psychology students also marketed their services by introducing themselves to patients when they were in the queues as well as attending workshops where patients were taught how to take medication etc.

It was important for them to be able to reach most patients because people who have been diagnosed with HIV/AIDS tend to experience negative affective states, which include disorders such as anxiety and depression among others (Hosek et al., 2000; Gonzalez et al., 2009; Van Dyk, 2005). These disorders can lead to distress, frequent somatic complaints, greater risk of suicide, and poor compliance with medical care (Brown et al., 2000).

As already discussed, the social context for many children and adolescents with HIV in South Africa involves poverty, a lack of resources, and multiple family losses. These factors influence adherence to medications, utilization of treatment services, family relationships, bereavement, and disclosure of illness (Brown et al., 2000). These were the issues that most patients at the Clinic presented with. The psychology service programme was implemented at the Clinic so that it could assist patients to deal with the above mentioned concerns. It was through therapy, as well as support groups that most issues were addressed.

Social stressors and losses seemed to be common among the patients at the Clinic. These affected most adolescents's sense of self and worth (Hosek et al., 2000). For example, they also had to deal with the emotional pain relating to social stigma, isolation and hopelessness, anxiety about their medical prognosis, loss and bereavement, and physical appearance and body image (Brown et al., 2000).

The anxiety experienced by those who were infected by HIV/AIDS was due to the “prognosis of the illness; the risk of infection with other diseases; the risk of infecting loved ones with HIV; social, domestic and sexual hostility and rejection; abandonment, isolation and physical pain; fear of dying in pain or without dignity; and inability to alter circumstances and consequences of HIV infection” (Van Dyk, 2005, p. 217).

Furthermore, “uncertainty about how to keep as healthy as possible in the future; fears about the ability of loved ones and family to cope; worries about availability or unavailability of appropriate medical treatment; a loss of privacy and concerns about confidentiality; future social and sexual unacceptability; their declining ability to function efficiently; and their loss

of physical and financial independence” were other causes of anxiety (Van Dyk, 2005, p. 217).

Other studies (Patel et al., 2008; Van Dyk, 2005) have reported that one third to half of the HIV positive population meets the criteria for at least one mental health disorder. The most common concern included a psychological symptom: sadness or depression and a medical problem: “being tired and having less energy” (Patel et al., 2008 p. 389). They felt that so much has been lost in their lives and they themselves are to be blamed for it. Anger may be directed inward and may experience suicidal ideation or intentions. Suicide may then be perceived as a way of avoiding pain, obtaining a sense of control over the illness as well as a way of lessening the shame and grief of the loved ones (Van Dyk, 2005). Thus counselling was a necessity for the HIV infected patients at the Clinic.

Research has shown (Brown et al., 2000) that the paediatric HIV patients experience more subjective distress than their uninfected peers as a result of the deterioration of developmental skills and the many stressors associated with HIV infection. These include hopelessness, preoccupation with their illness, and poor body image. Repeated hospitalisations can have an adverse effect on the HIV infected child's social, cognitive, and communicative development (Brown et al., 2000). Most patients presented with anger, confusion, fear, denial, numbness, and guilt (Hosek et al., 2000; Brown et al., 2000; Van Dyk, 2005). Therapeutic services offered by the psychology service programme focused on helping clients deal with the above-mentioned feelings.

Intervention was intended to identify the distressors in the patients’ lives, as well as the caregivers and to provide emotional support to these patients. It was imperative that the patients felt safe so they could open up and be themselves without fear of being judged or stigmatised. The programme also involved educating the adolescents about lifeskills which included, among other things, loving and accepting themselves, as well as accepting their HIV status, positive attitude, assertiveness etc.

Education also focused on teaching patients how to take their medication appropriately, promoting good health, as well as issues on sexuality as it was a concern among most adolescent patients. The programme also made the service of individual counselling available, to deal with among other issues, depression, anxiety as well as bereavement. Stress management was also offered by the psychology service programme.



## 2.9 CONCLUSION

In this Chapter, previous studies on HIV/AIDS were described. These studies focused specifically on factors that were significant and of relevance to the Clinic. The psychology service programme at the Clinic was also discussed in detail. The next Chapter deals with the theoretical framework of this study.

## CHAPTER 3

### THEORETICAL FRAMEWORK

#### 3.1 INTRODUCTION

I (researcher) have chosen narrative theory as an approach suitable for this study. I wanted to explore the participants' meanings and experiences. Hence, I have used story telling as a way of collecting data. In this Chapter I began by explaining what a narrative approach is about, I also defined narratives. Furthermore, I explored the role of narratives, the relationship between narratives and experience, culture as well as with language. Lastly, I discussed the role of the researcher within the narrative framework.

#### 3.2 NARRATIVE APPROACH

According to the narrative approach, realities are socially constructed and they are organized, expressed, maintained, and made sense of, through narratives or stories (Freedman & Combs, 1996; White & Epston, 1990). Murray (2008) reports that people are born into a narrative (storied) world, live their lives through narratives, and are described in terms of narratives. That is, people select those elements of experience to which they will attend, and they pattern those chosen elements in ways which reflect the stories available to them (Bell, 2002).

Botella, Herrero, Pacheco and Corbella (2004, p. 119) stated that "stories are everywhere; the human race's history is full of stories". Different religions are filled with stories, people fall in love through stories and sometimes with stories, family myths are passed on through stories. "Stories are the fabric of our personal lives, our relational networks, our social traditions, and our cultural and historical institutions" (Botella et. al., 2004, p. 119).

This approach suggests that we all have stories about certain events in our lives thus the objective, among other things, is to interpret how others are storying their world, as well as understand their (stories) meaningfulness to them (White & Epston, 1990). It captures the view that as human beings our lives are ‘becomings’ or journeys in which actions and happenings occur before, after, and simultaneously as other actions and happenings (Polkinghorne, 2004). However, not every event, action or “happening” is meaningful to us. Freedman and Combs (2004, p. 137) states that “the sun rises every morning but not all sunrises are meaningful”

What the stories are about is known as the plot. The plot consists of characters, events, time(s) and sequence, meanings, interpretations, effects, evaluations, justifications as well as meanings of the events. When thickening or expanding the plot or the story, two types of questioning are involved, that is, the landscape of actions as well as the landscape of consciousness. While the landscape of actions questions explore the sequence of events as they were perceived by the participants and others, the landscape of consciousness questions intend to develop the meaning of the story as described by the landscape of actions. These questions explores motives, beliefs, hopes, values, intentions as well as purposes (Carr, 1998; Polkinghorne, 2004).

### **3.2.1 Definition of narratives**

A narrative can be defined as an organized interpretation of a sequence of events (Murray, 2008). Riessman (1993) claims that narratives are representations thus interpretation is inevitable. During story-telling, human agency and imagination determine what gets included and excluded, how events are plotted and what they are supposed to mean. McAllister (2001), makes a distinction between a narrative and a story. A narrative is considered to be a scheme used by people to give meaning to their experiences and refers to a story as a structure for the communication of an experience. According to McAllister, (2001), a story is a lived experience.

Bold (2012, p. 17) describes narrative as “being central to human experience and existence, providing an opportunity to share the nature and order of events at particular times in history”. According to McLeod (2004, p. 355), a narrative “can be a joke or a story told from one individual to another. It can be a structure for organizing individual experience. It can be a myth or an autograph. Narrative is a form of language use and meaning making that is embedded in place and forms of life”.

### **3.2.2 Role of narratives**

Stories about people’s lives are told to others, and themselves. People recognise themselves in the stories that they tell, forming a self and personal identity. They try to make sense of an ever-changing world through storytelling, which enables them to describe their experiences and define themselves (Murray, 2008; Bold, 2012). They construct past events and actions in personal narratives to claim identities and construct their lives (Riessman, 1993). According to Bold (2012), narratives tell the events of human lives, as well as reflecting human interest. They support our sense-making processes and have the ability to transform our lives and the contexts in which we live in.

When trying to understand ourselves, we tell ourselves about ourselves, making up stories about who we are, what we are, what has happened, what we are doing and why we are doing that (Angus & McLeod, 2004). The success of the storytelling experience provides a sense of continuity and meaning in the storyteller’s lives. In telling their story, one can be able to resist or challenge the dominant socially accepted story (Freedman & Combs, 1996; White, 2005). People are proactively oriented towards a meaningful understanding of the world they are living in, as well as their own place in it, hence actively making efforts to interpret experience, seeking purpose and significance in the events that surround them (Neimeyer & Neimeyer, 1993 as cited in Botella et al., 2004).

### 3.2.3 Narratives and experience

The narrative approach is about interpreting experience, telling and re-telling of stories that have remained untold thus thickening the plot (Freedman & Combs, 1996; White, 2005). These stories continue to exist and they become new stories even long after they have been told (Andrews, Sclater, Squire & Tamboukou, 2004). They are constantly being restructured in the light of new events, and these stories do not exist in a vacuum but are shaped by lifelong personal and community narratives (Bell, 2002). Meanings of life events are not fixed or constant, but they evolve, as they are influenced by subsequent life events. People make sense of events and experiences in their past and how they are related to their current selves; they then change their meanings (Riessman, 1993).

Some stories are more memorable or moving than others and thus may have more power for sharing, reinforcing or transforming a cultural narrative. Good stories may induce aspects of the experience, such as the events or the mood, and appear to be an accurate reflection of the experience (McAllister, 2001). Wiltshire (1995) as cited in McAllister (2001) explains how stories can detour rather than reflect experience. He compares a story of an experience to a window, which presents a view. The size and type of window frame as well as the opacity of the glass will affect how clearly, and close to reality, the view is perceived. Because the window acts as a mediator between reality and perception, the view may be distorted, minimised, emphasised or even lost.

Mediators of reality can also be viewed as thinking about an event, and telling about that event. While stories may not be an exact representation of an experience, they assist others to understand the experience since they offer listeners/readers an opportunity to engage, even though it might be from a distance (McAllister, 2001). Stories can offer access to an experience from which a person might otherwise be excluded from. In stories events are not described in abstract terms, but rather as experiences, thus stories can be easily assimilated, remembered and recalled (McAllister, 2001). No matter how fictionalized, all stories provide a window into people's beliefs and experiences (Bell, 2002).

### 3.2.4 Narratives and culture

McLeod (2004, p. 354) believes that “it will make little sense to attempt to understand a person, or understand ourselves, in isolation from the tradition within which the person lives”. McLeod (2004) pointed out that when trying to comprehend and get to know individuals, we should also take their relationships into consideration.

Individuals’ understandings of life and identity are based within a certain culture or history. These understandings are informed by a specific way of thinking which is embedded on a stock of cultural knowledge and practices (White, 2004). Zimmerman and Dickerson (1996), believed that stories are constructed within a cultural context (cultural meaning system), and according to White (2004, p. 43), they are also shaped by these cultural and historical knowledge, as well as practices. It is these stories that become carriers of culture from one generation to the next. Rooted in them, are knowledges that supports a certain way of living. Therefore, White (2004) viewed narratives as a vehicle of culture.

Certain stories are saturated in certain cultures therefore becoming part of the tradition in which the people construct their lives (McLeod, 2004). Nevertheless, White (2004) suggests that these narratives can be unpacked through the process of deconstruction as well as re-authoring conversations. When questioned and exposed they can no longer be accepted as certainties about life or truths about human nature as well as identity.

These are cultural discourses that exist within the cultural meaning system. They are what we label as a “problem”. Therefore, an individual or a family is not seen as a “problem”, it’s these cultural discourses that are a “problem”. They are defined as norms and standards set by the dominant culture or stories. Dominant stories are taken for granted (Freedman & Combs, 2004); they are the “givens”, expectations and cultural ideas. Dominant cultural stories, dictates the preferred ways of believing and behaving within a certain culture (Freedman & Combs, 2004; Carr, 1998) and each day of our lives, being in relationships we participate in the process of positioning ourselves within these discourse or being positioned by others (McLeod, 2004).

Examples of cultural discourses or the dominant narratives are: gender discourses, within our society wives and husbands have expected roles to perform as a couple; developmental discourse which implies to what is normal or not normal for children of different ages, discourses about sexuality, socio-economic classes, race and discourses on how parents ought to raise their children etc. (Zimmerman & Dickerson, 1996). According to McLeod (2004), some cultural discourses obtain a position of power and authority, while some are located as shameful and are silenced. The value of stories is not similar within a culture.

### **3.2.5 Narratives and language**

Language also plays a vital role since through language we share our everyday lives and experiences (Freedman & Combs, 1996; White & Epston, 1990) and experiences in themselves do not carry meaning (Botella, et al., 2004). As discussed by Terre Blanche, Durrheim and Painter (2006), people's social meaning is encoded in language and language assists them in constructing their reality. Language is therefore viewed as a system of meanings.

A process of externalising conversation/language is often used in narrative therapy (White, 2004). It is common for people to formulate negative conclusions about themselves, or others when they are faced with major challenges in their lives. It is during these circumstances when externalizing conversation is introduced. This process opens up a number of options, for individuals to redefine or revise their relationship with those challenges with aim of breaking away from the negative formulations they have constructed (White, 2004).

Moreover, externalising language is an act of deconstruction, whereby the intention is to separate and differentiate the problem from the individual (Zimmerman & Dickerson, 1996; Freedman & Combs, 2004). By so doing, the influence of the cultural beliefs may be noticed and individuals or families may become aware of other possibilities of living their lives outside the norms and standards set by dominant narratives and are able to experience a sense of personal agency. Through the process of externalisation, individuals gain a reflexive

perspective on their lives and new alternatives become available to them (Zimmerman & Dickerson, 1996; White & Epston, 1990).

Through externalisation, unique outcomes can also be identified (White & Epston, 1990). Unique outcomes are facts, events or aspects that contradict the dominant story. They are often neglected by those in favour of the cultural story yet they are always present. They include events, feelings, intentions, thoughts and actions that have a historical, present or future location. These cannot be accommodated by the dominant story. They can facilitate development of new meanings in the present and also new meanings that empowers the individual to reach back and revise their personal and relationship histories (White & Epston, 1990).

Narrators use particular linguistic devices to hold their accounts together and communicate meaning to listeners. When telling their stories, people strive to configure space and time, deploy cohesive devices, and reveal identity of actors and relatedness of actions across scenes. They create themes, plots and drama. Thus, making sense of themselves, social situations, and historically and culturally situate themselves (Riessman, 1993, McLeod, 2004). Narrative inquiry encourages individuals and families to explore, question and be aware of these cultural discourses. It further challenges them not to take matters for granted but to examine certain issues and decides how they are appropriate, compatible and relevant to their preferences (Zimmerman & Dickerson, 1996).

### **3.2.6 Role of the researcher**

Researchers using the narrative approach are viewed as collaborators rather than experts. They listen for stories instead of symptoms (Freedman and Combs, 2004). They also provide space and time for the individuals, so they can reflect on their own stories as they emerge, thus becoming their own witnesses. They invite participants to remember, make meaning of, and evaluate aspects of their experience. Researchers' value meaning that participants make of their own experience, over the meaning that they can make concerning the participants' experiences (Freedman and Combs, 2004).



Moreover, researchers also need to take a position of openness regarding their intentions and values (Carr, 1998). They also privilege the participants' language use above theirs, as well as listening over questioning. They assist participants to describe their preferred valued experiences as well as identifying the kind of questioning that will help the participants feel that their stories are actively constructed rather than passively recounted and set. Also, the researcher respects participants' pace, meaning that collaboration occurs at a pace comfortable to the participants (Carr, 1998).

Furthermore, reflecting team is used whenever possible, (Freedman & Combs, 1996, 2004). As discussed by White (2005), researchers ought to take up a "decentred and influential" position meaning that in regard to their participants' personal stories, they should consider that they (their participants) have a "primary authorship status". By being influential, White (2005) explains that it's in a sense building support through questions and reflections that makes it possible for clients to describe their alternative stories more richly. Also, to be more equipped with the knowledges and skills of their lives that are relevant to addressing the concerns, predicaments and problems that are at hand (White, 2005).

"Each session is an iterative or unfolding process of externalizing, deconstructing, extending the field of influence of the problem, searching for unique outcomes, finding a history of contradictions, and continuing to develop and maintain whatever alternative story evolves" (Zimmerman & Dickerson, 1996, p. 88).

### **3.3 CONCLUSION**

This Chapter was based on the discussion regarding the theoretical framework. Narrative approach was seen fit for this study. In the next Chapter, research methodology is discussed.

## CHAPTER 4

### RESEARCH METHODOLOGY

#### 4.1 INTRODUCTION

In this Chapter, I provide a description of the research process. The definition of the qualitative research is discussed in detail. Thereafter, the overview of the research design is deliberated. This includes sampling, data collection and the method that was applied for data analysis. Furthermore, ethical considerations are discussed.

#### 4.2 QUALITATIVE RESEARCH

Qualitative research is a field of inquiry, which studies real-world situations as they unfold naturally. The researchers aims to make sense of feelings, experiences or social situations as they occur in the real world. They therefore, want to study individual and groups as they go about their everyday lives, meaning in their natural settings. Qualitative research makes an effort to interpret or even makes sense of people's meanings (McMahon & Watson, 2009; Denzin & Lincoln, 1998; Terre Blanche et al., 2006) and it is specific to a particular context, time and group of participants (Thomas & Harden, 2008).

Methods that are used for data collection include personal experiences, case studies, observations, interviews, life stories and others. Qualitative methods allow a researcher to study selected issues in depth and in detail as they identify and make an effort to understand themes that emerge from the data (McMahon & Watson, 2009; Denzin & Lincoln, 1998; Terre Blanche Durrheim & Painter, 2006).

Qualitative research is relevant towards studies where there is a need for acknowledgement of a particular meaning and details (McMahon & Watson, 2009). Other research methods found

within the qualitative approach include ethnography, grounded theory, dramaturgical interviewing, content analysis, participant observation and phenomenology (Osborne, 1994).

As previously mentioned, data is collected in a form of written or spoken language, or observation, that are recorded in language. Since the intention of this study was to explore and to provide detailed experiences of the personnel at the Clinic and the meanings they attribute to the psychology service programme, qualitative approach within the interpretive narrative framework was seen as the best approach for this research (Kelly, 2006).

## **4.3 RESEARCH DESIGN**

### **4.3.1 Sampling**

A purposeful sampling was selected (Terre Blanche et al., 2006). The participants of the research were the personnel of the Clinic. Seven participants were chosen. Their ages range between twenty- eight and sixty years old. These were the people who have been identified by me, the researcher as having played a key role during the process of the implementation at the Clinic. Samples of qualitative studies are usually smaller (Terre Blanche et al., 2006). Seven participants were enough so as to avoid having additional participants who may not add any new information and that may lead to reaching a point of theoretical saturation (Kelly, 2006).

The proposed participants were involved in setting up appointments for us (students involved in the psychology programme), referring clients, making arrangements for support groups and also familiarised us on how the system worked, for example, the running of the Clinic, accessibility of files and setting dates for appointments. Furthermore, they helped us with the logistics of the programme, for example, office space and recommended which days will be suitable for us to be at the Clinic etc. Therefore their stories were considered to be able to richly describe the narratives concerning the psychological service programme offered at the Clinic.

It should be noted that the participants were not the only people who were involved in the implementation of the psychology service programme. Other professionals including counsellors, doctors, social workers, paediatricians, dieticians, occupational therapists and nurses as well as a Pastor were also involved. I, the researcher, chose a few who were actively involved by performing the afore mentioned tasks.

As I have indicated, initially I had intended to have seven participants for this research study, but two of them declined. Even though they were actively involved at the time, they reported to have not been present during the foundation stages of the implementation of the psychology programme. The programme had already been established when they started working in the Clinic thus did not feel confident to participate in the research.

#### **4.3.2 Data collection**

The primary source of collecting data was through interviews and observation. The interviews were recorded using an audio device. Permission for the use of an audiotape was required from the participants, as it is mentioned in the consent form (Appendix A). Written notes during, and immediately after, the interviews were taken and numbered accordingly to eliminate the possibility of data being missed during the process of interviews (Denzin & Lincoln, 1994).

The researcher had intended to schedule two interviews with each participant. The interviews were going to take approximately one hour respectively (Kelly, 2006). The first interview was for gathering the needed data, whereby the participants were requested to tell their story about the implementation of the psychology services programme at the Clinic.

The second interview was to further explore and clarify, while simultaneously checking the data collected on the first interview, so as to be certain that the data was convincing and credible (De Vos, Strydom, Fouche, & Delpont, 2002). Second interviews were also to be used for member checks, that is, as a method of assuring trustworthiness and that the transcription is what the participants had said (De Vos et al., 2002).

The first meeting was arranged telephonically with the participants. In this meeting, participants were thoroughly explained to what the study entailed and what was expected of them and the reason why they were chosen. Participants were given an opportunity to read the consent form, ask questions where they needed clarity. Moreover, to sign the consent form (Appendix A), as well as receive a duplicate copy of the consent form.

Logistical issues were also discussed in the above mentioned meeting, concerning the scheduled time for the first interview, the length of the interview and the location. A private office at the Clinic was secured for the interviews as suggested by Murray (2008). Participants were met individually but not all of them could attend this meeting.

For those who were not able to be present at the first meeting, the information about the study was explained to them telephonically. They were given a chance to agree to be part of the study or to decline. Most participants were eager to participate in the research study. Thus it was arranged that they will be briefed before the first interview, sign a consent form (Appendix A) as well as receive a duplicate copy. Each participant was to be interviewed individually.

The first interview took approximately an hour with all the participants (Kelly, 2006). It was during this interview that most participants requested that we eliminate the second interview and instead communicate electronically and telephonically, since they had busy schedules. The second interview was therefore carried electronically and telephonically. Participants who did not suggest such, agreed to the proposition. Email addresses were therefore provided to the researcher as I only had their telephone numbers to begin with.

All communication was conducted in English and the participants were allowed to ask questions if they did not understand any aspect of the questioning. Some participants were fluent in speaking both English and Setswana. They were given an option to use any of the languages, since the researcher was also fluent in both languages, but all of them chose to use English as a medium. The researcher translated and transcribed the interviews herself.

According to Riessman (1993), less structure in interview instruments is preferable, so as to give greater control to participants. Researchers are advised to develop an interview guide with five to seven broad questions about the topic of inquiry, supplemented by probe questions in case the participant has trouble getting started (Riessman, 1993).

Therefore, an interview guide (Appendix B) was compiled by the researcher, as part of the research tools for conducting the interviews, more so for the first interview. It was intended to guide the researcher and serve as a reminder of the questions that needed to be asked in order to explore the participants' stories richly and in detail. An in-depth, semi-structured interview and unstructured follow-up questions were asked based on the information that the participants provided thus, allowing myself, the researcher to let the process as well as the story to unfold.

During 2009 and 2010 the researcher was able to develop a good working relationship with the participants and believes this was advantageous to the research since a rapport had already been established. Participants were granted an opportunity to give a detailed narrative account of the experience of implementing the psychology service programme at the Clinic.

Interviews were approached as conversations in which the both participant and the researcher develop meaning together. The researcher, as a listener, clarified uncertainties with follow up questions and the answers given continually inform the evolving conversation (Riessman, 1993). Qualitative research became more of a two-way interactive process through narrative framework whereby the researcher took the position of a collaborator. The researcher adopted a more participative and active role while the narratives or stories of the participants were of greater significance (McMahon & Watson, 2009).

It was imperative to the researcher that the personnel of the Clinic tell their story, as Mair (1989, as cited in Crossley, 2007) stated that stories make and break us and that they sustain us in times of trouble. Stories also encourage us to work towards an outcome in our lives that we wouldn't picture for ourselves. The less we think about what we want and the less we express our stories, the more emotionally stunted and less intune we become with ourselves.

### **4.3.3 Data analysis**

This study used interpretive narrative analysis as a method of data analyses as according to Riessman (1993). Narrative analysis allows systematic study of personal experience and meaning: how events have been constructed. It took as its object of investigation the story

itself. The purpose was to see how participants in interviews impose order on the flow of experiences to make sense of events and actions in their lives. Analysis opens up the forms of telling about experience (Riessman, 1993).

Interpreting experience took place at the five levels of representation in the research process. The levels according to Riessman (1993) are the following:

- Attending to experience: Being aware of one's surroundings. It includes certain features in the stream of consciousness which are reflecting, remembering and recollecting.
- Telling experience: I, the researcher encouraged the participants to attend to and tell the story of the implementation of the psychology service programme. I asked questions that opened up topics and allowed participants to construct answers, in ways they (participants) found meaningful. Meaning was constructed at this level during the process of interaction (Riessman, 1993).
- Transcribing experience: At this level, the verbal interviews were transformed into a written text by the researcher. I began by listening to the recorded interviews, then continued to a rough transcription, that is, a first draft of the entire interview. This included words and other striking features of the conversation, for example, laughing, very long pauses, repetitions of words, interruptions. (Riessman, 1993)

Once I was finished with the rough transcription, I listened to the recorded tapes again and repeatedly read the rough transcription to familiarise myself with the content of the interviews. Thereafter, I retranscribe selected portions for detailed analysis. It was during this process that “interpretive categories emerge, and the oral record- the way the story is told-provides clues about meaning” (Riessman, 1993, p. 58).

It was at this level that I began to listen for entrance and exit talk; and break down the narrative into numbers. That is the first step to interpretation according to Riessman, 1993. Riessman (1993) further claims that participants' direct interpretation by the way they organize their narratives.

- Analysing experience: According to Riessman (1993), analysis cannot be easily

distinguished from transcription. The challenge is to identify similarities across moments into a combined summary. Labov's six elements for data reduction and interpretation were used. Labov's six elements were included in the analysis since they provided a skeleton plan and a generalisable structure that could be used to compare the plots of individuals who share the same experience.

The elements were:

1. An abstract (AB): summary of the essence of the narrative. It usually appears at the beginning of the interview. It is also known as the point of the story (Riessman 2008; Riessman 2005).
2. Orientation (OR): time, place, situation and participants. It generally occurs early in the narrative text but it can also occur at a later stage as some narrators sometimes give background information close to the end (Riessman, 2008; Riessman, 2005; Patterson, 2008).
3. Complicating action (CA): sequence of events or plot (Riessman, 2008; Riessman, 2005). Other times its called the "skeleton plot" or the "spine of the narrative". It relates the events of the story, as if it responds to "and then what happened?" The events ought to be in a chronological order (Patterson, 2008).
4. Evaluation (EV): significance and meaning of the action; and attitude of the narrator. It is also known as the "soul of the narrative" (Riessman, 2008; Riessman, 2005 p. 4). It makes known the narrators' perspective on the events being told, as well as involves the feelings about the experience at the when the story was told (Patterson, 2008).
5. Resolution (RE): what finally happened, the outcome of the plot or the results. It tells the listener how the story ends (Riessman, 2008; Riessman, 2005; Patterson, 2008).
6. Coda (CO): ends the story as well as returning the perspective to the present. It indicates that the story is over (Riessman, 2008; Riessman, 2005; Patterson, 2008).



According to Patterson (2008, p. 25), “researchers who present their data following Labov’s method and model, typically extract narratives from the full transcript of an interview, number and categorise each clause according to the elements of the model and then present a core narrative, which leaves out evaluation and anything else that does not fit into the categories of Abstract, Orientation, Complicating action and Resolution, for example, interactions between teller and listener, descriptions and asides” Furthermore, not all the stories enclose all the elements, as they can occur in varying sequences (Patterson, 2008).

When analysing the data, I identified narrative segments, reduced clauses, examined how word choice, structure and clauses reverberated to one another, and observed how the sequence of action in one story builds on a prior one. Moreover, the emphasis was on language, how people said what they do and the narrative structures they utilised to construct experience by telling about it (Riessman, 1993).

Utterance were parsed into clauses, lines were numbered and the parts of the narrative were identified by their function (Riessman, 1993). I arranged the clauses based on how the teller at the Clinic (participant) was narrating his or her story. During the reduction of the clause, in order to make line breaks, I attended to the function of the clause as well as the speakers’ changes in their pitch. Therefore, other clauses were long, while others were easily breakable due to the pauses or the commas in between the sentences. Deciding the beginning and end of the clauses was a complex interpretive assignment (Riessman, 1993).

The re-transcribed version excluded all the researcher’s utterances, and all the participants’ false starts, break offs, pauses, verbal emphasis, unfinished sentences, words repetitions, non-lexical expressions, paralinguistic utterances (“uhms, “ehs” etc.) and other features of spoken language (Riessman, 1993, 2000) Even though this was the case, I was careful not to miss important information. Having listened to the audiotapes and repeatedly read the rough transcripts helped in this regard. Other parts of the re-transcribed version were not attended to, so as to keep the identity of the participants anonymous.

The story as accounted by each participant was presented in a way that compares the plots of individuals who share the same experience. This was therefore a comparative approach to interpreting similarities and differences among the participants’ stories (Riessman, 2000). I decided to present the emerged interpretive categories as questions since Labov stipulates that

a narrative is always responding to a question (Riessman, 1993). The interpretive categories were influenced by the 10 broad questions formulated in the Interview Guide (Appendix B).

- Reading experience: It is during this level that a written report is compiled and the draft was issued to the participants for member checks. This is a process whereby the data, analytic categories, interpretations and conclusions are tested by the participants (Riessman, 1993).

## **4.4 ETHICAL CONSIDERATIONS**

### **4.4.1 Informed consent**

Participants were informed of the aims and purpose of the research verbally and in detail during the first meeting and some during the day of the interview. They were requested to sign an informed consent form (Appendix A) and also received a duplicate copy of the consent form. According to De Vos, Strydom, Fouche, Poggenpoel, and Schurink (1998), obtaining informed consent means that all possible or sufficient information concerning the study, the procedures to be followed, and anticipated benefits, and dangers, which may occur to the participants, may be brought forth and exposed.

Participants were given an opportunity to ask questions concerning the study at that particular meeting. The meeting was held with each participant, respectively. The consent form was also related to issues of beneficence, stating that participants can withdraw from the research programme at any time, and anonymity, also stating that their real names will not be used but pseudonyms will be utilised instead. (Van der Riet & Durrheim, 2006).

A clause pertaining to confidentiality was included in the informed consent form as well as on requesting permission from participants to audio tape the interviews.

Permission has been granted to conduct the research study at the Clinic (Appendix C), as well as from Kalafong Hospital (Appendix D). The Postgraduate and Ethics Committees of the

Tertiary Institution also granted their permission to conduct the research ( Appendix E).

#### **4.4.2 Confidentiality and Anonymity**

All information was treated confidentially and anonymity was assured. Only the research team (the researcher and supervisor) had access to the data including the audio tapes (Van der Riet, & Durrheim, 2006). All information provided by the participants was kept confidential and was treated with respect and sensitivity. As explained earlier, a clause pertaining to confidentiality was included in the informed consent form. Furthermore, more professionals were involved in the implementation of the psychology service programme thus it was not be apparent and noticeable who the participants were.

#### **4.4.3 Beneficence**

Participants were requested to participate in the research study voluntarily. They were able to withdraw from the research programme at any time. There was no need for counselling/debriefing, though psychologist, Neo Pule, who had agreed to offer her services to the participants at a rate, if the need arose (Appendix F) was available. There was no personal or financial benefits for the participants (Van der Riet, & Durrheim, 2006).

### **4.5 CONCLUSION**

In this Chapter, research methodology was discussed. These included qualitative research, research design as well as the ethical considerations. The next Chapter will be focusing on analysing the data.

## CHAPTER 5

### FINDINGS

#### 5.1 INTRODUCTION

This Chapter begins by discussing the participants and describing the impressions they gave during the interviews. Participants were given pseudo names, to conceal their identities. Emerged interpretive categories were identified during data analysis. These emerged categories were presented as questions since Labov stipulates that a narrative is always responding to a question (Riessman, 1993). These questions were influenced by the questions asked during the interview. Findings of the analysis were therefore discussed in this Chapter.

##### 5.1.1 Participants

The story of the implementation of the psychology service programme at the Clinic at Kalafong Hospital was told by the five participants who were more than willing to participate in this study. Most had been involved when the idea of the implementation was thought through by the multi-disciplinary team and they were all involved while it was executed. They presented different and similar experiences concerning the process of implementation of the psychology programme, but each story told by each participant was significant.

During the interviews, all the participants were cooperative, as well as supportive of the research study. They were open, friendly as well as enthusiastic to participate in the research study. Even though others were elaborative in their explanations than others, they were all highly willing to provide more information. They appeared eager and keen throughout the interviews. They gave the impression that they loved their jobs and would go beyond a call of duty for their patients. The researcher-interviewee relationship was good as rapport had been established before. Underneath is a more detailed description of each of the participants.

Lerato was keen to participate in the research study. She was open, free to speak her mind and volunteered necessary information. Throughout the interview process, she seemed passionate about the research topic, to a point when she spoke, a lot of issues came to mind and she would tackle them immediately. The researcher- interviewee relationship was firm and harmonious.

Lesego appeared enthusiastic to participate in the research study. She was cooperative. Her answers to the questions asked during the interview were short and straight to the point, thus there was a point where she felt that the questions were too repetitive. The researcher-interviewee relationship was satisfactory.

Lethogonolo was friendly and appeared eager to be part of the study. She spoke freely and seemed to be passionate about her job. She communicated how she was interested to hear the psychology's students experience as well. The researcher- interviewee relationship was good.

Lesedi was motherly as well as easy to relate with. She felt that the study was beneficial as she was wanted the psychology service programme to continue at the HIV Clinic. She appeared passionate and dedicated to her job. The researcher- interviewee relationship had a strong rapport.

Lebogang was friendly and seemed devoted to be of help to the research process. She exhibited willingness to cooperate and seemed comfortable during the interview. She expressed the importance of the programme and answered all the questions to her best ability. The researcher- interviewee relationship was good.

Furthermore, during the interviews, the participants mentioned an individual who played a significant role during the implementation of the psychology service programme. I, the

researched named her Person Z (not her real name). She was the Manager of the Clinic during the implementation process. She granted the researcher permission to conduct the study at the Clinic, as well as to can reveal her identity.

The participants' stories and experiences together gave more understanding into how the programme developed and progressed. Views, as well as perceptions of the participants were presented in this Chapter. The emerged categories are presented below.

## **5.2 EMERGED INTERPRETIVE CATEGORIES**

### **5.2.1 How did the decision to implement psychological services in the clinic come about?**

I (the researcher) was curious on how the programme came into existence; what happened, how it happened, who was involved, etc. When the question of how the psychological services came about was asked, all participants stated that a need for psychological intervention was identified by the multi-disciplinary team based at the Clinic. According to Lerato (personal communication, June 23, 2011), the decision to implement the psychology service programme came at a time when they were discussing the issue of establishing an adolescent clinic which was late 2007 or in 2008. It was during this time when the multi-disciplinary team felt that the counselling that they were offering as doctors, counsellors, social workers, pastor, etc. were not adequate. There was a need for a “professional psychological intervention” (Lerato, personal communication, June 23, 2011). Lesedi (personal communication, July 25, 2011) added that their multi-disciplinary team consisted of nurses, data captures, occupational therapists, dieticians, etc. Their patients were children from birth to adolescents of nineteen years of age, according to Letlhogonolo (personal communication, July 25, 2011).

The decision to include psychology services at the Clinic came about when we were thinking about starting the adolescents' clinic. It was late 2007, 2008 then there was no

clinic specifically for adolescents. All the patients were being seen like all together (Lerato, personal communication, June 23, 2011).

We normally hold our two-weekly meetings, where we find that as the multi-disciplinary team: nurses, data captures, counsellors, occupational therapists, dieticians. We could have given them (patients) everything except the psychological part (Lesedi, personal communication, July 25, 2011).

Lerato (personal communication, June 23, 2011) explained further:

We had an agreement that they had to know about their status, so disclosure problems came with other issues, like where they had to now deal with knowing about their status and the stigma and everything that was attached to knowing about their status. And with adolescents, that's when we had all these psychological problems whereby they have to deal with more and they start being rebellious and they start asking questions about why they should be taking medication and so on. And with us the counselling that we were offering them, we felt that it wasn't adequate enough to address all those issues. That's why we wanted a psychology intervention.

Lethogonolo (personal communication, July 25, 2011) explained that according to the law, the adolescents had a right to know about their status at the age of twelve. "Legally they have the right to know at the age of twelve. A twelve year old can come and consent to be tested and treated. We find that the children start asking questions between the ages of nine and ten, because that's when the transition from Grade Three to Grade Four takes place. The juniors are learning life skills but when they get older they learn Life Orientation. And they learn about what are viruses, what are bacterias, what are infections, what really gets you sick".

Though Lesego (personal communication, May 26, 2011) did not remember exactly when the decision to implement the programme was taken, she recalled that the decision was motivated by the fact that there were "children who were emotionally traumatised and those who were not coping with the diagnoses". Other patients "were not willing to take their medication correctly" even after the team had intervened by educating them on the correct intake of

medication. Thus the need for psychological support was recognised (Lesego, personal communication, May 26, 2011).

From what the participants stated it was clear that the psychological intervention was a necessity, not just for the patients, but also for the caregivers. As Letlhogonolo (personal communication, July 25, 2011) explained “We were beginning to identify issues with depression, difficulty accepting the diagnosis, not just with the patients but with the caregivers as well”. Dealing with the HIV status, once the patients discovered that they were HIV positive seemed to be the main challenge. Letlhogonolo (personal communication, July 25, 2011) and Lesedi (personal communication, July 25, 2011) observed that depression was also becoming a concern. According to them patients also struggled to accept their diagnosis once it was disclosed to them (patients).

According to Lebogang (personal communication, May 27, 2011), a need to support teenagers was identified.

We felt that there was a need. And we needed someone to be here to support them. And also we found out that some of the kids had other issues which had to be dealt with in order for them to function optimally. That’s the reason we felt a psychologist for them would definitely be beneficial for the department because there’s so much that a person can take in when they are diagnosed with something like HIV, so they need our support throughout so that they can function adequately... and how to get the skills necessary to be assertive and to deal with different situations, so that you (patient) can function in a normal environment (Lebogang, personal communication, May 27, 2011).

The multi-disciplinary team felt that “there is so much a person can take in, when they are diagnosed with something like HIV” therefore for a person to function adequately in a normal environment, necessary skills had to be obtained as well as support (Lebogang, personal communication, May 27, 2011). She mentioned for example, that their patients needed to learn assertiveness to be able to deal with their different circumstances. Also, the team wanted their patients to be assessed in totality including psychologically, Lesedi reported.



She explained that they realized that they “could have given their patients everything except the psychological part” (Lesedi, personal communication, July 25, 2011).

Most of the participants elaborated on the fact that

...Kalafong only has one psychologist and that psychologist services all the departments. And it meant that if we had a patient who needed psychological services, that patient had to be on a waiting list. And sometimes the problems that they would be having at the time needed attention at that time, instead of being addressed three, four months down the line when the psychologist will be available. So initially we tried that route and it did not work very well (Lerato, personal communication, June 23, 2011).

There is only one psychologist in Kalafong and she does not have a particular specialty with child psychology... (Lethogonolo, personal communication, July 25, 2011).

Lerato (personal communication, June 23, 2011) explained that initially they had referred patients to the psychologist who was based at the Kalafong Hospital, but because she was very busy, patients were seen on an appointment basis which was in three or four months. That was not appropriate for patients with life threatening issues, those who were suicidal for example, to be seen after a long period of waiting.

Furthermore, Lethogonolo (personal communication, July 25, 2011) added that the same psychologist at Kalafong Hospital was not a specialist in child psychology. Different solutions had been tried including considering the appointment of another psychologist; but that was not possible according to Lesego (personal communication, May 26, 2011).

We identified the need, and then we were trying to get a fulltime psychologist but it was not possible... (Lesego, personal communication, May 26, 2011).

Lerato (personal communication, June 23, 2011) reported that another solution was to try to involve the psychologists based at the local clinics but not all the clinics had a psychologist

on staff. The report that Lesedi (personal communication, July 25, 2011) received from the patients who accessed social services in the local clinics was also not satisfactory. Hence their dilemma still remained and thus needed to find a solution for their patients in the Clinic. It was during this time when the multi-disciplinary team saw it fit to invite the University of Pretoria psychology students to assist the Clinic with their expertise while simultaneously gaining experience within the medical field (Lerato, personal communication, June 23, 2011).

...And then we thought about involving the psychologists from the local clinics where the patients will be coming from but even that did not work very well because the psychologists wouldn't be available and not all the clinics around, where the patients came from, had psychologists. So it was a big problem. And then that's when the idea of why can't we involve psychology students who will be interested to help us and why couldn't we involve them so that if they can help us with the issues that we are dealing with while at the same time they get clinical experience as well (Lerato, personal communication, June 23, 2011).

The challenges that we actually encountered were that when we referred the caregivers for social services in the location, they normally struggled to get services and they'd come back to us, like say "this social worker told me to wait" or that "I must go back to my husband" who is abusing me. They don't get proper the services outside (Lesedi, personal communication, July 25, 2011).

### **5.2.2 What were your expectations from the psychology service programme?**

Lethogonolo (personal communication, July 25, 2011) explained that they had expected "setting up of both group therapy and individual identification of children with high risk of mood disorder or social dilemmas in their lives". Lebogang (personal communication, May 27, 2011) agreed that the team was thinking about support groups especially for adolescent patients. Moreover, play groups or play therapy for the younger patients. Lebogang explicated that the latter did not take place as she had expected. Instead of play therapy, it

became an informal play group, to a point that any child who was walking around the clinic would be called to join in, and participate in the activities (Lebogang, personal communication, May 27, 2011).

Well, we were first thinking about the support groups that we get help, I guess the aim was more to work with the adolescent children. The younger ones we just thought of more like, being informal like a play group... The picture I had in mind was the play therapy approach for the kids and I thought that would help them but then what happened was not actually that, it ended up being a very informal group and some of the children who were walking around, were called to join in on the activities. So it ended up being a play group instead of a play therapy (Lebogang, personal communication, May 27, 2011).

To Lesego (personal communication, May 26, 2011) the picture of having the psychology service programme right at her door step was a great relief. “To me it was a great relieve because I needed to have more time with patients attending to the (other) problems but the psychological part was a problem,” She was going to focus on her job without worrying about the psychological state of the patients since the psychology students were going to deal with that part. For Lesedi, part of the team’s expectations once the programme was established, was that their patients would feel comfortable with them, being open with whatever involved their lives or was involved in their lives (Lesedi, personal communication, July 25, 2011). She had hoped that once their patients have been reassured of confidentiality, they would trust them (Lesedi and the team, psychology students included) enough to allow them to take care of them (patients) and help them. It was important to Lesedi that the patients should buy into the idea of the psychology service programme and believe that it was for their own good (Lesedi, personal communication, July 25, 2011).

Well we wanted our patients to feel comfortable with us that whatever they tell us or it involves their lives or it is involved in their lives, is not going to be published anywhere. And that it is for their own good, so that we can really look after them

properly and especially because most of them are depressed. They haven't disclosed, they don't trust anybody, but we reassured them as far as the psychology problem was consent, we could really help them a lot and they really appreciated our help in that regard (Lesedi, personal communication, July 25, 2011).

For Lerato (personal communication, June 23, 2011), the picture of having psychology service programme at the clinic “looked rosy from the theoretical point of view but practically it was not working”. It was a good idea to bring the programme on board but “implementing it and sorting out the logistics was a bit difficult”. For example, regarding booking of appointments, they had to find solutions to these questions: “How are we going to accommodate you in terms of time? Where do we book you? Do we book you on our system? Do we have a separate booking system for you?” (Lerato, personal communication, June 23, 2011). Lerato also noted that what contributed to making matters worse was the fact that the personnel were very busy, therefore at times were not able to give the psychology students “attention”, to help them address the above mentioned concerns (Lerato, personal communication, June 23, 2011).

### **5.2.3 What steps were taken to implement the decision regarding the psychology service programme?**

Person Z, one of the multi-disciplinary team members did most of the work initiating the implementation of the psychology service programme. Most of the participants gave credit to this individual as she played a major role to make sure that the programme was implemented at the Clinic. Person Z communicated with the University of Pretoria, Department of Psychology concerning bringing on board the psychology students. She conducted necessary meetings with the relevant stake holders, until the programme was officially implemented in 2009. One of the actions performed, according to Letlhogonolo (personal communication, July 25, 2011), to make the decision to implement the psychology service programme, was to identify, together with the personnel at the Department of Psychology, the psychology

students who were able and willing to offer their services, as well as providing adequate space for therapy sessions.

I think that was done by person Z, we were not part of that. She was the person that made it possible (Lesego, personal communication, May 26, 2011).

After deciding on that, then that's when person Z consulted with the Psychology Department here (University of Pretoria) and spoke to the head of department to look at our problem and the challenges that we were facing. That's where now the decision was made from both our side and the Psychology Department here at Tuks to involve the students. It was a nice thing. And that's when also more ideas came forth- to help with the support group and also to help with the OT (Occupational Therapy) Department, in terms of developmental assessments could be done together with the psychologist (Lerato, personal communication, June 23, 2011).

To be honest, person Z is the one who arranged everything. I think she even contacted the University as well. So she is the one who took the initiative. We were all there to say whether we agree or disagree. At the end of the day all the credit goes to her because she is the one who did the nitty-gritty details before the programme was implemented (Lebogang, personal communication, May 27, 2011).

...contacting the people who would be involved in the programme, identifying the psychology students who would come offer their services and also help the children, letting the immunology clinic know that you were coming, providing the adequate space for the therapy session in a confidential manner since it is such a touchy subject for anybody (Letlhogonolo, personal communication, July 25, 2011).

#### **5.2.4 What was your role?**

Each participant had a vital role to play during the implementation of the psychology service programme. All the participants were part of the multi-disciplinary team, implying that they were part of the decision making process regarding the implementation of the programme.

Furthermore, they referred patients to the psychology students. Among other things, Lebogang (personal communication, May 27, 2011) reported to have identified patients who needed psychological intervention, as well as advised the psychology students on the list of activities appropriate for a certain age.

We kind of identified the patients that we felt needed therapy, so that was for the one set of the students who came. They gave us their numbers and we said, we will contact them if anyone comes up, and you were one of them. So that was for the children who needed therapy because of the emotional problems that they were having. And then the other group, we were involved in the process where they would give us a list of activities they wanna work on and we would advise them if they were appropriate or not, and say maybe try this or try that (Lebogang, personal communication, May 27, 2011).

Letlhogonolo identified her role as:

...to identify when a care giver is stressed, depressed or in denial or when a child is stressed, depressed or in denial. And then what was easiest for me was seeing you from on site and introducing you personally and making that connection versus giving you a book and making the appointment. So my role was to identify patients specifically with high risks needs and that needed to be assessed on one to one bases (Letlhogonolo, personal communication, July 25, 2011).

While Lesego, Lerato and Lesedi offered orientation, Lesego (personal communication, May 26, 2011) provided orientation for the students. Lesedi (personal communication, July 25, 2011) and Lerato (personal communication, June 23, 2011) orientated the patients about the psychology service programme. Lesedi was also part of the caregivers support group while Lerato was part of the adolescent support group. Lerato (personal communication, June 23, 2011) reported to have been vocal about the needs of the adolescents. She even went to see the psychologist at the clinic, whenever things were not working out. She reported to have worked closely with person Z (Lerato, personal communication, June 23, 2011).

The other thing is that I think I offered a bit of orientation. I did orientation with the students (Lesego, personal communication, May 26, 2011).

Normally explaining to the patients beforehand what is going to happen... I also referred a lot of patients whom during my assessments with them, I could see that some of them needed psychological support... I was part of the caregivers support group, with the help of some of the counsellors and those who are working in the Department of Health, as far as the support group was concerned (Lesedi, personal communication, July 25, 2011).

In terms of, when we were talking about the adolescents clinic, that was my baby, that was the one thing I was passionate about when it started I was like I want to do this, I want this to happen and it happened. I was very vocal about the needs of the adolescents, as we needed the psychological services. And I had an idea of going to speak to our psychologist; I went there and spoke to her, whenever it was not working out. Person Z would come in more to help me communicate with the department... I was more involved in terms of the planning process and talking to the patients about the services and so on, referring the patients... (Lerato, personal communication, June 23, 2011).

### **5.2.5 What are psychological services according to you?**

When the programme was implemented there were issues surrounding referral. There was no sufficient clarity concerning what qualified a patient to see the psychology students. Other cases were clear but some were not. As Lerato (personal communication, June 23, 2011) explained, “because it was a new service, nobody knew how it worked and how it supposed to be, and who is supposed to be referred and the referral process”.

At some point there was a suggestion that maybe every patient ought to be seen by the psychology students. Lerato (personal communication, June 23, 2011) believed that it was because the support groups were not working, and “almost all the patients that we had seen experienced some kind of social problem which impacted on the medical management”.

Also, it was noted that other problems that they (personnel) might not be able to pick up, may be brought to the attention of the psychology students during consultation (Lerato, personal communication, June 23, 2011). Therefore, because of this, I (researcher) was interested in the understanding of the personnel regarding the psychological services.

Lerato (personal communication, June 23, 2011) explained that her understanding of psychological services was that it included counselling which dealt with providing education as well as support. Furthermore, it focused on helping patients with “deep emotional issues, psychological issues”. In her field, Lerato (personal communication, June 23, 2011), was not able to support her patients emotionally due to the pressure of time. There was frequently a long queue of patients which needed to be attended to at the end of the day. Moreover, dealing with the psychological aspect of the patients was not her field of expertise. She believed that the role of the psychologist was to help the patient understand the education that she had provided, to also enquire of the patients’ feelings regarding the information he or she has received, as well as to work through the patient’s issues (Lerato, personal communication, June 23, 2011).

In addition, Lerato (personal communication, June 23, 2011) stated that sometimes she could sense that a patient is experiencing difficulties but could not really put her finger on what the problem might be, as a result a psychologist was required “to get to the bottom of the problem”. Other times she felt that patients were not trustful towards her; hence did not open up. She reckoned that they (patients) thought that she did not have adequate skills to deal with their problems. Lastly, Lerato was aware that other psychological problems, presented physically, and because she is medically orientated, her focus was on the physical presentation, thus for her working together with the psychology students was more beneficial for her patients (Lerato, personal communication, June 23, 2011).

...my understanding is that you are there to help with deep emotional issues, psychological issues that I cannot address, so meaning counselling. Counselling in terms of my understanding is providing education, providing support but sometimes (in my field of expertise) I don’t have the time to support that patient emotionally because there is a queue, I need to push the queue. So I believe a psychologist is there to sit with this patient and make them understand the education that I have given them. You know,



like taking the medication; how do they feel about it. They will put the two together and work with their issues. I believe that was what we required out of you in terms of psychological services. And also sometimes (during consultation), I'm sitting here with the patient, I can sense there is a problem but I can't quite put my finger on what the problem is. I believe you guys had the experience to get to the problem without using too many tactics. Sometimes the patient doesn't trust you (referring to herself) because they don't think that you've got adequate tools to deal with their issues. And then somebody who talks to them on their psychological level- that's when they can start opening up and then you get to the bottom of the problem. Sometimes the patient says I've got a pain and (being medically focussed) I wanna deal with the pain, meantime the pain is not just a pain. It's a pain because of some deep rooted emotional problem... They may present with this problem which is a physical problem to me and my job is to address the physical problem. In the meantime it's not a physical problem it's a psychological problem. And I don't have the skills to diagnose it as such (Lerato, personal communication, June 23, 2011).

Lesego (personal communication, May 26, 2011) stated that her understanding of psychological services is that they attend to the "psychological impact or the condition, if a patient is traumatized even if they can't cope". She also explained that after her intervention, if she finds that the patient is still not coping, she will then refer for psychological services.

... attending to the psychological impact or the condition, if a patient is traumatised even if they can't cope... after my intervention, if I see that the patient is not coping and there is no change with my intervention then I refer (Lesego, personal communication, May 26, 2011)

Lebogang explained that her understanding of psychological services, was that it "has a lot to do with emotions especially and working with people more on a psychological aspect" (Lebogang, personal communication, May 27, 2011). The focus is on the society, as well as the reactions and feelings of an individual. She gave examples of individuals diagnosed with

cancer or those who have been raped; reporting that in such cases a psychologist will then intervene and assist the individuals by supporting them as well as equipping them with coping strategies. Lebogang also highlighted that among other things, psychological services involved family therapy and play therapy (Lebogang, personal communication, May 27, 2011).

...from my understanding it has a lot to do with emotions, especially and working with people more on the psychological aspect of a person. Also looking more on society and how someone would react to certain things, for a diagnosis of cancer for instance and how you would cope or use your coping strategies. So a psychologist would be able to assist you with that. If you were raped for instance a psychologist would again help you with coping strategies, help and support you, do some family therapy as well. So in terms of that, that's my understanding of psychological services, and especially with play therapy because that's what we wanted you guys to do... (Lebogang, personal communication, May 27, 2011).

Lesedi felt that most of their patients were like friends to them, as they have seen them often times during consultations (Lesedi, personal communication, July 25, 2011). They had developed a bond with their patients. According to Lesedi, these patients needed "someone who can be so close to them, so that they feel like offloading all their stresses". They needed someone whom they knew for sure would assist them, and psychology students were the relevant people for such, hence, the multi-disciplinary team exhausted their resources as well as tried their best to support the patients by implementing the psychology service programme (Lesedi, personal communication, July 25, 2011).

Lesedi (personal communication, July 25, 2011) continued to explain that not all the patients needed psychological services but fifty per cent of them did. She found that some of them would break down in tears when she spoke to them. It was evident to her that they needed to offload, as well as someone to listen to them. She emphasised that the best thing a person can

do for someone in that situation, “is to give a listening ear rather than always telling what you feel is right for them” (Lesedi, personal communication, July 25, 2011).

You know most, actually all our patients are like friends to us, so they really depend on us on how we treat them and they sort of bond with the people that they see every day more than they bond with their families, so they need someone who can be so close to them that they feel like you know taking off, offloading all their stresses on them and they know that for sure that they will get help. We tried our best to exhaust all the resources we have as far as the multi-disciplinary team is concerned, to get help for them and we try our best (Lesedi, personal communication, July 25, 2011).

#### **5.2.6 What did the psychology service programme mean to you?**

For Lerato (personal communication, June 23, 2011) the programme meant a lot to her. When the idea of the implementation of the psychology service programme came about, she had this desire that the patients may find a space and a place where “they can voice out whatever frustrations” they experienced, as well as obtain counselling at the level of their understanding. That was her wish, especially for the adolescent patients (Lerato, personal communication, June 23, 2011).

Lerato had hoped that the psychology students were going to be available for all the patients in the adolescent clinic (Lerato, personal communication, June 23, 2011). She felt that at that particular stage, “they meet up with a whole lot of challenges, not just with the illness but with life in general”. She believed that to be able to intervene medically and socially, they (personnel) needed to be able to comprehend their patients on a psychological level (Lerato, personal communication, June 23, 2011). She explained that “adolescents who are infected with HIV have a lot to deal with, a lot more than somebody who is not infected”. Knowing that they have a sexually transmitted disease, they are also faced with “boyfriend issues or girlfriend issues and sexual issues”. Lerato longed that the psychology service programme

could address such stressors before they became a problem in the adolescents' lives (Lerato, personal communication, June 23, 2011).

Furthermore, Lerato wanted the programme to be a “prevention measure” as well as an educational tool, “addressing life skills and also empowering them (patients) in terms of giving them the confidence to deal with peer pressure, stigma and so on” (Lerato, personal communication, June 23, 2011). Lerato elaborated on how she had hoped that the psychology service programme would contribute in helping the adolescents to develop a healthy sense of self and acceptance of their condition, to a point where they would confidently educate their fellow friends about HIV/AIDS, “making sure that their friends know that, it is just an illness like any other illnesses and I’m not a risk to you as much as the next person is”. She wanted the patients to get across the message that “you can be my friend and love me as much as you love the (HIV) negative person, without having any prejudice against me” (Lerato, personal communication, June 23, 2011).

Lastly, according to Lerato, the programme was a way to make sure that when problems arose, there will be a place where they could find support, comfort and immediate intervention, since some of the patients have been suicidal in the past. Support groups were also meant to be a place where they can relax and be themselves rather than only about teaching life skills (Lerato, personal communication, June 23, 2011).

To me it meant a lot. In my mind initially when the idea came about, I had this idea in terms of the adolescents, of having a place where they can voice out whatever frustrations and they can also get whatever counselling at their level with the psychological understanding for their level. That was the idea in my mind that we’d have a psychologist available, even though it was not just for patients who had problems per se. It was gonna be for all the patients in the adolescents clinic because I believe that as they get into that stage they meet up with a whole lot of challenges. Not just with the illness but with life in general. And understanding what is going on with them and being able to comprehend what was going on in terms of their psychology, would help them to deal with the medical part and social issues that they were facing. Because at the end, adolescents who are infected with HIV has a lot to deal with, a lot more than somebody who is not infected. They have to deal with boyfriend issues or

girlfriend issues and sexual issues. How are they going to deal with those when they know they have a sexually transmitted diseases? And that's what is a stressor to them even though they wouldn't voice it. That was something that I thought would be dealt with before it became a problem...It was a prevention measure, in a way it was supposed to be educational as well, addressing the life skills and so on and also empowering them in terms of giving them the confidence to deal with peer pressure and the pressure they get from other people, the stigma and so on... (Lerato, personal communication, June 23, 2011).

To Letlhogonolo (personal communication, July 25, 2011), the psychology service programme "meant that someone cares about these kids". In addition, it meant that someone has realised that HIV/AIDS affected all the areas of the child's life. The whole lifestyle of a child changes when diagnosed with the HIV/AIDS disease, "it's not just about going to a doctor and getting medication". She reported that because there is medication available, children are no longer dying from HIV/AIDS even if they take their medication as per instructions (Letlhogonolo, personal communication, July 25, 2011). She felt that children were living complicated lives because of HIV/AIDS. Letlhogonolo's view is that: "HIV nowadays doesn't kill you directly, but it controls you, it completely engrosses your life". Everything that the child does has to do with HIV/AIDS and these includes, "spending hours on the queues once every month if not more, taking medication twice a day, trying to get a hearing and caring from the caregivers". These children has to live with a knowledge that this virus is "like a ticking bomb" inside their bodies (Letlhogonolo, personal communication, July 25, 2011).

It means someone cares about these kids and realizes that this particular disease, HIV affects the whole child. It's not just going to the doctor and getting some medication. What I explain to a lot of folks is that nowadays with ARVs the children not dying, they are living more complicated lives. HIV nowadays doesn't kill you directly, but it controls you, it completely engrosses your life. The children spend hours on the queues once every month if not more often, they're taking medication twice a day, and they know that they have this virus that is inside them like a ticking time bomb. Trying to

get a hearing and caring from the care-givers, is such a core and main thing, it's such a challenge (Letlhogonolo, personal communication, July 25, 2011).

Lesedi stated that the psychology service programme was of benefit to the personnel as well. They also consulted, got advice and were referred to relevant people (Lesedi, personal communication, July 25, 2011). Furthermore, Lesedi was satisfied with the help their patients received. She had observed during orientation that most patients, especially the adolescents were keen about the programme. They needed a space where they could feel free and open to discuss whatever difficulties they were experiencing, for example, peer pressure, stigma (Lesedi, personal communication, July 25, 2011). Most of them were staying with their relatives (aunts, grandparents, etc.), whom they could not open up to, since their parents were deceased. And at times it was the very same aunts and grannies discriminating against them. And according to Lesedi, the adolescents did get that space they longed for and utilised it (Lesedi, personal communication, July 25, 2011).

You know our adolescents; most of them don't stay with their parents. Their parents have passed away, so they don't feel free from talking to their relatives, their aunts or their grannies about their problems that they face especially when it comes to peer group pressure. If they feel they are not treated equally with their cousins and they don't feel free to say whatever comes to their mind, especially because of stigmatization (Lesedi, personal communication, July 25, 2011).

Lesego (personal communication, May 26, 2011) indicated that the psychology service programme meant a lot to her, as well as being of a great relief to her. She hoped that the patients also felt the same way she felt about the programme. Lebogang believed that the programme was a "good thing" (Lebogang, personal communication, May 27, 2011). She commemorated it for providing emotional support, as well as activities for children while the awaiting to be serviced at the clinic. Instead of spending five hours on a queue doing nothing, they were kept busy which was helpful according to her (Lebogang, personal communication, May 27, 2011).

It meant a lot to us, hopefully to the patients too...it was such a great relief for me... (Lesego, personal communication, May 26, 2011).

Well for me I thought it was a good thing, it was helpful in terms of providing emotional support, as well as the kids had something to do instead of them just lazing around and not getting any feedback when they were here. They spend about five hours sitting here, and it's a long time, so it was something to keep them busy as well, with the activities also (Lebogang, personal communication, May 27, 2011).

### **5.2.7 Did you receive feedback from the cases you referred and what were the cases about?**

Lerato (personal communication, June 23, 2011) did not remember the total number of the cases she referred, could only remember a few cases that were significant to her and she reported to have received “a good feedback with those particular patients”. The feedback she got was from both the psychology students and the patients. According to her there were “couple of successes”. From a medical perspective, it was easier to deal with patients who were more relaxed, that is after having received a psychological intervention, since they were more receptive to the treatment offered to them (Lerato, personal communication, June 23, 2011).

I don't remember but I can remember a few cases that were significant to me, there were three or four cases that I referred. I found that these issues needed to be addressed, without the psychological part being addressed then we ain't gonna go anywhere with those patients, and I must say there was good feedback with those particular patients... (Feedback) from you guys and the patients and in terms of the improvement in the patients' condition - there was an improvement in those patients. That helped a lot in terms of the management because whilst you (psychology students) deal with the psychological part it's easy to deal with the medical part because now the patient

understand more and more, and the patient is more receptive of whatever management that you are offering then, because in terms of their stress level psychologically they're more relaxed. So I think we had a couple of successes (Lerato, personal communication, June 23, 2011).

Lethogonolo (personal communication, July 25, 2011) remembered that she referred a patient at least once a week. "At least once a week, but I would just grab you and say or maybe not formally in your dairy book, but I would say please come, we must help this child". She usually handed over the patient to the psychology students and rarely made appointments formally in the diary. It was easier for her to see the students on sight and to make referrals in that manner. Most of the cases she referred involved difficulties accepting the diagnoses, as well as non-adherence to medication (Lethogonolo, personal communication, July 25, 2011). She explained that often time's patients experienced upset stomach due to the medication, therefore, they would stop taking it. Furthermore, once they became aware that the reason they take this medication is because of the diagnoses to this terrible disease, they then "think that their friends will make fun of them, thus discontinue the medication which leads to their condition becoming worse (Lethogonolo, personal communication, July 25, 2011).

Lethogonolo continued to explain the challenges that the adolescents patients encountered. They deal with bereavement due to the loss of their parents and worse of all they have to witness them die due to HIV/AIDS, knowing that they also have the same disease (Lethogonolo, personal communication, July 25, 2011). They then "start wondering who they got the transmission from, is it mommy, or maybe from daddy?" What then followed were changes in caregivers, as they were looked after by their grannies or aunties. "This becomes overwhelming for them" thus a need for referral to the psychology service programme (Lethogonolo, personal communication, July 25, 2011).

Mostly it was difficulties of accepting the diagnosis and complains that once the children know their diagnosis they become non-adherent. They don't want to take the medication anymore. We call it teenager effect to chronic illness... These children



don't want to feel sick, but they take these medicines every day, it upset their stomachs and once they hear that they have this terrible disease they think their friends are going to make fun of them. They stop taking their medicines and then it gets worse and later on their parents die. They grow up to witness their mom and dad dying of HIV and so now they start wondering who they got the transmission from, is it mommy, or maybe from daddy. They then have to be cared for by an aunt or granny. So changes in caregivers, from death to grieve, to loss of a family member for the younger children and then now the teenagers is living with grannies and aunties and having to know that they have this disease. It becomes overwhelming for them (Letlhogonolo, personal communication, July 25, 2011).

The feedback that Letlhogonolo (personal communication, July 25, 2011) got was “not from the student. And feedback was that the children enjoyed them being there. “It was a great diversion from just sitting in a long hallway knowing you have to wait for hours to see the doctor. It really lightened the clinic's load” (Letlhogonolo, personal communication, July 25, 2011). Unlike Letlhogonolo, Lesedi received feedback from the psychology students (Lesedi, personal communication, July 25, 2011). She also witnessed the psychology students giving feedback to the parent/caregiver with the patient's consent, on the progress and the intervention offered. According to Lesedi most problems were resolved (Lesedi, personal communication, July 25, 2011).

Yes I did (received feedback from the psychology students), they tried their best to give feedback and would call the concerned parent with the teenager consent to come and give a feedback and how far we have went with the problem, most of the problems were actually solved” (Lesedi, personal communication, July 25, 2011).

Lesego, similarly to Letlhogonolo, did not receive any feedback from the psychology students (Lesego, personal communication, May 26, 2011). She was told that they wrote reports in the patients' files but she has never seen them herself, in fact for her that was one of the challenges concerning the psychology service programme. She believed that the

appropriate way, was for the psychology students to write the report in the files and discuss the same report with whoever had referred the patient (Lesego, personal communication, May 26, 2011).

The problem that I identified is that whenever we referred we were not getting like direct feedback, if we work as a multi-disciplinary team, we don't just write reports and hand it over. We have to discuss about the report and the client (Lesego, personal communication, May 26, 2011).

Lebogang reported to have received feedback from both the students who were working with the small children and those who were working with the adolescents (Lebogang, personal communication, May 27, 2011). Though when the group that worked with children changed, she no longer received feedback. Those working with adolescents also stopped attending the multi-disciplinary meetings and she was not sure about their reasons for such. Lebogang used to be updated and informed in those meetings but because the psychology students were no longer attending, she did not know much of what was happening with the cases she referred or with the psychology service programme itself (Lebogang, personal communication, May 27, 2011).

Furthermore, Lebogang (personal communication, May 27, 2011) also received feedback from the patients or the patients' families. She recalled referring about ten cases and the feedback was good. The families reported the progress that came due to therapy and they (personnel) also witnessed the improvement due to therapy. For example, other children who had difficulties, who had attended therapy, did much better in school. She mentioned few cases which were resolved successfully due to therapy (Lebogang, personal communication, May 27, 2011).

Well, I think in total it was about ten we gave you guys, the feedback was good, from the families involved, they felt it was beneficial and we actually saw with our perception, children that had difficulties that they were actually doing better in

school...one child was being abused, we suspected there was abuse, and then we found out that it was true and he ended up staying with his grandfather, as a result of that, we noticed that there was a deterioration in his school work but then when he started attending the psychological services, there was an improvement and the grandfather was very much happy because he then knew how to support and help the child, so that was the one kid. The other one was a little girl who just didn't wanna do anything in therapy and we thought that she had some psychological problems and it wasn't actually psychological problems, she just wasn't used to us and she kind of clicked very well, with the psychologist and we ended up finding out that there was nothing wrong with her speech and we thought she couldn't speak and she ended up speaking in the sessions, guess she just had a good approach and those were few we referred (Lebogang, personal communication, May 27, 2011).

#### **5.2.8 How was your relationship with the psychology students?**

Lesedi (personal communication, July 25, 2011) believed that her relationship with the students was very good; she reported to have learned from the students as well as enjoyed their company. She felt like they were her siblings. In addition, they had missed the psychology students (as they were no longer coming to the clinic during the time of the interview) and so did the patients (Lesedi, personal communication, July 25, 2011). Lebogang also reported to have had a good relationship, especially to the students who did therapy with the adolescents and children. As for the second group who were working more with children in a "play group", they hardly knew who they were (Lebogang, personal communication, May 27, 2011).

Lerato labelled her relationship to the psychology students as "fine". She believed they got along well, and she had enjoyed their presence. She explained that maybe she could have tried a bit more by making use of the services the programme offered, but she like any other person, had her good and bad days. During her bad days, she just didn't want to talk to anyone, never mind greeting anyone and even asking how they were. Lerato also felt that the

psychology service programme could have also benefitted the personnel as they deal with traumatic situations on a daily basis. Therefore, debriefing was a necessity for the personnel.

Lethogonolo (personal communication, July 25, 2011) described the psychology students, as a “very enthusiastic, very delightful group; focused and ready to interact with the children. Furthermore, Lesego stated that her relationship with the students was “cordial” (Lesego, personal communication, May 26, 2011).

I think it was very good and I also learned a lot from the psychology students and I enjoyed their company, they are like brothers and sisters to us. We didn’t see them like you know people who are just coming to give and we don’t give back. We enjoyed their company, we actually missed them even our kids, they wanted those people who were playing with them and were teaching them a lot of things (Lesedi, personal communication, July 25, 2011).

The ones who were doing play therapy, I think we had a good relationship, the ones who were doing play groups, because they were always changing, we didn’t always knew who they were. We would see them take their stuff and go, so we never really knew them you know; these were the new students (Lebogang, personal communication, May 27, 2011).

Well, personally I think my relationship was fine. I didn’t have any issues. I think we got along well. I enjoyed like, whenever you (psychology students) were there whatever you had to offer I enjoyed it, I don’t know. I think I could have tried a bit more, to use you more but sometimes you know, you (referring to herself) just wanna get through the day and go home. And I think besides using you for the patients, it would have been nice also to have you guys helping us, with the staff as well. Because the staff as well deal with traumatic situations on a daily basis and you leave there and you go home. The next day even when you see people you just don’t wanna talk to them. So sometimes you guys would get there and I would sense that you feel that nobody is giving you attention. I would get those days as well where I just don’t wanna feel like saying hi, how are you, just not today. But I think, generally I think we got on well, I don’t know (Lerato, personal communication, June 23, 2011).

The students were very enthusiastic, very delightful group, focused, ready to interact with the children (Letlhogonolo, personal communication, July 25, 2011).

It was cordial (Lesege, personal communication, May 26, 2011).

### **5.2.9 Were there any challenges experienced and what were they?**

According to the participants, there were few challenges experienced. Lebogang mentioned that, the fact that the Clinic did not accommodate all the multi-disciplinary team in one section posed a challenge (Lebogang, personal communication, May 27, 2011). On clinic days (when patients came for check-ups and to fetch medication), they moved from the Clinic to the dietician and sometimes to the occupational therapists. All these professionals were in different sections of the Hospital. The psychology students had to somehow find a suitable time to see the patients in between seeing the above mentioned professionals (Lebogang, personal communication, May 27, 2011). Lebogang believed having some sort of structure “would have made life easier”. She also felt that communication was an issue, especially with the second group of the psychology students who were working with children only. “If we knew who they were and if they came to us and asked when they needed help, that would have made a difference” (Lebogang, personal communication, May 27, 2011).

On the clinic days it is a bit challenging because the patients are not in one place all the time, they are moving from one place to the other, from the ARV clinic to the dietician to us, if everyone was spaced in one, sort of like an intersection, the pharmacist, the dietician etc., it would make life so much more easier because the psychologist would not have to just pull out whoever was walking around and say okay you have done this, this is what you still have to do, or you can join the group now, there would be more structure. It is unfortunate that the ARV clinic doesn't accommodate all the multi-disciplinary team in one section, if they did, it would have been far more better.” (Lebogang, personal communication, May 27, 2011).

Lesego (personal communication, May 26, 2011) reported that two challenges were experienced. One was that the psychology students were not always available. Another was the issue of communication since the psychology students only wrote the reports inside the patients' files without discussing the cases with the person who had referred those patients (Lesego, personal communication, May 26, 2011).

Lethogonolo identified the challenges as, “the space, the structure, more active involvement of the physicians to refer clients to you (psychology students), to know that you were there and how to reach you” (Lethogonolo, personal communication, July 25, 2011). She noted that the psychology students were at Kalafong one day a week and during the school recess they were not available at all. According to her during school recess that is when their patients were more available, hence needed the students to be available then. She felt that they wanted more of the psychology students not “half” of them (Lethogonolo, personal communication, July 25, 2011).

The space, the structure, more active involvement of the physicians to refer clients to you, to know that you were there and how to reach you. You were only there one day a week and during the school holidays you were off and that was when the kids were available. We want more of you not half of you (Lethogonolo, personal communication, July 25, 2011).

Also, Lethogonolo articulated that arranging a consultation for psychological intervention to coincide with the date that the doctor had arranged for the same patient was difficult (Lethogonolo, personal communication, July 25, 2011). Lesedi (personal communication, July 25, 2011) also raised the same issue, which appointment with the psychology students needed to be made the same day as the doctors' check-up. She explained further that most of their patients are from a poor background thus transport costs had to be taken into consideration. Lethogonolo (personal communication, July 25, 2011) agreed as well as explained that there was a transport fund that was donated but the money would get finished. Sometimes she even took out money from her own pocket to help other patients.

We had transport money that was donated by a lot of churches because sometimes families borrow R10 from a neighbour to get here and they still gotta get home and they gotta pay their neighbour back. R10 to come to the doctor and bringing them home back. So we did run out of transport money last month. From time to time, I take out from my own pocket; look for some loose change (Letlhogonolo, personal communication, July 25, 2011).

Lerato shared the same concerns as Lesedi and Letlhogonolo. The system worked in the manner that, all relevant professionals were to be seen in one day of consultation; therefore the psychological intervention also fell within that system (Lerato, personal communication, June 23, 2011). The fact that psychology students were available for consultation on Monday afternoons only was not feasible. It was not possible for clients after seeing doctors and collecting their medication, to sit and wait for the students to arrive in the afternoon. Most clients wanted to leave immediately after receiving their medication, since they had been in the clinic since in the morning (Lerato, personal communication, June 23, 2011).

...one of the difficulties was arranging the visits with the psychologists to coincide with the visits that the doctor had arranged with the patients... So identifying those patients and setting up actual dates and visits with the psychology students was difficult (Letlhogonolo, personal communication, July 25, 2011).

The problem that we encountered was that most of our patients are from a poor background, some couldn't afford coming to see the psychologists and then to see the doctor. I think it would have been easier if you make the appointment on the same day that they are here for the doctor's check-up (Lesedi, personal communication, July 25, 2011).

(Psychology students came at Kalafong on)...Mondays and in the afternoons only. It meant that it was difficult to get the patients at the times when you were there and also to get the patients to sit and wait, when they were booked. After they get their medication then nothing else mattered they just wanted to go home. So implementing the system was the difficult part. And also because it was a new service, nobody

understood how it worked and how it supposed to be and who is supposed to be referred and the referral process and that was another stumbling block. We had to work through that and I don't think we got it right...“On the other hand, on the patients' side, most of our patients came from like poor background, money was an issue, transport money was an issue. We had a transport fund and we tried to help wherever necessary but it could not accommodate them as much as we would have liked to, because the money came from sponsors whenever there was a sponsor so we would tell them, look if you come we would try to help, and sometimes we wouldn't be able to meet that need and that frustrated the patients that “I can't spend this money because this money is needed for other things” and I think that was another thing that would need to be addressed (Lerato, personal communication, June 23, 2011).

Furthermore, Lerato (personal communication, June 23, 2011) explained that during the school recess, the psychology students did not avail themselves at all, and the personnel continued seeing clients as usual. They would then forget to refer some clients and since the problems remained unresolved, they would still get to face those same issues in the future. Another challenge that was not addressed was the issue of the programme's administration which involved bookings etc. There was no-one responsible for that, according to Lerato (personal communication, June 23, 2011).

During holidays, you guys (psychology students) - whenever the schools were closed you'd also close. And sometimes that would be the times when we have the patients available because schools are closed, and then they are more willing to hang around... Sometimes we would we would want to refer patients but we would think we don't know when they are available or they are on holiday and anyway it doesn't matter we'll see when they come and the next time when the patient comes you've forgotten about that referral and the patient also doesn't remind you because they don't see the need as well, and then the patient ends up not getting referred. Not that the problem has gone away but we are too busy focussing on other things than dealing with that psychological part which actually also impacts on the overall management of the patient. And then eventually it comes out again after few months the problem comes



again and we realize this patient by the way was supposed to have been referred. I think that was another thing that we were not doing very well. And also in terms of the booking, who was gonna deal with your administration, that was an issue that we did not address (Lerato, personal communication, June 23, 2011).

Moreover, according to Lerato (personal communication, June 23, 2011) the fact that the doctors needed to see their patients once in three months while the psychological intervention needed regular consultations. Apparently other patients would complain of such. Contributing to that was the fact that most of the patients in the Clinic came from a poor background, therefore transport costs was a problem (Lerato, personal communication, June 23, 2011). There was a transport fund as Letlhogonolo explained, it was received from a sponsor but it was not sufficient to meet the needs of most of the patients (Lerato, personal communication, June 23, 2011).

Lerato also pointed out another challenge being that because this was a new service, as well as a new programme at the Clinic, no-one understood how it worked, how it was supposed to be, who was supposed to be referred and what the referral process was (Lerato, personal communication, June 23, 2011). This was “another stumbling block” according to her. Also the patients did not understand the need for the programme; hence they did not honour their appointments. They needed to be explained to, that the psychology service programme “was good for them”. Lerato reported that other patients thought that the medical service alone was enough (Lerato, personal communication, June 23, 2011).

...and also in terms of their management, make them understand that look this is good for you- the necessity in terms of your management. I think because it was a new service patients just thought what they needed was just the medical service, the medical intervention and they did not understand this psychological intervention. They just thought the doctor spoke to me and that’s good enough. And with the adolescents it was especially difficult because you need to be functioning at their level in terms of psychologically for them to understand and get the point and be able to honour the relationship (Lerato, personal communication, June 23, 2011).

In addition Lerato (personal communication, June 23, 2011) noticed that the issue of space was a predicament- there was a limited number of offices in the Clinic. Space was a concern already among the personnel, therefore allocating an office for psychology students made matters worse, more so that the psychology students could not share an office due to the issue of confidentiality. Whenever the students had a patient to see, they would “start by running around looking for a room that is available” (Lerato, personal communication, June 23, 2011).

Lastly, Lerato believed that there was a loss of interest from the personnel’ side due to the above mentioned issues (Lerato, personal communication, June 23, 2011). At some point they concentrated more on the medical intervention and left the psychology students to deal with their issues on their own. She acknowledged the students’ frustrations as they (psychology students) dependent on them (personnel) for referrals. Other times they would refer and yet not make any follow-ups. Lerato expressed how difficult it was to implement the psychology service programme (Lerato, personal communication, June 23, 2011).

Well, now I think it’s still not working, I think there was loss of interest somewhere because of all the issues that were there that we couldn’t quite deal with, so there was loss of interest from especially from our side where we started concentrating more on our the medical part and we were like okay fine, let those ones deal with their issues (Lerato, personal communication, June 23, 2011).

#### **5.2.10 What are your views concerning the establishment of the support groups?**

Lerato (personal communication, June 23, 2011) explained that the support group did not have members who were known to belong to the group, the attendance was poor, other patients felt that “I don’t need to be discussing my problems in a group” or “I don’t need to be in a group to address my problems” while others believed that being in a support group was a time waster or assumed that the support group was going to address issues that they

knew or already addressed and thus was not going to be helpful. According to Lerato, the support group was not successful and she suspected that the issue of stigma might have contributed to that (Lerato, personal communication, June 23, 2011).

Also the support group was designed to fit within the system at the Clinic; therefore it was an “open group” whereby members could go in and out- even during the sessions (Lerato, personal communication, June 23, 2011). When patients were waiting to see whoever professional they needed to see, they were encouraged to wait while attending the support group, instead of being on the queue. Other patients were apprehensive due to this arrangement: “people would feel like well, if I go in that room and my name gets called then I’ll miss my turn and the next thing I’ll get to leave here late”. So they chose to be on the queue instead of attending the support group, even though they were assured that the personnel would come to fetch them from the group when it was their turn (Lerato, personal communication, June 23, 2011).

The attendance was poor, we gave people an option, that okay there is a support group, there are people who will help you, while you are waiting can you go and attend. People would feel like well if I go in that room and my name gets called then I’ll miss my turn and the next thing I’ll get to leave here late. So I’d rather sit here and wait to hear my name being called so that I can be attended to and leave this place. So that was an issue we had to deal with. And it was difficult explaining...when your name gets called we’ll come there and fetch you, it was not getting through. They thought oh well they just wanna waste more of my time. And the other thing was that people thought well they’re just gonna talk about things that I know, and they are not going to help me anyway. And I think with the support groups there was still that issue of stigma so the patients felt, I don’t need to be discussing my problems in a group, so I don’t want to be in a support group (Lerato, personal communication, June 23, 2011).

Another encounter with the support group, for Lerato (personal communication, June 23, 2011) was the fact that those who had attended still presented with the same issues that would have been addressed in a group setting. It seemed as if “people would just get there and sit

and listen, if they are listening and leave”. Lerato felt that the Clinic still did not have “proper support groups” (Lerato, personal communication, June 23, 2011). Lesego believed that the group formation phase was not conducted correctly, she felt that the patients were bombarded with “everything at the same time”. She reckoned that “we forgot that we are dealing with kids not adults (Lesego, personal communication, May 26, 2011).

Well, I don’t think it went well because I can tell you up to now we don’t really have proper support groups. The patients would be there, then there would be a talk there but we didn’t have like members that we knew that these members belong to the support groups and people would just get there and sit and listen and if they are listening and leave then, the next thing they present to me with the same problems that would have been addressed in the support groups. So I don’t think that went well (Lerato, personal communication, June 23, 2011).

I think the formation, the group formation phase was not conducted correctly because it was like you were, we forgot that we are dealing with kids not adults. We wanted to bombard them with everything at the same time. I think that’s where we went wrong... We were not user friendly (Lesego, personal communication, May 26, 2011).

Letlhogonolo (personal communication, July 25, 2011) thought that the support group may not have worked so well, because of the space. Also she mentioned that “some of the personnel didn’t understand that the students were there for the immunology clinic or understood what they were about”. She believed that the actual clinic did not recognize or realize the reason for the students’ presence. Letlhogonolo acknowledged that the few patients, who attended the support group, enjoyed themselves as well as learned a lot from it (Letlhogonolo, personal communication, July 25, 2011). Lebogang (personal communication, May 27, 2011) believed that the support groups were unsuccessful due to lack of attendance also reported that, such caused disinterest to others. On the other hand she could not be sure if those who attended found them useful, since there were no questionnaires that rated the patients’ level of satisfaction (Lebogang, personal communication, May 27, 2011).

It was because of the space... Some of the personnel didn't understand that the students were there for the immunology clinic or understood what they were about... the actual clinic I don't think understood why you were here...The few that came did enjoy themselves and learned a lot from it (Letlhogonolo, personal communication, July 25, 2011).

Because people promised that they were gonna be attending support groups and when meetings were taking place, some people came some people didn't come. There was a loss of interest afterwards, it was like we spoke about it but then nobody did anything about it... with regards to the groups I can't be 100% sure because there wasn't any clients satisfaction questionnaires that I am aware of, that will give us an indication, if they were either happy or did they find improvements, something of that nature, I'm not sure about that. But with regards to that I just felt that the kids were occupied and they had something to do, but I think it could have been structured differently (Lebogang, personal communication, May 27, 2011).

### **5.2.11 Do you think that the psychology service programme met the needs of the**

#### **Kalafong community?**

Lesedi (personal communication, July 25, 2011) believed that the programme did make a difference in the community. According to her "we managed to get a lot of our patients and their caregivers to understand that we can also look at their psychological and the social part of their lives. Most gave consent to be assessed psychologically and we tried, really with our psychology students to can get to the core of the problem" (Lesedi, personal communication, July 25, 2011).

Lesedi also reported that even after the students no longer came at the Clinic, other patients still requested for their services (Lesedi, personal communication, July 25, 2011). She stated that they also profited as the personnel, "we also benefitted a lot from the psychology students, to the extent that we actually, I don't know if we abused them or what. We wanted

to take all our problems even those that were simple. You were really of great help to us, I must say” (Lesedi, personal communication, July 25, 2011).

Lesego (personal communication, May 26, 2011) felt that there were no big changes brought forth by the programme, though it made a difference yet she still felt that we could have left something with them, for example, an established support group. She expressed herself by saying that “you came and left, and then I don’t think you left anything with us, when you left”. According to her, there were no highlights (Lesego, personal communication, May 26, 2011).

Lerato (personal communication, June 23, 2011) held a view that “on a small scale, where we had the patients, and the time and the space, it did (make a difference)”. She felt that the programme benefitted some patients, especially those who required “intervention over a short period of time”. For those who needed intervention over a long period of time, the programme did not work for them, to such an extent that, they somehow got “lost” and would default their medical treatment (Lerato, personal communication, June 23, 2011).

Furthermore, Lerato thought that idea of play room where there were play groups and activities for children to be involved in was successful (Lerato, personal communication, June 23, 2011). The children were kept entertained and it also brought relief to the parents. Instead of sitting together with their children while waiting on the queue, they could have peace of mind, knowing that their children were safe and having fun while they themselves had the opportunity to interact with other parents. To the children, the benefits were that, they would look forward to coming to the clinic, as well as interact with other children; especially those who were not attending crèche. Lerato described the playgroup as having been pleasurable to the children (Lerato, personal communication, June 23, 2011).

Yes, on a small scale where we had the patients and we had the time and we had the space, it did (work). And I think especially on the level of the smaller children, with the playgroup and so on, it did because it helped and that is still continuing. The playgroup is still there it’s still helping, it keeps the kids entertained... some of the kids don’t even go to crèche so when they are there they get the opportunity to do something that other children do at crèche. They get to interact with the other children and it becomes more

pleasurable for them to be at the clinic so they start looking forward to coming to the clinic. And for the moms as well it's a nice idea because instead of just sitting there with your child on your lap the whole day waiting to be serviced, knowing that your child is somewhere safe and being entertained. They also get to relax and they get to chat more, and they becomes more open about what is bothering them and also interacting with the other moms. It'll get much, much easier for them to interact with the other moms because they didn't have to be looking after the children for that time and so on. Regarding that, it went very well. And also in terms of the OT (Occupational Therapists) as well, helping the OT with assessment in terms of the developmental assessment, it helped a lot. And then with the support group, it worked for some patients and also it didn't work for other patients at the support groups (Lerato, personal communication, June 23, 2011).

Also Lerato reported that, the programme did work regarding "getting the children to be more positive about their status from a younger age" (Lerato, personal communication, June 23, 2011). Furthermore, she pointed out that "the idea of having you (students) available immediately worked very well" since the psychology students did not only see the HIV patients but also got referrals from the "general paediatric outpatient". She also believed that it was of a great help to the OT (Occupational Therapy) section in terms of assessments. Lerato expressed that the team tried to get it right but it was not possible for all the patients (Lerato, personal communication, June 23, 2011).

Letlhogonolo thought that the programme did meet the needs of the Kalafong community (Letlhogonolo, personal communication, July 25, 2011). The services were accessible and user-friendly. She also noted that "it opened up a new forum of team work". According to her, intervention towards the patients involved every professional within the multi-disciplinary team, "it's not just about a doctor prescribing medicine", everyone else's input matters considerably, including psychological intervention (Letlhogonolo, personal communication, July 25, 2011).

So having your services right there available weekly was very accessible, very user friendly. We'd like to have you back... the students who came on the heavy clinic day really helped the kids to work and cope better. The parents even say that they like to come to the doctor; they want to come to the doctor (Letlhogonolo, personal communication, July 25, 2011).

During heavy clinic days, the students were very helpful according to Letlhogonolo (personal communication, July 25, 2011). It delighted the children and assisted them to cope better. Some parents gave feedback that their children are starting to like "coming to the doctor". Her highlights were when children asked to speak to one of the psychology students, as well as receiving feedback from the patient saying "she was really nice". For her that was encouraging. Lastly, the psychology service programme brought forth a change and that is, space renovations (during the time of the interview, the clinic had been renovated and there were more counselling rooms/offices). Also according to her, the programme opened "a new forum of team work" (Letlhogonolo, personal communication, July 25, 2011).

Lebogang (personal communication, May 27, 2011) believed that the needs of Kalafong community were met by the programme, especially for individual therapy whereby play therapy was also involved, but regarding support groups, she was not sure. She mentioned that if there were "clients satisfaction questionnaires", such would give an indication of whether the patients were happy or not and if there was any need for improvement. With regard to the play group, she felt that "the kids were occupied and had something to do". One of the honours group had asked for donations from a church and that was one of the highlights. "I think the one group, they used to do a lot of donations for the church and got sponsors from the church, they had gathered toys, that was a highlight, the kids were very happy about that" (Lebogang, personal communication, May 27, 2011).



### 5.2.12 What are your recommendations?

All the participants would like the psychology service programme to continue to exist at the Clinic despite the challenges that were experienced. Lesego recommended improvement on communication, availability of the psychology students- “there should always be someone standing in for referrals”, as well as sustainability (Lesego, personal communication, May 26, 2011).

Lerato (personal communication, June 23, 2011) believed that the psychology service programme was a good initiative, done in the right way, as well as addressing the challenges it can yield good results. It can help not just the patients but the personnel as well. In addition, the psychology students can also benefit from it, in terms of acquiring experience. Lerato pointed out that for the programme to be as they hoped it will be, it’s going to require proper planning, attention, as well as availability of everyone involved (Lerato, personal communication, June 23, 2011). She emphasized that the logistics also needed to be addressed. The patients also need to yearn for it and the services it offers, so that it can be of advantage to them. Therefore, she recommended that the patients be educated about the psychology service programme to help them see how the programme could be of benefit to them (Lerato, personal communication, June 23, 2011).

I think if done the right way if it can be given the right time and the right place, it’s a good programme, it can work very well and it can help everyone not just the patients but for you guys as well it can give you a lot of experience in terms of the patients that you are gonna meet when you are practicing (Lerato, personal communication, June 23, 2011).

Lerato (personal communication, June 23, 2011) recommended that the psychology students be available at the same time that patients are available. “...we need to make sure that we can we can make things easy for you so that you can become available, in terms of the patients- like if you can definitely provide transport” (Lerato, personal communication, June 23,

2011). She suggested that the psychology students be available the whole day, not only in the afternoons. She referred to “unavailability” as a stumbling block. Lerato also raised the issue of the patients’ availability, which will need to be resolved, especially since the medical treatment only needed the patients to come to the clinic once in three months, while on the other hand the psychological intervention needed a regular consultation. She also suggested that transport money be made available to the patients, to make it easier for them to attend or honour their appointments (Lerato, personal communication, June 23, 2011).

Furthermore, another recommendation from Lerato was that the clinic should provide the psychology students with a space to work in (Lerato, personal communication, June 23, 2011) Lerato also noted that “they (personnel) could have done better in terms of referral- “getting patients for you (psychology students)” but the issue of the students unavailability also hindered the process. Lastly, she suggested that the issue of the programme’s administration also be addressed (Lerato, personal communication, June 23, 2011).

From our side I think in terms of making sure that when we were expecting you, we had space for you to work. I think that is very important because if we are expecting you to offer provide a service to help us then we were supposed to make sure that you are comfortable in the surroundings, and patients also feel comfortable, not when you get there and the patients is sitting there then you have to start running around looking for a room that’s available. That was the one thing that we could have done better, and the other thing we could have done better was in terms of referral, getting the patients for you (Lerato, personal communication, June 23, 2011).

Lethogonolo (personal communication, July 25, 2011) recommended visibility of the psychology students. For her what worked was seeing the students on sight, for example in the hallway, which reminded her to refer patients. She preferred taking the patients by hand and introducing them to the psychology students, verses making an appointment for them in the diary. She added that the students ought to do orientation so that the nurses and the sisters know that they are available. Moreover, she recommended that more follow ups be arranged,

as well as provide feedback to whoever had referred the patient (Letlhogonolo, personal communication, July 25, 2011).

Letlhogonolo raised an issue of confidentiality, which during feedback sessions, there was a concern from the psychology students' side regarding confidentiality, she explained that it was also their mandate to keep whatever is revealed about the patients confidential. She emphasized that the team consists of health care professionals; therefore it works a lot better to communicate about cases as a team. Lastly, Letlhogonolo recommended that all the support that the students provided to the patients should stay the same (Letlhogonolo, personal communication, July 25, 2011).

I said often times we used to run into each other and just chat, so many kids come into the clinic. I would personally remember that you were there, when I see you there. In my own personal way, I have seen you being visible, right there in the hallway, right there saying good morning. So being more visible, having to do orientation, also for the sisters and the nurses to know that you are available. To add more follow-ups, to come to us and say, we saw that patient this week this is what we talk about, keeping everything confidential and not forgetting of course we're all in the health care profession but it coordinates the team work a lot better to communicate about cases (Letlhogonolo, personal communication, July 25, 2011).

Lebogang (personal communication, May 27, 2011) recommended that the programme be structured differently, as she already explained when she reported about the challenges that were experienced. She also indicated a need for a "clients' satisfaction questionnaire", which will assist the team to be aware of the patients' level of satisfaction as well as where could the programme or the support groups be improved (Lebogang, personal communication, May 27, 2011). She also expressed that she would appreciate if part of the services the programme offers was psychometric testing. Lastly she suggested that if it's feasible, during clinic days, all the multi-disciplinary team should work in one section, as well as highlighted the importance of discussing cases together as a team (Lebogang, personal communication, May 27, 2011).

...and also if you guys could also help us with psychometrics testing as well, especially for the school going kids, that would be wonderful... I think if we can liaise with person Z and try to say on the clinic days if the multi-disciplinary team can all be in one area and utilize the space in terms of that, I think that would work much better because we would now have that play area available in the Clinic, so it would make you guys' life much more easier as well. And then if we had our meetings, multi-disciplinary meetings and we highlighted the child that we worried about emotionally, then we could always say, we worry about this child and apart from the counsellors, can we also get the psychologist to work with this child to help us out" (Lebogang, personal communication, May 27, 2011).

### **5.3 Second Interviews**

Emails were sent to the participants, to further explore or clarify their initial data if they deemed it necessary to do so. Also, to assure if the data was correct, and that the transcripts reflected their experiences, as they communicated them. None of the participants responded to the email communication. Some were notified of the email via a telephone, others I could not access them via telephone.

## 5.4 CONCLUSION

In this Chapter findings of the results were presented. The findings indicate that the process of the implementation of the psychology service programme at the Clinic was complex. Other expectations were met while others were not. There were challenges experienced from the psychology students' side, the Clinic's as well as the patients. Furthermore, the findings also revealed areas where everyone involved can improve on, for the sake of the programme running smooth. Nevertheless, it seems the programme made a difference in the lives of the patients to some extent. Participants had similar, as well as different experiences during the implementation of the programme.

In the Chapter to follow, the discussion of the findings, limitations of the study, as well as the recommendations are presented.

## CHAPTER 6

### **DISCUSSION, LIMITATIONS AND RECOMMENDATIONS**

#### **6.1 INTRODUCTION**

This study intended to explore and develop an understanding of the experiences of the Kalafong personnel during the implementation of the psychology service programme at the Paediatric HIV Clinic. The aim of the study, as stipulated in section 1.4 of Chapter One, was to describe the personnel's experiences, as well as allowing them to tell a story about the programme's implementation. This study aimed not to evaluate the programme.

Research findings reflected the experiences of the personnel, as described by themselves. During analysis interpretive categories emerged that were extracted from the data were presented as questions. The results of the findings are discussed in this Chapter as well as the limitations of the study and the recommendations.

#### **6.2 DISCUSSION OF THE FINDINGS**

Research findings indicated that the decision to implement the psychology service programme was made by the multi-disciplinary team at the Clinic. The team consisted of doctors, counsellors, social workers, a pastor, nurses, data captures, occupational therapists, dieticians, etc. Before the implementation of the psychology service programme, the multi-disciplinary team explored other options first. There was one psychologist at the Kalafong Hospital, and she was so busy that it was difficult for her to meet the needs of all the patients at the hospital. Patients from the Clinic had to wait long periods of time to be seen by her. That was not practical since in other cases patients were suicidal, therefore immediate intervention was necessary.

Furthermore, the team considered appointing the Clinic's own psychologist but that was not possible. They also tried to involve the psychologists who were based at the local clinics but that also did not work, since some of the clinics did not have psychologists. They then decided that inviting psychology students to the Clinic, to assist the patients psychologically was the best option, hence the idea of the psychology service programme was then put into action.

The study explored the reasons for the existence of the programme at the Clinic at Kalafong Hospital and it found that the multi-disciplinary team identified the need for psychological intervention, more so during the time when some of the adolescent patients had discovered that they were HIV positive. The patients were struggling to cope with the reality of accepting the diagnosis, thus starting to be rebellious, as well as questioning their reasons for taking medication. The team realised that they "could have given their patients everything except the psychological part" as described by Lesedi (personal communication, July 25, 2011).

As discussed on section 2.3 of Chapter Two, at the Clinic, most children were told of their status at the age of eleven by either their caregivers or the health professional worker or both. It was found that though according to the law disclosure should take place at age of twelve, children already asked questions regarding their reasons for taking medication between the ages of nine and ten. Section 2.3 of Chapter Two confirms that disclosure of HIV/AIDS status can cause stress and anxiety (Brown et al., 2000); therefore adequate support should be provided for the period following the disclosure.

The multi-disciplinary team were also worried about all the other factors that the patients were going to be exposed to once the disclosure of their HIV status, and that included the issue of stigma. As discussed in section 2.4 of Chapter Two, stigma promotes emotional distress in people living with HIV/AIDS (Gonzalez et al., 2009). Section 2.5 of Chapter Two indicated that other studies found that HIV stigma was responsible for poor medication adherence with regard to adolescents. Patients feared that friends or family members may discover their status and reject them, when witnessing them taking their medication (Martinez et al., 2012). This was also the case at the Clinic, other patients were not willing to take their medication as prescribed, even after the team had intervened, thus the need for psychological services was acknowledged.

It was also imperative to note that not only the HIV positive patients were faced with issues of disclosure and stigma but also the caregivers. Murray (2010) explains that caregivers also found themselves in the same position as those infected with HIV/AIDS with regard to stigma, as well as disclosure. Hence, the team at the Clinic also wanted the psychology service programme to address the needs of the caregivers. According to the findings, part of what was expected from the programme was the establishment of the adolescent, as well as the caregivers, support groups. It seemed that the support groups did not take off as expected. The findings indicated that the formation phase was not necessarily conducted correctly, as well as having limited space within the Clinic.

Furthermore, poor attendance, lack of interest from the patients, the issue of stigma, as well as lack of understanding the benefits of a support group, contributed. According to Galinsky and Schopler (1995), environmental resources and constraints have an impact on the initial formation of the support groups, as well as their development over time. Factors such as screening procedures, transportation, institutional barriers, conflicting organisational priorities and other demands on the participants' time may affect group activity, as well as outcomes. This was the case at the Clinic.

The study found that other expectations from the psychology service programme were individual therapy, play group, as well as play therapy. Moreover, the programme was also expected to assist at the occupational therapy section. The team had hoped that their patients were going to be assisted in terms of counselling, provision of education, as well as emotional support since that was their understanding of what psychological services were about. They had anticipated that their patients were going to feel free and open to utilise those services.

The study also indicated that though the multi-disciplinary team took the decision to implement the programme, person Z played a major role in taking all the necessary steps to make sure that the programme became a reality. Person Z was the Manager of the Clinic during the implementation of the psychology service programme. Each participant played a vital role and that included referrals to the psychology students, orientation, as well being part of either the adolescent or caregiver support group.

Once the participants referred a patient to the psychology students, it was found that the personnel had expected feedback. Other participants did receive feedback from the



psychology students either verbally or written. Others received the feedback only from the patients or both (students and patients). The necessity for communication in terms of sharing feedback about the patients among the multi-disciplinary team was highlighted in this study. It seemed that the relationship between the participants and the psychology students was good and professional, overall.

The research findings further revealed that the idea of the psychology service programme meant a lot to the participants. It also brought relief and was a way of providing a safe place for patients to offload their stressors, as well as find support, comfort and immediate intervention. Once the programme was implemented, some participants shared their experience of the programme as having made a difference on a small scale. Some thought that it totally made a difference to the community of Kalafong, while others were somewhere in the middle. Nonetheless, the study noted the challenges that were experienced during the implementation, as well as the highlights.

Availability of the psychology students seemed to be the greatest challenge, they were only available few hours during the week, and that was when most of the patients had already left the Clinic. During school recess when most patients were available, as well as not in a hurry to go home, the students were not available as they also were on recess. It appeared that during that period the programme also lost momentum. Another participant reported that for her it was easier seeing the students on sight because then she could take a patient by hand and introduce to a student. That was an easier way for her to refer patients.

Another challenge pointed out by the study was the issue of arranging psychological consultations to coincide with the same date for other consultations, that included the doctor', dietician, pharmacy, etc. The latter consultation usually took place after two or three months, differing from case to case, while the psychological intervention needed regular intervention meaning patients ought to be seen on a weekly or fortnight basis. That raised another challenge which was the issue of poverty.

Most patients could not afford to go to the Clinic on a regular basis (weekly or fortnightly). For some it was even difficult to go on a two/three month basis, hence there was a transport fund that was received from a sponsor, but it was insufficient to cover the needs of all the patients. These finding were consistent with previous studies. In section 2.5.11 of Chapter Two, Kagee (2008) confirms that poverty affects adherence, as funds for travelling to the

ART clinic may not be available, and transport problems may be experienced as well as the need to take time off work without pay to attend Clinic appointments.

The research findings also indicated another challenge being the issue of space. There were not enough offices to accommodate the psychology students. When the students had a patient to see they had to look around first for an open office. And due to the issue of confidentiality they could not share offices. Furthermore, the issue of the structure and logistics were highlighted. Somehow the psychology students had to figure out when and how to see the patients in the midst of their other consultations. Lastly, due to all the other challenges experienced, it seemed the personnel somehow lost interest in resolving the issues affecting the psychology service programme; instead they focused on the medical intervention which was their field of expertise. In addition, at the time of the interviews, the psychology service programme was no longer functioning, as the psychology students were no longer going to the Clinic for their practicals.

The study found that even though challenges had been present, the participants wanted them to be resolved and for the psychology service programme to continue to exist. Another participant reported that the programme brought changes in terms of the space. During the time of the interviews, there were more offices in the Clinic. Lerato (personal communication, June 23, 2011) felt that it can also be of benefit the personnel, while Lesedi (personal communication, July 25, 2011) believed that it was of great help to them as the personnel. It seemed some personnel utilised the services offered while others did not. The programme was commemorated for being successful with play groups, as well as with cases that needed brief counselling.

It seems as if the relationship between the patient and the health worker at the Clinic was good. Section 2.5 of Chapter Two, highlights that one of the factors which relates to adherence, is the latter relationship (Van Dyk, 2005). The study found that the personnel at the Clinic really tried to make the programme to be of benefit to their patients.

It appears that the implementation of the programme was not an easy process. There were few challenges that needed to be addressed, as well as few successes that needed to be celebrated. As one of the participants reported, this was a new programme, a new service; no one knew how it was supposed to work and how to go about it. This study exhibited a mutual

feeling that the implementation of the psychology service programme was a good initiative and ought to be continued at the Clinic.

### **6.3 LIMITATIONS OF THE STUDY**

This section will address the limitations of the study. These are the following:

#### **6.3.1 Sampling and inclusion criteria**

A limited number of participants were chosen for this study due to the fact that the population I had to choose from was limited. Even though the aim was not to generalise, a bigger number could have contributed towards a deeper and richer meaning of the participants' experience. The honours as well as the master's psychology students should have been included in this study, to capture the overall picture of the implementation of the programme but due to the scope of this mini dissertation they were not included.

#### **6.3.2 Duration of the study**

The psychology service programme was officially implemented in 2009. The interviews were conducted in 2011, during the time when the programme had been withdrawn from the Clinic. The participants had to provide a detailed version of the events leading to the implementation, as well as during the implementation. Some of the participants did not even remember exactly when the programme was implemented. The process of remembering and retrieving information from the memory may have limited the research findings.

Furthermore, I, the researcher had an agreement with the participants that I was going to conduct the second interviews for member checks, whereby I was to send them the analysed data via email and then expect a reply via email. This was to confirm if the analysed data

reflected their experiences properly and assure if the data was correct. I did send the emails, and contact others via telephone, to make them aware of the emails but none responded. The participants that I could not access via the telephone were still sent the emails with the transcripts attached. This may have affected the credibility of the research findings. I suspect one of the reasons they did not respond is because it has been almost two years since the first interview.

### **6.3.3 Method of analysis**

I struggled with Labov's methods of analysis. It left me with decisions to make regarding the style and form of presentation of the data. I found myself reporting data in a way that made sense to me, instead of following the method of analysis exactly as it was. For example, I presented both the "core narrative" as well as the "soul of the narrative" together, whereas the Labovian method separates the two (Section 4.3.3 of Chapter Four). This may have made the process subjective.

### **6.3.4 Role of the researcher**

Both the honours and master's psychology students took part in the psychology service programme and our duties were different. Having reflected on my role as the researcher, I think because I was a master's student, I may have expressed more interest on the role of the master's students during the implementation of the programme. Furthermore, the fact that I was part of the implementation of the programme, may have affected my objectivity.

## **6.4 STRENGTHS OF THE STUDY**

The study had limitations as well as strengths. Having been part of the implementation of the psychology service programme, I had established good rapport with the participants. This had encouraged the participants to feel free, open and honest during the interviews. In terms of communication it was also easier, as I had access to their contact details.

This study can assist institutions of higher learning, as well as hospitals in the design and implementation of future programmes. This programme is of value to communities as it addresses core issues (for example, stigma, medication adherence, peer pressure etc.) pertaining to HIV/AIDS.

Furthermore, it seems that this programme also facilitated change at the Clinic. As reported by Letlhogonolo (personal communication, July 25, 2011), the programme introduced a new forum of team work. In addition, due to the issue of limited space that became a challenge during the implementation of the programme, the personnel saw it fit to renovate the Clinic and add more offices.

## **6.5 RECOMMENDATIONS**

The study found that the multi-disciplinary team had identified the need for the adolescents as well as caregivers to obtain emotional support as well as sharing of information within a group setting. The findings further revealed that there was little success with the support groups and the contributing factors were poor attendance, lack of interest from the patients, the issue of stigma, as well as lack of understanding the benefits of a support group among other things. There is a need for future studies to investigate specifically adolescents as well as caregivers support groups with regard to HIV/AIDS.

Also the study was consistent with previous studies, indicating that due to poverty, most patients could not access medication as well as other interventions contributing to their well-being. Evidently there is a need for further investigation into this predicament and ways to resolve such.

Future studies to consider identifying, monitoring and evaluating other programmes as the psychology service programme, so as to provide more information on what works and what does not work.

Lastly, to conduct a comparative study of the experiences of the psychology students, with experiences of the personnel at the Clinic.

## **6.6 CONCLUSION**

The study aimed to allow the personnel at the Clinic to tell the story of the implementation of the psychology service programme. The participants demonstrated their eagerness to report on their experiences by sharing their thoughts, feelings, details, perceptions, views as well as what the programme meant to them. It appeared there were challenges and highlights during the process of the implementation nevertheless data revealed that the programme had made a difference to the community of Kalafong to a point that all the participants asked that they wish and hope that the psychology service programme can continue to exist at the Clinic.

In this Chapter, I discussed the research findings, the limitations as well as the strength of the study. Furthermore, recommendations were provided.

## REFERENCE LIST

- Agochiya, D. (2002). *Every trainer's handbook*. London: Sage.
- Andrews, M., Sclater, S., Squire, C., & Tamboukou, M. (2004). Narrative research. In C. Seale, G. Gobo, J.F. Gubrium & D. Silverman (Eds.), *Qualitative research practice* (pp. 109-121). London: Sage.
- Angus, L.E., & McLeod, J. (2004). Toward an integrative framework for understanding the role of narrative in the psychotherapy process. In L. E. Angus & J. McLeod (Eds.), *The Handbook of narrative and psychotherapy: Practice, theory and research* (pp. 365-374). London: Sage.
- Bell, J.S. (2002). Narrative inquiry: More than just telling stories. *TESOL Quarterly*, 36(2), 207-213.
- Bold, C. (2012). *Using narrative in research*. Los Angeles: Sage.
- Botella, L., Herrero, O., Pacheco, M., & Corbella, S. (2004). Working with narrative in psychotherapy: A relational constructivist approach. In L. E. Angus & J. McLeod (Eds.), *The Handbook of narrative and psychotherapy: Practice, theory and research* (pp. 365-374). London: Sage.
- Brown, L.K., Lourie, K.J., & Pao, M. (2000). Children and adolescents living with HIV and AIDS: A Review. *Journal of Child Psychology and Psychiatry*, 41(1), 81-96.
- Carr, A. (1998). Michael White's narrative therapy. *Contemporary Family Therapy*, 20(4), 485-502.

- Crossley, M. (2007). Narrative analysis. In E. Lyons, & A. Coyle (Eds.). *Analysing qualitative data in Psychology* (pp. 131-144). Los Angeles: Sage.
- Deacon, H., Stephney, I., & Prosalendis, S. (2005). *Understanding HIV/AIDS stigma: A theoretical and methodological analysis*. Cape Town, South Africa: Human Sciences Research Council.
- Demmer, C. (2007). Responding to AIDS- related bereavement in the South African context. *Death Studies*, 31, 821-843. doi: 10.1080/07481180701537287
- Denzin, N.K., & Lincoln, Y.S. (1994). Introduction: Entering the field of qualitative research. In N.K. Denzin, & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 1-17). Thousand Oaks, California: Sage.
- Denzin, N.K., & Lincoln, Y.S. (1998). Introduction: Entering the field of qualitative research. In N.K. Denzin, & Y.S. Lincoln (Eds.), *The landscape of qualitative research: Theories and issues* (pp. 1-34). Thousand Oaks, California: Sage.
- De Vos, A.S., Strydom, H., Fouche, C.B., Poggenpoel, M., Schurink, E., & Schurink W. (1998). *Research at grass roots: A primer for the caring professions*. Pretoria: J.L. Van Schaik.
- De Vos, A.S., Strydom, H., Fouche, C.B. & Delpont, C.S.L. (2002). *Research at grass roots: For the social sciences and human service professions*. (2<sup>nd</sup> Ed.). Pretoria, South Africa: Van Schaik.
- Dlamini, P.S., Kohi, T.W., Uys, L.R, Phetlhu, R.D., Chirwa, M.L., Naidoo, J.R.,.... Makoae, L.N. (2007). Verbal and physical abuse and neglect as manifestations of HIV/AIDS stigma in five African countries. *Public Health Nursing*, 24(5), 389-399.



Freedman, J., & Combs, G. (1996). *Narrative therapy*. New York: Norton.

Freedman, J., & Combs, G. (2004). A Poststructuralist approach to narrative work. In L. E. Angus & J. McLeod (Eds.), *The Handbook of narrative and psychotherapy: Practice, theory and research* (pp. 137-155). London: Sage.

Galinsky, M.J., & Schopler, J.H. (1995). Expanding our view of support groups as an open system. In M.J. Galinsky, & J.H Schopler (Eds.), *Support Group: Current Perspectives on Theory and Practice* (pp. 3-10). New York: The Haworth Press.

Gonzalez, A., Solomon, S.E., Zvolensky, M.J., & Miller, C.T. (2009). The interaction of mindful-based attention and awareness and disengagement coping with HIV/AIDS-related stigma in regard to concurrent anxiety and depressive symptoms among adults with HIV/AIDS. *Journal of Health Psychology, 14*(3), 403-413.

Hardy- Bougere, M. (2008). Cultural manifestations of grief and bereavement: A clinical perspective. *Journal of Cultural Diversity, 15*(2), 66-69.

Heam, K.D., & Jackson, K.R. (2002). African American women and HIV risk: Exploring the effects of gender and social dynamics. *African American Perspectives, 8*(1), 10-22.

Hecker, J.E., Fink, C.M., Levasseur, J.B., & Parker, J.D. (1995). Perspectives on practicum: A survey of directors of accredited PhD programmes and internships (Or, what is a practicum hour, and how many do I need). *Professional Psychology: Research and Practice, 26*(2), 205-210.

Hoffman, M. A. (1996). *Counselling clients with HIV disease: Assessment, intervention, and prevention*. London: The Guilford press.

- Hosek, S.G., Harper, G.W., & Domanico, R. (2000). Psychological and social difficulties of adolescents living with HIV: A qualitative analysis. *Journal of Sex Education and Therapy*, 25(4), 269-276.
- Kagee, A. (2008). Adherence to antiretroviral therapy in the context of the national roll-out in South Africa: Defining a research agenda for psychology. *South African Journal of Psychology*, 38(2), 413-428.
- Kalichman, S., & Simbayi, L. (2003). HIV testing attitudes, AIDS stigma and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. *Sexually Transmitted Infections*, 79(6), 442-447.
- Kalichman, S., & Simbayi, L. (2004). Traditional beliefs about the cause of AIDS and AIDS-related stigma in South Africa. *AIDS Care*, 16(5), 572-580.
- Kang, E., Rapkin, B.D., & DeAlmeida, C. (2006). Are psychological consequences of stigma enduring or transitory? A longitudinal study of HIV stigma and distress among Asians and Pacific Islanders living with HIV illness. *AIDS Patient Care and STDs*, 20(10), 712-723.
- Kelly, K. (2006). From encounter to text: collecting data in qualitative research. In M. Terre Blanche, K. Durrheim, & D. Painter (Eds.), *Research in practice: Applied methods for the Social Sciences* (2<sup>nd</sup> ed., pp. 285-319). Cape Town, South Africa: University of Cape Town Press.
- Martinez, J., Harper, G., Carleton, R.A., Hosek, S., Bojan, K., Glum, G.,... the Adolescent Medicine Trials Network. (2012). The impact of stigma on medication adherence among HIV- positive adolescent and young adult females and the moderating effects of coping and satisfaction with health care. *AIDS Patient Care and STDs*, 26(2), 108-115. doi: 10.1089/apc.2011.0178

- McAllister, M.M. (2001). In harm's way: a postmodern narrative inquiry. *Journal of psychiatric and Mental Health Nursing*, 8, 391-397.
- McLeod, J. (2004). Social construction, narrative, and psychotherapy. In L. E. Angus & J. McLeod (Eds.), *The handbook of narrative and psychotherapy: Practice, theory and research* (pp. 351-365). London: Sage.
- McMahon, M., & Watson, M. (2009). Career psychology research challenges: a systems theory response. *South African Journal of Psychology*, 39(2), 184-194.
- Murray, M. (2008). Narrative Psychology. In J.A. Smith (Ed.), *Qualitative Psychology: A practical guide to research methods* (pp.111-132). London: Sage.
- Murray, C.J.S. (2010), Collaborative community-based care for South African children orphaned by HIV/AIDS. *Wiley Periodicals, Inc*, 15(1) 88-92. doi: 10.1111/j.1744-6155.2009.00222.x
- Osborne, J.W. (1994). Some similarities and differences among phenomenological and other methods of psychological qualitative research. *Canadian Psychology Association*, 35, 167-189.
- Patel, S., Weiss, E., Chhabra, R., Ryniker, L., Adsuar, R., Carness,... Rapkin, B. (2008). The events in care screening (ECSQ): A new tool to identify needs and concerns of people with HIV/AIDS. *AIDS Patient Care and STDs*, 22(5), 381-393. doi: 10.1089/apc.2007.0105
- Patterson, W. (2008). Narratives of events: Labovian narrative analysis and its limitations. In M. Andrews, C. Squire, & M. Tamboukou (Eds.), *Doing narrative research* (pp.23-40). London: Sage.

- Polkinghorne, D. E. (2004). Narrative therapy and postmodernism. In L. E. Angus & J. McLeod (Eds.), *The handbook of narrative and psychotherapy: Practice, theory and research* (pp.53-67). London: Sage.
- Purdy, J.B., Freeman, A.F., Martin, S.C., Ryder, C., Elliott- DeSorbo, D.K., Zeichner, S., & Hazra, R. (2008). Virologic response using directly observed therapy in adolescents with HIV: An adherence tool. *Journal of the Association of Nurses in AIDS Care*, 19(2), 158-165. doi: 10.1016/j.jana.2007.08.003
- Riessman, C.K. (1993). *Narrative analysis*. London: Sage.
- Riessman, C.K. (2000). Analysis of personal narratives. Retrieved from <http://alumni.media.mit.edu/~brooks/storybiz/riessman.pdf>
- Riessman, C.K. (2005). Narrative analysis. Retrieved from <http://cmsu2.ucmo.edu/public/classes/Baker%20COMM%205820/narrative%20analysis.riessman.pdf>
- Riessman, C.K. (2008). *Narrative Methods for the Human Sciences*. Los Angeles: Sage.
- Skinner, D., & Mfecane, S. (2004). Stigma, discrimination and implications for people living with HIV/AIDS in South Africa. *Journal of the Social Aspects of HIV/AIDS*, 1(3), 157-164.
- Terre Blanche, M., Kelly, K., & Durrheim, K. (2006). Why qualitative research?. In M. Terre Blanche, K. Durrheim, & D. Painter (Eds.), *Research in practice: Applied methods for the Social Sciences* (2<sup>nd</sup> ed., pp. 271-284). Cape Town, South Africa: University of Cape Town Press.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(45). doi: 10.1186/1471-2288-8-45

- Thupayagale- Tshweneagae, G., & Benedict, S. (2011). The burden of secrecy among South African adolescents orphaned by HIV and AIDS. *Issues of Mental Health Nursing*, 32, 355-358. doi: 10.3109/01612840.2011.576128
- Umerah-Udezulu, I.E., & Williams, P.B. (2001). Combating the HIV/AIDS crisis in Africa: Sustainable and preventive models. *Journal of Sustainable Development in Africa*, 3(1), 35-47. Retrieved from <http://www.jsd-africa.com/Jsda/spring2001/articlespdf/ARC%20-%20Combating%20the%20HIV.pdf>
- Van der Riet, M., & Durrheim, K. (2006). Putting design into practice: Writing and evaluating research proposals. In M. Terre Blanche, K. Durrheim, & D. Painter (Eds.), *Research in practice: Applied methods for the Social Sciences* (2<sup>nd</sup> ed., pp. 80-111). Cape Town, South Africa: University of Cape Town Press.
- Van Dyk, A. (2005). *HIV AIDS care & counselling: A multidisciplinary approach*. (3<sup>rd</sup> ed.). Cape Town, South Africa: Pearson Education.
- Vaz, L.M.E., Eng, E., Maman, S., Tshikandu, T., & Behets, F. (2010). Telling children they have HIV: Lessons learned from findings of a qualitative study in Sub-Saharan Africa. *AIDS Patient Care and STDs*, 24(4), 247-256. doi: 10.1089/apc.2009.0217
- Visser, M.J., Makin, J.D., Vandormael, A., Sikkema, K.J., & Forsyth, B.W.C. (2009). HIV/AIDS stigma in a South African community. *AIDS Care*, 21(2), 197-206.
- Vlug, M.S., Feucht, U.D., & Kruger, M. (2008, December 4-5). *Establishing an adolescent antiretroviral therapy clinic at Kalafong hospital in Pretoria: Lessons learnt*. Paper at 2<sup>nd</sup> Priorities in Child Health Conference.
- Vreeman, R.C., Nyandiko, W.M., Ayaya, S.O., Walumbe, E.G., Marrero, D.G., & Inui, T.S. (2010). The perceived impact of disclosure of Pediatric HIV status on Pediatric Antiretroviral Therapy adherence, child well- being, and social relationships in a resource- limited setting. *AIDS Patient Care and STDs*, 24(10), 639-649. doi: 10.1089/apc.2010.0079

- Yang, H., Li, X., Stanton, B., Fang, X., Lin, D., & Naar-King, S. (2006). HIV- related knowledge, stigma, and willingness to disclose: A mediation analysis. *AIDS Care, 18*(7), 717-724. doi: 10.1080/09540120500303403
- White, M., & Epston, D. (1990). *Narrative Means to Therapeutic Ends*. New York: Norton.
- White, M. (2004). Folk Psychology and narrative practice. In L. E. Angus & J. McLeod (Eds.), *The handbook of narrative and psychotherapy: Practice, theory and research* (pp. 15-51). London: Sage.
- White, M. (2005, September 21). *Michael White workshop notes*. Retrieved from <http://www.dulwichcentre.com.au>
- Wilson, D., & Fairall, L. (2010). Challenges in managing AIDS in South Africa. In S.S. Abdool Karim, & Q Abdool Karim (Eds.), *HIV/AIDS in South Africa* (pp. 503-528). Cambridge: Cambridge University Press.
- Wood, R. (2007). Antiretroviral Therapy. In S.S. Abdool Karim, & Q Abdool Karim (Eds.), *HIV/AIDS in South Africa* (pp. 529-550). Cambridge: Cambridge University Press.
- World Health Organisation. (2008). *Epidemiological fact sheet on HIV and AIDS: Core data on epidemiology and response*. Geneva: Switzerland.
- Zimmerman, J.L., & Dickerson, V.C. (1996). *If problems talked: Narrative therapy in action*. New York: The Guilford Press.

## Participant Information

### **Title of the Research Project:**

The experience of implementing a psychology service programme at a Paediatric HIV Clinic.

I would like to invite you to participate in a research study that involves your experiences as personnel of the Kalafong Hospital, during the implementation of the psychology service programme at the Paediatric HIV Clinic. Please take some time to read the information presented in this document, which will explain the details of this project. Do ask myself, the researcher any questions about any part of this project that you do not understand. It is very important that you clearly understand what this research entails and what your involvement is. Also, your participation is entirely voluntary and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part initially.

This research study is about the story of implementing the psychology service programme at the Kalafong Paediatric HIV Clinic. The story explores how the decision of implementation came about and the motivation behind it. In addition, the study intends to unfold the process of implementation, in terms of what happened, when and how the programme came to existence in the clinic. Furthermore, the researcher is interested in your view of the psychology service programme, the meaning you attribute/d to the programme, your opinions on how the programme's future appears at the clinic; and to ascertain whether there is a need to adapt any changes. You were identified by the researcher as having played a key role during the process of implementation of the psychology service programme at the clinic, since you were and still are part of the multidisciplinary team.

Two interviews will be scheduled with you by the researcher. The first interview will be for gathering the needed data, whereby you will be requested to tell your story about the implementation of the psychology service programme at Kalafong Paediatric HIV Clinic. The second interview will be utilised for further exploration and clarification if need be, while simultaneously checking if the data collected on the first interview, is convincing and credible. Second interviews will also be used for member checks, that is, as a method of assuring that the transcription is what you had said. Moreover, you will have the opportunity to give your opinion regarding the data analysis and interpretation of the data. The interviews are estimated to last for an hour each and will be recorded using an audiotape.

Information obtained about you and the data collected for this study will be kept confidential. Only the researcher and supervisor will have access to it during the time of the study but once it is finished it will be handed over to the University of Pretoria at the Department of Psychology, where it will be stored for 15 years. The results of the study will be made available in a Master's Dissertation format and will also be published in a paper. However, your identity will not be given out; instead pseudo names will be used in this research study.

There are no risks involved and if the need for counselling/debriefing arises, an appointment will be scheduled with the Psychologist, Neo Pule (Appendix D). I, the researcher will pay for your sessions with the Psychologist. This study may help us understand better how the process of implementing a psychology service programme in a medical setting occurs.

Thank you,

---

**Ms Olga Molebatsi**

**Researcher**

---

**Ms Ilse Ruane**

**Supervisor**



## Participant Consent Form

### Declaration by Participant

By signing below, I \_\_\_\_\_ agree to take part in the research study entitled: The experience of implementing a psychology service programme at a Paediatric HIV Clinic.

### I declare that:

- ✓ I have read this information and consent form and it is written in a language with which - I am fluent and comfortable.
- ✓ I have had a chance to ask questions and all my questions have been answered.
- ✓ I understand that taking part in this study is voluntary and I have not been pressurised to take part.
- ✓ I am giving permission that the interviews maybe recorded using an audiotape.
- ✓ I have received a signed duplicate copy of this consent form for my records.

Signed at \_\_\_\_\_ on this day \_\_\_\_\_ of this month \_\_\_\_\_ of the year 20 \_\_\_\_

### Participant:

Signed: \_\_\_\_\_

Name: \_\_\_\_\_

### Declaration by Researcher

I \_\_\_\_\_ declare that:

- I explained the information in this document to the participant
- I encouraged her to ask questions and took adequate time to answer them.

Signed at \_\_\_\_\_ on this day \_\_\_\_\_ of this month  
\_\_\_\_\_ of the year 20 \_\_\_\_\_

**Researcher: Olga Molebatsi**

Signed: \_\_\_\_\_

## INTERVIEW GUIDELINES

### **The experience of implementing a psychology service programme at a Paediatric HIV Clinic.**

#### **1. How did the decision to implement psychological services in the clinic come about?**

- 1.1. What happened that encouraged/ motivated such a decision to be made?
- 1.2. Were you part of the decision-making team?
- 1.3. What needs were supposed to be met by this programme (psychology service)?
- 1.4. What did the team have in mind, when they decided to make such a decision?
- 1.5. When was this decision made?

#### **2. What steps were taken to implement such a decision?**

- 2.1. Can you tell me more about what actions were taken to make the decision a reality?
- 2.2. What happened during the implementation of the psychology service programme?
- 2.3. How was the process for you?
- 2.4. How did the picture of having psychology service programme look like to you?
- 2.5. How does it look like now?

#### **3. What has been your role during the implementation of the psychology service programme?**

- 3.1. How involved have you been in this programme?
- 3.2. What is your role?

#### **4. What has been your experience of the implementation of psychology services programme?**

- 4.1. Ever since the psychology service programme was implemented, how has it been for you in the clinic?
- 4.2. How has the programme been like for you?
- 4.3. What does this programme mean to you?
- 4.4. Can you find a metaphor to describe it for me?
- 4.5. Are there any particular changes in the clinic that you like that were brought forth by this programme? If yes, what are they?
- 4.6. Are there any particular changes in the clinic that you dislike that were brought forth by this programme? If yes, what are they?
- 4.7. What are your impressions about this programme?
- 4.8. What conclusions have you drawn about the programme?

#### **5. What is your understanding of psychological services?**

- 5.1. What are psychological services about according to you?
- 5.2. How would you describe them to someone who has never heard about them?
- 5.3. When would one need to refer a patient for psychological services?
- 5.3. Have you ever referred, if so how many cases and what were the cases all about?

Please do not mention names.

**6. What has been your experience of the psychology students?**

6.1. How was your relationship with the students like?

6.2. Have you ever referred a patient to them and did you get feedback?

**7. How has this programme met the needs of the Kalafong community according to you?**

7.1. In what way?

7.2. What motivates you to say that?

**8. What challenges did you face during the implementation of the psychology service programme?**

8.1. How was it like, experiencing them?

8.2. How were they resolved?

3. What did you learn from them?

**9. What have been the highlights of implementing the psychological services?**

9.1. Can you tell me more about them?

9.1. How were they celebrated?

**10. If you had to implement this programme again, how would you go about it?**

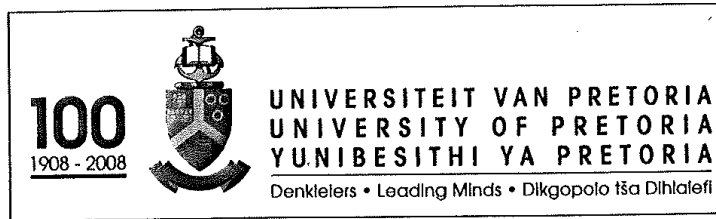
10.1. What would remain the same in your view?

10.2. What would you change?

10.3. Are there any improvements that you can think of that needs to be made on the programme?

10.4. Where to from here, according to you?

10.5. What does the future look like for this programme according to you?



---

Enquiry: Dr UD Feucht  
☐ [ute.feucht@up.ac.za](mailto:ute.feucht@up.ac.za)  
☐ [elize.weideman@up.ac.za](mailto:elize.weideman@up.ac.za)

Faculty of Health Sciences  
Department of Paediatrics & Child Health  
Kalafong Hospital

P/Bag X396, Pretoria, 0001, RSA  
☎ 012 - 373-1038/1009  
☎ 012 - 373-7977

---

Date: 03 March 2010

To: Department of Psychology  
Faculty of Humanities, University of Pretoria

CC: Prof T. Avenant, HOD Paediatrics  
Dr L. Phalatsi, CEO Kalafong

Re: Permission to undertake research study at Kalafong Hospital Paediatric HIV Clinic

Mrs O.M Molebatsi has requested permission to undertake a research study at the Paediatric HIV Clinic at Kalafong Hospital. Her study is about the experiences of implementing the psychological services at the clinic and she has chosen the personnel at Kalafong HIV clinic as her participants. The research is for the purposes of completing Mrs. O.M. Molebatsi degree in Ma Counselling Psychology at the University of Pretoria, and will be conducted in 2010. Her study leader is Ilse Ruane from the University of Pretoria's Department of Psychology.

I, Dr. U. D. Feucht, manager of the Paediatric HIV Clinic, hereby give permission to Olga Molebatsi, student number 21080870, to undertake the requested research study at the Clinic. Final approval by the Ethics Review Board of the University of Pretoria as well as the senior management of the Kalafong Hospital is required before the research study may be undertaken.

Yours sincerely

on behalf of Dr feucht

Dr UD Feucht  
MBChB, FCPaed (SA), MMed Paed (Pretoria), Dip HIV Man (SA), CAHM  
SPECIALIST & SENIOR LECTURER  
DEPARTMENT OF PAEDIATRICS AND CHILD HEALTH  
KALAFONG HOSPITAL & UNIVERSITY OF PRETORIA

*Ilse Ruane*  
MBChB, Mmed paed's  
snr specialist.  
Kalafong Hospital - UH  
acting HOD - HIV paed's  
clinic



**DEPARTMENT OF HEALTH**  
**Lefapha la Maphelo**  
**Departement van Gesondheid**  
**Umyango wezempilo**

**KALAFONG HOSPITAL**  
**PRIVATE BAG X396**  
**PRETORIA**  
**0001**

**ENQUIRIES : DR L M PHALATSI**  
**TEL NO : (012) 318 6500**  
**FAX NO : (012) 373 9021**

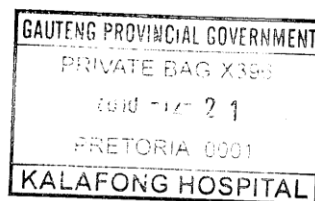
Management has granted permission for Ms Olga Molebatsi to conduct her research "The experience of implementing a psychology service programme at a Paediatric HIV Clinic

Kindly give her your cooperation.

Yours sincerely

A handwritten signature in black ink, appearing to read "Phalatsi".

**DR L M PHALATSI**  
**CHIEF EXECUTIVE OFFICER**  
**DATE: 21/12/2010**







UNIVERSITEIT VAN PRETORIA  
UNIVERSITY OF PRETORIA  
YUNIBESITHI YA PRETORIA

Faculty of Humanities  
Research Ethics Committee

10 November 2010

Dear Prof Marchetti-Mercer

**Project:** The experience of implementing a psychology service programme at a paediatric HIV clinic  
**Researchers:** OM Molebatsi  
**Supervisor:** Ms I Ruane  
**Department:** Psychology  
**Reference number:** 21080870

Thank you for your response to the Committee's letter of 12 October 2010.

I have pleasure in informing you that the Research Ethics Committee formally approved the above study at an *ad hoc* meeting held on 9 November 2010. Please note that this approval is based on the assumption that the research will be carried out along the lines laid out in the proposal. Should your actual research depart significantly from the proposed research, it will be necessary to apply for a new research approval and ethical clearance.

The Committee requests you to convey this approval to the researcher.

We wish you success with the project.

Sincerely

Prof. John Sharp  
Chair: Research Ethics Committee  
Faculty of Humanities  
UNIVERSITY OF PRETORIA  
e-mail: john.sharp@up.ac.za

Research Ethics Committee Members: Dr L Blokland; Prof M-H Coetzee; Dr JEH Grobler; Prof KL Harris; Ms H Klopper; Prof E Krüger; Prof A Mlambo; Dr S Ouzman; Dr C Panebianco-Warrens; Prof G Prinsloo; Prof J Sharp (Chair); Prof E Taljard; Dr J van Dyk; Dr FG Wolmarans

TO WHOM IT MAY CONCERN

DATE: 23/ 06/ 2010

Re: Olga Molebatsi's research project

This is to confirm that Neo Pule has agreed to offer counselling/debriefing for Ms Olga Molebatsi's research participants for the project entitled: The experience of implementing a psychology service programme at a Paediatric HIV Clinic. Should there be a need for her services in terms of counselling/debriefing, She will be available to provide them at a rate which will be agreed upon, according to the needs of the participant/s and the regulations of payments for psychological services.

For any queries please contact Olga on 0824895035.

Thanking you.

Yours sincerely

Neo Pule\_\_\_\_\_

Olga Molebatsi

Counselling Psychologist

Researcher

M.Sc. (Counselling Psychology)

PS 0108502

082 715 9703

n.pule@yahoo.com

## LESEGO'S TRANSCRIPT

**How did the decision to implement psychological services in the clinic come about?  
(0:23)**

1. We identified the need AB
2. And then we were trying to get a fulltime psychologist CA
3. it was not possible because, there was no post for that OR
4. and the FPD (Foundation for Professional Development) tried to appoint one for us CA
5. but unfortunately that was also not possible

**What encouraged/ motivated the decision to implement the psychology service programme? (1:10)**

6. We were having children who were emotionally traumatized OR
7. and then those who were not coping with the diagnoses CA
8. and then those who were not willing to take the medication correctly CA
9. even after our intervention

**What was expected from the psychology students? (1:37)**

10. Okay we thought you were coming
11. to attend to the psychological aspects of the HIV diagnoses OR
12. yah, that was actually what we wanted you to do OR

**When was this decision to implement the psychology service made? (1:54)**

13. I can't remember

**What steps were taken to implement the psychology service programme? (2:04)**

14. Okay, I think that was done by \*Person Z OR

15. we were not part of that OR

16. She was the person that made it possible OR

**How did the picture of having psychology service programme look like to you? (2:21)**

17. To me it was a great relieve EV

18. because I needed to have more time with patients attending to the (other) problems EV

19. but the psychological part was a problem EV

**Was there a difference once the programme was implemented? (2:41)**

20. Yah there was a difference EV

21. because I have been referring a lot of patients EV

**What was your role? (2:55)**

22. The other thing is that

23. I think I offered a bit of orientation EV

24. I did orientation with the students EV

25. Even though it's seems little EV

**Ever since the psychology service programme was implemented, how has it been like for you, at the clinic? (3:21)**

- 26. The problem that I identified EV
- 27. is that whenever we referred EV
- 28. we were not getting like direct feedback EV
- 29. if we work as a multidisciplinary team EV
- 30. we don't just write reports and hand it over EV
- 31. We have to discuss about the report and the client EV

**So you were not receiving feedback from the psychology students? (3:43)**

- 32. Yes, we were only getting..
- 33. in fact I was told that there were reports in the files EV
- 34. but I did not see them EV

**What does this programme mean to you? (4:13)**

- 35. Yah it meant a lot to us EV
- 36. hopefully to the patients too EV
- 37. Like I indicated it was such a great relief for me EV

**Were there any particular changes that were brought forth by the psychology service programme? (4:53)**

- 38. No, I don't think there were big changes EV
- 39. because you came and left EV
- 40. and then I don't think you left anything with us, when you left CA

**What is your understanding of psychological services? (6:09)**

41. attending to the psychological impact or the condition EV

42. if a patient is traumatized even if they can't cope EV

**When would one need to refer a patient for psychological services? (6:23)**

43. Okay, after my intervention EV

44. if I see that the patient is not coping EV

45. and there is no change with my intervention CA

46. then I refer (RE)

**How was your relationship with the students like? (6:45)**

47. It was cordial EV

**What challenges did you experience during the implementation of the psychology service programme? (7:31)**

48. The challenges that we experienced OR

49. is that you were not always available EV

50. that's one challenge we had CA

51. the second one it's like I indicated, the communication EV

52. You only wrote reports EV

53. and then you did not communicate with the person who referred CA/ EV

**Was there anything that stood out that would make you remember the psychology service programme? (8:39)**

54. I wouldn't say that but I can recommend something EV

55. if you had the, maybe like group sessions EV

56. we were definitely going to feel that you are no longer with us EV

**What do you think went wrong with the support groups? (9:04)**

57. we were distracted by the strike, remember EV

**What happened before the strike since the support groups started before the strike? (9:18) and (9:47)**

58. Okay, no I remember EV

59. I think the formation, the group formation phase was not conducted correctly EV

60. because it was like we forgot that we are dealing with kids not adults EV

61. We wanted to bombard them with everything at the same time EV

62. I think that's where we went wrong EV

**(9:47)**

63. We were not user friendly EV

**If we had to implement the psychology service programme again, how should we go about it? (10:10)**

65. Improve communication EV

66. and then, you must not go all of you EV

67. You mustn't be unavailable the whole lot EV

68. There must be someone standing in for referrals EV

69. and then sustainability EV

**Is there anything that should remain the same? (11:13)**

70. we must always have Honours students EV

71. Were you Masters, Masters students EV



## LEBOGANG'S TRANSCRIPT

**What encouraged/ motivated the decision to implement the psychology service programme? (0:09)**

1. With the teenagers, there was a need AB
2. and we felt that there was a need OR
3. as we needed someone to be here to support them OR
4. And also we found out that
5. some of the kids had other issues which had to be dealt with OR
6. in order for them to function optimally OR
7. That's the reason we felt a psychologist for them OR
8. would definitely be beneficial for the department OR
9. because there's so much that a person can take in OR
10. when they are diagnosed with something like HIV OR
11. so they need our support throughout so that they can function adequately OR
12. as a results we had to call you to know what's going on OR
13. in terms of how other will react towards you (patient) OR
14. once they get to know about your diagnoses OR
15. and how to get the skills necessary to be assertive CA
16. and to deal with different situations CA
17. so that you can function in a normal environment OR

**What was the picture that you had in mind concerning the programme? (1:38) and (3:20)**

18. Well, we were first thinking about the support groups that we get help OR

19. I guess the aim was more to work with the adolescent children OR
20. The younger ones we just thought of more like, being informal like a play group OR
21. Because obviously they wouldn't understand what their condition is as yet OR
22. and some of them don't even know what is happening to them CA
23. and why they have to be on medication CA
24. And their moms maybe tell them that it'll make your body stronger or whatever it is CA
25. so when they are young they are not really aware OR
26. but with the adolescents OR
27. we just felt that the support groups were going to be beneficial OR

**(3:20)**

28. The picture I had in mind was the play therapy approach for the kids EV
29. and I thought that would help them EV
30. but then what happened was not actually that EV
31. it ended up being a very informal group EV
32. and some of the children who were walking around CA
33. were called to join in on the activities EV
34. so it ended up being a play group instead of a play therapy EV

**When was the decision made? (2:33)**

35. Three years ago

**Can you tell me more about the steps that were taken to make the decision a reality?  
(2:42)**

36. Well, to be honest with you person Z is the one who arranged everything thing OR

37. I think she even contacted the university as well OR

38. So she is the one who took the initiative OR

39. We were all there to say whether we agree or disagree OR

40. At the end of the day all the credit goes to her EV

41. because she is the one who did the nitty-gritty details EV

42. before the programme was implemented EV

**How were you involved? (4:05) and (4:15)**

43. We kind of identified the patients that we felt needed therapy OR

44. so that was for the one set of the students who came OR

45. They gave us their numbers and we said OR

46. we will contact them if anyone comes up OR

47. and you were one of them CA

**(4:15)**

48. So that was for the children who were needed therapy OR

49. because of the emotional problems that they were having OR

50. And then the other group CA

51. we were involved in the process OR

52. where they would give us a list of activities they wanna work on OR

53. and we would advise them if they were appropriate or not CA

54. and say maybe try this or try that CA

**Did you ever get feedback? (4:54)**

55. Yes, he (in the honours group) was the one who gave us feedback OR

56. and as soon as he left there was none CA

57. What happened was that our store room OR

58. was used for the stuff that they used in the groups OR

59. so we would only see them when they came to collect or return them OR

60. so we never really had feedback afterwards OR

61. That was the first year OR

63. With the masters, the group were more like giving us feedback, informing us OR

64. they were attending meetings as well OR

65. whereas last year that wasn't happening OR

66. I don't know what was happening there OR

**Ever since the program was implemented here, how has it been at the clinic? (5:25)**

67. Well at the moment it's currently not being implemented EV

68. But I thought it was nice to have it EV

69. it was good to have it EV

70. and is something that we keep looking forward to have in the future as well EV

71. It was something that the kids looked forward to as well EV

**What did the program mean to you? (6:17)**

- 72. Well, for me I thought it was a good thing EV
- 73. it was helpful in terms of providing emotional support EV
- 74. as well as the kids had something to do EV
- 75. instead of them just lazing around EV
- 76. and not getting any feedback when they were here CA
- 77. They spend about five hours sitting here EV
- 78. and it's a long time EV
- 79. so it was something to keep them busy as well EV
- 80. with the activities also EV

**What is your understanding of the psychological services? (6:59)**

- 81. From my understanding it has a lot to do with emotions especially EV
- 82. and working with people more on the psychological aspect of a person EV
- 83. Also looking more on society and how someone would react to certain things EV
- 84. for example, for a diagnoses of cancer for instance EV
- 85. and how you would cope or use your coping strategies CA
- 86. so a psychologist would be able to assist you with that EV
- 87. if you were raped for instance EV
- 88. a psychologist would again help you with coping strategies EV
- 89. help and support you EV
- 90. do some family therapy as well EV
- 91. so in terms of that, that's my understanding of psychological services EV
- 92. and especially with play therapy because that's what we wanted you guys to do CA

93. so I am aware of what you guys do EV

**Do you remember how many cases you referred to us? (7:55)**

94. Well, I think in total it was about ten we gave you guys EV

95. the feedback was good V

96. from the families involved, they felt it was beneficial EV

97. and we actually saw with our perception CA

98. children that had difficulties that they were actually doing better in school EV

**Do you remember what the cases were about? (8:22)**

99. One child was being abused, we suspected there was abuse OR

100. and then we found out that it was true CA

101. and he ended up staying with his grandfather, as a result of that CA

102. we noticed that there was a deterioration in his school work OR

103. but then when he started attending the psychological services OR

104. there was an improvement and the grandfather was very much happy OR

105. because he then knew how to support and help the child OR

106. so that was the one kid OR

107. The other one was a little girl who just didn't wanna do anything in therapy OR

108. and we thought that she had some psychological problems CA

109. and it wasn't actually psychological problems CA

110. she just wasn't used to us OR

111. and she kind of clicked very well with the therapist ,with the psychologist CA

112. and we ended up finding out that there was nothing wrong with her speech CA

- 113. and we thought she couldn't speak CA
- 114. and she ended up speaking in the sessions CA
- 115. guess she just had a good approach OR
- 116. and those were few we referred CA

**How was your relationship with the students? (9:32)**

- 117. The ones who were doing play therapy EV
- 118. I think we had a good relationship EV
- 119. the ones who were doing play groups EV
- 120. because they were always changing EV
- 121. we didn't always knew who they were EV
- 122. We would see them take their stuff and go EV
- 123. so we never really knew them you know, these were the new students EV

**Do you think the programme met the needs of the community of Kalafong? (10:07)**

- 124. Well, I think it did EV
- 125. especially the play therapy part EV
- 126. for me I thought it did EV
- 127. because we saw a difference in the children EV
- 128. that's more for individual therapy EV
- 129. With regards to the groups I can't be hundred percent sure EV
- 130. because there wasn't any clients satisfaction questionnaires that I am aware of EV
- 131. that will give us an indication EV
- 132. if they were either happy or did they find improvements EV

- 133. something of that nature, I'm not sure about that EV
- 134. But with regards to that I just felt that the kids were occupied EV
- 135. and they had something to do CA
- 136. but I think it could have been structured differently EV

**Any challenges experienced? (10:54)**

- 137. On the clinic days it is a bit challenging EV
- 138. because the patients are not in one place all the time EV
- 139. they are moving from one place to the other EV
- 140. from the ARV clinic to the Dietician to us EV
- 141. if everyone was spaced in one EV
- 142. sort of like an intersection EV
- 143. the pharmacist, the Dietician etc. EV
- 144. it would make life so much more easier EV
- 145. because the psychologist would not have EV
- 146. to just pull out whoever was walking around EV
- 147. and say okay you have done this CA
- 148. this is what you still have to do EV
- 149. or you can join the group now EV
- 150. there would be more structure EV
- 151. It is unfortunate that the ARV clinic doesn't accommodate EV
- 152. all the multidisciplinary team in one section EV
- 153. if they did, it would have been far more better EV
- 154. I think communication as well EV
- 155. with the other students, the ones working in the play group EV



156. if we knew who they were EV

157. and if they've come to us and ask if they needed help CA

158. it could have made a difference EV

**What do you think went wrong with the support groups? (15:23)**

159. Because people promised that they were gonna be present at the support groups OR

160. and when meetings were taking place CA

161. some people came some people didn't come OR

162. There was a loss of interest afterwards EV

163. it was like we spoke about it but then nobody did anything about it EV

164. But then this year the social worker said she's gonna do it again EV

**Any recommendations? (13:30) and (14:16)**

165. I think if we can liaise with person Z EV

166. and try to say on the clinic days if the multidisciplinary team can all be in one area CA

167. and utilize the space CA

168. I think the problem would work much better EV

169. because we would now have that play area available in the clinic EV

170. it would make you guys' life much more easier as well EV

171. And then if we had our meetings, multidisciplinary meetings CA

172. and we highlighted the child that we worried about emotionally CA

173. then we could always say, we worry about this child EV

174. and apart from the counselors CA

175. can we also get the psychologist to work with this child to help us out EV

**(14:16)**

176. and if you guys could also help us with psychometrics testing as well CA

177. especially for the school going kids, that would be wonderful EV

## LESEDI'S TRANSCRIPT

**What encouraged/ motivated the decision to implement the psychology service programme? (0:26)**

1. During the assessments of most of our patients AB
2. we realized especially for the adolescents and the caregivers OR
3. that most of them needed psychological support OR
4. so we decided to use the opportunity OR
5. that we had with our psychology students, including the play therapy OR

**What exactly did you have in mind that the students should do? (1:03)**

6. We wanted to assess our patients in totality OR
7. you know mentally, physically and look at their social circumstances OR

**What steps were taken to make the decision of involving the psychology students, a reality? (1:36)**

8. We normally hold our two weekly meetings OR
9. where we find that as the multi-disciplinary team OR
10. nurses, data captures, counsellors, occupational therapists, dieticians OR
11. we could have given them everything except the psychological part OR
12. That one we could not fulfil for all the patients OR
13. and as such we had a lot of defaulters that could not give their reasons to us CA
14. except that we did not have the expertise of getting OR
15. you know digging out all the problems that they had OR

16. especially the psychological part OR

**How was the process of implementation for you? (2:30)**

17. We managed to get a lot of our patients and their caregivers OR

18. to understand that we can also look OR

19. at their psychological and the social part of their lives OR

20. most of them gave consent to be assessed psychologically OR

21. and we tried EV

22. really with our psychology students to can get to the core of the problem EV

**How did the picture of having psychological services look like in the beginning? (3:22)**

23. Well we wanted our patients to feel comfortable with us OR

24. that whatever they tell us OR

25. or it involves their lives OR

26. or it is involved in their lives OR

27. is not going to be published anywhere OR

28. and that it is for their own good OR

29. so that we can really look after them properly OR

30. and especially because most of them are depressed CA

31. they haven't disclosed OR

32. they don't trust anybody OR

33. but we reassured them as far as the psychology problem was consent OR

34. we could really help them a lot EV

35. and they really appreciated our help in that regard EV

**Did the patients accept the idea of the psychology service programme? (4:12)**

- 36. They did EV
- 37. most of them EV
- 38. because we premeditated them OR
- 39. we told them that we are going to get a program OR
- 40. that will help you even for your kids OR
- 41. that they can be free with us OR
- 42. things that they could not tell their caregivers EV
- 43. they were free with the psychologists EV
- 44. because they have the expertise of talking to them EV

**What was your role? (4:41), (5:40) and (5:57)**

- 45. Normally explaining to the patients beforehand what is going to happen EV
- 46. if they need any help EV
- 47. it has been of, really a great influence to our patients EV
- 48. that they did buy into it, to this psychology programme EV
- 49. especially you know our adolescents EV
- 50. most of them don't stay with their parents OR
- 51. their parents have passed away OR
- 52. so they don't feel free talking to their relatives, their aunts or their grannies OR
- 53. about the problems that they face OR
- 54. especially when it comes to peer group pressure OR
- 55. If they feel they are not treated equally with their cousins OR
- 56. and they don't feel free to say whatever comes to their mind CA

57. especially because of stigmatization OR

58. It was a success, really! EV

**(5:40)**

59. I also referred a lot of patients whom during my assessments with them EV

60. I could see that some of them needed psychological support EV

**(5:57)**

61. Yes I was part of the caregivers support group EV

62. with the help of some of the counsellors EV

63. and those who are working in the Department of Health CA

64. as far as the support group was concerned

**Do you think the psychology service programme met the needs of Kalafong community?**

**(6:26)**

65. It has really made a difference in most of our patients' lives EV

66. that even after our psychologist were no more with us EV

67. they were busy writing exams OR

68. some of the caregivers and the patients would still request to see the psychologist EV

**What did this programme mean to you? (6:55)**

- 69. We also benefitted as the staff from the psychology programme EV
- 70. in that we could voice our own problems with them EV
- 71. and then we would get advice CA
- 72. and where they felt we needed further referral CA
- 73. they referred us to their seniors CA
- 74. so we really benefitted as staff EV
- 75. and we felt our patients we more open and they felt free CA
- 76. so most of them complied EV

**Were there any changes that were brought forth by this programme that you did not like? (7:46)**

- 77. Not really EV

**What are psychological services according to you? (8:06)**

- 78. You know most, actually all our patients are like friends to us OR
- 79. so they really depend on us on how we treat them OR
- 80. and they sort of bond with the people that they see CA
- 81. everyday more than they bond with their families OR
- 82. so they need someone who can be so close to them OR
- 83. that they feel like you know taking off
- 84. offloading all their stresses on them OR
- 85. and they know that for sure that they will get help CA
- 86. we tried our best EV

- 87. to exhaust all the resources we have EV
- 88. as far as the multi-disciplinary team is concerned EV
- 89. to get help for them and we try our best EV

**Did all the patients need psychological services? (9:05)**

- 90. Some of them
- 91. but I think fifty percent of them needed psychological services EV
- 92. because you find some of them breaking up EV
- 93. they just cry when you talk to them EV
- 94. and you can see this person has got a lot to offload CA
- 95. and she needs someone who can listen CA
- 96. you know most of the time
- 97. the best thing you can give a person is the listening ear EV
- 98. rather than always telling what you feel is right for them EV
- 99. so if you see that really this person is overloaded EV
- 100. give a listening ear EV
- 101. take more minutes because everybody is an individual EV
- 102. and you end up winning the game EV

**How was your relationship with the psychology students? (10:01)**

- 103. I think it was very good EV
- 104. and I also learned a lot from the psychology students EV
- 105. and I enjoyed their company EV
- 106. they are like brothers and sisters to us EV



107. we didn't see them like people who are just coming to give EV

108. and we don't give back EV

109. We enjoyed their company EV

110. we actually missed them EV

111. even our kids you know they wanted those people EV

112. who were playing with them EV

113. and were teaching them a lot of things EV

**Did you ever get feedback from the psychology students? (10:48)**

114. Yes I did EV

115. they tried their best to give feedback EV

116. and would call the concerned parent with the teenager's consent EV

117. to come and give a feedback EV

118. and how far we have went with the problem EV

119. most of the problems were actually resolved EV

**Were there any challenges that were experienced by the personnel? (11:17)**

120. Well there are not many challenges EV

121. the challenges that we actually encountered

122. was that when we refer the caregivers for social services in the location EV

123. they normally struggle to get services EV

124. and they'll come back to us CA

125. like say "this social worker told me to wait" OR

126. or that "I must go back to my husband" who is abusing me OR

127. they don't get proper the services outside EV

128. it takes long and they normally comes back with stories like EV

129. they told me that the waiting list is too long OR

130. there's only social worker in the whole centre so we end up not accessing them OR

131. When they go out to the location, it's quite problematic EV

**Were there any challenges with the psychology service programme? (12:11)**

132. No, we didn't have any challenges EV

**Were there any highlights brought forth by the psychology service programme? (12:28)**

133. Well, I must say, we also benefitted a lot with the psychology students EV

134. to the extent that we actually

135. I don't know if we abused them or what EV

136. we wanted to take all our problems EV

137. even those that were simple EV

138. you were really of great help to us I must say EV

**What do you make of the fact that other times, clients did not honour their appointments? (13:30)**

139. The problem that we encountered OR

140. was that most of our patients are from a poor background OR

141. some couldn't afford coming to see the psychologists OR

142. and then to see the doctor CA

143. I think it would have been easier EV

144. if you make the appointment on the same day EV

145. that they are here for the doctor's check-up EV

**Where to from here? (17:58)**

146. We would love you to come back EV

147. you were such a great help to us EV

148. really do come back EV

## LETLHOGONOLO'S TRANSCRIPT

**What needs were supposed to be met by the psychology service programme? (0:10)**

1. What we had expected was the special needs of our patients to be addressed AB
2. our patients being HIV infected children OR
3. anywhere from birth to adolescence of 19 years old OR
4. particularly in the pre-teen and teenage groups OR
5. We were beginning to identify issues with depression OR
6. difficulty accepting the diagnosis OR
7. not just with the patient but with the caregivers as well OR
8. there is only one psychologist in Kalafong OR
9. and she does not have a particular specialty with child psychology CA
10. so we were interested in more identification OR
11. and what therapy and support groups could be offered to our particular patients CA

**What exactly did the team have in mind? (1:24)**

12. We had in mind setting up of both group therapy OR
13. and individual identification of children with high risk of mood disorders CA
14. or social dilemmas in their lives OR

**Tell me about the actions that were taken to make this decision a reality (1:47) and (2:23)**

15. Contacting the people who would be involved in the programme OR
16. identifying the psychology students who would come offer their services OR

17. and also help the children CA
18. letting the immunology clinic know that you were coming OR
19. providing the adequate space for the therapy session in a confidential manner OR
20. since it is such a touchy subject for anybody EV

**(2:23)**

21. So identifying the space OR
22. we had to pick children for you to see OR
23. or see if you would be able to identify those children just in normal consultation OR

**How were you involved in the programme? (4:35)**

24. My role was positioned to identify when a care-giver is stressed, depressed or in denial  
EV
25. or when a child is stressed, depressed or in denial EV
26. And then what was easiest for me was seeing you from on-site EV
27. and introducing you personally CA
28. and making that connection versus giving you a book and making the appointment CA
29. So my role was to identify patients specifically with high risks needs EV
30. and that needed to be assessed on one to one bases CA

**Have you ever referred patients? (10:10)**

31. Yea, while they were here EV

**Did you get feedback from the psychology students? (6:16)**

- 32. Not from the students EV
- 33. and feedback was that the children enjoyed them being there CA
- 34. It was a great diversion from just sitting in a long hallway EV
- 35. knowing you have to wait for hours to see the doctor EV
- 36. It really lightened the clinic's load EV

**How many cases have you referred, if you do remember roughly? (10:16)**

- 37. At least once a week EV
- 38. but I would just grab you (psychology students) EV
- 39. maybe not formally in your dairy book EV
- 40. but I would say please come EV
- 41. we must help this child EV

**Do you remember what the cases were about? (10:34)**

- 42. Mostly it was difficulties of accepting the diagnosis OR
- 43. and complains that once the children know their diagnosis they become non-adherent CA
- 44. They don't want to take the medication anymore OR
- 45. We call it teenager effect to chronic illness, Diabetes and HIV OR
- 46. These children don't want to feel sick OR
- 47. but they take this medicines everyday OR
- 48. it upset their stomachs OR
- 49. and once they hear that they have this terrible disease CA

50. they think their friends are going to make fun of them OR
51. They stop taking their medicines OR
52. and then it gets worse CA
53. and later on their parents die CA
54. They grow up to witness their mom and dad dying of HIV OR
55. and so now they start wondering CA
56. who they got the transmission from OR
57. is it mommy, or maybe from daddy OR
58. They then have to be cared for by an aunt or granny OR
59. So changes in care-givers, from death to grieve OR
60. to loss of a family member for the younger children OR
61. and then now the teenagers are living with grannies and aunts CA
62. and having to know that they have this disease CA
63. It becomes overwhelming for them EV

**When do you tell them about their status? (14:01), (14:15) and (16:10)**

64. Legally they have the right to know at the age of 12
65. A 12 year old can come and consent to be tested and treated
66. We find that the children start asking questions between the ages of 9 and 10
67. because that's when the transition from Grade 3 to Grade 4 takes place

**(14:15)**

68. Grade 1 to Grade 3 in primary schools are considered juniors OR
69. Grade 4 to 7 are seniors in primary school OR

70. In the senior level all the social dynamics of the school are completely different OR  
71. and the teaching also  
72. The juniors are learning life skills OR  
73. but when they get older they learn Life Orientation OR  
74. And they learn about what are viruses, what are bacteria's CA  
75. what are infections, what really gets you sick OR

**(16:10)**

76. The Grade 4 to 7 are starting to learn that this and this makes you sick OR  
77. and they start to ask: why do I take this pills mom? CA  
78. It's amazing to see how care-givers lie to their kids OR  
79. One granny said she told the child that it's TB medicine OR  
80. imagine TB medicine for six years! OR  
81. Another granny also lied OR

**Where are the children's parents? (18:46)**

82. Dead, they must be deceased OR  
83. Mom deceased, dad not around OR  
84. and maybe the granny feels guilty that she didn't raise her child right CA  
85. and now with her child dead and has this grandchild whom she tries to protect CA  
86. So the mom dies, the granny takes over OR  
87. and then the child knows nothing of what is going on CA



88. They just know that mom got really sick OR
89. and now the teenagers find out that now I have this virus too CA
90. I'm gonna get real sick like mom or like mom died OR
91. So that's why we need your services EV

**How was your relationship with the students? (5:23)**

92. The students were very enthusiastic EV
93. very delightful group, focused, ready to interact with the children EV
94. the clinic had just undergone structural renovations OR
95. and so often finding the space for them to work in a small group was difficult CA
96. between the paediatric and the immunology clinic department
97. but we did our best to coordinate EV

**How has the programme been for you? (6:44)**

98. I didn't need any services myself EV
99. but I know it delighted most of the kids EV
100. but it also helped us like I told you there was one psychologist EV
101. that the whole Kalafong refers to OR
102. So having your services right there available weekly was very accessible EV
103. very user friendly EV
104. We'd like to have you back EV

**What does this programme means to you? (7:26) and (8:30)**

- 105. It means someone cares about these kids EV
- 106. and realizes that this particular disease HIV affects the whole child CA
- 107. It's not just about going to the doctor and getting some medication EV
- 108. What I explain to a lot of folks is that nowadays with ARV's (Anti Retro Virals) EV
- 109. the children are not dying EV
- 110. they are living more complicated lives EV
- 111. HIV nowadays doesn't kill you directly EV
- 112. but it controls you EV
- 113. it completely engrosses your life EV
- 114. The children spend hours on the queues once every month if not more often EV
- 115. they're taking medication twice a day EV
- 116. and they know that they have this virus CA
- 117. that is inside them like a ticking time bomb EV
- 118. Trying to get a hearing and caring from the care-givers EV
- 119. is such a core and main thing EV
- 120. it's such a challenge EV

**(8:30)**

- 121. It's a whole lifestyle the children and the care-givers have to endure EV

**Any particular changes in the clinic brought forth by the psychology programme?  
(8:53)**

- 122. Actually setting up a place for you, counselling room EV

123. areas for you to work in, those changes we've made now EV

**What do you think were the challenges experienced by the programme? (21:42), (24:12) and (3:27)**

124. The space EV

125. the structure EV

126. more active involvement of the physicians to refer clients to you EV

127. to know that you were there and how to reach you EV

128. You were only there one day a week EV

129. and during the school holidays you were off EV

130. and that was when the kids were available EV

131. We want more of you not half of you EV

**(24:12)**

132. And we always scheduled these kids one month, two months, three months EV

133. whether you were on holidays or not EV

**(3:27)**

134. One of the biggest difficulties is that we have a lot of rotating doctors EV

135. half of the doctors were held rotating positions OR

136. and there were only two permanent doctors in the clinic supervising everybody OR

137. Not the same doctors saw the patients at the same time OR

138. And one of the difficulties was arranging the visits with the psychologists EV

139. to coincide with the visits that the doctor had arranged with the patients EV

- 140. Because children coming to the hospital once a month EV
- 141. or once every two months were at high risk or ill OR
- 142. Identifying those patients EV
- 143. and setting up actual dates and visits with the psychology students was difficult EV

**What have we learned from the challenges? (27:23)**

- 144. Just to understand that these kids EV
- 145. they really come after school or one whole day out of every month of their lives EV
- 146. Trying to set special appointments for them was difficult EV
- 147. So working around the clinic schedule is a lot more helpful EV
- 148. to know they are coming back and not try to set a date for them that can't work EV

**Were there any highlights? (27:04)**

- 149. When the children wanted to talk to you EV
- 150. "Can I talk to that lady" again? EV
- 151. "She was really nice" EV
- 152. That was very encouraging EV

**Did the psychology programme meet the needs of Kalafong? (30:14)**

- 153. I think so EV
- 154. I think it opened up a new forum of team work EV
- 155. The phone call that I just got was from a dietician very concerned about a child OR
- 156. We are a team EV

- 157. it's not just about a doctor prescribing medicine EV
- 158. The dietician, the occupational therapist, the sisters
- 159. the clerk, the counsellors, the social worker
- 160. We're all involved EV
- 161. and the psychologist expertise and knowledge are also needed EV
- 162. it's really important EV

**You said that you think you want to invite us back. What should change or what should stay the same, if we do come again? (35:32), (39:16) and (45:45)**

- 163. Like I said often times we used to run into each other and just chat OR
- 164. so many kids come into the clinic OR
- 165. I would personally remember that you were there EV
- 166. when I see you there EV
- 167. In my own personal way EV
- 168. I have seen you being visible EV
- 169. right there in the hallway, right there saying good mornings EV
- 170. So being more visible EV
- 171. having to do orientation EV
- 172. also for the sisters and the nurses to know that you are available EV
- 173. To add: more follow-ups EV
- 174. to come to us and say, we saw that patient this week EV
- 175. this is what we talk about EV
- 176. keeping everything confidential EV
- 177. and not forgetting of course we're all in the health care profession EV
- 178. but it coordinates the team work a lot more better to communicate about cases EV

**(39:16)**

- 179. The students who came on the heavy clinic days OR
- 180. really helped the kids to work and cope better EV
- 181. The parents even say that they like to come to the doctor OR

**(45:45)**

- 182. All the support from the students (should stay the same) EV
- 183. just making the kids feel like “ hey coming to the doctor is not such a terrible thing” EV
- 184. You can come here and find someone who hears you
- 185. someone who can’t talk about your illness with your friends
- 186. And also for the younger kids to see the older kids OR
- 187. that they see how healthy they are OR
- 188. that they are taking medicine just like them OR

**The support group didn’t seem to work out, what do you think happened? (49:03), (49:48) and (50:03)**

- 189. It was because of the space EV
- 190. because of the renovations in the clinic EV
- 191. Some of the personnel didn’t understand EV
- 192. that the students were there for the immunology clinic EV
- 193. or understood what they were about EV

**(49:48)**

194. the actual clinic I don't think understood why you were here EV

**(50:03)**

195. The few that came did enjoy themselves and learned a lot from it (support group) EV

## LERATO'S TRANSCRIPT

**How did the decision of implementing the psychological services come about and when did it happen? (0:23)**

1. The decision to include psychology services at Kalafong AB
2. came about when we were thinking about starting the adolescents clinic CA
3. It was late 2007, 2008 then there was no clinic specifically for adolescents OR
4. All the patients were being seen like all together OR
5. And the need also came about CA
6. because of all the challenges we met with all the new moms OR
7. who had just discovered about their children's statuses OR
8. and they were going through all sorts of problems, dealing with it CA
9. And also that meant that all the kids now had a problem CA
10. in terms of getting the services OR
11. because mom had psychological issues that we couldn't address adequately CA

**Was there no paediatric clinic at the time? (1:14)**

12. There was a general paediatric clinic OR
13. but we were having problems addressing the adolescents OR
14. who have specific psychological needs OR
15. even medical needs specific general care of adolescents OR
16. which is much different from just general paediatric small children
17. So when we thought of having adolescents clinic OR
18. that's when we thought
19. it will be nice if we could have psychological intervention as well OR



**What happened after you decided about the psychological intervention? (1:55)**

20. From there it was a bit difficult initially EV
21. because Kalafong only has one psychologist OR
22. and that psychologist' services all the departments CA
23. And it meant that if we had a patient who needed psychological services CA
24. that patient had to be on a waiting list OR
25. and sometimes the problems that they would be having at the time CA
26. needed attention at that time OR
27. instead of being addressed three , four months down the line OR
28. when the psychologist will be available OR
29. So initially we tried that route OR
30. and it did not work very well EV
31. And then we thought about involving the psychologists from the local clinics CA
32. where the patients will be coming from OR
33. but even that did not work very well EV
34. because the psychologists wouldn't be available OR
35. and not all the clinics around, where the patients came from, had psychologists CA
36. So it was a big problem EV
37. And then that's when the idea of CA
38. why can't we involve psychology students who will be interested to help us OR
39. and why couldn't we involve them CA
40. so that if they can help us with the issues that we are dealing with OR
41. while at the same time they get clinical experience as well OR

**What steps were taken to make the decision of involving the psychology students, a reality? (3:13)**

- 42. After deciding on that, then that's when Person Z OR
- 43. consulted the Psychology Department here (University of Pretoria) OR
- 44. and spoke to the head of department OR
- 45. to look at our problem and the challenges that we were facing OR
- 46. and that's where now the decision was made RE
- 47. from both our side OR
- 48. and the Psychology Department here at Tuks to involve the students OR
- 49. It was a nice thing EV
- 50. And that's when also more ideas came forth- to help with the support group OR
- 51. and also to help with the OT(Occupational Therapy) Department OR
- 52. in terms of developmental assessments OR
- 53. could be done together with the psychologist OR

**What exactly did you have in mind that the students should do? (4:00)**

- 54. The challenges that we were having is that OR
- 55. we had problems for the patients to be admitted to the adolescents' clinic OR
- 56. We had an agreement that they had to know about their status OR
- 57. so disclosure problems came with other issues OR
- 58. like where they had to now deal with knowing about their status OR
- 59. and all the stigma and everything that was attached to knowing about their status CA
- 60. And with adolescents CA
- 61. that's when now we had all these psychological problems CA
- 62. whereby they have to deal with more CA

63. and they start being rebellious CA
64. and they start asking questions about why they should be taking medication and so on CA
65. And with us the counselling that we were offering them CA
66. we felt that it wasn't adequate enough to address all those issues EV
67. and that's why we wanted psychology intervention RE
68. like professional psychological intervention
69. where these issues could be addressed adequately OR
70. The other thing we were having problems with OR
71. it was not just about the disclosure OR
72. like at the age where they start experimenting with a whole lot of things OR
73. like they start experimenting with things like peer pressure and so on OR
74. So we needed that intervention to help us deal with that EV
75. so that we can deal with the medical part OR
76. and not just concentrate on CA
77. like spending a lot of time during the consultation OR
78. dealing with the psychological part OR
79. then we could have people who can help us deal with those issues CA
80. that impact on the psychology and social issues OR
81. that arose from knowing about the HIV status OR

**How was the process of implementation for you? (6:17), (6:56) and (7:41)**

82. The process of implementation was a bit difficult EV
83. because we had to come up with a way OR
84. of how we were going to integrate this services OR
85. because now we have a booking system of patients OR

86. and we didn't want a problem CA
87. whereby a patient in like a short period of time OR
88. had to be seen by different people OR
89. so we had to come up with a booking system OR
90. whereby on the same day that the patient comes OR
91. then they can also be seen by the psychology department CA

**(6:56)**

92. (Psychology student were at Kalafong) Mondays and in the afternoons only OR
93. It meant that it was difficult to get the patients at the times when you were there EV
94. and also to get the patients to sit CA
95. and wait when they were booked CA
96. After they (Patients) get their medication then nothing else mattered OR
97. they just wanted to go home OR
98. So implementing the system was the difficult part EV
99. And also because it was a new service OR
100. nobody understood how it worked OR
101. and how it supposed to be OR
102. and who is supposed to be referred OR
103. and the referral process OR
104. and that was another stumbling block EV
105. We had to work through that OR
106. and I don't think we got it right EV

(7: 41)

107. We tried getting it right EV
108. because for some patients it did work EV
109. and for others it just did not work EV
110. And then the other thing we had problems with- it was follow-up EV
111. We would refer the patients OR
112. and the feedback, you know
113. you have all these issues between the psychologist and the patients OR
114. and the doctor and confidentiality issues OR
115. so those were issues that we had to deal with OR
116. But I think for some patients it did work EV
117. like especially those who needed intervention over a short period of time CA
118. and then for those who needed intervention over a long period of time CA
119. unfortunately I can't say that it worked for them EV
120. because I think a lot of them actually got lost OR
121. like they would default the treatment EV
122. because of those psychological issues that were not addressed EV
123. and eventually they come back CA
124. we'll have to start afresh EV
125. but I think where the issues were acute it did help EV
126. and especially with the play room CA
127. and getting the children to be more positive CA
128. about their status from a younger age CA
129. it did work EV

**How did the picture of having psychological services look like in the beginning? (9:09)**

130. It looked rosy from the theoretical point of view EV
131. but practically it was not working EV
132. because we needed space first of all to accommodate you for all the sessions OR
133. and that was an issue because even among ourselves we had issues about space OR
134. who worked where and also the issue of confidentiality OR
135. we couldn't share rooms and so on OR
136. That was an issue EV
137. and the other issue I think was more about the bookings EV
138. how are we going to accommodate you in terms of time EV
139. Where do we book you? OR
140. Do we book you on our system? OR
141. do we have a separate booking system for you? OR
142. and that was a bit of a mess EV
143. but the idea of having you available immediately worked very well EV
144. because it ended up on just being the HIV patients that you were seeing CA
145. you would also get patients from the general outpatient, paediatric outpatient CA
146. and you would also get patients from there as well CA
147. So that was a good idea EV
148. it's just that implementing it and sorting out the logistics was a bit difficult EV
149. Especially, I think that made it worse was that we all EV
150. we were all hectic EV
151. during the times that you would be there EV
152. you wouldn't be given the attention because we would be busy with other things EV

**How does that picture of psychological services looks like now? (11: 06) and (11:38)**

153. Now, well now I think it's still not working EV

154. I think there was loss of interest somewhere EV

155. because of all the issues that were there that we couldn't quite deal with EV

156. so there was loss of interest from especially from our side EV

157. where we started concentrating more on our the medical part EV

158. and we were like okay fine, let those ones deal with their issues EV

**(11:38)**

159. Which was a bit frustrating to you as well EV

160. because you dependent on us to refer the patients EV

161. and follow-up with them and everything EV

162. and we just like okay refer EV

163. and then we wouldn't follow up CA

164. and we were not sure CA

165. and also I think for you in terms of the patients, you would make appointments EV

166. and the patients wouldn't follow up OR

167. you would pitch there OR

168. and the patients wouldn't be available OR

169. and that was really frustrating EV

170. but the whole idea was a good idea EV

171. it's just that it could not be implemented properly EV

172. it was very difficult to find a way of implementing it EV

**What should be done, what would make the psychology service programme to work?  
(12:31), (13:18) and (16:34)**

173. I think now, what would make it work would be the availability CO

174. in terms of your (Psychology students) availability OR

175. I think that was the biggest stumbling block from your side EV

176. whereby the patients would be there at a certain period of time EV

177. and that time you would not be available EV

178. because you had classes to attend to EV

179. you had other things to do on campus EV

180. and you would be available like on the times when the patients were not there EV

181. so I think that would be one thing that would need to be addressed EV

**(13:18)**

182. Yes, available the whole day EV

183. but the problem with that would be about the patients then EV

184. Would it mean that patients would have to come on the same day for the medical  
services as well? EV

185. and that was another issue that we couldn't have patients EV

186. like sometimes we would see one patient OR

187. for the medical part we would need only to see them in three months' time OR

188. whereas you would need to follow them up more regularly OR

189. sometimes a few times in one month OR

190. and then the patients would just look at us CA

191. and asks: but the doctor only needs to see me in three months' time CA

192. why should I be coming so many times CA



193. So that would be the problem in terms of the patients being available EV
194. The other thing was that the patients did not understand EV
195. the need for psychology services EV
196. therefore they did not make time for their appointments EV
197. they would not honour their appointments EV
198. and that was frustrating for you EV
199. because you have an appointment with the patient EV
200. and the patient would not pitch EV
201. One the other hand, on the patients' side EV
202. most of our patients came from poor background EV
203. money was an issue, transport money was an issue EV
204. We had a transport fund OR
205. and we tried to help wherever necessary OR
206. but it could not accommodate them as much as we would have liked to OR
207. because the money came from sponsors whenever there was a sponsor OR
208. so we would tell them, look, if you come we would try to help OR
209. and sometimes we wouldn't be able to meet that need OR
210. and that frustrated the patients that I can't spend this money OR
211. because this money is needed for other things OR
212. and I think that was another thing that would need to be addressed EV
213. that okay we need to see you (Patient) OR
214. but we need to make sure that we can we can make things easy for you OR
215. so that you can become available CA
216. in terms of the patients like if you can provide EV
217. like definitely provide transport EV
218. and also in terms of their time management EV

- 219. make them understand that look this is good for you EV
- 220. the necessity in terms of your management
- 221. I think because it was a new service EV
- 222. patients just thought what they needed EV
- 223. was just the medical service, the medical intervention EV
- 224. and they did not understand this psychological intervention EV
- 225. they just thought the doctor spoke to me and that's good enough EV
- 226. and with the adolescents it was especially difficult EV
- 227. because you need to be functioning at their level in terms of psychologically EV
- 228. for them to understand and get the point EV
- 229. and be able to honour the relationship EV

**(16:34)**

- 230. From our side I think in terms of making sure that when we were expecting you EV
- 231. we had space for you to work EV
- 232. I think that is very important EV
- 233. because if we are expecting you to offer provide a service to help us EV
- 234. then we were supposed to make sure that you are comfortable in the surroundings EV
- 235. and patients also feel comfortable EV
- 236. not when you get there and the patients is sitting there EV
- 237. then you have to start running around looking for a room that's available EV
- 238. That was that was the one thing that we could have done better EV
- 239. and the other thing we could have done better was in terms of referral EV
- 240. getting the patients for you EV
- 241. Sometimes we would want to refer patients EV

242. but we would think that we don't know
243. when they (Psychology students) are available EV
244. or they (Psychology students) are on holiday EV
245. and anyway it doesn't matter we'll see when they come EV
246. and the next time when the patient comes you've forgotten about that referral EV
247. and the patient also doesn't remind you EV
248. because they don't see the need as well EV
249. and then the patient ends up not getting referred CA
250. Not that the problem has gone away EV
251. but we are too busy focussing on other things EV
252. than dealing with that psychological part EV
253. which actually also impacts on the overall management of the patient EV
254. And then eventually it comes out again after few months EV
255. the problem comes again EV
256. and we realize this patient by the way was supposed to have been referred EV
257. and I think that was another thing that we were not doing very well EV
258. And also in terms of the booking, who was gonna deal with your administration? EV
259. that was an issue that we did not address EV

**What is your view in terms of establishing the support groups? (18:38) and (19:12)**

260. I don't think it went well EV
261. because I can tell you up to now CO
262. we don't really have proper support groups CO
263. The patients would be there OR
264. then there would be a talk there CA

265. but we didn't have like members OR
266. that we knew that these members belong to the support groups OR
267. and people would just get there and sit and listen and if they are listening and leave CA
268. then the next thing they present to me with the same problems OR
269. that would have been addressed in the support groups OR
270. So I don't think that went well EV

**(19:12)**

271. The attendance was poor OR
272. we gave people an option OR
273. that okay there is a support group OR
274. there are people who will help you OR
275. while you are waiting OR
276. can you go and attend OR
277. People would feel like well if I go in that room and my name gets called OR
278. then I'll miss my turn and the next thing I'll get to leave here late OR
279. So I'd rather sit here and wait to hear my name being called OR
280. so that I can be attended to and leave this place OR
281. So that was an issue we had to deal with EV
282. And it was difficult explaining EV
283. look these people are not going to whatever OR
284. when your name gets called OR
285. we'll come there and fetch you OR
286. it was not getting through EV
287. They thought oh well they just wanna waste more of my time EV

288. and the other thing was that EV
289. people thought well they're just gonna talk about things that I know EV
290. and they are not going to help me anyway EV
291. and I think with the support groups CA
292. there was still that issue of stigma OR
293. so the patients felt OR
294. I don't need to be discussing my problems in a group OR
295. I don't need to be in a group to address my problems OR
296. so I don't want to be in a support group OR

**What was your role? (21:31) and (22:35)**

297. In terms of, when we were talking about the adolescents clinic OR
298. that was my baby EV
299. that was the one thing I was passionate about EV
300. when it started I was like I want to do this EV
301. I want this to happen and it happened EV
302. and I was very vocal about the needs of the adolescents EV
303. as we needed the psychological services EV
304. And I had an idea of going to speak to our psychologist CA
305. I went there and spoke to her EV
306. whenever it was not working out EV
307. Person Z would come in more EV
308. to help me communicate with the department EV

**(22:35)**

309. I was more involved in terms of the planning process EV

400. and talking to the patients about the services CA

401. and so on, referring the patients CA

**How many patients have you referred? (23:13)**

402. I don't remember EV

403. but I can remember a few cases that were significant to me EV

404. there were three or four cases that I referred EV

405. I found that these issues needed to be addressed EV

406. without the psychological part being addressed EV

407. then we aint gonna go anywhere with those patients EV

408. and I must say there was good feedback with those particular patients EV

**Who did you get feedback from? (23:38)**

409. From you guys and the patients OR

410. and in terms of the improvement OR

411. the improvement in the patients' condition EV

412. there was an improvement in those patients EV

413. and that helped a lot in terms of the management EV

414. because whilst you deal with the psychological part EV

415. it's easy to deal with the medical part EV

416. because now the patient understand more and more EV

417. the patient is more receptive of whatever management that you are offering then EV

418. Because in terms of their stress level psychologically EV

419. they're more relaxed EV

420. so I think we had a couple of successes EV

**What did this programme mean to you? (24:24) (26:19)**

421. To me it meant a lot EV

422. In my mind initially when the idea came about OR

423. I had this idea OR

424. in terms of the adolescents OR

425. of having a place where they can voice out whatever frustrations OR

426. and they can also get whatever counselling at their level OR

427. with the psychological understanding for their level OR

428. That was the idea in my mind OR

429. that we'd have a psychologist available OR

430. even though it was not just for patients who had problems per se OR

431. it was gonna be for all the patients in the adolescents clinic OR

432. because I believe that as they get into that stage CA

433. they meet up with a whole lot of challenges OR

434. not just with the illness OR

435. but with life in general OR

436. and understanding what is going on with them OR

437. and being able to comprehend what was going on CA

438. in terms of their psychology

439. would help them to deal with the medical part and social issues OR

440. that they were facing OR
441. because at the end
442. adolescents whose infected with HIV has a lot to deal with OR
443. a lot more than somebody who is not infected OR
444. They have to deal with boyfriend issues or girlfriend issues and sexual issues OR
445. How are they going to deal with those OR
446. when they know they have a sexually transmitted diseases? OR
447. And that's what is a stressor to them CA
448. even though they wouldn't voice it OR
449. That was something that I thought would be dealt with OR
450. before it became a problem OR

**(26:19)**

451. It was a prevention measure OR
452. in a way it was supposed to be educational as well OR
453. addressing the life skills and so on and also empowering them OR
454. in terms of giving them the confidence to deal with peer pressure OR
455. and the pressure they get from other people CA
456. the stigma and so on
457. It would empower them OR
458. If they are more confident and psychologically empowered OR
459. then they can be able to deal with those issues CA
460. much better than they would have without those OR
461. and also even like empowering their negative sense CA
462. to say okay accept me



463. Making sure that they can educate their friends OR
464. and make sure that their friends know that this is just an illness like any other illnesses  
CA
465. and I'm not a risk to you as much as the next person is CA
466. and you can be my friend and love me CA
467. as much as you love the negative person OR
468. without having any prejudice against me OR
469. so it was supposed to address such issues OR
470. that was the idea I had in my mind EV
471. then again to make sure that when the problems arose OR
472. like when they start experiencing the problems OR
473. they would be immediate attention to address them OR
474. instead of booking them for help three four months down the line OR
475. whereby by then it might have gone much worse OR
476. and we've had cases where they would even become suicidal OR
477. and if somebody is suicidal now OR
478. you can't wait for them to be addressed three four months down the line CA
479. They need attention now OR
480. That was that idea we had OR
481. And also we had an idea OR
482. for them to have a support group which never worked out OR
483. the support group was supposed to teach them OR
484. not just teach them about life skills OR
485. but also to have them in a place where they can relax OR

**What are your conclusions about this programme? (29:17)**

486. I think if done the right way EV

487. if it can be given the right time and the right place EV

488. it's a good programme EV

489. It can work very well and it can help everyone not just the patients EV

490. but for you guys as well it can give you a lot of experience EV

491. in terms of the patients that you are gonna meet when you are practicing EV

492. I don't think like here in University you get (such kind of exposure) EV

493. it's a different community altogether OR

494. but when you go out when you start working EV

495. those are the people you are gonna meet EV

496. so that experience would have been nice for you EV

497. because when you get out there EV

498. to start working you wouldn't even meet something new EV

499. and sometimes it's not that you don't know the theory EV

500. the theory is there but practically applying the theory EV

501. is completely different from what you read from the books EV

**What is your understanding of psychological services? (30:50)**

502. Because now you are sitting there with a patient OR

503. they have a problem OR

504. sometimes it's a minor problem that you can address quickly OR

505. but you feel no, refer to psychologist OR

506. So my understanding is that you are there OR

507. to help with deep emotional issues, psychological issues OR
508. that I cannot address, so meaning counselling OR
509. Counselling in terms of my understanding OR
510. is providing education, providing support OR
511. but sometimes (in my field of expertise) I don't have the time to support that patient emotionally CA
512. because there is a queue, I need to push the queue OR
513. So I believe a psychologist is there to sit with this patient OR
514. and make them understand the education that I have given them CA
515. You know, like when taking the medication, how do they feel about it OR
516. They will put the two together and work with their issues CA
517. I believe that was what we required out of you in terms of psychological services EV
518. And also sometimes (during consultation), I'm sitting here with the patient OR
519. I can sense there is a problem but I can't quite put my finger on what the problem is OR
520. I believe you guys had the experience EV
521. to get to the problem without using too many tactics EV
522. Sometimes the patient doesn't trust you (referring to herself) OR
523. because they don't think that you've got adequate tools to deal with their issues CA
524. And then somebody who talks to them on their psychological level CA
525. then that's when they can start opening up OR
526. and then you get to the bottom of the problem CA
527. Sometimes the patient comes CA
528. and says I've got a pain and (being medically focused) CA
529. I wanna deal with the pain OR
530. meantime the pain is not just a pain OR
531. It's a pain because of some deep rooted emotional problem that they are having OR

532. and getting to that you have to use some means CA
533. and (being medically focused) I may not be having the skills to get the real problem CA
534. They may present with this problem which is a physical problem to me OR
535. and my job is to address the physical problem CA
536. In the meantime it's not a physical problem it's a psychological problem OR
537. And I don't have the skills to diagnose it as such CA

**What happened to the idea that the psychology students should see all the patients coming at the clinic? (33:52)**

538. There was that idea OR
539. because I think that came about OR
540. because of sending the patients to you OR
541. in terms of the mom sitting there saying OR
542. there is a support group going, listen and participate OR
543. was not working OR
544. then we said okay
545. almost all the patients that we were seeing there had some kind of social problem OR
546. which impacted on the medical management OR
547. so why can't everyone at least get to be interviewed OR
548. and eventually some problems that we wouldn't normally pick up CA
549. then they could be picked up that way CA
550. Because sometimes a patient has a problem OR
551. but it's not a significant enough problem OR
552. for them to raise during a medical consultation OR
553. whereas if they're dealing with somebody who is focused on such problems OR
554. even if it's just on a social

555. like under relaxed circumstances OR

556. they might feel CA

557. why can't I bring this up maybe this person will be able to help me OR

558. and that's why the idea came about OR

**How was your relationship with the psychology students? (35:50)**

559. Well, personally I think my relationship was fine EV

560. I didn't have any issues EV

561. I think we got along well EV

562. I enjoyed like, whenever you were there whatever you had to offer CA

563. I enjoyed it EV

564. I don't know EV

565. I think I could have tried a bit more EV

566. to use you (psychology students) more

567. but sometimes you know, you (referring to herself) just wanna get through the day CA

568. and go home EV

569. And I think besides using you for the patients EV

570. it would have been nice also to have you guys helping us EV

571. with the staff as well EV

572. Because the staff as well CA

573. deal with traumatic situations on a daily basis EV

574. and you(referring to herself) leave there and you go home CA

575. The next day even when you(referring to herself) see people CA

576. you (referring to herself) just don't wanna talk to them EV

577. So sometimes you guys would get there EV

578. and you I would sense that you feel that nobody is giving you attention CA

579. I would get those days as well where I just don't wanna say hi, how are you EV

580. just not today

581. But I think, generally we got on well EV

582. I don't know EV

**Do you think the psychology service programme met the needs of Kalafong community?  
(37:21)**

583. Yes, on a small scale where we had the patients EV

584. and we had the time and we had the space it did EV

585. And I think especially on the level of the smaller children EV

586. with the playgroup and so on OR

587. it did because it helped and that is still continuing EV

588. The playgroup is still there it's still helping EV

589. it keeps the kids entertained EV

590. I think there are some students who still come OR

591. honours students and also we get more Mohau volunteers OR

592. so the playgroup I hear it's still going on there OR

593. and some of the kids don't even go to crèche CA

594. so when they are there they get the opportunity CA

595. to do something that other children do at crèche CA

596. They get to interact with the other children CA

597. and it becomes more pleasurable for them to be at the clinic CA

598. so they start looking forward to coming to the clinic CA

599. And for the moms as well it's a nice idea CA

600. because instead of just sitting there with your child on your lap the whole day CA

601. waiting to be serviced,-
602. knowing that your child is somewhere safe and being entertained OR
603. They also get to relax and they get to chat more OR
604. and it becomes more open about what is bothering them CA
605. and also interacting with the other moms CA
606. It'll get much much easier for them to interact with other moms EV
607. because they didn't have to be looking after the children for that time and so on EV
608. that thing it went very well EV
609. And also in terms of the OT (Occupational Therapist) as well EV
610. helping the OT with assessment in terms of the developmental assessment EV
611. it helped a lot EV
612. where it did not work well EV
613. I think it was with the individual patients OR
614. whereby there were no logistics about appointments and follow- ups and so on OR
615. And then with the support group CA
616. it worked for some patients EV
617. and also didn't work for other patients EV
618. With the support groups it still not working EV
619. I think it's gonna take a whole lot of planning and attention and availability EV
620. of everyone to make it work EV
621. And also I think the patients themselves EV
622. they don't have it in them to want it EV
623. they don't want the support group so you can't really force it onto them EV

### Where to from here? (39:51)

624. I would like to see the service continue EV

625. But like what we've been talking EV

626. probably throughout this whole thing EV

627. We need to get the plan properly EV

628. and we need to get the logistics in order CA

629. so that it could work EV

630. It shouldn't just work for EV

631. like that portion EV

632. it should work overall EV

633. we should be having a situation where we can say EV

634. this patient can be addressed and followed up and see the X results EV

635. after whatever number of sessions CA

636. we can have a definite positive results EV

637. So I think that would help especially for the individual patients EV

638. because those are the ones who eventually CA

639. have bigger problems EV

640. because those are the ones who will default their treatment EV

641. those are the ones who are going to do whatever stupid thing EV

642. like try to kill themselves and so on CA

643. I would like to see the programme continue EV

644. but we must just get the logistics in order CA







