WHAT ROLE DO PSYCHOSOCIAL FACTORS PLAY IN INFLUENCING HIV POSITIVE PEOPLES' COMPLIANCE WITH MEDICAL TREATMENT?

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Abstract

Antiretroviral therapy has given hope and expectations for a better life to HIV positive individuals, however, HIV medication cannot be effective without HIV positive individuals' compliance to it. This study investigated the ways in which living with HIV and taking medication is located within the psychological, social and cultural context of everyday life and relationships in Greece. It also examined gender and identity issues, which make compliance/non-compliance understandable from the HIV positive peoples' perspective. In addition, emphasis was given to locating compliance to medical regimes in which the perspectives of HIV positive persons were prioritised and understood in relation to relationships with health care professionals.

A mixed methods approach was undertaken to provide understanding of compliance and non-compliance factors to HIV medication in a holistic way. A self-completed questionnaire was used to examine the psychosocial factors underpinning compliance to medication. Face-to-face semi-structured interviews were used to explore issues of identity, gender, relationship between doctors and patients and social understandings of HIV. Finally, self-completed weekly diaries were used to document compliance actions, thoughts and feelings in order to reveal the ways medical regimes fit into everyday life. The study was conducted in three Public Hospitals, one Governmental Hospice and one Non-governmental Organization. Eighty (63 males and 17 females) Greek HIV positive patients completed the questionnaire. Interview sample consisted of 7 and 3 males and females respectively. Finally, 6 Greek HIV positive males and 3 females completed the diaries of the research. The questionnaire data was analysed using descriptive statistics via SPSS 11. In addition, a range of non-parametric tests (Mann Whitney and Kruskal Wallis) were used in order to check if ordinal variables influence compliance with HIV medication. Finally linear regression analysis was used in order to establish the influence of factors on compliance with HIV medication. Interviews and the diaries data were analysed though thematic analysis, focusing on identification of patterns and behaviours which were then interpreted in terms of themes.

The findings of the study indicated that, when support was given from life partners compliance with HV medication was increased. However, when support was given from family members, compliance with HIV medication was decreased. According to the findings, family dynamics have changed in several cultures over recent decades, partner roles have changed especially in the west and in Mediterranean societies. In regards to

medicalization in everyday life, the study showed that when individuals were experiencing side effects, or had fears of future side effects, religious issues (punishment for homosexuality), loss of one’s freedom due to medication, non-compliant behaviours could occur. Finally, the study indicated that some HIV positive individuals perceived their health levels as good and believed that not taking medication once or twice a week was a compliant behaviour. Hence, false perceptions regarding health levels and compliance issues could lead to non-compliant behaviours.

A further examination on the communication patterns of the family system and its impact on HIV positive individuals is recommended as it is clearly not very helpful any more. Further exploration of the general socio-cultural positioning of Greece is recommended as certain HIV positive individuals coped with HIV diagnosis and taking medication, by rejecting it. Finally, the need for psychological support is recommended as it is very rarely provided within the Greek health care system.

Contents

CHAPTER ONE: INTRODUCTION AND RATIONALE OF THE STUDY

1.1 Introduction

The purpose of this study was to explore the factors which influence compliance/non-compliance to medical regimes, amongst HIV positive individuals within the cultural context of Greece. To achieve this, the research focused upon understanding the ways in which:

- psychosocial factors,
- socio-cultural positioning,
- gender and identity issues,
- medicalization in everyday life,
- the relationship of HIV individuals with health care professionals impact on compliance and non-compliance and
- the general health status of the HIV positive individuals,

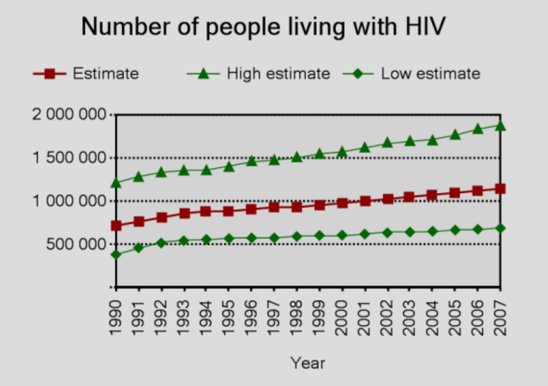
impact on compliance and non-compliance to medical regimes.

The present research examined the psychological, social and cultural factors which impact upon living with HIV with relation to taking antiretroviral therapy. This was achieved through exploring the everyday experiences of individuals living with HIV. Experiential approach was used to investigate the twinned notions of gender and identity and how gendered identities play a role in facilitating or obstructing compliance amongst HIV positive individuals. Throughout this thesis, emphasis was given to locating compliance to medical regimes within a more holistic context in which the perspectives of HIV positive persons were prioritised and understood in relation to relationships with health care professionals.

Much of the previous work on compliance to medication had been examined within the context of chronic illnesses such as cancer, heart disease or diabetes (Taylor, 1991) but very little research effort had been devoted to understanding this issue from the perspective of people living with HIV/AIDs despite the fact that evidence from international charities and aid organisations indicated that the number of people living with HIV/AIDS was rising across Europe, the United States and Canada as can be seen in figures 1.1 -1.6 (WHO, UNAIDS & UNICEF, 2008).

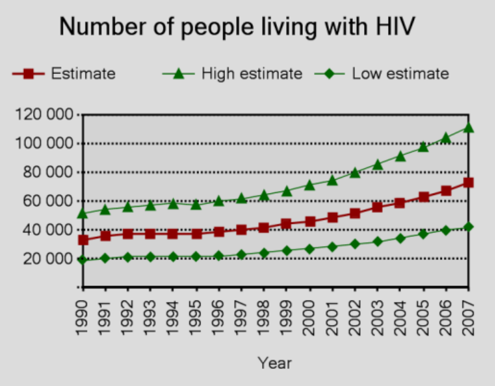
Figures 1.1- 1.6: Number of people living with HIV around the world

Figure 1.1



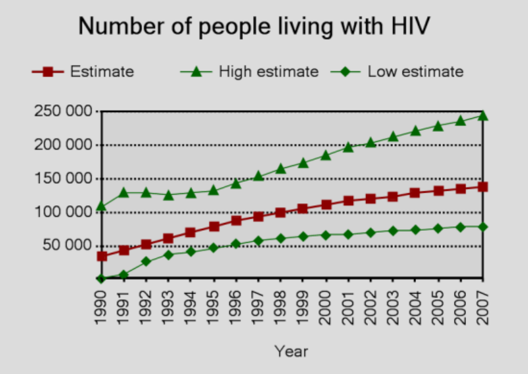
(United States of America)

Figure 1.2



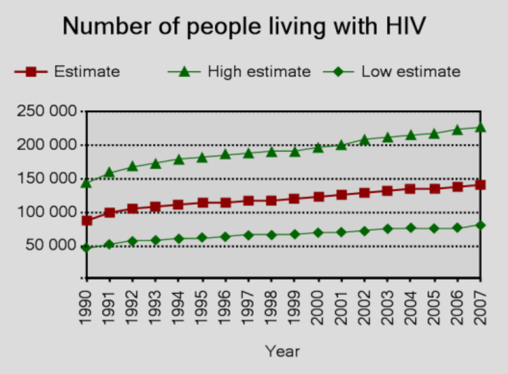
(Canada)

Figure 1.3



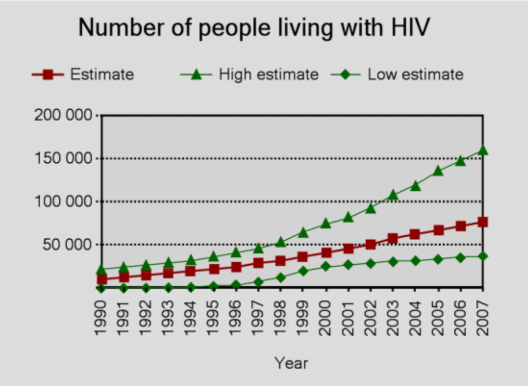
(France)

Figure 1.4



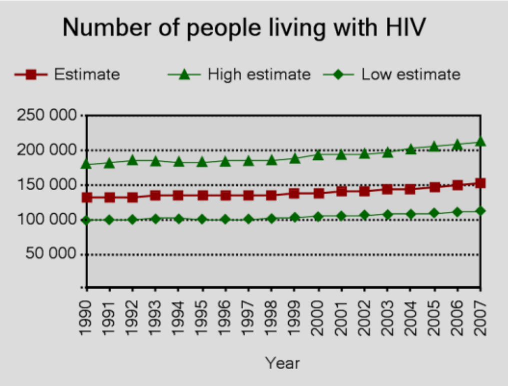
(Spain)

Figure 1.5



(United Kingdom)

Figure 1.6



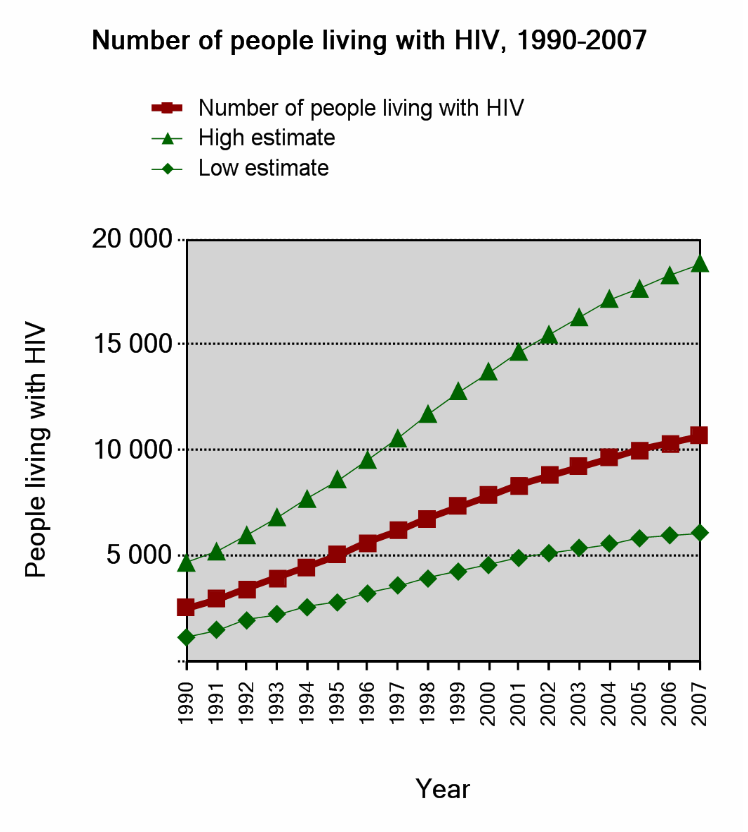
(Italy)

This increase in the number of HIV/AIDS cases suggested a need for more research into the psychosocial factors that impact upon compliance and non-compliance amongst those living with HIV. Additionally, the literature on compliance, relating to other chronic diseases (Loghman, 2003) suggested a number of factors which influence medical compliance amongst the general population such as the patient’s decision to comply to the medical regimes (Loghman, 2003) and their level of understanding of the treatment process. This is important because medical research shows that those people who comply with antiretroviral therapy enjoy better health and better quality of life than those who only partially comply or who do not take medication (Ramirez Garcia & Cote, 2003).

Furthermore, current knowledge indicated that psychosocial factors can affect compliance in other illness categories (Gore-Felton & Koopman, 2008). However it was not fully known which psychosocial factors might influence compliance amongst people living with HIV (Gore-Felton & Koopman, 2008). These psychosocial factors were explored from the perspective of those already living with HIV to identify reasons for non-compliance with medication within the context of living with the virus and life improvement. Understanding of the underpinnings of compliant behaviour was necessary to assist health workers and governmental workers in developing services which more accurately reflected the real world experiences of those living with HIV. Documenting these experiences may also was of significant value for family members in developing a more accurate understanding of the needs and wants of those living with HIV.

Studies amongst the HIV/AIDS population have overwhelmingly derived from the specific cultural contexts of the United States of America (USA) and United Kingdom (UK), revealing a paucity of research across other cultures (Sachperoglou & Bor, 2001). Although reported cases of HIV and AIDS were not high in Greece at the time of the study when compared to other European countries, the US and Canada, the rates were increasing (Sachperoglou & Bor, 2001). Indeed there had been a three-fold increase in the number of people living with HIV in Greece over a seventeen year period. Figure 1.7 shows the growth of the number of people living with HIV in Greece between the years 1990-2007 (WHO, UNAIDS & UNICEF, 2008). However, the rates may not be accurate as there is a possibility that not all cases had been reported. Indeed, the possibility is that rates were underreported here given the stigma which is associated with HIV and AIDs in Greece.

Figure 1.7: Number of people living with HIV in Greece



In particular, Southern Mediterranean cultures have been under-researched with respect to HIV and specifically in examining compliance to antiretroviral medication. A possible explanation for this lack of research is that these countries are more family orientated where problems are resolved within the context of the family (Georgas, 2003), and families strive to maintain their privacy. However, it has been noted by some researchers that this structure of families has changed over time, and the same applies for Greek families, as new members are added and other members may leave the family or even die (Papero, 1997). Hence, as the family members change through certain life changes such as new marriages, births or deaths, demands for new adjustments will arise in terms of dealing with difficult situations such as a family member's possible HIV infection (Papero, 1997). Due to these observed changes, new research into the experience of HIV/AIDS and compliance to medication was needed.

This thesis aimed to develop understandings of compliance to medical regimes in order to alleviate problems of non-compliance in general and specifically in the case of Greece where little research had been carried out.

In contrast to previous studies which have examined the role of individualised factors upon compliance (Remien et al., 2003), this study examined the combination of these factors within everyday life contexts and their impact on medical compliance. To achieve this, a mixed methods approach was undertaken to examine compliant/non-compliant behaviours across different perspectives. Tashakkori and Teddlie (2003) argue that mixed methods, through the collection and analysis of qualitative and quantitative modes of inquiry, can provide diverse insights into research problems that cannot be provided through a single methods approach.

This introductory chapter provides a rationale for this research and presents an outline of the thesis structure.

1.1.1 Rationale

Acquired Immunodeficiency Syndrome represents an increasingly complex challenge for health services and societies across the world due to the HIV rates which are steadily and rapidly increased (Sachperoglou & Bor, 2001). Social sciences have examined HIV/AIDS and its impacts on HIV positive individuals' lives whilst focused on the factors that might influence seropositive individuals' beliefs, thoughts, feelings or behaviours. However, little research had identified the unique issues of compliance to medication and how the taking of medication was integrated (or not) in the everyday lives of people with HIV. This is important because HIV and AIDS, as with many other chronic illnesses, can affect various facets of persons' life (Burish & Bradley, 1983; Taylor & Aspinwall, 1990; Taylor, 1991) and this can have implications for medication compliance.

Findings from the study of Chesey (1997) showed that HIV positive people have problems complying to antiretroviral therapy, a problem recognised long before these individuals begin taking "protease inhibitors" (types of HIV medication). Additionally, Luszczynska et al. (2007) indicated that although antiretroviral therapy improves HIV positive individuals health status, one third of them miss one medication dose every five days. HIV and AIDS, as with many other chronic illnesses, affect various facets of persons' life (Burish & Bradley, 1983; Taylor & Aspinwall, 1990; Taylor, 1991).

Although HIV medication had become more effective during the decade of the 1990's, this group of people continue to face feelings of fear, uncertainty and stigma whilst living with HIV or even associated with HIV and interacting with other people (Nyblade et al., 2009).

Furthermore, problems of compliance with antiretroviral therapy can arise from tensions between the attitudes and perceptions of doctors and patients. This is likely to occur due to doctors' conflicting understandings and own values surrounding issues related to abortion, homosexuality, AIDS and other conditions or behaviours invested with "moral evaluations" (Morgan, 1997). Alternatively, there are also certain patients' demands on doctors that are considered as obliged to serve as well as act for the best of their patients' needs (Morgan, 1997).

In addition to this tension, those living with HIV also feel challenged by prevailing attitudes within society, through which *"Infected people not only face an uncertain future, but also widespread ignorance, fear and prejudice*" (Aggleton et al, 1989, p.105). Examining these issues within Greek society, Sachperoglou & Bor (2001) identified a negative societal perception towards HIV positive individuals which leads to a fear of stigmatisation and discrimination within those living with HIV. Such perceptions impact upon the willingness of HIV positive individuals to reveal their status to their close environment and consequently losing the opportunity to receive support in general and in complying with antiretroviral therapy. Previous studies across populations have also shown that attitudinal perceptions towards AIDS stem from knowledge acquired through radio and television sources (Henderson et al, 2004). The study of Henderson et al, (2004) identified that HIV positive individuals who had received information mainly from the radio or the television had insufficient knowledge for HIV prevention and transmission.

Human behaviour and motivation has also been examined within the context of gender and identity. Bem (1993) identified significant identity differences between males and females, especially within the context of social networks and more specifically within the context of HIV. The literature suggested that there is a number of factors which influence medical compliance amongst the general population. These factors are: a) the patient's decision to comply with the medical regimes, b) understanding the treatment process; and c) emotional satisfaction with the doctor-patient relationship (Taylor, 1991). Therefore, the present study also examined the relationship between gender/identity issues and patients' compliance with HIV medication.

A further set of psychosocial factors are also implicated in compliance with medication amongst the general population. These include anxiety, denial, depression, self-esteem and self-blame, all of which have been examined in relation to compliance to medical regimes for several chronic illnesses such as cancer and diabetes (Taylor, 1991). However, knowledge of the researcher about compliance to treatment amongst HIV positive individuals was limited due to the lack of research in the area. A number of tentative reasons have been identified as a reason for non-compliance. A significant factor is that HIV positive individuals consider HIV medication to be a burden to their everyday lives and consequently they often show poor compliance with medication. The literature suggests that poor compliance is attributed to the amount of medication that they are required to take, the complexity of the regimes, such as dietary and medical prescriptions, and the interference of medication with their lifestyle and habits (Chesney, 1997).

Additionally, HIV positive individuals may also experience other health related issues such as encephalopathy even if they are not connected to HIV related symptoms (Bornstein et al., 1993; Miles et al., 2001).

Drawing from knowledge of the literature, the focus of the present research was placed on understanding:

- the psychosocial factors that might influence compliance and HIV positive people’s personal experiences, thoughts and feelings regarding antiretroviral therapy,
- socio-cultural positioning: their perceptions regarding themselves as HIV positive individuals in relation to wider society,
- their knowledge and perceptions of antiretroviral therapy,
- identity and gender issues,
- how medicalization fitted into the everyday life context,
- patients’-doctors’ relationship and
- the general health status of the HIV positive individuals.

Understanding compliance from these different perspectives was complex and indicated the need for research to clearly identify the role of different factors play in compliance to medication amongst people with HIV.

1.1.2 Outline of Thesis

1. Introduction and Rationale: This chapter provides the introduction and the rationale for the present research and presents the outline of the thesis.

2. Theoretical Framework: In this chapter the literature is critically examined, regarding HIV/AIDS and issues of compliance/non-compliance. Psychosocial factors, socio-cultural positioning, gender and identity issues, the role of antiretroviral therapy into everyday life and doctors/patient relationships issues are critically discussed.

3. Methodology: This chapter presents the methodological approach used in this study. Given the diversity of paradigms described in the literature, a discussion of the four dominant paradigms (positivism, post-positivism, constructionism and pragmatism) is presented, followed by a justification of the use of the pragmatic paradigm as the most appropriate for establishing the epistemological and ontological basis for this area of research. Description and justification for the methods chosen is covered including pilots, questionnaires, diaries and interviews. In addition, ethical and practical issues are presented and discussed.

4-5 Interview and Diary Findings: To clarify and aid a better understanding of the findings, these are presented in two distinct chapters: chapter 4 “Being HIV positive: personal, social and cultural perspectives’; and chapter 5 ‘Compliance in the context of everyday life’. In these chapters, analysis and interpretation of data from the semi-structured interviews and diaries are presented. This includes issues of identity, gender, the relationship between doctors and patients, social understandings of HIV and compliance within the Greek society, and the way medical regimes impact upon everyday life.

6-7 Survey Results: To facilitate a better understanding of the quantitative survey results, two chapters are presented: chapter 6) “Descriptive analysis of factors”, associated with becoming HIV positive and health care provision, the lifestyles, support, and psychosocial status & health characteristics of people with HIV in Greece; and chapter 7) “Predictors of compliance with HIV medication regimes”. Here, the psychosocial factors (e.g. depression, anxiety, denial, isolation, self-esteem, confidence) related to compliance are identified and relationships between them explored.

8. Discussion: The final chapter is divided into the following: the aims and objectives of the research which are presented together with a summary of the empirical findings. This consists of two tables detailing the qualitative and quantitative findings; an integration of the quantitative and the qualitative findings; followed by an extended discussion on these findings that are related to the aims and objectives of the study. Psychosocial factors, gender and identity issues, medicalization in everyday life, relationship with health care professionals, socio-cultural positioning and general health status are discussed. Next, a section identifying the ways in which the thesis contributes to knowledge within this area is preceded by a methodological critique that analyses the limitations of the current study. The practical implications of the work are then presented followed by recommendations for future research. Finally, the conclusions reached during the study are examined.

9. Reflexivity: This chapter presents the reflexive thoughts of the researcher regarding the application and development of the research methods and the experiences gained from interacting with participants, including those living with HIV, medical staff from the settings where the study took place and the supervisory team. It also outlines the thoughts and considerations of the researcher regarding the issue of subjectivity as related to supervision issues such as reflections on different cultural and social backgrounds between the supervisory team and myself and our socio-cultural positioning. In addition, a reflexive analysis is carried out on my experiences of working with participants within their socio-cultural context, personal thoughts on the beginning and the ending of the research itself. I also reflect upon my feelings, thoughts and approach as the research developed.

CHAPTER TWO: REVIEW OF LITERATURE REVIEW

2.1 Introduction

In this chapter, HIV/AIDS is overviewed as a medical condition, incidence and prevalence rates are presented and a review of the current knowledge on issues of compliance and non-compliance is given. Following this, an extended review of the previous work regarding socio-cultural positioning, general health issues, psychosocial factors everyday life issues that are associated with compliance, gender and identity issues and doctors and patients relationship is presented. The chapter ends with an in depth examination of the Greek society’s construction and the Greek culture as the present research examined compliance with HIV medication within the cultural context of Greece.

2.2 Literature search

A number of databases were used such as Google scholar, Medline, Science Direct, Biomed Central, Ovid full text, Emerald full text, Blackwell science, LWW using several terms as the area researched was very big. For example some terms such as HIV/AIDS, General health, depression, sexual life, fear, support and so on were used. The inclusion criteria were:

- Full text
- HIV/AIDS
- Chronic diseases
- English and or Greek language
- Designed to access severity to diagnosis

The exclusion criteria were:

- User involvement in research
- Have not documented for reliability and validity
- Not related to HIV/AIDS

Databases and Number of hits Table

Database	Search Term (s)	Hits	Reviewed
Google scholar	need for a daily schedule/ sexual choices/ visiting hospitals/medication user / medication/ Greece/ full texts	5898	29
Medline	HIV/AIDS/compliance/ Fear/Loss /Aggression/Death /Denial/ full texts	7567	9
Emerald full text	General Health /Perceptions/anxiety/ full texts	694	15
Ovid full text	Perceptions of support:/practical help/advice/companionship/ full texts	16	2
Elsevier	Self-Esteem/Locus of control/ full texts	12	2
Science Direct	Internal “chance” external /powerful others beliefs/ full texts	0	0
Blackwell science	Antiretroviral therapy /despair or similar words to it/ medication/ compliance	24	1
LWW	Fear/Danger/ Death/ Homosexuality/ Sexual life /Relationships /Understanding/Rejection/ Support/ Friends/ full texts	84	6
Biomed Central	Insecurity/ fear/ social relationships/appearance/pessimism/ full texts	263	12

2.3 Understanding Human Immunodeficiency Virus (HIV)

This thesis presents an exploration of compliance with medical treatment in the context of the everyday lives of people who are living with Human Immunodeficiency Virus (HIV) as a consequence of contracting the Acquired Immunodeficiency Syndrome (AIDS) virus.

HIV is a virus that attacks the immune system, which is the system that gives the human body the ability to defend itself from infections. HIV destroys T cells or CD4 cells (a type of white blood cells) that are necessary for the immune system in order to fight diseases (Centre for Disease Control and Prevention (CDC), 2009). HIV can be separated into two categories, HIV-1 and HIV-2 and is a virus that invades those cells which bear a special receptor site on their surface (Saroglou, 2002). In other words, HIV/AIDS attacks the body’s immune system and leaves it largely unprotected and vulnerable to numerous health problems, which normally would not develop in a healthy and uninfected immune system (Saroglou, 2002).

An HIV infected person can live for years without reaching the stage of AIDS as AIDS is the final stage of HIV infection. According to the literature half of the HIV infected people develop AIDS within 10 years, if they do not receive any HIV medical treatment, and there are only few cases that HIV infected people do not develop AIDS within 20 years. However, when receiving antiretroviral therapy the risk of developing AIDS can be reduced to 80 per cent (Avert, no date: online).

Having AIDS means that the body has reached a point where the immune system is very weak, due to the HIV virus, and cannot fight any infection. Hence, when a person suffers from certain infections or certain cancers such as sarcoma Kaposi, has a low number of CD4 cells which is considered to have reached the stage of AIDS (CDC, 2008). According to medical history, the HIV virus was first identified in a type of chimpanzee in Africa as the source of infection in humans. As people were hunting those chimpanzees for meat, they came into contact with their blood which was infected with the HIV virus. As a result people accidentally infected themselves and spread the virus around the world (CDC, 2008).

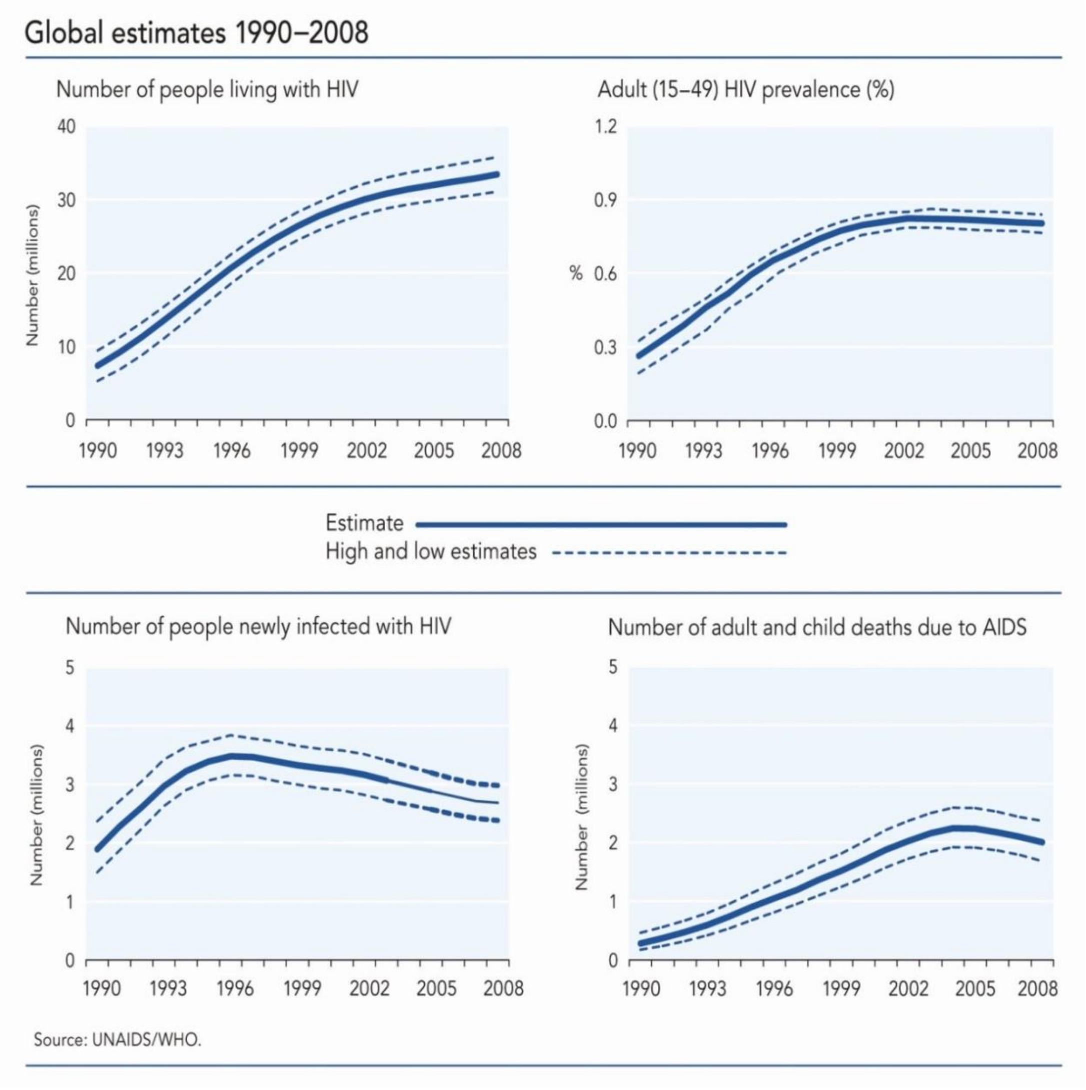
Recognition of the serious problem HIV/AIDS presented began in the early 1980's; when the first official HIV/AIDS cases were reported in the USA in 1981 (Saroglou, 2002). Initially three patients, all homosexual men, were suffering from a very rare form of pneumonia, Pneumocystis Carinii pneumonia accompanied by Kaposi's sarcoma, a very rare form of cancer. The co-occurrence of two such rare conditions provoked medical investigations into causation. Because there was limited information about the new disease and the process of transmission there was substantial concern about contagion. Knowledge of this disease was changing very quickly and assumptions scientists made on the basis of existing knowledge were soon revealed as unfounded or valueless a few months later (Saroglou, 2002).

Moreover, the disease did not even have a name and scientists were referring to it in several different ways such as lymphadenopathy (swollen glands). In May 1983, Institute Pasteur in France reported that doctors had isolated a new virus which was probably the cause of AIDS. In 1982 the World Health Organisation was the first that used the definition of AIDS in the USA. By the end of 2001 the World Health

Organisation reported that more than 40 million people were infected with the virus world-wide (Saroglou, 2002). Specifically in Greece, by the end of 2001, 6.237 cases of HIV positive people were reported and at that point 2.678 patients were undertaking antiretroviral therapy (Saroglou, 2002). Since then, growth in the number of HIV infections has been considerable, although not always at an exponential rate.

For example, the number of new HIV infections in the United States declined from 130.000 cases in the mid-1980s to 50.000 in the early 1990s. New HIV cases increased in the late 1990s when, in 1996, the global spread of the disease peaked at approximately 3.5 million *(3.2 million–3.8 million) new HIV infections.* From the year 2000 there were approximately 55.000 new cases reported per year (CDC, 2009). By 2008, the CDC estimated that there were approximately 40.000 new HIV infections each year in the United States alone (CDC, 2009) and the global incidence was at an estimated 2.7 million (2.4 million – 3.0 million) (CDC, 2009). In 2008, new infections had dropped by 30 per cent from the epidemic peak of 1996. Unsurprisingly, the death rates from AIDS related illnesses have increased. The following table shows the global numbers of HIV cases between the years 1990-2008 (World Health Organisation, United Nations AIDS, 2009):

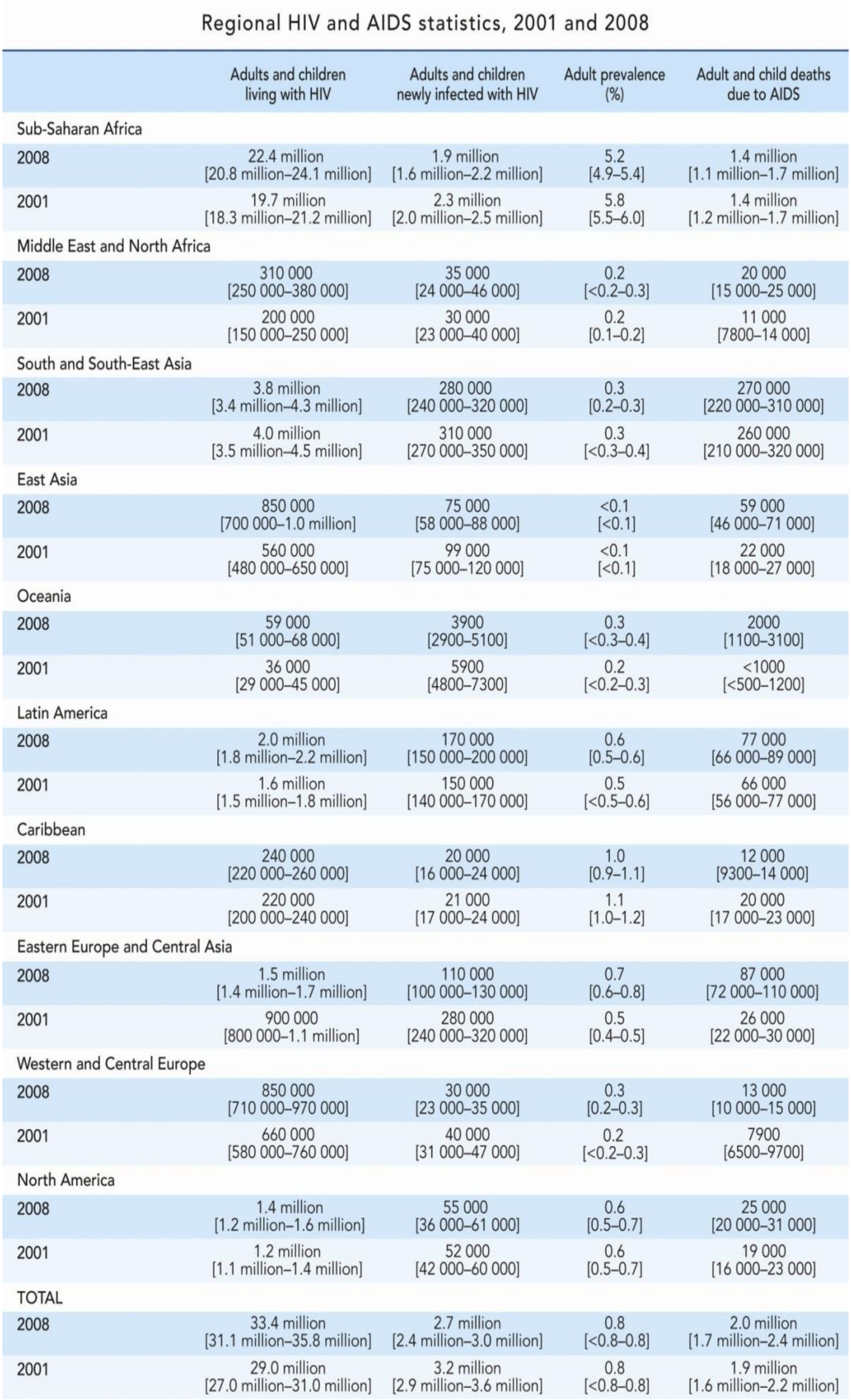
Table 2.1: Global estimates for HIV and AIDS cases between the years 2001-2008



Source: UNAIDS/WHO.

The summarised data of the following table (2.2) highlight the areas where more strong actions are needed so as to achieve a more desired result at the AIDS response (WHO, UNAIDS, 2009). The following Tables show regional statistics for HIV and AIDS cases between the years 2001-2008 (WHO, UNAIDS, 2009, p. 11).

Table 2.2, Statistics of HIV and AIDS



Regional HIV and AIDS statistics, 2001 and 2008

	Adults and children living with HIV	Adults and children newly infected with HIV	Adult prevalence (%)	Adult and child deaths due to AIDS
Sub-Saharan Africa				
2008	22.4 million [20.8 million–24.1 million]	1.9 million [1.6 million–2.2 million]	5.2 [4.9–5.4]	1.4 million [1.1 million–1.7 million]
2001	19.7 million [18.3 million–21.2 million]	2.3 million [2.0 million–2.5 million]	5.8 [5.5–6.0]	1.4 million [1.2 million–1.7 million]
Middle East and North Africa				
2008	310 000 [250 000–380 000]	35 000 [24 000–46 000]	0.2 [<0.2–0.3]	20 000 [15 000–25 000]
2001	200 000 [150 000–250 000]	30 000 [23 000–40 000]	0.2 [0.1–0.2]	11 000 [7800–14 000]
South and South-East Asia				
2008	3.8 million [3.4 million–4.3 million]	280 000 [240 000–320 000]	0.3 [0.2–0.3]	270 000 [220 000–310 000]
2001	4.0 million [3.5 million–4.5 million]	310 000 [270 000–350 000]	0.3 [<0.3–0.4]	260 000 [210 000–320 000]
East Asia				
2008	850 000 [700 000–1.0 million]	75 000 [58 000–88 000]	<0.1 [<0.1]	59 000 [46 000–71 000]
2001	560 000 [480 000–650 000]	99 000 [75 000–120 000]	<0.1 [<0.1]	22 000 [18 000–27 000]
Oceania				
2008	59 000 [51 000–68 000]	3900 [2900–5100]	0.3 [<0.3–0.4]	2000 [1100–3100]
2001	36 000 [29 000–45 000]	5900 [4800–7300]	0.2 [<0.2–0.3]	<1000 [<500–1200]
Latin America				
2008	2.0 million [1.8 million–2.2 million]	170 000 [150 000–200 000]	0.6 [0.5–0.6]	77 000 [66 000–89 000]
2001	1.6 million [1.5 million–1.8 million]	150 000 [140 000–170 000]	0.5 [<0.5–0.6]	66 000 [56 000–77 000]
Caribbean				
2008	240 000 [220 000–260 000]	20 000 [16 000–24 000]	1.0 [0.9–1.1]	12 000 [9300–14 000]
2001	220 000 [200 000–240 000]	21 000 [17 000–24 000]	1.1 [1.0–1.2]	20 000 [17 000–23 000]
Eastern Europe and Central Asia				
2008	1.5 million [1.4 million–1.7 million]	110 000 [100 000–130 000]	0.7 [0.6–0.8]	87 000 [72 000–110 000]
2001	900 000 [800 000–1.1 million]	280 000 [240 000–320 000]	0.5 [0.4–0.5]	26 000 [22 000–30 000]
Western and Central Europe				
2008	850 000 [710 000–970 000]	30 000 [23 000–35 000]	0.3 [0.2–0.3]	13 000 [10 000–15 000]
2001	660 000 [580 000–760 000]	40 000 [31 000–47 000]	0.2 [<0.2–0.3]	7900 [6500–9700]
North America				
2008	1.4 million [1.2 million–1.6 million]	55 000 [36 000–61 000]	0.6 [0.5–0.7]	25 000 [20 000–31 000]
2001	1.2 million [1.1 million–1.4 million]	52 000 [42 000–60 000]	0.6 [0.5–0.7]	19 000 [16 000–23 000]
TOTAL				
2008	33.4 million [31.1 million–35.8 million]	2.7 million [2.4 million–3.0 million]	0.8 [<0.8–0.8]	2.0 million [1.7 million–2.4 million]
2001	29.0 million [27.0 million–31.0 million]	3.2 million [2.9 million–3.6 million]	0.8 [<0.8–0.8]	1.9 million [1.6 million–2.2 million]

The evidence of the above report highlights the necessity of the priority outcomes in the new UNAIDS framework as long as the possibility to accomplish a progress in certain areas. According to the report though the progress is not universal, instead, where the progress has been achieved it is only partial. The data of the above regional profiles highlight the areas where more actions have to be done in order to increase the levels of the AIDS response.

At an individual level, it is very important that HIV is diagnosed as early as possible since health status can benefit from receiving education, counselling and antiretroviral treatment early in the disease trajectory (HIV medication which will be explained in the following paragraph). Additionally, early diagnosis plays a role in preventive public health strategies, especially in terms of protecting the existing and potential sexual partners of those infected and consequently reducing the transmission of the virus through sexually risky behaviours (Fennema et al., 2000).

As mentioned above, individuals diagnosed as HIV positive receive antiretroviral treatment. The antiretroviral treatment is not a cure for HIV and AIDS although medication can prevent HIV infected people from becoming ill with AIDS. This treatment involves drugs that have to be taken by the infected person for the rest of his/her life. The aim is to keep the HIV virus at a low level with the result of stopping the reduction of the CD4 cells and the weakening of the immune system. These drugs are referred to as antiretroviral treatment, anti-HIV or anti-AIDS drugs, HIV antiviral drugs or ARVs (Avert.org, 2009). The five groups of the antiretroviral drugs are listed and described in Table 2.3.

Table 2.3: The groups of antiretroviral drugs

ANTIRETROVIRAL DRUG CLASS	ABBREVIATIONS	FIRST APPROVED TO TREAT HIV	HOW THEY ATTACK HIV
NUCLEOSIDE/NUCLEOTIDE REVERSE TRANSCRIPTASE INHIBITORS	NRTIs, nucleoside analogues, nukes	1987	NRTIs interfere with the action of an HIV protein called reverse transcriptase, which the virus needs to make new copies of itself.
NON-NUCLEOSIDE REVERSE TRANSCRIPTASE INHIBITORS	NNRTIs, non-nucleosides, non-nukes	1997	NNRTIs also stop HIV from replicating within cells by inhibiting the reverse transcriptase protein.
PROTEASE INHIBITORS	PIs	1995	PIs inhibit protease, which is another protein involved in the HIV replication process.
FUSION OR ENTRY INHIBITORS		2003	Fusion or entry inhibitors prevent HIV from binding to or entering human immune cells.
INTEGRASE INHIBITORS		2007	Integrase inhibitors interfere with the integrase enzyme, which HIV needs to insert its genetic material into human cells.

Reproduced with permission from (Avert, 2009)

Antiretroviral medication are effective in alleviating the symptoms of HIV/AIDS, however, they may also cause certain side effects which in turn may be associated with non-compliant behaviours (AVERT, 2008). For example, the medication named as “efavirenz” is associated with psychiatric symptoms. In addition, protease inhibitors are mostly associated with high levels of cholesterol and triglycerides. Not all HIV positive people experience the same side effects; in fact it is quite impossible to predict the exact way or in what extent each person will be affected. For example, there are some people that receive antiretroviral therapy for years and experience very few side effects, while other people find certain HIV medication intolerable (AVERT, 2009).

However, apart from the antiretroviral treatment, the discovery of a vaccine which can prevent HIV infection is one of the great challenges in the scientific world in order to fight AIDS permanently (Miedema, 2008). Ever since the first HIV cases the scientific world is making great efforts to deliver the AIDS vaccine within the next five to ten years. Although scientists are making incredible efforts and great progress has been made so far, unfortunately an effective vaccine has not been discovered yet (Miedema, 2008).

Antiretroviral treatment is the only treatment for HIV/AIDS and for it to be beneficial, those who are HIV positive need to comply with arduous medical routines. When it is decided that the treatment has to start, then the doctors decide from a variety of drugs and combinations which are the most suitable for each person (AVERT, 2009). Nevertheless, receiving antiretroviral therapy is not as simple as it may sound. As before mentioned, HIV medication has to be taken exactly as prescribed. In the following section, compliance and non-compliance issues will be explained.

2.4 Compliance, Adherence or Concordance?

The terms compliance and adherence came into consciousness during the 1970's so that health care providers could understand patients' attitudes towards healthcare professionals' advice and discuss this in "non-judgemental" ways. Patients failing to follow medical advice were acknowledged as a continual problem for doctors and a new study area for social scientists. Although Haynes and Sackett (1979), who coined these terms considered them as similar and interchangeable, deconstruction of 'compliance' and 'adherence' have indicated that each has different implications suggesting important differences between them (Lutfey & Wishner, 1999) in the way power is ascribed to doctor and patient. As such, both terms, compliance and adherence, are going to be explained during the following paragraphs.

In terms of medical usage, ''compliance'' refers to the level to which a person corresponds to a health care professional's advice, such as taking medication as well as following diet and lifestyle changes (Lutfey & Wishner, 1999). Additionally, the term compliance suggests that a patient fully obeys the healthcare professional's instructions (Lutfey & Wishner, 1999). Here, it is the doctor who is placed in the position of ultimate power over the behaviours of patients who are expected to passively comply with medical instruction. The patient is not expected to exert any decision making of their own in deference to the expertise, knowledge and acknowledged hierarchy of the medical profession.

In contrast, adherence is defined more in terms of an “equal” interaction between healthcare professionals and patients (Lutfey & Wishner, 1999). Adherence is located more in terms of the patient’s independence and intelligence so as to take a more participatory role within the medical interaction by being involved in the definition and setting of goals for the best possible medical treatment (Lutfey & Wishner, 1999). This coheres strongly with current governmental policy directions in western countries, especially the UK, where a drive towards more choice and control and person centred approaches within health contexts have appeared high on governmental and health authority agendas (DoH, 2006).

Although both compliance and adherence appear as along power issues, one fundamental difference is that compliance focuses more on attitudes concerning the actual taking of medication whereas adherence focuses more on attitudes toward medication, or else the product of numerous beliefs about any possible outcomes associated with medication (Weiden & Rao, 2005).

However, a relatively and recent term mainly used in the United Kingdom on the other hand is concordance. Concordance encompasses ways in which the doctors and patients co-operate in therapeutic decisions that integrate their personal views. This refers to a new model of medical negotiation which includes not only prescribing communication but also patient support for medication taking (National Co-Ordinating Centre Service Delivery Organisation, 2005, p. 12).

However, although health care professionals select the most possibly appropriate medication scheme for each HIV positive individual, even if it is very carefully chosen, it cannot work if the HIV positive person does not take it appropriately. Taking medication appropriately, whether this is called compliance, adherence or concordance, is essential for a successful health outcome (Claxton et al, 2001). According to the literature, HIV positive individuals are separated into three categories 1) full compliers, 2) partial compliers, that receive some of their doses and 3) non-compliers, that receive few or no doses at all (Claxton et al, 2001).

Due to the above, the present study examines the reasons why HIV positive individuals do or do not fully correspond to their doctors’ medical prescriptions, as well as lifestyle or diet choices. Additionally, it aims to explore the underlying reasons of HIV positive individuals’ partial compliance to their doctors’ instructions.

According to the literature, the existence of direct quality relationships between the doctor and the patient is limited (Morgan, 1997). This may be a product of changes in medical education whereby doctors are encouraged to request numerous check-ups and invasive tests from patients so as to feel protected from patient's health complications and complaints. Hence, doctors do not feel as their patients' health is a personal responsibility any more. Patients on their side do not feel close to their doctors with the result of engaging in searches for medical information and second opinions until they will find something that will make them feel safe so as to passively follow the medical prescriptions (Morgan, 1997).

In terms of explaining, the literature suggests that patients spend only a few time in health care professionals' offices, although the later are not central to patients' lives (Lutfey & Wishner, 1999). Moreover, the information that is being exchanged between health care professionals and patients is quite different, as health care professionals tend to present facts and discuss technical issues although patients tend to discuss and share personal experiences related to their health condition (Lutfey & Wishner, 1999). Therefore, it seems that although health care professionals seek only for compliant behaviours from their patients, health care users seem to seek for something more than that in order to receive their medication appropriately. According to the above the term compliance was chosen over adherence or concordance for the present study. The following section, presents an in depth explanation of compliance and non-compliance issues in individuals with HIV/AIDS as identified within the academic literature.

2.5 HIV and Compliance: Issues of Compliance/Non-compliance

A review of past literature suggests that, depending on the disorder (not only for HIV) and the therapy, patients' compliance with medical regimes vary from 15 per cent to 93 per cent (Alpert 1964; Baekeland & Lundwall, 1975; Davis 1968a; Rapoff & Christophersen, 1982; Taylor 1991).

In terms of HIV specifically, a study conducted by Shernoff (2001) showed that 75 per cent of HIV participants reported missing their protease inhibitor in the previous six months and almost one third had missed a dose in the past week. This is a serious problem because compliance lower than 95 per cent can be detrimental to viral resistance to medication making adherence to antiretroviral therapy an extremely important practice (Remien et al., 2003).

In other words, HIV positive individuals should ideally comply totally with medication. This situation is compounded by the fact that partial compliance can result in greater risk of medication resistance (Fogarty et al, 2002). HIV resistance means that the genetic structure of HIV changes and the virus becomes resistant to HIV medication regimes. In other words, these genetic changes allow the HIV virus to reproduce despite the antiretroviral therapy taken (Cichocki, 2007). Furthermore, taking antiretroviral therapy can be complicated as patients need to take numerous pills, sometimes before dinner, sometimes after; at very specific hours and for many people the drugs themselves cause unwanted and unpleasant side-effects such as nausea or dizziness. Despite this, previous studies among HIV-infected patients have shown that levels of compliance to antiretroviral therapy were similar to patients' compliance to medications in general and averaging an 80 per cent compliance rate (Mehta et al., 1997).

Given the importance of taking antiretroviral therapies and the accompanying difficulties presented by arduous medical regimes and unpleasant side effects, research has turned towards understanding HIV positive individuals' reasons for non-compliance. Understanding issues of compliance and non-compliance could help practitioners to create the conditions which encourage more people to succeed in managing their illness through medication. Taylor (1991) highlighted several factors underpinning non-compliance in patients that suffer from chronic diseases: being away from home without medication, scepticism over the health benefits of treatment, absence of a support network, inability to tolerate side effects, conflict between medication and eating habits and poor communication with health care providers. Furthermore, practitioners' suggest that non-compliance is often due to patients' uncooperative personalities, ignorance, lack of motivation and forgetfulness (Taylor, 1991). In addition, personality theorists have suggested that poor patient-practitioner communication may be implicated in levels of non-compliance (Meichenbaum & Turk, 1987).

The need to stop or interrupt medication can be strong amongst HIV positive people than amongst other categories of illness and disease. Boredom with taking medication is also common among antiretroviral therapy users (Anderson & Weatherburn, 1998) and may contribute to non-compliance. However, even amongst those who comply with the regimen, the medication routine can cause frustration within the context of daily living, as taking medication at very specific hours may conflict with lifestyle priorities. For example, when individuals are out to dinner and they are not meant to eat before taking their HIV medication, the decision to fit in with the social dinner situation can assume more importance than taking medication at designated times. Being at work can also interfere with compliance to the medical regime as work deadlines, meetings or social situations can get in the way of the precise medical regime.

Many HIV positive individuals express a wish to break from treatment. Indeed, many HIV patients are relieved of the continuous, lifelong therapy as they might stop it, after their doctor’s suggestion. Many HIV positive individuals express a wish to break from treatment. Apparently, individuals expressing such a wish tend to interrupt medication sooner or later anyway (Hoffmann et al., 2003). It would seem that antiretroviral therapy is perceived as an unpleasant experience from the HIV positive individuals’ point of view. Further research into HIV and compliance with antiretroviral therapy was required to understand the ways in which medical treatment regimens could be considered at once helpful but unpleasant at the same time in the context of HIV positive people’s everyday life. Accordingly, the first aim of the current research was to establish how far HIV positive individuals comply with their medical regimes and to explore a range of factors that might underpin non-compliant behaviours. Research indicated that compliance to medication is a problematic issue dependent on the medical disorder in question and the recommended treatment.

Research on HIV compliance to medication has not considered the role of gender in compliance rates. Evidence that gender can affect compliance is implicated in the findings of a survey conducted between December 1998 and June 1999 (De Truchis et al., 2000). This work which was based on 528 patients recruited in 27 centres in France showed that 69 per cent of HIV positive men were compliant versus 56 per cent of the women. Clearly, the women in this study were less compliant with medication than the men. However, their situations also differed in that they tended to be younger than the men of the study, had children, were not educated and had little information regarding the HIV virus and they lived in difficult social circumstances. According to this study women required more time, attention and support from their caregivers, doctors and social care than do men in order to better follow medical instruction (De Truchis et al., 2000). The notion of gender difference in compliance highlighted here presents an interesting avenue for future research since there is currently little research on the relationship between gender and compliance to HIV medication (De Truchis et al., 2000).

Provided HIV treatment begins the exact time that the doctor decides, it improves people's quality of life (Aggleton, 1989). As it was already mentioned all groups of antiretroviral therapy are complicated and has numerous side effects, such as dizziness, withdraw and diarrhoea. Sometimes these side effects may be as severe as to require withdraw from therapy (Aggleton, 1989). Many treatment regimens require patients to abandon enjoyed activities such as overeating, smoking and drinking due to medication restrictions. Such restrictions may make patients feel that they have lost control over their environment or their lives (Taylor, 1991) or may be difficult to follow because of alcohol or nicotine addictions.

On the other hand, compliance to medication may be easier to follow and less unpleasant if partners, family or friends are being supportive. Previous research has indicated that social support often helped patients to tolerate side-effects and to adjust to their medication (Taylor, 1991). For example, if the doctors have access to the patient's family members or if the family members or the patient him/herself enter in self-help programmes with people who experience the same problems, then non-compliance can be reduced (Taylor, 1991). Indeed, in these cases, managing the medical regimen was commonly cited as an opportunity for the involvement of partners (Anderson & Weatherburn, 1998). However, not all HIV positive individuals manage to tolerate medication and as a consequence have turned to alternative and complementary medicine (Aggleton, 1989) such as homeopathy and yoga. Clearly, issues associated with compliance to antiretroviral therapy are numerous.

During the literature review factors that might strengthen compliant or non-compliant behaviours were revealed. However, much was yet to be understood concerning the way in which compliance to a medical regime impacts on everyday life and social relationships and how gender might be important in compliance behaviours. The present study aimed to reveal not only key factors that underpin compliance and non-compliance, but also addressed through the voices and real experiences of people who are suffering from HIV, how HIV positive patients built their medical regime into their everyday personal and social lives.

To begin this investigation, a review of factors identified within the academic literature is explored in the next section.

2.6 Socio-cultural Positioning

Another important factor which according to past studies is a great influence on medical compliance among HIV positive people is their socio-cultural positioning. It is HIV positive individuals' perceptions regarding their positioning within society, and how such perceptions can underpin compliance to antiretroviral therapy. Within this section the identified sources of information that influence people's perceptions are going to be presented. Additionally, the socio-cultural positioning of the Greek population, including HIV positive individuals themselves is going to be examined so as to give a better view of the way that Greek people react towards HIV and how stigmatisation and discrimination of HIV positive people occurs.

According to previous studies, the most commonly identified sources that act as an influence on HIV positive people's perceptions regarding HIV/AIDS are television (85 per cent), friends (54 per cent), and newspaper reports (51 per cent) (Henderson et al., 2004). It appears that the media acts as an educational tool in framing public understandings of HIV. As a consequence, such received messages may result HIV positive individuals perceptions for their positioning within society (Ostrow, 1990).

As far as Greek individuals' perceptions, studies' results have shown that certain perceptions are quite negative as when revealing ones seropositivity usually leads to fear of stigmatisation and discrimination (Sachperoglou & Bor, 2001). In addition, due to the fact that seropositivity and the revealing of it often results in confrontation with family members and friends with revelations about the HIV positive individual's lifestyle and sexual preferences shows that being HIV positive in Greece may be directly associated with unaccepted habits and lifestyle from society (Sachperoglou & Bor, 2001). As a consequence, it may be that HIV positive individuals have to deal not only with their seropositivity but also with other people's perceptions regarding their lifestyle. This is exacerbated by the relationship between homosexual lifestyles and HIV/AIDS whereby: *"...moral entrepreneurs have toiled tirelessly in attempting to persuade society that homosexuality is abnormal and immoral. It is beliefs that homosexuality is evil, sick, or undesirable and the corresponding efforts to punish, cure, or prevent it that make homosexuality deviant"* (Greenberg, 1988, p. 2; Huber & Gillaspy, 1997 p. 197-198).

Consequently, this has led to discrimination against HIV patients who try to participate in same sex unions, as well as repression of them (Huber & Gillaspy, 1997 p. 195).

Of particular relevance to this research is that being HIV positive in Greece is directly associated with unaccepted habits and lifestyle from society. HIV and the perceptions of it within the Greek society can have a negative impact on HIV positive individuals' social relationships and functioning due to the beliefs and the stigma that surround the disease (Sachperoglou & Bor, 2001). Disrupted social and personal relationships may occur; hence, the quality, quantity and the type of those personal relationships may not be as functional and supportive as they needed to be (Green, 1993; Sachperoglou & Bor, 2001). In addition, how such perceptions might influence HIV positive individuals willingness to comply with antiretroviral therapy in little known. Indeed, little is known about socio-cultural positioning of HIV individuals and how this might influence medical compliance among HIV positive individuals in Greece.

2.7 General Health Issues

As mentioned in earlier sections, *"Early identification and advances in antiretroviral therapies have begun to prolong the lives of infected individuals diagnosed with HIV"* (Miles et al., 2001, p. 42-43). As a result, medical and social thought about the HIV trajectory has been re-conceptualized from that of imminent catastrophe to HIV as a *"...chronic but fatal illness"* (Miles et al., 2001, p. 42-43). The HIV virus shows itself in a number of different symptoms such as weight loss, fatigue, diarrhoea and more which can get progressively worse with the passage of time (Ader, 1992; Miles et al., 2001, p. 43). Additionally, HIV positive people may experience other cognitive impairment such as encephalopathy even if they do not experience other HIV related symptoms (Bornstein et al., 1993; Miles et al., 2001). Hence, as HIV progresses both physical and mental health issues can occur (Stanton et al., 1994; Miles et al., 2001).

According to the literature, *"there is a strong association between the psychological distress and the quality of life, and consequently implications for the clinical management of HIV positive patients occur"* (Henderson et al, 2005, p. 350). Other health issues associated with such a diagnosis and even poor compliance are the presence of psychiatric illnesses such as anxiety, depression, paranoia, grandiosity further and more detailed reference to psychiatric/psychological health issues is going to be presented in the next section concerning psychosocial factors (Mehta et al., 1997). As Aversa & Kimberlin (1996) have argued, when compliance to HIV does not occur as prescribed then non-compliant HIV people are more likely to experience more intense declines in their physical and mental health.

Therefore, the present study further aimed to examine the general physical and mental health of HIV positive people in Greece and explicate any possible implications of compliance to medication.

2.8 Psychosocial Factors

Considering the role psychosocial factors play in compliance and non-compliance it was important to examine these factors specifically in relation to HIV and antiretroviral therapy. When diagnosed with HIV, an individual has to deal with several factors such as denial, depression, anxiety and even self-esteem issues (Taylor, 1991). One reason that makes HIV/AIDS and its treatment different from other chronically illnesses is that usually people deny realising the seriousness and the danger of this illness (Ostrow, 1990). Because HIV symptoms are variable and appear in a linear downward trajectory towards fatality, even when HIV positive individuals stop denying the seriousness of the infection, depression is a common reaction to a chronically illness such as HIV/AIDS (Taylor, 1991).

People with HIV may also experience additional problematic issues such as disrupted home life, mental issues or family history of mental issues, substance abuse or rejection (Frunk- Benrtano, 2005). As mentioned in the previous chapter, HIV medication has become more effective during the decade of 1990’s. However, HIV positive people continue to face feelings of fear and uncertainty whilst living with HIV (Taylor, 1991). Whilst experiencing the above mentioned feelings is quite rationale to expect depression symptoms among this group of people as according to a study in east countries such as Asia and the Pacific showed that 36 per cent of HIV positive patients had evidence of depression (Wright et al., 2008; Morolake et al., 2009). Their fear of living with HIV and confronting other people’s reactions and beliefs makes us wonder how these people deal with social pressures and how these might affect the way they live their everyday lives.

In contrast, when HIV positive people identify a supportive and encouraging person within their social network with whom they can share HIV related issues, then hope messages might occur. In this case, the HIV positive individual may be empowered to achieve compliance with HIV medication (Nam et al., 2008). According to Nam et al., (2008), it is very important for HIV positive individuals to have hope for their lives and future. This hope is often provided by a confidant or else this supportive and encouraging person. According to this particular study, when HIV positive individuals comply well, then they gain hope for having children of their own, hope for a relationship or hope for a better health so as to provide more to their children, at least until the children will reach adulthood. These encouraging people in their lives manage to deliver messages of hope to the HIV positive individuals through their supportive behaviour.

In addition, threats to self-concept and self-esteem of these individuals' remain and problems concerning mental and physical functioning can lead to experience of fear not only regarding HIV itself, as abovementioned, but also fear of social interaction (Taylor, 1991). "*The desire to believe that one is worthy or valuable drives behaviour and shapes how people think about themselves, other people, and events in their lives"* (Crocker & Park, 2004, p. 392). Such issues may have serious impacts to compliance with the medical treatment; hence, research into HIV and medical compliance needs to take into account not just psychological factors but also selfhood and the pressures of social interaction. This is especially interesting in a world that is trying to make HIV more understood, more acceptable and antiretroviral therapy more palatable. Nevertheless, even if the progress of medication is hopeful, feelings of denial, depression and anxiety are still an issue for HIV/AIDS individuals. And it is not only that, because an individual that tries to maintain health status is mostly influenced by its living and working conditions, food supplies and access to basic goods and services (Acheson, 1998, p.6):

Considering Acheson's finding it is not only the emotional aspect of a person's ability to cope with such an illness and willingness to maintain good health status but also the person's economic status, cultural and environmental conditions.

Therefore, understanding compliance to HIV medication is not simply about accepting the diagnosis and the value of taking medication but concerns psychosocial issues, issues of identity and selfhood, gender and culture as well as fitting into everyday life. The present study aimed to explore these factors and their influence on HIV positive individuals' beliefs in today's Greek society; and to examine in depth the way People living with HIV cope or not with the above mentioned psychosocial factors and at the same time comply or not with medication in order to deal with mental and physical changes as well.

2.9 Everyday Life, HIV and Compliance to Medical Regimes

According to the literature, the effects of HIV/AIDS on HIV positive individuals’ lives are numerous (Aggleton, 1989). Community based medicine has encouraged doctors to investigate illness as a phenomenon within the broader context of individuals’ lives and the society they belong (Aggleton, 1989). Hence, many researchers have identified the impact of chronic illnesses on people’s everyday life (Ciambrone, 2001). For example, a chronic disease may cause alterations in a patient’s physical, social and vocational activities (Taylor, 1991). For instance, cancer patients, even the ones with temporarily inactive cancer, have to remain alert to any possible recurrence of the disease; or heart and stroke patients have to dramatically alter their daily activities due to their physical and psychological impairments (Taylor, 1991).

HIV positive individuals not only have to deal with HIV/AIDS as a chronic illness, but also with the beginning of the complex new regime which constitutes antiretroviral therapy and which becomes a part of their lives.

Many HIV positive individuals do not change their risk related habits such as drinking alcohol. This fact consequences the reduction of HIV positive individuals’ healthy lifestyles, and their co-operation with the medical care system (Rotheram-Borus et al., 1997). HIV positive individuals usually report that taking medication is a burden to their lives and as a result they show poor compliance (Chesney, 1997). The numerous medications, complexity of regimen, need for special storage and interference of medication with lifestyle and habits become a burden in HIV positive individuals lives (Chesney, 1997).

At this point it is worth considering that being HIV positive and taking antiretroviral therapy may not only constitute negative experiences. Some people view medication as a pathway towards living healthily, maintaining good health and being able to function in society. The study of Goldman & Bao, (2004) showed that antiretroviral therapy can improve individuals’ quality of life, being effective in helping them to remain employed and feel useful. Penedo et al. (2003) found that quality of life was related to HIV medication and considers both positively related to better compliance. Hence, more compliant HIV positive individuals undertake physical, social and job related activities, and therefore experience more quality in their lives.

According to the literature, there are contradictory findings regarding the ways in which HIV positive people operate to fit HIV medication into everyday life. However, limited literature was available concerning HIV/AIDS medication and its relation to everyday life and quality of life (Penedo et al., 2003). The present study explored how HIV positive people deal with taking medication in the context of their everyday life and identified the impact of such behavioural and lifestyle changes on individuals' social relationships and quality of life.

2.10 Gender and Identity Issues

Living with HIV/AIDS is an extremely important aspect of a person's life. An HIV/AIDS diagnosis results in decisions about what to change in the living of everyday life and impacts upon many life domains such as employment, socialising or romantic life (Ciambrone, 2001). In addition, plans for the future may be compromised. Taken together, this can affect an individual's sense of selfhood and identity (Ciambrone, 2001).

Earlier in this chapter, compliance rates were shown to vary between men and women. However, such research, while pointing to differences between HIV positive men and women (Bem, 1993), it failed to explore why such differences occur and there has been little investigation on the way in which gender construction is implicated in compliance to medical regimes. The present study aimed to reflect on gender identity as a social construction in order to more fully explain what it is about the different ways that HIV positive men and women approach the problem of compliance to medication. Also, traced how this was contextualised within a tradition society such as Greece and examined new aspects in modern society (Best, 2003).

In order to make clear how men and women react on the experience of living with HIV/AIDS and examine their behaviours towards medication in more depth, it is important to begin with identifying gender and identity differences. According to literature, although men and women are capable of experiencing the same range of emotions, men are more likely to experience frustration and have less opportunities of experiencing positive feelings (Larson & Pleck, 1999). Moreover, according to Mirowsky and Ross (1995), men feel less free expressing emotions than women do. In addition, men tend to cope more poorly than women with major life events (Mirowsky & Ross, 1995). In terms of homosexual men, evidence indicated that they often prefer living with uncertainty rather than knowing their health status. That is, because homosexual men's behaviour regarding HIV/AIDS is characterised by "denial" (Folowerset al., 2003). Perhaps homosexual men adoption of denial as a coping mechanism may play a part in their denial of the value of taking medication.

In addition, previous studies tend to separate findings regarding HIV/AIDS behaviours between HIV positive heterosexual and homosexual men. The present study aimed to examine any possible differences between HIV positive homosexual and heterosexual men in regards to living with HIV/AIDS and identify any possible difference that influences their compliance.

Where women are concerned, according to the literature HIV positive women in United States tend to be poor, non-white, IV users and come from a low social and economic background (Ciambrone, 2001). They tend to exhibit very different reactions towards their status as HIV/AIDS individuals and taking antiretroviral therapy. In contrast to men, women usually report reactions of hopelessness, social isolation and blame when experiencing HIV as a chronic condition (Ciambrone, 2001). However, research has largely ignored the biological, social and psychological effects of HIV/AIDS on women in particular and thus available information is limited (Ciambrone, 2001). To date, research knowledge derives mainly from feminist theorists regarding women's experiences (Ciambrone, 2001). These report experiences of trauma when diagnosis is confirmed (Ciambrone, 2001). Moreover, women lack the support of political organisations in contrast to homosexual men who managed to gain it (Ciambrone, 2001).

However, some cautiousness regarding the experiences of infected women in Greece should be maintained as the country's unique geographical, political and cultural position was a factor that might influence the conceptualisation of their sexuality and identity (Best, 2003). For example, in Greece, the female body is perceived as "the symbol of family integrity" (Dubisch, 1986: Best, 2003). Therefore, an infected female body tends to be considered as shameful (Ciambrone, 2001). While in more modern times this belief is not perhaps so strong held, "*a review of feminist anthropology pertaining to modern Greece will easily reveal that the sexual and social subordination of women is still prevalent"* (Best, 2003, p.3); such issues may impact on medical compliance. The present study aimed to explore such issues, regarding gender and identity and understand any possible effect of wider socio-psychological and cultural issues on compliance as this line of research had not been followed at the time of the study in Greece.

2.11 Doctors' and Patients' Relationship

The relationship between doctors and patients regarding the management of chronic disease has always been an important matter (Taylor, 1991). When doctors engage a warm and caring style, patients tend to be more cooperative and even more compliant to taking medication (Taylor, 1991). A mutual relationship between the two is characterised by equal involvement in decision making and has been described as a meeting between two experts who participate in the same subject by exchanging ideas and sharing coping strategies and belief systems (Morgan, 2003). However, past studies indicate that both parties do not always share the same opinions and attitudes towards each other. For example, patients tend to believe that when the doctors see their patients and announce them their diagnosis, then they do not show any propensity in curing these patients (Taylor, 1991). Additionally, numerous patients have reported mistrust towards their doctors as they felt that doctors did not always have their best interests in mind. Sometimes patients feel they are simply a statistic on the doctors' books rather than being treated as a human being in need of help (Remien et al., 2003). Conflicts between the doctor and the patient based on their values derive also especially in relation to abortion, homosexuality, AIDS and other conditions or behaviours invested with moral evaluations. (Morgan, 2003).

Additionally, there are times when patients have identified unreasonable stigma and prejudice associated with HIV/AIDS among practicing doctors and medical undergraduates (Kelly et al., 1987, Shapiro et al., 1992; Cooke & Sandle, 1989: Robinson, 1998).

On the other hand, doctors often report themselves as adopting patient centred styles in caring environments and to be flexible in response to patients' uniqueness (Morgan, 2003). Nevertheless, there are doctors who have said that they do not have time to discuss with patients in a caring environment because of the pressures of large patient loads and some of them have admitted that they do not feel comfortable talking about patients' personal lives (Yee, 2003).

Rakel et al., (2009) conducted a study concerning the influence of doctors' empathic attitudes towards 350 individuals who were asked to contact the researchers as soon as they noticed the first sign of a cold. According to this study the empathic style had positive influences on patients' recovery. According to the above mentioned study, empathy and attentiveness did affect patients' quicker recovery from a cold. The doctors involved had received training from actors so as to show a more empathic and understanding attitude towards half of the participants, while being less understanding and warm towards the remaining study participants. In total, 84 of the participants gave high empathic scores for doctors that showed empathic attitudes and tended to recover one day earlier from the cold than the remaining participants who had given low their doctors low scores of empathic attitudes (Rakel et al., 2009).

Apart from empathic and understanding styles "*researchers have argued that social cognitions held by health care providers about patients' racial/ethnic groups can also contribute to racial/ethnic disparities in treatment decisions*" (van Ryn, 2002; Bogart et al., 2004, p. 1049).

Doctors' empathic and understanding styles or attitudes towards patients are not the only issues though, as "*although having less power than doctors in the consultation, patients can nevertheless influence the interaction by their willingness or otherwise to ask questions and assume a more participative role"* (Morgan, 2003, p. 56).

Moreover, communication styles between doctors and patients are affected by age, social status and educational level. Younger people, people with high social and educational attainment participate more actively in patients'-doctors' consultations (Morgan, 2003). It seems that when the status gap between the doctors and patients decreases then better communication occurs between them (Morgan, 2003). Additionally, there is evidence that when patients are educated, doctors tend to provide more information and explanations to the patients during the consultations (Morgan, 2003).

According to the abovementioned issues, it seems that the patients' position is quite different from the doctors' in regards to the communication between them during the consultations. The present study aimed to explore this issue in depth and in relation to HIV positive people and their medical regimes as little information was available in regards to the relationship between health care professionals and patients in the experience of HIV/ AIDS and medical compliance.

2.12 HIV in the Greek Context

As mentioned above, the aim of the present study was the gaining of an insight into how psychosocial, cultural factors along with the everyday life and gender/identity issues might influence compliance with HIV medication within the cultural context of Greece. This required attention to the construction of Greek society as well as an examination of Greek culture.

However, in order to explain the role of culture, a definition of what constitutes ‘‘culture’’, no matter how limited, is required. According to the literature (Gould and Marsh, 2004; Healthlink, 2007, p.2) culture consists of the following:

- Culture as context factors specific to local life: beliefs, value systems, history, geography, social hierarchies, gender, faiths, and concepts of time.

- Culture as content languages, practices, objects, traditions, clothing and heritage.

- Culture as method, the medium or cultural forms that projects will use to engage/communicate with communities eg drama, dance, proverbs, song, music, video, radio or television.

- Culture as expression of the intangible, creative elements of culture that connect with our beliefs, values, attitudes, feelings and ways of viewing the world.

In other words, the cultural context in which communities exist, involve geography and history, traditions and heritage, cultural forms that help communication with the communities and finally beliefs and values that influence communities and their view of the world. According to research (UNESCO, 2000; Healthlink, 2007,) a worldwide health crisis such as HIV/AIDS is deeply rooted in personal and social issues which are linked to culture. Hence, HIV and AIDS influence people’s cultural and social lives.

An additional challenge in regards to HIV/AIDS is the ability of the science world to deliver a message that will affect people and manage to be heard in a way that it holds cultural significance (Healthlink, 2007). Up until now, communication models to deliver such messages have been criticised as being overly westernised (Marsh, 2004;

Healthlink, 2007), therefore not always relevant to Eastern cultures. Hence, the current study aimed to examine compliance/non-compliance issues and make them understandable not only by examining the HIV positive peoples' perspective, but also by exploring the underlying cultural beliefs of these people within today's Greek society.

The history of the development of the HIV/AIDS epidemic in Greece has been monitored by the Hellenic Centre for Infectious Diseases Control which comes under the Ministry of Health and Welfare. The Ministry provides HIV testing and services to inpatients and outpatients without any financial encumberment. The reporting of AIDS cases became mandatory in 1984 and four years later the reporting of HIV cases became mandatory as well. According to the Hellenic Centre for Infectious Diseases Control (or else KEELPNO) which released an epidemiological report of HIV/AIDS statistics from 1984 – 2001 the total number of HIV and AIDS reported cases was 5.859 in which the majority were male patients (80.9 per cent) and a smaller number were females (18.4 per cent) (Best, 2003, p.1-2). Throughout the decade of 1990 the HIV/AIDS reported cases were steadily and significantly increasing. Due to that, more attention was paid in the matter and further public education took place. After that intervention, at the beginning of the next decade the rates were not as high as they were during the 1990's (Best, 2003, p.1-2).

Since the beginning of the 2000's (2000-2001 statistics) the HIV/AIDS statistics followed a similar pattern whereby the majority of reported cases were males and fewer reported cases were females. As far as the mode of HIV transmission of all recorded cases, sexual contact continued to be the most common. Nevertheless, it was only recently that Greece was becoming more aware of issues of sex education, and one reason that it was happening was the fear of HIV/AIDS (Best, 2003). However, by the end of 2011 the total number of reported HIV infections (including AIDS cases) in Greece had increased to 11.492. Among them 9.346 (81.3 per cent) were males and 2.098 (18.3 per cent) were females (Nikolopoulos et al., 2011). The following figures (Figures 2.1 and 2.2) highlight the reported HIV infections in Greece by 31/12/2011 and the HIV infections by year of diagnosis by 31/12/2011:

Figure 2.1

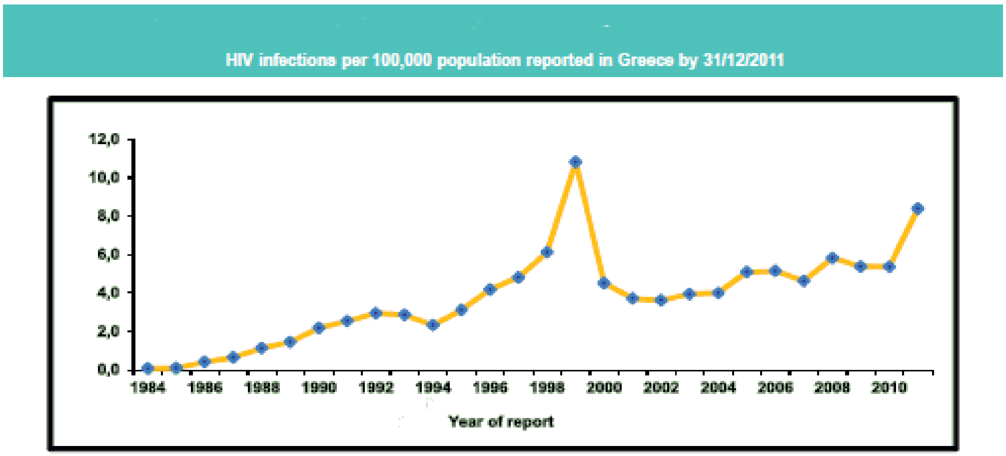
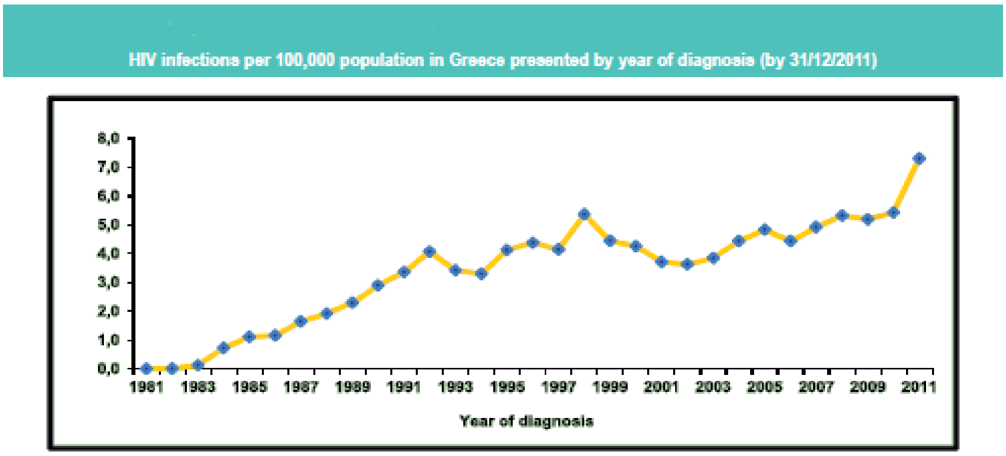


Figure 2.2



Considering the fact that the rates of HIV reported cases are steadily increasing, it is worth to wonder, how this phenomenon is dealt with in Greek society. According to Best (2003), the family and the home are integral units of organisation within Greek society, followed by community and then nation. Hence, dealing with an epidemic as HIV/AIDS resides more within the family context than being perceived as a worldwide health phenomenon. However, in Greece the family does not only include biologically bonded members. Rather, it involves members from the family of origin (biological relationships) and family of choice (non-biological relationships such as friends). Here, it is important to highlight that Greek families exhibit different behaviour patterns from other cultures. In Greece, the family is considered as a solid institution in which the members are expected to share each other's problems and count on each other's help in periods of crisis (Sachperoglou & Bor, 2001).

Hence, the family is considered as a strong matter in the Greek society's culture. However, a detailed exploration of the Greek family system was not included in this study due to certain restrictions of such a study (word limit, risk of becoming off the point of the topic/verbalism). Nevertheless, any findings regarding that topic were considered as valuable and treated as a route to address understandings of compliant/non-compliant issues in Greece.

Through the overview of the literature review there were certain questions that arose. These questions as well as the aims of the present study are going to be presented and examined in depth during the following chapter. Apart from the above, the purpose of the following chapter includes the methodological procedures such as the design of the present study, the participants' selection, the data collection and the data analysis.

2.13 Chapter Summary

In this chapter, a review of the current knowledge on issues of compliance and non-compliance has been discussed. This has been accomplished through an extended review of the previous work within and out of the Greek context on socio-cultural positioning, general health issues, psychosocial factors everyday life issues, gender and identity issues and doctors and patients relationship that are associated with compliance. The following chapter presents methodological, practical and ethical issues that are related to the research objectives and research questions.

CHAPTER THREE: METHODOLOGY

3.1 Aims of the Research

The purpose of this chapter is to present the aims and the design of the research including the methodological procedures and the choices that have been made by the researcher. The aim of this work was to examine the psychological, social and cultural factors which impact on people living with HIV and taking antiretroviral therapy. The five key objectives and linked research questions are the following:

1. The examination of the psychosocial factors influencing compliance to medication/treatment regimens amongst HIV/AIDS positive individuals.

   Research Questions: What are patients' thoughts and feelings about HIV and medical treatment?

   - What is the impact of education/lifestyle/support network on compliance with medical treatment in people living with HIV?

   - How might economic status influence individuals' compliance to medical treatment of people living with HIV?

2. The exploration of the ways in which issues of identity and gender may influence compliance to medication/treatment regimes in people with HIV.

   Research Question: What roles do (sexual) identity and gender play in dealing with the virus and associated medical treatment?

3. The exploration of compliance to medicalization in everyday life for HIV/AIDS individuals.

   Research Question: How does taking medications fit into everyday life and impact on social relationships in people with HIV?

4. The exploration of how the relationship between health care professionals and HIV positive individuals impacts on compliance to treatment.

   Research Questions: How does the doctor-patient relationship influence patient compliance to HIV medication?

- What are patients' expectations of their doctor and of medication?

5. The understanding of the socio-cultural positioning of HIV positive people and how such positioning influences compliance to medication.

Research Questions: What are the patients' perceptions of the position of HIV positive people within society?

- How might such perceptions underpin compliance to medication?

6. The examination of participants' general health status.

Research Question: Is an HIV positive person's general health status implicated with compliance to HIV medication?

To begin this investigation, an explanation of the epistemological considerations and the methodological approaches used is presented in the next sections.

3.2 Research Paradigm: Pragmatism

According to Guba & Lincoln (1994, p.105; Denzin & Lincoln, 2005) the paradigm is defined as "the basic belief system or world view that guides the investigator, not only in choices of method but in ontological and epistemological fundamental ways". As such, the direction of any research enterprise is influenced by the paradigm that the researcher works with (Guba, 1990; Gini, 2008). Therefore, paradigms are individual structures that provide understanding of different phenomena then address issues of epistemology, ontology, methodology (Denzin & Lincoln, 1998) and finally ideology (Nelson & Prilleltensky, 2005). In terms of explaining:

In the context of knowledge sharing, the use of the term ontology means a *specification of a conceptualization*. That is, ontology is a description (like a formal specification of a program) of the concepts and relationships that can exist for an agent or a community of agents. This definition is consistent with the usage of ontology as set-of-concept-definitions, but more general. And it is certainly a different sense of the word than its use in philosophy.

Ontology is related to the nature of "reality" and what can be known about this reality (Guba & Lincoln, 1994). Hence, ontology is a description of the concepts and relationships that may exist among communities or an agent (Gruber, 1993).

Epistemology concerns the relationship between what can be known and the researcher himself (Guba & Lincoln, 1994). Epistemology relates to an examination of the status of knowledge or more specifically, it deals with how we know things in the world. Epistemology underpins the methodological choices we make in order to conduct research. When we talk about epistemology, we mean the philosophical choices we make between rationalism and empiricism or the scientifically based methodological choices between positivism and humanism (Bernard, 2000).

Methodology refers to the methods that the researcher chooses in order to find out what can be known (Guba and Lincoln, 1994). A vast range of methods is available for research, often, but not exclusively, linked to particular paradigmatic views. For instance, experiments are associated with positivistic ways of understanding knowledge and the world, while narrative interviews fall more within the constructionist paradigm.

Ideology refers to the possible different values that the researcher and the participants bring to the research design and process. For example if the researcher and participants believe that there is a “single factual reality” that can be discovered via research, then the research methods will be chosen to reflect this and the results interpreted objectively. However, if research and participants accept that there are “multiple realities” then methods chosen and interpretation frames applied would encourage the range of ‘‘multiple realities’’ to emerge (Nelson & Prilleltensky, 2005a).

There are a number of different paradigmatic views that underpin research. These include: positivism, post-positivism, constructivism, critical theory and a range of interpretive paradigms (Denzin & Lincoln, 2005; Nelson & Prilleltensky, 2005) as well as pragmatism (Tashakkori & Teddlie, 1998,). Given the diversity of paradigms described, four paradigms underpin much of the present research orientations. These are positivism, post-positivism, constructionism and pragmatism. A comparison of the four dominant paradigms is outlined on table 3.1 of the following page (taken from Tashakkori & Teddlie, 1998, p23):

Table 3.1: Comparison of the four dominant paradigms

PARADIGMS				
	POSITIVISM	**POST- POSITIVISM**	**CONSTRUCTIVISM**	**PRAGMATISM**
EPISTEMOLOGY	Objective point of view. Knower and known exist in a dualistic relationship.	Modified dualism. Findings are interpreted as probable objective "truth".	Subjective point of view. Knower and known are inseparable.	Both objective and subjective points of view are accepted as valuable.
ONTOLOGY	Naive realism.	Critical or transcendental realism.	Relativism.	Accept external reality. Choose explanations that best produce desired outcomes.
CAUSAL LINKAGES	Direct cause and effect relationships are sought whereby real causes are precedent to or simultaneous with effects.	There are some reasonably stable relationships among social phenomena. These may be known imperfectly. Causes are identifiable in a probabilistic sense and changes over time.	All entities simultaneously shape each other. It is impossible to distinguish causes from effects.	There may be causal relationships, but we will never be able to pin them down.
IDEOLOGY	Inquiry is value-free and totally objective in orientation.	Inquiry involves values, but they may be controlled.	Inquiry is value-bound.	Accept values play a large role in interpreting results.
METHODS	Quantitative such as experiments, questionnaires etc	Primarily quantitative	Qualitative such as semi-structured interviews	Qualitativeand quantitative are both seen as providing useful information

As explained earlier, the choice of paradigm impacts on all aspects of the research process. In the current context, research questions demand both qualitative and quantitative data and hence the pragmatic paradigm was chosen as the framework for the current methodology. The pragmatic paradigm accepts both the existence of factual and socially constructed knowledge and sees the researcher as occupying different positions in relation to the data collected (both as objective and subjective depending on the information sought) (Johnson & Onwuegbuzie, 2004). In this, causal relationships may exist, but pinning them down may not be possible (and indeed may never happen in any new piece of research).

In its attempt to reach understanding of research phenomena that is then useful/applied in the world, pragmatic researchers emphasise the idea that what is important in research is understanding, explanation and ‘‘workability’’, rather than paradigmatic dogmatism. Johnson and Onwuegbuzie (2004, p.18) stated that, “*the project of pragmatism has been to find a middle ground between philosophical dogmatisms and scepticism and to find a workable solution (sometimes including outright rejection) to many longstanding philosophical dualisms about which agreement has not been historically forthcoming.”*

The main characteristics of pragmatism are extensively presented at the table 3.2 of the following by Johnson and Onwuegbuzie (2004, p18)

Table 3.2: Characteristics of pragmatism

- Rejects traditional dualisms (e.g., rationalism vs. empiricism, realism vs. antirealism, free will vs. determinism, Platonic appearance vs. reality, facts vs. values, subjectivism vs. objectivism) and generally prefers more moderate and commonsense versions of philosophical dualisms based on how well they work in solving problems.

- Recognizes the existence and importance of the natural or physical world as well as the emergent social and psychological world that includes language, culture, human institutions,and subjective thoughts.

- Places high regard for the reality of and influence of the inner world of human experience in action.

- Knowledge is viewed as being both constructed *and* based on the reality of the world we experience and live in.

- Replaces the historically popular epistemic distinction between subject and external object with the naturalistic and process oriented organism-environment transaction.

- Endorses fallibilism (current beliefs and research conclusions are rarely, if ever, viewed as perfect, certain, or absolute).

- Justification comes in the form of what Dewey called “warranted assertability.”

- According to Peirce, “reasoning should not form a chain which is no stronger than its weakest link, but a cable whose fibers maybe ever so slender, provided they are sufficiently numerous and intimately connected” (1868, in Menand, 1997, pp. 5–6).

- Theories are viewed instrumentally (they become true and they are true to different degrees based on how well they currently work; workability is judged especially on the criteria of predictability and applicability).

- Endorses eclecticism and pluralism (e.g., different, even conflicting, theories and perspectives can be useful; observation, experience, and experiments are all useful ways to gain an understanding of people and the world).

- Human inquiry (i.e., what we do in our day-to-day lives as we interact with our environments) is viewed as being analogous to experimental and scientific inquiry. We all try out things to see what works, what solves problems, and what helps us to survive. We obtain warranted evidence that provides us with answers that are ultimately tentative (i.e., inquiry provides the best answers we can currently muster), but, in the long run, use of this “scientific” or evolutionary or practical epistemology moves us toward larger Truths.

- Endorses a strong and practical empiricism as the path to determine what works.

- Views current truth, meaning, and knowledge as tentative and as changing over time. What we obtain on a daily basis in research should be viewed as provisional truths.

- Capital “T” Truth (i.e., absolute Truth) is what will be the “final opinion” perhaps at the end of history. Lowercase “t” truths (i.e., the instrumental and provisional truths that we obtain and live by in the meantime) are given through experience and experimenting.

- Instrumental truths are a matter of degree (i.e., some estimates are more true than others). Instrumental truth is not “stagnant,” and, therefore, James (1995: 1907) states that we must “be ready tomorrow to call it falsehood.”

- Prefers action to philosophizing (pragmatism is, in a sense, an anti-philosophy).

- Takes an explicitly value-oriented approach to research that is derived from cultural values; specifically endorses shared values such as democracy, freedom, equality, and progress.

- Endorses practical theory (theory that informs effective practice; praxis).

- Organisms are constantly adapting to new situations and environments. Our thinking follows a dynamic homeostatic process of belief, doubt, inquiry, modified belief, new doubt, new inquiry, in an infinite loop, where the person or researcher (and research community) constantly tries to improve upon past understandings in a way that fits and works in the world in which he or she operates. The present is always a new starting point.

- Generally rejects reductionism (e.g., reducing culture, thoughts, and beliefs to nothing more than neurobiological processes).

- Offers the “pragmatic method” for solving traditional philosophical dualisms as well as for making methodological choices.

As can be seen from the above characteristics pragmatism, instead of examining complex philosophical concepts, considers “truth to be what works”, something that pragmatism has been criticised for as being *“naive”* (Tashakkori & Teddlie, 1998). And as in the case of all paradigms, pragmatism has been criticised on a number of counts. As Johnson and Onwuegbuzie (2004) have suggested, pragmatism tends to neglect ‘‘pure’’ or ‘‘basic’’ research in favour of applied research. This could create lack of understanding of the basic ‘building blocks’ of knowledge which are required to progress science. As such, incremental change in society is more possible that ‘‘fundamental, structural or revolutionary change’’ (Johnson and Onwuegbuzie, 2004 p.19).

In addition, in its emphasis on ‘‘workability’’, attention to power relations and how these structure research can be less important within the pragmatic paradigm than elucidating who the research might benefit and why (Mertens, 2003). Some critics of pragmatism have questioned the basic definition of ‘‘workability’’ which is often left by researchers as a vague principle of attainment in pragmatic research (Johnson and Onwuegbuzie, 2004). In addition, the use of the pragmatic paradigm by research has been seen as an ‘‘easy option’’ choice, since the researcher can then avoid dealing with difficult philosophical disputes about the nature of reality and the place of the researcher within knowledge creation. Finally, for some neo-pragmatists and postmodernists such as Rorty (Johnson & Onwuegbuzie, 2004), acceptance of a single ‘‘truth’’ that can be discovered via research is not a possibility. Pragmatism is not then acceptable as a paradigm because of its accommodation of such ‘‘truth’’.

In the context of the current research, such criticism are seen as problematic but not sufficient to invalidate the value of the paradigm. In essence, the current research posits that the adoption of mixed qualitative and quantitative approaches will enable the production of information which will contribute to development of scientific knowledge in the field of compliance to medication concerning people living with HIV. The methods chosen by a researcher are appropriate when they achieve their purposes (Maxcy, 2003). Therefore, mixed methods are not seen as better than single methods, their value lies in their appropriateness (Seale, 2004).

The purpose of the present study was the exploration and understanding of the numerous psychosocial factors that might influence compliance to taking medication in HIV positive individuals. Over recent years, whilst being a volunteer at a drop-in centre working with HIV positive individuals, I realised that some people were not complying with their antiretroviral therapy, although they could see the advantages of it. They came from different cultural, social and economic backgrounds, but held similar attitudes towards compliance to medication. The mixed methods approach was chosen as a way to access the different factors responsible for such behaviours.

3.3 A Mixed Methods Approach

In mixed methods approach means that both qualitative and quantitative methods are used within the same methodology. Here, attention is paid to both nomothetic and idiographic frameworks. Nomothetic frameworks examine issues and assumptions across many cases whereby information is accumulated from several individuals such as in questionnaire data. Idiographic frameworks focus on the meanings of single cases (Bernard, 2000). The advantage of conducting nomothetic research is that the research is more ‘objective’ in the sense that idiosyncratic responses are nullified. However, one disadvantage of it is that it neglects to properly account for situational context as rich data is not taken into account. On the other hand, although the idiographic process gives lot information regarding the contextual meanings of peoples’ actions, it tends to neglect the intrapersonal relationships between them (Bernard, 2000).

According to Reich et al. (2000, p 4), “*findings at different levels of analysis need not be regarded as contradictory. Idiographic and nomothetic research paradigms may enjoy equal scientific status, complementing one another in their respective images of the empirical world.”*

Therefore, one of the main questions regarding qualitative and quantitative research is the differences between them and whether these are important (Spicer, 2004; Seale, 2004). However, Tasshakkori and Teddlie (2003) argue that the combination of qualitative and quantitative methods can give answers to researchers in ways that none of the single methodologies would ever be able to do. In addition, according to Ostrow and Kessler (2002) qualitative and quantitative methods differ in their purposes, goals, objectives, tactics, strategies, strengths, and weaknesses. As such, a more comprehensive set of research questions can be posed in mixed methods research.

The original questions that drive a research project can lead onto new questions that emerge during the process of conducting research which sometimes require the use of mixed methods. As a result of this, many researchers use ‘‘multi-mixed’’ measurement techniques (Ostrow & Kessler, 2002). As mentioned above, the aim of the present study was to examine psychosocial, cultural, identity and gender factors underpinning compliance to HIV medication regimes. A mixed methodology of questionnaires, diaries and interviews was appropriate to address and examine in a more holistic way the above complex issues.

According to an extensive literature review of Greene et al. (1989), there are five main purposes of using a multi-mixed method approach:

> *a) "Triangulation or seeking convergence of results",*
> *b) "complementarity, or examining overlapping and different facets of a phenomenon",*
> *c) "initiation, or discovering paradoxes, contradictions, fresh perspectives",*
> *d) "development, or using the methods sequentially, such that results from the first method inform the use of the second method", and*
> *e) "expansion, or mixed methods adding breadth and scope to a project"* (Greene et al., 1989 in Tashakkori & Teddlie, 1998, p.43).

Considering all of the above factors, the possibility to:

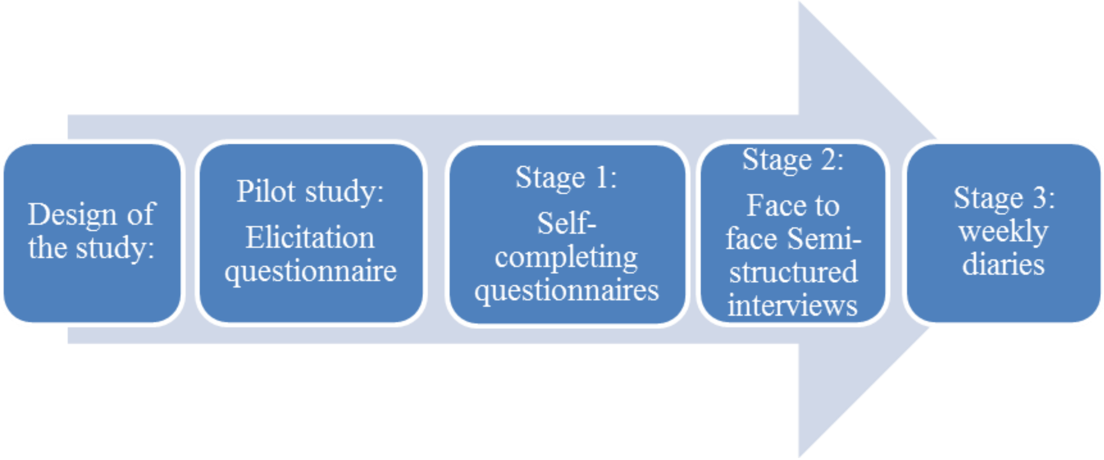
- establish confidence through triangulation of the different data sets,
- the complementarity of qualitative and quantitative data which will help to extend understandings of the complex issues involved,
- the opportunity to develop new insights into this area of research via interviews and diaries where participants are free to discuss matters important to them,
- learning gained from the questionnaires as input to interview and diary data collection and
- the breadth and scope enabled through the use of all methodologies

led to a mixed methodology being chosen for this investigation. This would provide understandings of compliance and non-compliance factors and issues in a holistic way. And it is only when such understandings are achieved that medical regimes can be devised to alleviate problems of non-compliance, thereby satisfying the key mission of the pragmatic paradigm to produce useful, applied and workable information.

3.4 Design of Study

The design of the study involved a pilot study and three stages of the main research and employed a multi-mixed methodology, which aimed to examine issues of compliance behaviours from different perspectives (Seale, 2004).

Figure 3.1



Stage 1: The first stage, addressing research question 1, involved self-completing questionnaires that examined the psychosocial factors underpinning compliance to medication. These were designed taking into account current knowledge gleaned from the literature review, data derived from initial elicitation questionnaires and tested in pilot studies.

The questionnaire examined psychosocial factors: self-esteem, anxiety and depression, personality, coping, locus of control, support network and quality of life. The extent to which participants had experienced living with HIV, complying with antiretroviral therapy and co-operating with health care professionals was measured using the self-completion ‘‘Living with HIV’’ Questionnaire. The type of questions aimed to be easily completed by participants, as the questionnaires would be self-completed (Gilbert, 2001).

Self-administered questionnaires were used to reduce levels of sensitivity potentially experienced by participants, reduce the time demands placed on the researcher and enable a larger sample to be involved providing a wider coverage of population (Pedhazur & Pedhazur Schemelkin, 1991). A fuller description of the questionnaire is given in Appendix 6. Stage 1 allowed the examination of the following research questions:

1) The examination of the psychosocial factors influencing compliance to medication/treatment regimes amongst HIV/AIDS positive individuals.

Research Questions: What are patients' thoughts and feelings about HIV and medical treatment?

- What is the impact of education/lifestyle/support network on compliance with medical treatment in people with HIV?
- How might economic status influence individuals' compliance in people with HIV?

Stage 2: The second stage, addressing research questions two, four and five (see below), involved face-to-face semi-structured interviews to explore issues of identity, gender, the relationship between doctors and patients and social understandings of HIV within society and how these impact on compliance to medical regimes. The reason for choosing face-to-face interviews, instead of telephone or e-mail interviews was because face-to-face interviews are often described as one of the best ways to collect information that is more detailed regarding participants' past experiences, values, thoughts and beliefs (Foddy, 1993). E-mail or telephone interviews would constitute a risky option for the current research as if the interviews will not be short people may hang up (Bernard, 2000). Hence, telephone interviews might limit the amount of collected data.

Face-to-face semi-structured interviews enabled an in-depth discussion of issues of identity, gender, the relationship between doctors and patients, everyday experience and social understandings of HIV within society (See Appendix 7). During a semi-structured interview process open ended questions, answers and statements are not limited to a specific tightly defined interview schedule and the researcher has the opportunity to address more complex issues as they arise in the interview conversation and probe deeper into participants' meanings and reasoning (Pedhazur & Pedhazur Schemelkin, 1991).

Stage 2 allowed the examination of the following research questions:

2) The exploration of the ways in which issues of identity and gender may influence compliance to medication/treatment regimes in people with HIV.

Research Question: What roles do (sexual) identity and gender play in dealing with the virus and associated medical treatment in people with HIV?

4) The exploration of how the relationship between health care professionals and HIV positive individuals impacts on compliance to treatment.

- Research Questions: How does the doctor-patient relationship influence patients' compliance to HIV medication?
- What are patients' expectations of their doctor and of medication?

5) The understanding of the socio-cultural positioning of HIV positive people and how such positioning influences compliance to medication.

Research Questions: What are the patients' perceptions of the position of HIV positive people within society?

- How might such perceptions underpin compliance to medication?

Stage 3: The third stage, addressing research question three, involved participants living with HIV completing weekly diaries to document compliance actions, thoughts and feelings and reveal the ways medical regimes fit into everyday life (See Appendix 8). The reason of choosing diaries among other qualitative approaches, such as observations was that diary keeping is a natural and simple way of collecting data where actions, thoughts, feelings can be recorded easier and provide the researcher with documented valuable information (Boulton, 1994).

Diaries are valuable for the reason that "*as in content analysis, diaries are usually written in natural language format, and are subject to the same forms of analysis including syntactic, semantic and thematic analysis*" (Boulton, 1994, p.127). The diary methodology was completed over one week and documented compliance, thoughts and feelings and the way medical regimes fitted into everyday life. The reason for using weekly diaries instead of one day was because with this way more information regarding the participants' weekdays and weekends could be collected and would enable the participants' weekly routines to be open for the research. Additionally, weekly diaries could keep participants motivated and as well as were less demanding than monthly ones. Using a diary methodology enabled the researcher to capture details regarding the sequencing, duration, frequency and social and environmental context of behaviours (Bernard, 2000). More information regarding the completion and authenticity of the diaries is presented in sections 3.9 and 3.10.

Stage 3 allowed the examination of the following research questions:

3) The exploration of compliance to medicalization in everyday life for HIV/AIDS individuals.

Research Question: How does taking medications fit into everyday life and impact on social relationships?

The use of qualitative approaches in stages 2 and 3 of the current research allows the investigation of issues in more depth and the understanding of the role of context in compliance behaviours and feelings within the experience of lived everyday life.

3.5 Research Location and Procedure

The fieldwork for this study took place in the department of Infections Units at three Greek Hospitals (A, B, and C), at a governmental hospice for HIV positive homeless people and finally at a Non-Governmental Organisation (NGO) for HIV positive individuals, in Athens, Greece. The study was carried out between June 2005 and February 2006. Doctors and psychologists co-operated with the researcher to support the study. Only hospital A and the NGO included input from a psychologist in their programme.

Hospital A: Was one of the biggest in Athens for general pathologies. One of its departments is the transmitted infections unit. In hospital A, as in all other hospitals, the transmitted infections unit was located on the ground floor at the back of the building. The unit was small and had two offices where patients visited their doctors. The available staff team comprised doctors, a psychologist and two secretaries. There were approximately 300 HIV positive patients. Potential participants were approached in the corridor outside the offices where some chairs and a desk with information leaflets concerning sexual transmitted infections were placed. Regarding the three hospitals, the individuals who attended, were visiting the clinic for their usual check-up that happens approximately every three months or for being supplied with the monthly antiretroviral therapy.

Hospital B is also one of the biggest hospitals in Athens for general pathologies. In hospital B, the infections unit was placed on the ground floor at the back of the building. The unit of this hospital was very small, had two offices and a waiting area. The available staff consisted of doctors and a nurse. There were approximately 500 HIV positive patients at this hospital. Participants were approached only through doctors' as the policy of the hospital was not permitting any contact between the researcher and the participants. Questionnaires, envelopes and stamps were provided to the doctors who were informing the HIV positive visitors of the unit about the research issues. After this process the completed questionnaires were posted by the HIV positive participants to the researcher.

Hospital C constitutes the largest sexual transmitted diseases unit in Athens. In hospital C, the infections unit was placed at the side of the main building of the hospital in a separate smallest building. The available team staff comprised of doctors, nurses and secretaries. There were approximately 600 HIV positive patients at this hospital. As in hospital B there was no contact between the researcher and the optional participants. The procedure that was followed regarding the approaching of the HIV positive visitors of the hospital was the same as in hospital B.

In all three hospitals, HIV positive patients were treated by a team of doctors who were specialised in (sexually) transmitted infections.

The **governmental hospice**, provided accommodation for homeless individuals who were living HIV positive. The governmental hospice was located in a building provided by the Greek Centre of Infectious Diseases Control (KEELPNO) in a deprived area of Athens. The building was old but the internal environment was well appointed. It provided fourteen beds for HIV positive male and female individuals, Greeks or immigrants. Apart from the rooms where residents were sleeping, there were some communal areas such as the kitchen or the living room. Hospice staff consisted of the manager of the hospice, a psychologist, a social worker, a nurse and other auxiliary (such as cleaning, security) staff. Potential participants were approached by the researcher and the psychologist of the hospice in their rooms or the communal areas of the hospice. The researcher was providing the participants with the questionnaires, an envelope and a pen. It was explained to them that they could use as much time as they needed so as to complete the questionnaires. The researcher was waiting in an office of the hospice so as to give any possible definitions or explanations to the participants. After a few hours of waiting the participants were handing in the completed questionnaires to the researcher.

The **NGO** was attended by HIV positive males and females visiting the drop in centre twice a week. The NGO is a non-governmental organisation that is financially supported from bazaars (market with clothing, books and so on being sold at very low prices) that occur twice a year, and donations. It provided two living rooms, an info-centre, a kitchen and a water closet. The staff consisted of a psychologist, a social worker and a secretary. Apart from the working staff, the NGO also used volunteers to provide emotional support for HIV positive people. The researcher was providing the participants with the questionnaires, an envelope and a stamp. After this process the completed questionnaires were posted by the HIV positive participants to the researcher.

3.6 Pilot Study

The pilot study was divided according to the three stages of the research. All methods used were piloted with people living with HIV in Greece.

3.6.1 The Elicitation Questionnaire

The content of the pilot elicitation questionnaires was developed through the literature review where key issues were identified and issues arising from the delivery of an open ended elicitation questionnaire (See Appendix 11). Elicitation questionnaires are a data collection technique that involves three major forms: direct observation (technologically monitoring such as heartbeat), self-report (information provided by the participants) and archival methods (information recorded for other purposes than research) (Breakwell et al., 2006). These key issues were the following:

- experiences and knowledge of HIV,
- experiences of Doctors since being diagnosed, and
- experiences of taking HIV medication.

The questionnaire consisted of a total of twenty eight items separated in four sections. The first section consisted of six questions concerning participant demographic information. The second section consisted of eight items concerning issues related to experiences and knowledge of HIV. The third section consisted of three items dealing with experiences of doctors since diagnosis and the final section consisted of eleven items addressing experiences of taking HIV medication.

The elicitation questionnaires were constructed with open-ended questions where participants could give their own answers rather than being obliged to choose among closed response sets of given answers (Bernard, 2000). In this way, participants could be more creative and give individual information regarding their feelings, experiences and thoughts. Incomplete sentences were also included in the elicitation questionnaires so as to give the respondents the chance to reveal their inner feelings regarding the issues that were aimed to be explored (Sproull, 1988).

The wording of the elicitation questionnaire was simple so that participants would be able to understand all the questions (Foddy, 1984).

The field work of the pilot study took place in the department of Infections Unit at A and at the NGO for HIV positive individuals, in Athens, Greece. The study carried out between July and September 2004. The pilot was facilitated by the psychologist working in hospital A and the NGO psychologist.

Participants from hospital A that took part in the pilot study were approached with the help of the psychologist of the unit. The later was informing the participants about the research and the researcher and was requesting their participation. However, the participants from the NGO were approached by the researcher herself. The pilot work was conducted with a sample of thirteen (n=13) participants, corresponding to almost 0.2 per cent of the total HIV positive population in Greece. The sample was stratified by sexuality- five (n=5) were homosexual, eight (n=8) heterosexual-, gender -eight (n=8) males and five (n=5) females-, age -between thirty six to fifty nine (36-59) with an average of 47.5- and length of diagnosis -twelve (12) were under HIV medication for more than two years and one less than two years-. Participants were recruited through convenience sampling as during the summer period when the pilot was carried out many potential participants were not around. There were no homosexual female participants recruited as according to the National Statistics of Greece there are no reported HIV positive cases so far (Saroglou, 2002).

3.6.2 Analysis of Elicitation Questionnaire

Elicitation questionnaire data were analysed using content analysis. Content analysis is a technique for gathering and analysing any textual content. Content analysis can be conducted qualitatively as well as quantitatively (Syllabus for Justice, 2004). Content analysis was a useful analytical tool as it offers the chance of analysing all types of communication, and is acknowledged as the one of the methods for analysing open-ended questions (Sproul, 1988). It gives the researcher the chance of re-examining the data and checks their accuracy (Sproul, 1988). However, critics regarding content analysis point to its limitation in making inferences from the data since content analysis analyses only what is written on the text (Syllabus for Justice, 2004).

Analysis involved the reading of responses several times. Subsequent coding was then based on phrases used by participants and their frequency (where similarity of meaning was retained). This analysis enabled the identification of concepts related to compliance including psychosocial factors, issues concerning the socio-cultural positioning of people living with HIV, issues of gender and identity, everyday medicalization and relationships between doctors and patients. Any irrelevant information was taken under consideration. In particular, the content analysis of elicitation questionnaires pointed to the importance of investigating further the following:

1. Psychosocial factors:
    - i. Mental Health (General Health, Anxiety, Depression)
    - ii. Self- esteem
    - iii. Cognitive functioning
    - iv. Patient-provider communication
    - v. Self-efficacy
    - vi. Commitment to medication
    - vii. Personality
    - viii. Coping strategies
    - ix. Life satisfaction
    - x. Locus of control
    - xi. Support network
2. Identity and gender issues
3. Medicalization in everyday life
4. Relationship between health care providers and patients

5. Socio-cultural positioning of HIV positive individuals
    1. Participants’ perceptions regarding medication benefits
    2. HIV positive individuals’ attitudes to HIV and sexuality
    3. Perceptions of health status
    4. Susceptibility of HIV positive individuals’
    5. Perceived severity

These factors, alongside those identified in the literature were then operationalized within the main questionnaire. The decision of which questionnaires were included is going to be explained during the following section.

3.7 Main Questionnaire

3.7.1 Questionnaire Design

The main questionnaire was designed by the researcher to measure the six factors which according to the objectives of the research, the literature review and elicitation analysis were related to medical compliance among HIV positive individuals. The six domains were: 1) psychosocial factors (self-esteem, anxiety and depression, coping, influence of support network, quality of life) 2) general health status, 3) socio-cultural positioning 4) coping with medication 5) relationships with Doctors and 6) identity and gender. The questionnaire was designed for use within the HIV positive population in health care settings across several hospitals in Athens, Greece. It included pre-existing, validated scales (see below) where possible alongside especially designed closed questions, with “Likert type scales” response sets (Bernard, 2000).

At this stage of the research, closed questions were chosen because they can be easily coded in order to measure the level of importance of the issues and are easily completed within a self-completion questionnaire (Gilbert, 2001). The wording was designed to be clearly understood but not too simplistic so as to be easy to understand but not insulting to the participants’ intelligence (Gilbert, 2001). Some of the questions sought secondary information, for the reason that participants’ beliefs regarding other people’s thoughts on HIV positive individuals would be valuable (Gilbert, 2001).

At the end of the questionnaire a number of questions were placed, asking the respondents to make any comments on the questionnaire so as to help the researcher understand how completion had been perceived.

Pre-existed scales were included in the questionnaires in order to measure variables that might influence compliance in HIV positive population. Seventeen well known scales measured the following variables: Personality via the Ten Item Personality Inventory (TIPI) (Goldberg's, 1986), General Health Questionnaire shortened 12 question version (GHQ12), Health Status (SF-36, one item), the Hospital Anxiety and Depression Scale (HADS), Self-esteem (SES), Coping Strategies (CPS), Locus of control with Form C of the Multidimensional Health Locus of Control (MHLC), Life satisfaction (Cantril's Ladder of Life), Attitude Adherence Inventory (AAI), Satisfaction with health care using the Patient Satisfaction Questionnaire, Social support with the Interpersonal Support Evaluation List (ISEL12), HIV Severity, Susceptibility, Direct attitude measure of medication benefits, the Positive and Negative Affect Schedule (PANAS), Experienced symptoms with the HIV-Related Symptoms Checklist (SSC-HIV), coping with medication compliance by using a separate part of AAI.

According to Lewis & Abell (2002, p.111) regarding this part of the scale *"these questions* (coping with medication compliance) *are not scale items and are to be viewed independent of the other AAI construct. The psychometric properties of these items* (178-181, see appendix 5) *were not investigated and were not included in the global scale score."*

In addition to the above, two more scales, designed through pilots and literature review, were used to measure a) the sources of social support which indicated who provides social support in contrast to ISEL 12 which measures participants' perceptions of the perceived availability of social support, and b) attitudes to HIV and Sexuality, with higher scores indicating the better coping of the participants with the factors of each category. Back in 2002 that the research had started, previous research investigated each one of the all the above factors separately or combinations of them, that might influence compliance to HIV medication, but none of them had examined all factors together. Investigating all these factors together was attempted at the present research. Hence, this justifies the length of the main questionnaire. Each scale used at the questionnaire of the study is presented below:

- The measurement of anxiety and depression used the HADS scale (Hospital Anxiety and Depression) (Zigmond & Snaith, 1983). The Hospital Anxiety and Depression Scale (HADS) was designed to measure anxiety and depression in general medical patients. It is a scale that has been used for many years in the United Kingdom and across the world (Osborne, Elsworth, Sprangers, Oort & Hopper, 2004). HADS has been established as a valid and reliable measure, *"a well-performed questionnaire in assessing the symptom severity and caseness of anxiety disorders and depression in both somatic, psychiatric and primary care patients and even in the general population"* (Montazeri et al., 2003, p.1).

- The general health of participants was measured using the General Health Questionnaire (GHQ). Goldberg designed the General Health Questionnaire in 1972 and several shortened versions of this have since been produced. In the current study, the (GHQ12) was used. The GHQ12 was designed *"to identify two main classes of problem: inability to carry out one's normal healthy functions and the appearance of new phenomena of a distressing nature"* (McDowell &Newell, 1987, p. 139). Regarding the validity of the GHQ, numerous validation studies have taken place in several countries and these indicate the high degree of the scale's validity. *"The findings showed that several of the GHQ factors have been stable in spite of the different versions of it"* (McDowell & Newell, 1987, p.148-149).

- Under the area of compliance, the scale used was the Attitude Adherence Inventory. The use of an adherence rather than a compliance scale is that no scale regarding compliance has been designed; additionally, although AAI was not specifically designed for use with people with HIV, it was designed as an instrument for development for the HIV community (Lewis & Abell, 2002). Hudson's (1982) Adherence Attitude Inventory (AAI) was used to indicate the frequency of participant's compliance to medication (Hudson, 1982, cited in Nunnally & Bernstsein, 1994). It is constructed of twenty eight items with an extension of six discussion points related to medication and diet adherence. As above mentioned, these items are viewed independently of the rest of the AAI and their scores are not included in the total scale score due to the fact that have not been investigated yet (Lewis & Abell, 2002).

- Self-esteem was measured with the Self-Esteem Scale (SES). Rosenberg's (1986) Self-Esteem Scale (SES) was widely used as a unidimensional measure of self-esteem (Robinson et al., 1991). SES is used to measure the self-esteem of the participants which according to the literature review and pilots plays an important role in HIV positive individuals lives (Kelly, Lawrence, 1988) and may be implicated in compliance to medication. The Rosenberg's SES has demonstrated good reliability and validity across a large number of different sample groups. The SES has been validated for use with substance abusers and other clinical groups, but also with male and female adolescent, adult and elderly populations (Evaluation Instruments Bank, 2005).

- Measurement of personality was undertaken with the use of the Ten Item Personality Inventory (TIPI). The Ten Item Personality Inventory (TIPI) is a ten item measure of the "Big-Five" personality domains (Gosling, Rentfrow & Swann, 2003). It consists of two items per scale and measures Extraversion, Agreeableness, Conscientiousness, Emotional Stability, and Openness to Experience (Gosling, Rentfrow & Swann, 2003). The central benefit of the TIPI is that it extends the capacity of studies in which the Big Five can be measured because it is a much shorter version (Gosling et al., 2003). *"A second potential benefit of the TIPI is that by providing a standard instrument for use by the research community, knowledge about its psychometric properties and its external correlates can accumulate* (Gosling et al., 2003, p.524). However, according to Gosling et al., (2003) *"Despite the evidence for the value of the TIPI, very short measures are subject to some serious limitations. The first limitation is the psychometric cost of using short measures. Compared with standard multi-item measures of the Big Five, the TIPI is less reliable and correlates less strongly with other variables. The second limitation of brief measures is their inability to measure individual facets of multi-faceted constructs"* (Gosling,, Rentfrow, & Swann, 2003, p. 523).

- In order to measure participants' feelings regarding medication, the Positive and Negative Affect Scale (PANAS) was used. The PANAS (Watson, et al, 1988) consists of two ten-item mood scales and was developed to provide brief measures of Positive Affect (PA) and Negative Affect (NA). The items were derived from a principal components analysis of Zevon and Tellegen's (1982) mood checklist. According to (Crawford & Henry, 2004, p.262), *"The reliabilities of the PANAS scales, as measured by Cronbach's a, were .89 for PA and .85 for NA. The narrowness of the confidence limits associated with* *these coefficients indicate that they can be regarded as providing very accurate estimates of the internal consistency of the PANAS in the general adult population. Thus, both PA and NA scales can be viewed as possessing adequate reliability".*

- In order to measure HIV positive individuals' life satisfaction Cantril's Ladder of Life was used (Bernard, 2000). The Ladder of life is a self-anchored scale with which participants were asked to state their level of satisfaction with life on a scale of one to ten. *"The Ladder Scale has been frequently used, although rarely validated. Using the Ladder Scale, Palmore and Kivett showed considerable stability in life satisfaction in a longitudinal study of 378 community residents aged 46 to 70. Atiknson also showed significant associations between the Ladder Scale results and in life events"* (McDowell & Newell, 1987, p.217)

- Participants' locus of control was measured with Form C of the Multidimensional Health Locus of Control (MHLC) scale. The Multidimensional Health Locus of Control (MHLC) instrument was developed and validated by Wallston and Wallston and colleagues and used to measure health locus of control beliefs. The MHLC measures three dimensions of locus of control beliefs: (1) ''internal,'' (2) ''chance'' external, and (3) ''powerful others'' external beliefs about who or what is responsible for the respondent's health status (Aversa & Kimberlin, 1996). Form C of MHLC scales show concurrent and construct validity as they are moderately stable over time (Wallston, Stein, Smith, 1994).

- Social support was measured with two scales; the first one was Cohen and Hoberman's (1983) Interpersonal Support Evaluation List (ISEL-12). ISEL – 12 is a short version of ISEL that measures participants' perceptions of the perceived availability of social support (Cohen & Hoberman, 1983). *"The ISEL has been used previously with HIV-infected outpatients* (McClure et al., 1996 cited in McClure, Catz & Brantley, 1999, p.160), *and acceptable test-retest reliability for aggregate scores has been demonstrated"* (Cohen et al., 1985, cited in McClure, Catz & Brantley, 1999, p.160). A supplementary social support scale which indicated who provides social support was specially designed for the current research through the literature review and the pilots, since ISEL-12 does not provide this information.

- The experience of symptoms was measured using the HIV-Related Symptoms checklist (SSC-HIV) (Holzemer et al., 1999). The 26-item SSC-HIV is a reliable measure (Cronbach alpha ranged from 0.72 to 0.82) available to use in studies related to symptoms of HIV positive population (Holzemer et al., 1999).

- Health care satisfaction items were adapted from the Patient Satisfaction Questionnaire (Ware et al., 1983; Bogart et al., 2004). This consists of three items indicating participants' overall satisfaction with current health care (alpha = 0.92).

- The following four measurements (perception of health status, susceptibility, perceived severity and participants' perceptions regarding medication benefits) were designed and used in a previous study (Aversa & Kimberlin, 1996) to examine variables related to alteration of antiretroviral therapy.

- Perceptions of health status were measured with one item of SF-36 indicating the health and well-being of participants on a five-point scale with high scores indicating the good health of participants. SF-36 is a new scale measuring health perception in the general population. It is easy to complete and fulfils the criteria of reliability and validity (Brazier et al., 1992). Brazier et al. (1992) indicated the reliability of SF-36 (alpha greater than 0.85).

- Susceptibility of HIV positive individuals' feelings of vulnerability and whether to stop receiving antiretroviral therapy was measured by a three item scale adapted from an established scale of Aversa and Kimberlin (1996) indicating the consequences of stopping HIV medication (Aversa & Kimberlin, 1996).

- Perceived severity consisted of two items adapted from an established scale of Aversa and Kimberlin (1996) indicating the extent to which HIV positive individuals perceived HIV virus (Aversa & Kimberlin, 1996). The perceived severity scale consisted of two items requiring the participant to respond to the statement 'For me HIV/AIDS is...' by marking one of five numbers between two sets of opposites: ‘Not Serious/ Serious’ and ‘Mild/Severe.’ The responses ranged from 1, low perceived severity of HIV, to 5, high perceived severity (Aversa & Kimberlin, 1996).

- The measuring of participants’ perceptions regarding medication benefits was undertaken with the use of nine items adapted from an established scale of Aversa and Kimberlin (1996) indicating the benefits and barriers of antiretroviral therapy according to HIV positive individuals’ perceptions (Aversa & Kimberlin, 1996).
- In order to measure HIV positive individuals’ attitudes to HIV and sexuality a scale of ten items was designed. The scale was separated in two sections indicating HIV and sexuality in general public’s and HIV positive individuals’ opinion.

3.7.2 Pilot of Main Questionnaire

After the questionnaire was designed, it was piloted with two participants. The first participant (1st) was a well educated (University) HIV positive male and the second (2nd) was an HIV positive male with basic education (Highschool). No female participants were included in the piloting stage due to the difficulty in approaching HIV positive females. Approaching females was rather difficult during the study as they were very reluctant to participate due to confidentiality reasons.

The pilot process established the time needed for questionnaire completion and the clarity of questions. Participants needed forty five to sixty minutes to complete the questionnaires and both commented that the questionnaire was too long. Participant 1 found the questionnaire scientific and clearly understood. However, participant 2 found the questionnaire difficult but not impossible to comprehend. Although the pilot process showed that the length of the questionnaires was problematic, it was decided to retain all scales and questions in order to complete more comprehensive coverage of factors identified as important to compliance. This can be considered as a limitation of the study, as the length of the questionnaire possibly contributed to the low response rate. However, participants were well informed about the needed time to complete the questionnaire.

The pilot process established that questionnaires could be given to participants with a provided envelope and a stamp so that they could complete them at home and send them back to the researcher through the postal system. This process proved to be convenient to both participants and researcher and fitted well with the policy of two of the hospitals in which the researcher was not permitted personal contact with participants.

3.7.3 Translation

Translating the questionnaire into Greek proved difficult due to the difficulty of co-operating with the library staff of the Greek Universities in Athens. Translation and back translation (Bernard, 2000) was achieved with the voluntarily work of two Greek psychologists who were both educated in the United Kingdom. The questionnaire was created in English, translated into Greek by the two volunteers and then back translated from Greek to English by the two volunteers. Continuing with the process, the second individual translated the document of the former bilingual translator in the native language of the researcher. After the end of the translation and back translation process there were few changes made on the Greek version of the questionnaires.

3.7.4 Questionnaire Respondents

Eight hundred questionnaires were distributed to HIV positive individuals undertaking antiretroviral therapy, aged 22 to 77 years. However, only 80 (10% response rate) of them participated in the survey and completed the questionnaires. Due to that, the results should therefore be treated with caution, however it was required that the data provided should be shared. The participants derived from different socio-economic backgrounds with different sexual identities (homosexual males, heterosexual males and heterosexual females). None of the participants were newly diagnosed as HIV positive due to ethical considerations of the researcher and the co-operating Hospital Unit doctors who stipulated this.

As it can be seen in the following Table 3.3, the average age of the sample is 43.28 years old with a standard deviation of 10.07 years. Ages ranged from the youngest person at 22 years old and the oldest at 72 years old. 78.8% of the sample was male and 21.3% were female. The majority of the sample (52.5%, n = 42) was homosexual, 33.8%, n = 27 was heterosexual and the remaining respondents 13.8%, n = 11 were bisexual. The majority of the sample (45%, n = 36) had a full time job, 36.3%, n = 29 were unemployed and the rest 18.8% (n = 15) had a part time job. In Table 13

(Appendix 2) type of occupation is given, including teachers, salesmen, painters, trainers, translators and people who are self-employed. However, this data is incomplete since a significant percentage of the sample (46.3%, n = 37) failed to specify occupation. The average income per month of the sample was 852.65 Euros with a standard deviation of 453.329 Euros. Additionally to this the minimum income is 400 Euros and the maximum is 2,500 Euros. Demographic details of the sample are given in appendix 2 (Tables 1-14).

Table 3.3: Key Quantative: Demograchic characteristics and Lifestyle

TITLE	**FINDINGS**
Demographic and Lifestyle Factors	
Age	• M = 43.28; SD = 10.07
Sex	• Male = 78.8%; Female = 21.33%
Sexuality	• Homosexual = 52.5%; Heterosexual = 33.8%; Bisexual = 13.8%
Job	• Full time = 45.0%; Part time = 18.0%; Unemployed = 36.3%
Income	• M = 852.65 Euros; SD = 453.329 Euros

3.7.5 Data Analysis

The analysis involved a variety of statistical methods. The questionnaire data was analysed using descriptive statistics via SPSS11. This was to provide basic information and to increase the researcher familiarity with the characteristics of the respondents and the collected data (Malhotra & Birks, 2003; Pallant, 2003). It is important to add that the majority of the sample indicated that they found the questionnaire very useful in regards of researching the area of HIV (85%, n=68) which means that there was a positive attitude from HIV patients regarding responding to the questionnaire.

In addition, a range of non-parametric tests were used in order to check if ordinal variables influence compliance with HIV medicine, in particular Mann Whitney and Kruskal Wallis were selected for this purpose. Spearman’s rho coefficient was used to establish relationships among compliance with HIV medication and, symptoms, social support, health and psychological factors. The purpose of chosen non parametric tests was that parametric tests need the data to follow the normal distribution. The normality of the data was checked by using the Kolmogorof Smirnov test and the results indicated that did not follow the normal distribution. Therefore non parametric test were selected in order to have robust results. Additionally regression analysis was used in order to identify the influence of many important factors towards the variable concerning the HIV patients' compliance with medication. Finally linear regression was used in order to establish the influence of factors on compliance with HIV medication. Linear regression is the assessment of the linear relationship between a dependent variable and one or more independent variables or covariates (Field, 2005). Finally the significant p-value for the entire research was equal to 0.05.

3.7.6 Validity

In terms of validity, questionnaires need to measure what they are supposed to measure (Cooligan, 1996). By referring to the measurement of validity, we mean "*the degrees to which measures successfully indicate concepts"* (Seale, 2004, p72). Generally, there are two types of validity, the internal and the external validity, where internal validity is *"the extent to which causal statements are supported by a study and external validity is the extent to which findings can be generalised to populations"* (Seale, 2004, p72). It is very important to use valid measures so that internal validity is maintained and that there is an association between variables. However, whilst doing a study external validity should be checked as well in order to ensure that a representative sample was used (Seale, 2004).

In this study, pre-existing scales were used in order to measure the variables that were examined in this research. The results of validity measurement of each scale used in the questionnaire are presented in section 3.7.1 of this thesis.

3.7.7 Reliability

Establishing reliability is important in order to check how consistent and stable the measurements are. Reliability can be divided in terms of internal and external reliability of the measurements. A reliable measure is not influenced by random errors. Reliability can be tested by comparing findings from repeated applications of the same measure with small difference in the circumstances or by comparing the findings in the same circumstances by using measures which are similar in their techniques (Brewer & Hunter, 1989).

The reliability of a scale refers simply to its consistency (Bryman and Cramer, 1999). Three approaches are commonly used to examine the reliability of a scale, namely; test-retest, alternative form and internal consistency (Malhotra and Birks, 2003). However, since the former two approaches require the researcher to administer the questionnaire more than once, internal consistency had been adopted in this project; as data was collected at one time point.

The simplest measure of internal consistency is split-half reliability. However, in order to avoid biases arising as an artefact of how the scale items are split (Sullivan and Gilbert, 2004), Cronbach's alpha reliability coefficient is used; since it represents the average of all possible split-half coefficients resulting from different ways of splitting the scale items (Malhotra and Birks, 2003).

3.7.8 Reliability Analysis: Internal Consistency

Cronbach's alpha coefficient was used to establish how far the scales measure the construct they propose to measure. In order to apply this analysis all questions must have the same direction, either positive or negative. Therefore many questions were reversed in order to have the same direction. As far as the values of Cronbach's alpha the following must be mentioned: values above 0.7 are considered to be good (Field, 2005) which mean that the part of the questionnaire that is being checked is internally consistent. Values falling below 0.7 but close to this value (> 0.6) are considered acceptable. Twenty one different parts of the questionnaire were subject to this reliability analysis for internal consistency. Results are given in Table 3.3 below.

Almost all the values in the Table are above 0.7 indicating that the scales used in this study were reliable. Poor reliability was found for two scales: the personality scale; and items addressing 'Satisfaction with health care' where sixteen of the values were above 0.7, three above 0.62 and only two below 0.6. According to the existing literature, the role of personality in HIV/AIDS has received limited consideration (Penedo et al., 2001). Additionally, the literature has indicated that having faith in the healthcare provider whilst experiencing a trustful and satisfactory relationship seems to influence compliance positively (Vervoort et al., 2007). Hence although the fields of personality and satisfaction with health care showed low levels of reliability in the present study it was chosen to examine every personality trait as well as every characteristic concerning satisfaction with health care so as to evaluate relationships with compliance. It is worth mentioning that variables with high reliability levels were merged into a one variable per scale while those characterised by low reliability levels all variables were examined on an individual basis.

Table 3.3: Cronbach's alpha coefficients scales within the questionnaire

	Factors	Number of items	Cronbach's alpha
1	Personality	10	0.37
2	Health	12	0.78
3	Levels of Anxiety and Depression	14	0.86
4	Self Esteem	10	0.63
5	Coping Strategies	13	0.67
6	Locus of Control	18	0.78
7	Health Care	7	0.85
8	Satisfaction with health care	3	0.15
9	Social Support	12	0.84
10	Attitudes and Sexuality	10	0.62
11	Thoughts about taking medication (Overall)	16	0.89
12	Cognitive thinking	7	0.90
13	Self-efficacy	7	0.86
14	Health Beliefs, Susceptibility	3	0.93
15	Feelings about HIV medication	20	0.79
16	Malaise/Weakness/Fatigue	6	0.86
17	Confusion/Distress	6	0.88
18	Fever/Chills	4	0.76
19	Gastrointestinal Discomfort	4	0.65
20	Shortness of breath	3	0.84
21	Nausea/Vomiting	3	0.74
22	Compliance with HIV medication	4	0.81
23	Commitment to medication	7	0.78

3.8 Interviews

3.8.1 Semi-structured Interview Design

The second stage of the research involved face to face semi-structured interviews. Interviews allow greater ability to obtain rich information from the participants. They give the researcher the opportunity to be flexible within the interview situation and clarify participant meanings (Shaughnessy & Zechmeister, 1997). During the interview the researcher is able to gather information regarding the respondent's opinions, attitudes and behaviours (Pedhazur & Pedhazur Schmelkin, 1991). E-mail or telephone interviews were not appropriate given the sensitive area of the research's topic. Semi-structured, interviews aimed to explore issues of identity, gender, the relationship between doctors and patients and social understandings of HIV within society and how these could be related to medical compliance.

The main reason of choosing semi structured interviews rather than structured and unstructured interviews stems from the need to explore issues from the participants' perspective since it is acknowledged that the participant is the expert on their own experiences. According to Bernard (2000), "*semi structured interviews demonstrate that you are fully in control of what you want from an interview but leaves both you and your respondent to follow new leads"* (p.191). Topics covered in the interview process were:

- Experiencing symptoms
- Being diagnosed
- Medication and Compliance
- Revealing my HIV
- Impact of your social network
- Relationship between Doctors/Health care professionals and you
- The role of the general public on their experiences as HIV positive individuals
- Knowledge of HIV

The topics chosen to be discussed were developed through the literature review and the interview pilot study.

3.8.2 Pilot Interviews

The pilot interviews enabled the participants to lead the conversation however there were many times when interruption was necessary in order to re-focus interviews back onto the topics of relevance to the study. This was especially problematic and could be considered as a limitation of the study as at the beginning of the interviews where participants tended to briefly discuss the process of their diagnosis and then jumped to other issues. Another issue which arose during the pilots laid in helping participants clarify their meanings, especially when discussing issues relating to relationships, general acquaintances and the general public. This translated into clearer instructions during the main research whereby the differences between the two groups of people were made clear to participants. In addition, during the process of the pilot interviews a new topic of interest arose which had not previously been anticipated, this was:

- Social support (Family, friends, colleagues)

Consequently, the design of the semi-structured interviews was amended to be inclusive of pilot findings. Finally, during the pilot study probing techniques used by the researcher were not operating well in terms of eliciting information from participants. Such as requesting a clearer understanding of the participant's incomplete statements or remaining silent when interviewing a hesitant participant waiting for them to continue the conversation. Therefore, during the main research more fruitful probing techniques were used resulting in longer interviews that provided the researcher with more information.

3.8.3 Interviews Equipment

The interviews equipment included the information sheet, the inform consent, a form for participants' demographics, a tape recorder and two pens.

3.8.4 Sample

The interview research sample consisted of ten Greek HIV positive individuals, consisting of seven HIV positive males and three HIV positive females who were undertaking antiretroviral therapy. They were aged 32 to 45 years old. The participants were from different socio-economic backgrounds with different sexual identities. As in the questionnaires, none of the participants were newly diagnosed as HIV positive due to ethical considerations of the researcher and the Doctors of the Hospital Units who were co-operating in the research. Demographic information is given in Table 3.4 on the following page.

3.8.5 Accessing Interview Participants

Interviewees were recruited from the questionnaire sample. All the interviewees had already participated at the first stage of the research that included questionnaires. After completing the questionnaires, participants were informed regarding the interviews which were included at the second stage of the research and volunteered to participate in those too. Nine out of the ten interviewees that participated in both questionnaires and interviews were recruited while visiting the NGO. Finally, one the participants was a patient at hospital A, who approached the researcher himself after reading in the information sheet that there would be another two following stages at the research process. After this first contact the participants had the time to decide whether they would arrange a follow up meeting for the interview process.

Table 3.4: Interview Participant demographics

No	Name	Sex	Age	Date diagnosed	Sexual identity
1	AK	Male	37	1985	Heterosexual
2	PK	Male	45	10/1995	Homosexual
3	FK	Male	40	09/1995	Bisexual
4	GE	Male	37	19/08/85	Homosexual
5	NK	Male	32	2000	Homosexual
6	BK	Male	32	1995	Homosexual
7	GK	Male	44	1994	Bisexual
8	JK	Female	45	1995	Heterosexual
9	MK	Female	41	03/1995	Heterosexual
10	XK	Female	37	07/1992	Heterosexual

3.8.6 Procedure

At the first meeting the process of the interviews was explained to participants. When the participants gave their permission for the interview process a second meeting occurred for the actual interview to take place. The interviews took place mostly in private environments (either participants' or researcher's house). However, some took place in public places such as coffee shops, where the researcher attempted to establish quiet spaces for the interview to progress. The place of the interview was decided by the participants so that they would feel more comfortable with the environment. When interviews took place at the researcher's house, external factors (such as room temperature, provision of drinks and snacks) were accounted for so they would not influence the interview process. When interviews took place at participants' houses control of such external factors was dependent on participants'.

At the beginning of the process the interviewees were provided with an information sheet, an informed consent sheet, a pen and an interview schedule to help them to understand the process, rather than to provide a rigid structure for the conversation. This was made clear to participants. It was clearly explained to them that they had the right to stop the interview at any point if they desired. In addition, it was explained that any private information that they would not want to reveal would be respected and not used in the study. Following this it was clarified that after the end of the interview they would be asked to complete a demographics form. Finally, they were informed that they could contact the researcher if they had any questions or they were not feeling good after the end of the interview. Interviews lasted approximately 1 to 1 ½ hrs. After the end of the interview process the researcher spent time relaxing and talking about several issues to ensure participants were in a good psychological state post interview.

3.8.7 Data Handling: Transcriptions

Interviews were conducted in the Greek language. All interviews were transcribed in Greek. For the purposes of rigour of this thesis, English translation has been made of tracts from many of the interviews to be used as supporting evidence within the findings chapters. In addition, one whole interview was translated into English so that thesis readers can get a flavour of the interview process.

3.8.8 Data Analysis

Thematic analysis was applied to the interview data. This focuses on the identification of patterns and behaviours which are then interpreted in terms of themes (Aronson, 1994). According to Braun & Clarke (2006,p81) "*Thematic analysis can be an essentialist or realist method, which reports experiences, meanings and the reality of participants, or it can be a constructionist method, which examines the ways in which events, realities, meanings, experiences and so on are the effects of a range of discourses operating within society.*"

After collecting the data, the audio taped interviews were transcribed. Interview transcripts were read several times and patterns were identified. After combining the related patterns into sub-themes, themes were identified as units that capture similar meanings and create an understanding of participants' experiences, ideas, feelings and behaviours.

3.9 Diaries

3.9.1 Diary Design

The third stage of the research involved a diary methodology completed over a one week period concerning documented compliance to medication, thoughts and feelings and the way in which medical regimes fit into everyday life. Advantages of the diary methodology concern the reporting of valuable information within a short period of time, something that reduces problems of recollection, compared with other traditional methods of data collection such as interviews (Stopka et al., 2004). In addition, whilst using diaries, fine grained and sensitive information can be captured which may not be accessible through face to face methods of data collection (Huby, 1997; Stopka et al., 2004).

In this study, using a diary method, enabled participants to give more details of their feelings and thoughts of how medication fits in their everyday life (Boulton, 1994). The diaries were designed to be attractive in order to encourage participants to stay motivated to complete them. The cover page was differentiated in colours according to gender. Male diaries were blue and female diaries were pink, so that it would be easier for the researcher to identify them. The first pages of the diaries stated information regarding the aim of the study, completing instructions and written examples. The second part of the diaries consisted of the seven days of a week in coloured pages. Here, participants reported their everyday life, medicalization, the people that were with them during the day and the feelings that they experienced. The final part of the diaries requested demographic information and gave diary respondents an opportunity to comment on the diary experience.

3.9.2 Pilot Diaries

Pilot diaries were given to two participants prior the beginning of the diary data collection. Participants commented that the diaries were very helpful in terms of motivating them to locate feelings and reactions during their everyday life that they had not realised before the completion of the diary. After completion of the pilot study no changes were made to the diaries.

3.9.3 Sample

Nine Greek HIV positive males (n=6) and females (n=3) aged 32 to 41 completed diaries. Demographic information is in Table 3.5.

3.9.4 Accessing Diary Participants

Eight out of nine diary participants were recruited from the NGO and one attended Hospital B. The diary participants were questionnaire respondents who volunteered to participate to this stage of the research as well. After completing the questionnaires, participants were informed regarding the diaries stage of the research as well and volunteered to participate in those too. During telephone contact post hospital attendance, the diary process was explained and participants then decided whether or not to volunteer for the diary stage of the research. There was no face to face contact with these participants as diaries were sent through the post. Diaries were provided to the participants along with an empty envelope and a stamp for their return.

Table 3.5: Diary Participant demographics

No	Name	Sex	Age	Date diagnosed	Sexual identity
1	PK*	Male	45	10/1995	Homosexual
2	MK*	Female	41	03/1995	Heterosexual
3	XK*	Female	37	07/1992	Heterosexual
4	BK*	Male	32	1995	Homosexual
5	AK*	Male	37	1985	Heterosexual
6	NP	Male	33	06/1995	Homosexual
7	AY	Male	37	12/1995	Homosexual
8	EK	Male	26	03/1996	Heterosexual
9	GK	Female	38	04/1995	Heterosexual

* Participants who participated in both interviews and diary stages.

3.9.5 Procedure

Twelve participants were informed about the diary process and after their consent had been taken the diary was given to them. It was made clear to them that if more than three weeks passed without contacting the researcher, the researcher would contact them. Nine of the participants returned the diary immediately after completion. However, three participants did not contact the researcher within the predetermined time. Two attempts were made to contact them but without any positive result.

3.9.6 Data Handling

All diaries were written in Greek. However, for analysis they were translated into English from the researcher along with the voluntarily work of two Greek psychologists who were both educated in the United Kingdom.

3.9.7 Data Analysis

As in the case of interviews, diaries were analysed using thematic analysis. Diary data were interpreted in themes reflecting participant actions, feelings and thoughts (Seale, 2004).

3.10 Authenticity

Interview and diary data have been criticised as too subjective for scientific research since the chance of individual biases affecting results is (Creswell, 2003). This frames qualitative data within positivistic terms and neglects to see such data as valuable social constructions which people make of the world around them. Accordingly, rather than rejecting qualitative data because it fails to fulfil the expectations of the positivistic paradigm, Seale (2004) suggested that authenticity should be demonstrated rather than reliability. Authenticity is demonstrated when the researcher interprets a range of different issues and establishes the multiple realities with which people explain and understand the phenomena being studied. Authenticity can also be understood in relation to the establishment of empowering processes within the research (Seale, 2004). In the case of the diary data collected for the present study, authenticity was established by examining the diaries for unexpected changes, such as changes in paper or handwriting (Gilbert, 2001).

As far as the interview process was concerned, the aim of the researcher was the use of a non-judgemental and empathic style to encourage participants to reveal their own experiences, thoughts and feelings. This data is valued as subjective and the authenticity of the analysis was established when the researcher and her supervisors discussed the on-going data interpretation. In addition, evidence for the interpretations made is given throughout the findings chapters in the form of quotations taken directly from the interviews and translated into English. A full interview transcription is also presented in appendix 9 so that readers can get a sense of the interview process.

3.11 The Researcher

When conducting qualitative research, revelation of the social positioning of the researcher is critically important in order to establish the ways in which the research affects the creation of knowledge through research design, data collection and interpretation (Ruby, 1980). The following description is offered in the light of this, and a reflexive analysis is presented in chapter 9 of this thesis.

I am a Greek female, 35 years old coming from a middle class social background in Athens. My education is considered as reaching a high level, having had the chance to study not only in Greece but also in the United Kingdom, giving me the opportunity to experience and compare several cultural contexts and people's attitudes and behaviours. My parents did not have this educational opportunity given tight finances and family issues. Within my family, education was seen as a person's means of achieving a good quality of life, open mindedness and cognitive development. This has inspired me since childhood to pursue my education with enthusiasm and has influenced my commitment to contributing to the development of knowledge.

As far as my choice to do a research in the field of HIV is concerned, my experience of volunteering with HIV positive population played a major role in directing my research interests. During the years that I was a student I had the chance to work with several vulnerable populations such as ex- substance misuse addicts, people with mental disorders, HIV positive population, elderly people and people with special needs. HIV positive individuals touched me the most as I considered them a highly vulnerable group of people in today's society. These issues are discussed further in the reflexivity section. Indeed, the conduction of a reflexive analysis for the better understanding of this work has motivated me to understand myself better as a researcher, as a person and as a student during the process of the study.

3.12 Ethical Issues

Due to the sensitive area of this research (Melrose, 2002), a sensitive approach was required since participation in the research could affect compliance to medication. To ensure support for patients, it was ensured that the work took place within the auspices of hospitals and non-governmental organisations. Hospital staff was fully informed of the different stages of the processes. It was clarified to participants that if they needed to contact the researcher or the psychologist of the units after the end of each research stage they should not hesitate.

Ethical approval to conduct the research was obtained from Manchester Metropolitan University's Research Ethics Committee as well as from the Greek Health Services, the doctors of the hospitals and organisations where the research took place. This involved an examination of the research proposal and questionnaires. Following this, a personal interview between the doctors and the researcher took place and written approval was finally provided through Greek health service ethical and administrative procedures.

Approval stipulated that participation in the study was voluntary, based on informed consent. British Psychological Society's guidelines were adhered to concerning anonymity, protection from harm, and withdrawal from the research at any point. Issues of privacy and confidentiality were discussed with participants. In the following sections the ethical issues are presented in more detail.

3.12.1 Informed Consent

Informed consent is a crucial aspect of any research process (Seale, 2004). Informed consent ensures that participants can decide for themselves whether or not they want to take part in the research and gives them choices. Through inform consent individuals gain their autonomy and are ensured that they are going to be treated with respect (Seale, 2004). As far as the present study is concerned, participants in the three stages of the research and in the pilot studies were given information concerning what the study was about, the researcher herself, the process of the research, the handling of data and information about any potential publication of the data. During the research, all participants were informed in written form and orally. One week's time was given to them in order to consider whether they wished to be a part of the research study. Concerning interviews, an additional informed consent was given covering their right to withdraw from the process at any point up until production of the thesis and that their anonymity would be treated with respect and private information kept strictly confidential (See Appendix 7).

As far as the questionnaires, the research participants were also provided with a covering letter in which information was given concerning the topic of the study, the process of the research and contact numbers for support regarding any issues that may have arisen. Participants were informed in writing that their participation would be voluntary and it was specified that they would have any right to withdraw from the process at any point. Finally, participants were reassured about issues of anonymity and privacy. Regarding the collection of the data, participants were returning the completed questionnaires in a provided envelope, either to the staff of the unit, the researcher herself or through the post (envelope and stamp were provided) (See appendices 7 and 11).

3.12.2 Anonymity and Confidentiality Issues

Whilst conducting research participants are necessary for the collection of data. However, the collected data can reveal participants' personal information. Anonymity and confidentiality are two important issues in this respect, for the reason that any revelation of participants' personal information might result in psychological or physical harm (Seale, 2004). In response to the increased level of discretion in such a sensitive issue as HIV, anonymity and confidentiality needed to be treated with absolute respect. At the beginning of the research, and during the process of it, participants were informed of the ways that confidentiality would be maintained. Especially in interviews, participants were reassured in written form and orally that their anonymity would be maintained since their names would not be revealed, nor would the names of the institutes from which they had been recruited.

Before the beginning of the interview process it was quite usual that participants would ask what would happen with the tapes and who would listen to them or read the transcripts. It was clearly explained to them that only the researcher and the supervisory team would have access to the tapes or transcripts but that quotations would appear in the thesis. Such quotations would not however be traceable back to them. Regarding the participants who were approached at the unit of Hospital and the governmental hospice they were reassured that the face to face contact would remain confidential.

3.12.3 Participant Protection

During interviews and diary completions participants can expose themselves by reveal feelings that they might not be aware of or regret revealing at a later stage. At the beginning of the interviews participants were informed that if they became upset they would have time to relax and talk about the sensitive topic ‘‘off the record’’. Telephone advice line numbers were available to support any participants struggling with emotional burdens. As such, participants were reassured that they had somebody to talk to if needed. The interview could be terminated in the event of upset and at the request of the participant. Indeed, interview participants became upset on several occasions when the interview was stopped for a while until the interviewee was calm and gave permission to continue. Due to the discussions that occurred during the break in the interviewing it was decided by both sides that it would be better not to refer to the specific topic again.

At the beginning and end of each data collecting process the researcher spent time with the participants in case questions or upsetting feelings occurred.

3.12.4 Dealing with Sensitive Topics

There were two incidents during the interview process where sensitive topics were discussed. It was obvious that the topic was sensitive not only in terms of its subject matter but also from the participants' facial expressions, body language or emotional outbursts. Whilst in such a situation, the interview was stopped for a while as both times participants requested it. During the break of the interview the researcher's style was supportive by touching them on the shoulder and clarifying to them that they could have as much time as they needed until they would feel calm again. It was also explained to interviewees that they could discuss the sensitive issue off the record with the researcher. When participants were relaxed the interview process continued after their request. The topics which upset the participants were not discussed again due to participants' need not to mention them again while being audio taped. Although the issues that distressed the interviewees were important, it was decided not to continue talking about them as the interviewees found them too distressing and chose not to talk about them more.

3.12.5 Cultural Issues

There are times when cultural issues need to be dealt with in ethically sensitive ways, even when the researcher and participants share the same cultural background. Different experience of this culture that can occur dependent on social positioning and the treatment of socio-structural groups such as ethnic minorities, language issues, those with poor educational backgrounds and those stigmatised on health or social grounds (Muthuswamy & Vasantha, 2005).

During the process of the data collection, whilst having face to face contact with voluntary participants there were a few incidents that lead me to consider cultural issues and socio-cultural positioning, such as dealing with minority groups of different sexual identities, poor educational and language difficulties between the researcher and participants. Considering the fact that within the Greek cultural context homosexuality is not less accepted by society than other countries, homosexual and bisexual people are viewed as minority groups and are often stigmatised because of their sexual orientation.

According to Bauer and Wayne (2005) "*Cultural knowledge is critical for sexual health research or interventions in sexual minority populations because a project that inadvertently sends the message "We don't understand you" could alienate the very people it seeks to reach"* (p.45). Therefore, approaching this population was undertaken in the current research in an absolutely non-judgmental manner, even when participants were very detailed when describing their sexual performances. Participants were made aware that the researcher was a volunteer worker in this field and so had a great understanding of issues affecting people living with HIV. This style made the communication easier between participants and researcher and homosexual and bisexual participants in particular were very open about their sexual preferences and their experiences of HIV. In this way, cultural closeness was established which, as Muthuswamy (2005) states, affects the relationship and communication between doctors and patients and in this case between participants and researcher.

HIV positive women were difficult to locate (given the fact that relatively few women are known to have developed HIV in Greece) and when present they were quite cautious and sometimes unfriendly towards the research perhaps due to suspicion or fear of losing their anonymity. According to Ciambrone (2001), HIV positive women are more likely to face domestic violence and lack of financial support. Women with HIV often deal with fear, isolation, uncertainty and stigma. Due to the negative life experiences they may face including the isolation, stigma and uncertainty that this may lead them to be more fearful and suspicious and that this would result in a less open, friendly and forthcoming interviewee. They usually denied completing the questionnaires, and although they had to deal with a female researcher, their fear of stigmatisation was a burden for the progress of the research relationship.

During the process of the research educational and language issues arose as well. There were times that participants struggled to understand the wording of the questionnaires or to articulate their experiences and thoughts in the interviews. For instance, there were incidents that participants needed explanation for words such as "again" or "following". Poor education positioned these participants in ways which meant they were not fully able to contribute all relevant experiences to the research despite the best efforts of the researcher to explain what any questions or reassure them of the purposes of the research.

3.13 Chapter Summary

In this chapter methodological, practical and ethical issues have been discussed in relation to the research objectives and research questions and discussed. The chapter focused on topics related to the research design which was divided into three stages: questionnaires, interviews and diaries.

The following chapter presents findings of the present research based on data collect through the research methodology.

CHAPTER FOUR: BEING HIV POSITIVE: PERSONAL, SOCIAL AND CULTURAL PERSPECTIVES

4.1 Introduction

Findings from the qualitative interviews and diary methodology presented in this chapter explore individual understandings of participant’s experience of being HIV positive. Personal thoughts and feelings about revealing their status and the impact on social relationships are contextualised through cultural discourses. Analysing both interviews and diary data together has enabled a more comprehensive picture to emerge including what participants say they feel (interviews) and what they report they do in their diaries. Quotations have been included in the text below in order to provide evidence for the interpretations made. Each quotation is ascribed to the participants using a letter to stand for their nick name. This ensures that the principles of anonymity are safeguarded.

Thematic data analysis had produced a number of themes which provided an understanding of the contemporary experience of being HIV positive in Greece. The themes were:

1. Revealing HIV status
2. The HIV journey: Perceptions of viral infection
3. HIV and social networks
4. Knowledge/lack of awareness and justification of HIV status
5. Public attitudes

Each theme was divided into sub-themes through which similarities and differences across participants were explored. As far as the coding of interviews’ quotations, each interview quotation will include the first letter of the participant’s name, i.e. N: “...” and the first letter of the word researcher, i.e. R: “...”. No diary data will be examined within this chapter.

4.2 Revealing HIV Status

HIV positive individuals talked about their experiences of revealing their HIV positive status to family members, friends and life partners which was, they felt, an important context for compliance behaviours. Many reported their HIV status as their secret and went on to explain the reasons that prompted them to reveal this secret. Once their secret had been shared, then the social situations in which medication could be taken were broadened. However, revealing HIV status involved difficult decisions to be taken and emotional uncertainty to be overcome. It also involved the person exposing themselves to negative responses, losing friends and so on.

According to participants' accounts, the cultural context of the Greek society, that was rejecting and isolating anything ill, involved even more difficult decisions to be taken in regards to revealing their secret. Such decisions and explanations of revelations are examined in the following sub-themes: Fear of rejection, need for emotional support, asserting independence.

Fear of rejection: Concerning HIV positive individuals' decision to reveal their status, one of the themes that arose from the interviews was fear of rejection. However, it seemed that there were two informing discourses around fear of rejection. Participants reported several possible negative responses, which are written bellow that they were afraid that they might experience if revealing their seropositivity. On the other hand there were also numerous incidents reported in which HIV positive individuals actually experienced rejection from their friends, family or life partners, when they were first diagnosed, prompting them to consider carefully their decisions regarding revealing their status in other social contexts. The following statements show how the fear of possibly becoming socially rejected became one important decision making factor:

> *B: In the beginning I couldn't say anything to anybody, I was afraid just in case somebody would see me taking my medication, I was afraid to say it, even if I trusted someone (I wouldn't say it), I didn't know what his reactions would be…because…at some point they show that they trust you and love you but then when they see that you have a problem….they are …or they haven't been informed corectly they avoid you, and this was scaring me.* (Int1 p.1:33-39)

Inability to reveal such an important aspect of personal life felt psychologically damaging as the person kept secrets from those who might otherwise have acted as confidantes and thereby they were decreasing their possible sources of support:

> *R: So you hadn't spoken to anybody until then?*
>
> *B: No, I was keeping it inside me, it was a secret because I was afraid and this was stopping me, I mean that whatever I was thinking (in the past) it actually came true.*
>
> *R: You mean that there where specific incidents where you saw that kind of reactions? Or it was that you felt a kind of fear?*
>
> *B: No, I believe that it was a feeling that worked inside me, I felt like something bad like this would happen to me…*
>
> *R: ...that you wouldn't be accepted?*
>
> *B: Yes, I felt it. (*Int1 p.4:161-169)

However, fear of rejection was not always implicated in decisions to reveal HIV status. For some people, revealing their status simply was not relevant within the context of their social relationships and specifically their friends. The following participant had revealed her HIV positive status to the people she felt close to but, as she said, she felt it was unnecessary to reveal it to everyone she knew:

> *Ch: Hm…it's not that I am scared of rejection if I say it, it is…well I don't know, I don't even trust them, I mean I can't find the point, I could say, if it happens I might reveal it to people who do not know, I mean I am thinking 2-3 persons who are my friends, where I see that they don't know and it works in a way, it is like a shadow, but I don't know, I don't want to now, maybe I haven't felt this way yet? Maybe I will do it in the future, I don't want to share it yet.* (Int7 p18-19:894-900)

However, although this participant reported that she did not have a fear of rejection, she admitted that she did not trust some people enough to reveal her secret. In this instance, the issue of trust was prioritised over fear of rejection. The hesitation to trust certain people could possibly involve negative outcomes such as embarrassment or need for explanations, instead of a supportive environment (Dodds et al., 2003).

Hence, negative experiences of other people's revelations also played a part in decisions on whether or not they too would reveal their HIV positive status:

> *P: Yes, yes pretty much…in my opinion some people have more difficulties on how they got infected from HIV than the HIV itself. I happened to be in front of an incident where a son revealed his positive status and his personal preferences (sexual) to his mother and she got fixated about her son's choice of being homosexual than to his HIV positive status, which is (HIV/AIDS) more…straight… your life is in danger, she could lose her child, and she cared about what they were going to say to the people in the village (where they lived), and what will happen, and nobody should find out (about his being gay), this was her most important problem.* (Int3 p.395:425-432)(see Appendix 9)

Fear of rejection was just as powerful an obstruction to revealing HIV status to friends as it was to family members:

> *T: Nobody knew, but when they found out, they all left, and a few friends, and some relatives…ok we didn't have…and all my husband's friends, I didn't have my own friends.*
>
> *R: Hm hm...*
>
> *T: Even one or two that I tried to make friends, I left first so that they won't leave.*
>
> *R: Did you want to leave first?*
>
> *T: Yes, I wanted to do it first, and indeed when they found out they left.*
>
> (Int8 p6:263-269)

Asserting independence: The desire to assert independence was a further factor in participants' decisions about whether or not to reveal their HIV status. For one participant, revealing his status to family members was undertaken in order to clearly state that he did not need their support. This would become particularly important in times of ill health. Interestingly, he had sought to become HIV positive having been in a relationship with a former HIV positive partner for whom he had provided support (until death) and so was fully aware of the sorts of support needed. Having identified himself with that partner he felt he could also progress through his experience of HIV without family intervention.

According to the literature, HIV positive homosexual individuals may not disclose their seropositivity to family members and seek their independence for reasons such as protecting their family from this situation, avoiding disclosing the twin secrets of seropositivity and sexual preferences. Further, some feel they have sufficient support from other people and simply do not need to make themselves dependent for support from family members (Mason et al., 1995). In addition, it has been reported in other studies that past conflicts may react as an obstacle for disclosure to family members (Taylor, 1991). Hence, if the participant had to face his family members and disclose his secret, questions regarding his sexual life would might follow:

> *P: During that time my boyfriend came back to Greece with me, ehhh…I went ….with…my sister and I, were already talking about issues like that, so maybe she knew a few things, so she was the one that would announce it to the family, it was like a frozen picture, now I can explain it, after so many years, I mean I would prefer my frriends' reaction in England, (I wanted them) to come and hug me, only if someone from the family would do it, and they didn't…because we are not the type of family that hug or kiss each other and stuff.* (Int3 pp 390:154-160)

Possible past conflicts and experiences regarding reactions of family members might explain the need to maintain independence such as lack of close relations within the family context which contributed to one participants decision to reveal his HIV status as an assertion of his independence. Any lack in their emotional reaction could then be dealt with in terms of a reflection of his expectation. Consequently, this person decided to reveal his status in the most positive way possible through his sister who had knowledge regarding HIV and homosexuality, in an expectation that this adversity might help to bring his family closer together. He even described the exact way that he would have liked them to react. However, his "frozen" family failed to transcend their normal ways of relating and his health status did not bring them closer together.

According to the findings of the above sub-themes, revealing such a secret was a powerful barrier to family members as it was to friends or intimate partners. However, the decision not to reveal ones status was creating a distance between participants and other people who were otherwise is supportive. In spite of that, for some participants revealing HIV positive status was completely irrelevant in aspects of their social relationships. The findings have also showed that several HIV positive individuals' decision to reveal their health status hid emotional needs and expectations for changing relationships from distant and unsupportive to functional, closer and supportive (for further explanation regarding the change of relationships see the following section). When such expectations were not fulfilled HIV positive individuals asserted their independence from the family members.

4.3 HIV and Social Networks

The following theme involves examination of the impact that being HIV positive had on the social networks of HIV positive individuals. Participants' negative accounts exposed the ways in which the cultural context operated as an important factor in people's reactions towards HIV and HIV positive individuals. In addition, this analysis identified the deepening of relationships and how the support of an HIV positive intimate relationship could help in compliance. Sub-themes presented below are: the cultural context of changing social relationships, closeness, intimate relationship attachment and the absence of an intimate partner/companionship.

The cultural context of changing social relationships: According to the participants' accounts HIV had an important impact on their social network which was mediated by cultural context. Participants described the Greek culture as a society that was constantly experiencing fear of the unknown alongside fear of the 'unhealthy'. Indeed, Greece was characterised as a society that was marginalising anything that was not healthy or perfect. This explained, in part, that their fear of social rejection was rooted in their cultural context:

The Miasma theory became popular during the Middle Ages in order to explain the spread of cholera in London and Paris. It is a Greek word which means the pollution of the air (Wikimedia Foundation, 2009). The following participant compared attitudes about cholera held by the general public during the Middle Ages with people's attitude towards HIV in the twentieth century. According to the participant's account, the general public did not relate to him as a person with a chronic disease but as a person who was carrying a miasma with him, an infected person whose very presence would infect others:

> *A: Even now…and then much more, that it is like a miasma. It is something harmful from which he is in danger from, that same person that is looking at you…thinks that he is in danger.* (Int 4 p2:90-92)

The cultural need to isolate anything unhealthy was also implicated on people's decision to receive information regarding HIV:

> *A: And even information is not good enough, it doesn't have something specific…as they see it, they believe that it doesn't concern them, it only concerns a specific group of people who are not socially accepted ehhh…it has to do with our psychosocial status as a country and as people that as it concerns of health in general, we do not want anything ill, it is bad.* (Int3 p3:99-103)

So this explained that the Greek society was experiencing a constant fear of contagion. They seemed to reject and isolate anything ill driven by the fear of becoming a part of it:

> *R: Why are you saying this...that this is how we are as people?*
>
> *A: Eehhh…because all ill people are always far away from us, even if it is about cancer, we call it exorcised…imagine how..(we react) about something that theoretically we are in danger of getting infected, it has to do with this specific country.* (Int4 p 3:99-108)

Consequently, anything that was not identifiably perfect was inferior. Once more the cultural need for perfection this time led to racist reactions:

> *F: No of course not, there isn't any reason to, Greek society is very racist eehh…let's say that it makes several differentiations in a very racist way.* (Int5 p 9:407-409)

A further factor that was implicated to the cultural context of Greece was gossiping. According to a participant's report, although Greek people kept distance from anything ill or unhealthy, they seemed to enjoy talking about it. This also explained their need to distance themselves from it not only through actions but through verbal communication as well:

> *F: Well I work in the health field, where I dare to say that the are some managers that may forbid an HIV positive person to do several tasks in work, but most of all is the everyday gossiping, behind my back…*
>
> *R: This is…*
>
> *F: ...well this is…happening in such a high level in regards to these issues, matters, when they come up that I could say that nobody can stand it, it is scary how gossiping is done in Greece.* (Int5 p9: 430-438)

This gossiping seemed not to be bounded only to small social groups. Instead as it was a cultural characteristic it expanded to bigger social networks or even mass media:

> *A: I had been in France…and I was impressed at that time, that even then they were talking open about this issue and they were even show it on television. They were talking open since then, and here they still talk about it with a turned back on the camera.*
>
> *R: So they were showing their faces on TV?*
>
> *A: Yes, yes, even since then. (*Int4 p3:136-141)

According to a participant's experience, in contrast to the Greek attitude, in another European country people were not only familiar but also very comfortable with the issue of HIV as people were not hiding themselves; instead they were open regarding HIV. The participant had identified the difference in approaching HIV positive individuals between the two cultures. According to his accounts, HIV positive individuals in France were not isolated as they were in Greece.

Closeness: According to participants' statements, there were many times that they developed closer relationships with their existing friends or began more intimate relationships with people who had not formally been experienced as close personal friends. They revealed through their accounts that their social network in the form of friends and colleagues showed interest and empathy with their situation and this encouraged the development of stronger social and emotional bonds.

According to a previous research of Browning & Cordani (1996) it was found that it is highly unlikely that relationships remain unchanged after disclosure of a diagnosis of HIV or AIDS. In spite of the numerous problems that people face together can, many of these relationships become stronger through the pass of time (Browning & Cordani, 1996). A factor that empowered HIV positive individuals' relationships were alliances that were formed into environments such as work environment. And according to the literature, it has been proved that one of the reasons for successful and desired results was the transition from isolation to form of alliances with groups of people (Teo & Tan, 2002):

> *Ch: I had the (need)…I had the …I don't know, maybe because eh….because we are in the same office with this person that I said it (that she is HIV positive). She was somebody from my office and I wanted her to know, maybe because it felt like an alliance. (*Int7 p19: 920-923)

Forming alliances made some relationships' bonds stronger:

> *Ch: And…I believe that it (say what here…in brackets) made the bonds stronger concerning friends because I know that they know, I am talking about the ones who know; they know and they stay there, they will not hesitate to drink or eat with me.* (Int7 p18:878-880)

Whilst being a part of an alliance comfort replaced secrecy:

> *G: I felt more comfortable with the people that knew about it, because I could tell the "you know what? Give me a glass of water to take my pill", I had to hide from the rest and go to take it secretly.* (Int9 p5: 239-241)

Sometimes, it was not the HIV positive individual's need to form an alliance. It was an employer's thoughtful movement to form an alliance so as to create a good work environment for an HIV positive individual employee:

> *M: In 95' where I felt better, I became my old self again, I went back to work, everybody knew from my social security, even the manager knew…and he immediately said…I mean…what are we going to do now?*
>
> *R: Hm hm…*
>
> *M: For example, whom I wanted to inform (laughter)…, he started saying to me not to worry about it, that I am going to take my salary.* (Int10 p1:41-46)

Hence, forming alliances was a further factor for individuals to feel more comfortable among people whilst being in the work environment. The existence of alliances with somebody's social network seemed to have a positive impact in HIV positive individuals' lives.

Intimate relationship attachment: According to participant accounts, intimate relationships not only supported their efforts to deal with their health status, but also helped they even forget it sometimes. Maintenance of an intimate relationship, allowed participants to experience to enjoy supportive relationships and experience happiness (Myers, 1999):

> *B: I didn't have a stable relationship in the beginning, and I wasn't sure if I should tell it or not, when I was realising that it wasn't anything serious (serious relationship) the fact that somebody would see me taking medication was stopping me…since the moment that my partner got informed about the problem that I am dealing with ehhh….I am not stressed and he really helped me a lot. (*Int1 p15:719-722)

The maintenance of an intimate relationship also provided the HIV positive individual with courage in dealing with the virus. Sometimes participants forgot about their seropositivity, but when they were actually thinking about it, they knew they had someone to stand by them and help them deal with problems if their health deteriorated. Courage became a factor that according to the participant's accounts operated as a motivation to move on and deal with the HIV virus and its consequences, which according to the participant were antiretroviral therapy, loneliness, fear of the unknown. In this sense, they knew they were not alone in their distress:

> *B: Yes, he accepted it and he even helped me to deal with it, and…sometimes I even feel that I am not living with it, that I don't have this problem…*
>
> *R: So you are talking about it with him…*
>
> *B: A lot yes…and this helped me, there are many times that I even feel that I am not dealing with this problem…*
>
> *R: How come this is happening?*

> *B: Eehhh…he makes me forget it with his way, by spending a nice time together, he says "I am going to stand by you whatever will happen, whatever will happen to you, I'll stand by you'' he is giving me courage.* (Int1 p 15:734-742)

It was even more helpful when the intimate other was also HIV positive, whereby the two partners could support each other emotionally and practically in every aspect and from a basis of tacit knowledge. In this instance, as one participant said, things were much simpler in their lives:

> *R: So after a while you find a man who is HIV positive too, then things are simpler…*
>
> *T: ...much simpler, much simpler in any situation.*
>
> *R: Talk to me about that…*
>
> *T: He is helping me psychologically, I help him, there are times that we wonder what we were going to do if we didn't have each other.*
>
> *R: Yes…*
>
> *T: ...and we love each other, eh…we would exist, we would just exist, but it's better, it's so much better that we are together.*
>
> *R: You have each other's company...*
>
> *T: We have each other's company, we don't have stress, ok each of us has problems, he has problems too, I just have my psychological problems, that's what is killing me.* (Int 8 p 11: 501-513)

So, when participants were sharing their lives with another person, the complexity of being HIV positive, receiving medication and numerous other issues that these people had to deal with seemed to decrease. HIV positive individuals were not stressed out with the need to reveal their status, or afraid of being discovered when receiving medication. In fact, they did have another person to share their experiences of being infected with the virus, or experiences of taking medication or even experiences that had to do with each one's social surroundings.

They had mutual understandings and consequently explanations regarding feelings, thoughts fears or even symptoms were not always needed. On the other hand, during the current research, there were also HIV positive participants who were not experiencing an intimate relationship attachment. During the following section accounts regarding the absence of an intimate partner will be examined.

4.3.1 The Absence of a Life Partner, Companionship:

Some participants expressed their need for a life partner to bring about feelings of tenderness, companionship, emotional support and fulfillment. Specifically, the need for a life partner was characterized as essential for human life such as food and water. The lack of a life partner was described in terms of deep social isolation. Faced with the above challenges, female and male participants felt restricted in their intimacy choices which often resulted in feelings of loss and absence. For example, the following female participant had not been involved in a relationship for several years and reported:

> *Ch: It's just that I feel this need so strongly, the companionship, I mean I can't tell to myself, look you are alone, you will be fine alone, I wish I could say that this would be my choice, I will say…you are going to be fine well it's not like that though…*
>
> *R: It's pleasure…that is missing…somebody's companionship…*
>
> *Ch: It is…neccesary, it's only the…eh… I believe that love is like food and water lets say.* (Int7 p14: 671-677)

The female participant appeared to miss the emotional intimacy and support provided with a partner, which they differentiated from the benefits derived from having close friends:

> *Ch: No it doesn't need to happen (laugh), maybe that is why I feel like this and then I say that it doesn't matter, I am doing so many things and I feel like this sometimes, because you know what, I miss sharing….*
>
> *R: Sharing things with somebody…*
>
> *Ch: With somebody who is not a friend…*
>
> *R: Something different from that…*

> *Ch: You know a hug, something tender, a nice joke, stuff like that…* (Int7 p14: 681-687).

The absence of companionship not only made those females feel excluded from society but personally incomplete as well as they felt that they were not able to share experiences, thoughts, activities or ideas with an intimate partner. In some cases, this sexual deficiency due to the absence of an intimate relationnship, as they characterised it, consequently led to a total loss of their female identity. Despite commenting on other areas of their life as satisfactory, the participant felt that the absence of a partner left them feeling incomplete:

> *Ch: Not having a relationship for five years is deficiency, I mean there are many times that I feel deficient in this issue, I don't know if it is obvious, I hope it isn't in other fieds and activities of my life and personality. (laughing)* (Int7 p16: 757-759)

The following male participants discuss the issues of companionship from the male point of view. The participants discussed experiences of developing a new relationship with a possible future partner. At the first case, attempts at honesty were often met with a lack of understanding on behalf of the significant other. This lack of understanding sometimes culminated in feelings of humiliation and rejection, where the participant himself felt as if he was the problem. In the following case self-blame was the outcome, whereby the participant questioned issues of trust and honesty in the development of relationships between HIV and non-HIV infected people. This participant was considered as a person who wanted to harm and spread the HIV virus, although what he was seeking was the chance to formulate an intimate relationship.

According to the participant's accounts, when such a reaction takes place the significant other cannot be respected and issues of mistrust and disappointment come into the surface. According to the literature, individuals are reinforced by social norms to take certain strict roles (Liu, 2005). So, this male individual felt unable to support the masculine role. According to the literature, men may present themselves as healthy and non-problematical, however they may in fact feel pain, depression or anxiety (Liu, 2005). The following participant explains the feelings that he experiences when he attempted to develop a new relationship with a female partner:

A: Well look, I believe that it is everybody's right to make his/her choices and protect him/herself…what bothered me was the fact that she assumed that I wanted to harm her, that was what bothered me, if she was saying to me ok I don't…I would have compromised and respected it.

R: Yes, how a person can feel considering the fact that he is ready to reveal something personal?Clearly personal,and he is facing such a reaction, not only being rejected but also face verbal aggression. How can a man feel when facing this situation?You for example…

A: Ah, yes I felt bad, very bad, very bad and then…ok it passed…

R: And then…after this person's reaction?

A: Then it was ok, I haven't met another person since then that managed to inspire me in this way so as to make a move and see what will happen if I make this move…

R: Yes, have you ever imagined meeting a person that would interest you? Now that you have thought about all that (that happened in the past) *how do you believe you would react?Would you or wouldn't you make another attempt?*

A: No, I believe that in order for a relationship to move on…and this is my opinion and belief…that the other person has to be informed (about his HIV positive status) *before the sexual relationship…*

R: Hm…this is your…

A: Yes, this is my opinion with all its consequences…this is how I believe it must be done…but I will think about it (revealing the HIV positive status) *a lot before I will come up to this point…*

R: Yes?

A: So, it depends on the other person…unpredictable (the other person's reaction). (Int4 p6: 289-314)

At the second case, the participant's attempts of honesty involved fear of rejection and loss of an opportunity to develop a meaningful intimate relationship. Hence, hesitation came into the surface not only for attempts to honesty to the pottential partner but also even for starting a new relationship:

> *N: Ahhh…basically the greatest difficulty is how to tell to a person who is not HIV positive, in case I start a relationship (sexual) with him, that I am HIV positive, then the question on which is the right moment comes….ahhh…how will the other person accept it, if he will reject me, this one only.* (Int6 p.9: 400-403)

In summary, participants were hesitant starting a new relationship whilst being HIV positive. Although both males and females felt the absence of a life partner they did not approach potential partners. In contrast to them, there was only one male participant that demonstrated that, despite a negative experience he had in the past, the participant was nevertheless resilient enough to approach women again in the future. The participant was now aware of the risks associated with revealing he had HIV but although he was cautious due to the unpredictability of the other person's reactions, his principles and approach to the disease motivated him so as to take a risk for another possible unwanted reaction.

4.4 Knowledge/Lack of Awareness and Justification of HIV Status

Most participants had learned about what HIV virus was, from the mass media or the internet rather than from verified forms of expert knowledge or opinion. However, the mass media or the internet itself could not inform anyone; they were simply provided information as the act of informing is a human movement in contrast to the mass media or the internet which are not human. Here, information was often absorbed without active seeking behaviour and so built up without structure or attention to ensuring necessary information was known. Some active information seeking was prompted when difficult decisions were to be made or when the condition deteriorated. In this case, the Internet became a source of information. This was particularly useful as seeking information of the internet was de-personalised and could be done without the knowledge of others.

In addition, being informed by articles on the internet implied some sort of information seeking behaviour, in contrast to being informed by the mass media which could happen without the person seeking any information. However, such information was not always accurate or verified and could be misleading. The following sub themes expand on these issues: getting informed, misinformed and mislead.

Getting informed: Some of the participants chose to receive information only from their doctors, books or the internet, and a number of participants were not informed at all until they began to receive antiretroviral therapy. The time scale of receiving any kind of information was in between the time of the diagnoses and the time that participants started receiving antiretroviral therapy, which sometimes could be immediately after the diagnoses or some other times years after the diagnoses:

> *B: Anyway I started getting more informed about it, I wanted to learn about it, I was struggling with it, so I was taking information from the internet, I was taking leaflets or relevant books in order to inform myself, in general I was interested in it, I didn't leave it like that although I had a phobia…*(Int1 p 1: 45-48)

However, participants also became knowledgeable about the illness as a consequence of visiting HIV positive people in hospitals. In this case, they were faced with the actual development of the infection:

> *P: I went at the centre of inspirational living and I became a volunteer, I was visiting hospitals and all that stuff in order to learn everything around this subject, what will happen and when…you know I was feeling much stronger…I was feeling…*
>
> *R: When you are saying what will happen? In regards to health?*
>
> *P: Health yes.* (Int3 p390: 170-176)

The following participant had already revealed that in the beginning he was susceptible to any type of information as this important change was taking place in his life at that time. He was denying receiving any type of information about HIV/AIDS and an information seeking behaviour was absent. The decision to receive information for HIV was when the participant happened to have an article about this issue in his hands, so even the first time that information was received was not the act of information seeking.

The participant had actually received information when he visited a non-governmental organisation that supported HIV positive individuals and then from the hospital. The participant seemed not to have enough strength to face the situation and deal with it:

> *R: In the beginning you said that you didn't want to get informed, I would like you to tell me how you actually got informed regarding the virus in the end. From the doctor, books, magazines, internet? From what?*
>
> *N: I remember that the first time that I read something was an article from the "name of a newspaper", the first time that I decided to read something scientific, and then most of the information I got was from the centre…*
>
> *R: ...the centre of inspirational living?*
>
> *N: Yes the C.I.L. and then from the doctors at the hospital unit.* (Int6 p 5: 236-242)

The explanation of a non-information seeking behaviour might be denial of information which came about when participants had already found it difficult to deal with diagnosis and receiving further distressing information (such as what was involved in a rehabilitation programme) was over-burdening. It seemed that whilst being dismissive of any information about HIV, participants were experiencing denial of the new situation they had to deal with. In one case, the fact that the participant was simultaneously dealing with accepting their HIV status while also attempting to stop drug misuse was too stressful. Two stressful health issues were overwhelming, distance from both of them and denial of any information seeking behaviour seemed to be the result. According to the literature when people become aware of unexpected or shocking news they can experience denial as a psychological defence mechanism that allows them to collect themselves (Taylor, 1991):

> *N: How was it…the truth was that I was shocked a lot when I found out…the whole world had fallen apart underneath my feet ehh…how can I tell this to you…I was wondering why should this happen to me now…at this point of my life where I was already trying to sit (he means to settle down)…this try was already difficult by itself let's say, imagine how it is when you find out something like this…*
>
> *R: Yes...*

> *N: Now…how I reacted to this…entire ok basically I did not have any information, I did not have any information…*
>
> *R: At all?*
>
> *N: Not at all…eehh…while I was following the programme (substance misuse rehabilitation centre) the information I received from them was very general, in addition I was not susceptible to receive information, I did not want to know eh…well the doctor had told me a few things…when they took me to the hospital…that it was a chronic disease, that there was not any problem and that I should not be afraid of anything, I did not bother at all, it was one more time that my reaction was self-destructive, so I stopped the programme (rehabilitation centre) and I went out (I left), and then I relapsed…I had a relapse for five days and then…I…again…well after I relapsed I obstinate and I said it will not be like this, I will continue the programme…and I will deal with anything that I will have to face*. (Int5 p2: 54-72)

Large amounts of information appeared to act as a further stressor to HIV positive individuals. The over seeking of information regarding HIV by one person who had little medical knowledge became shocking and confusing:

> *Ch: It is not that I do not want occupy myself with this issue lately, you know I get informed with the latest scientific news, and it's not that I look in the internet or in books let's say, I did it for a period of time but I lost myself in it, I mean there was so much information and I didn't know with what to start with, so I decided that I didn't need all that in order to have…in order to live and all that stuff, it was too heavy*. (Int7 p9: 439-445)

Some participants happen to lack of basic information regarding HIV/AIDS. For example, the following participant was infected by her husband who eventually revealed to her that he was HIV positive. The female participant reported that she continued to engage in sexual intercourse without protection. This behaviour was understandable in relation to current social norms within Greece which indicated that (Greece now 2001; Best, 2003, p.2) *"It is also of interest that most Greek women do not take the initiative in contraceptive decisions and leave this up to the male partner"*. Even after she became infected, she was unaware of the meaning of HIV/AIDS and only found out what it was, when years after she had to start antiretroviral therapy. According to the literature, young people with basic education, usually below twenty years old, and especially women have showed that they were not using protection during sexual intercourse neither they had any information regarding HIV (Dodds et al., 2003). The following participant was middle aged at the time of the study, however the educational status was not been asked from the participants and it is considered as a limitation:

> *T: When I met him (husband who infected her), he told me that he was HIV positive but I didn't know anything then…*
>
> *R: So you hadn't asked? You hadn't read?*
>
> *T: It was when the disease had just came out and I wasn't informed, I was too young then…*
>
> *R: Yes…*
>
> *T: 24 years old, what could you know?*
>
> *R: But did have some information later…*
>
> *T: Like we say brains above the heads (an expression that usually describes young people who are immature and do not think before doing any actions)…*
>
> *R: So when you did got informed, how did you do it?*
>
> *T: Eehhh…when I was listening at something I was then sitting and reading about it or when I was listening at something I was watching it…*
>
> *R: So you took your information from t.v. for example?*
>
> *T: First of all from the doctors, how and what and all that, and then leaflets started to come out which they had every now and then.* (Int8 p12-13: 591-604)

In summary, many participants preferred to seek information regarding HIV from the internet, mass media or articles without talking to a professional. However, some of them preferred to come in contact with professionals and deal with the virus and their fears about it according to their medical advisors. On the other hand though, it appeared that the over seeking of information whilst using any source proved to be difficult and stressful for HIV positive individuals as little medical knowledge could be frustrating for the HIV positive individuals lives. An HIV diagnosis was already too heavy and confusing for them, the over seeking of information that was not comprehensible by simple people could generate more questions and bigger fears regarding the progress of one's health status. So, a non-information seeking behaviour was resulted. A totally uniformed participant was also met, as according to her report she was not informed at all when she was diagnosed with the HIV virus. However, after the diagnosis she did receive some information from doctors and from mass media.

Misinformed and Mislead: Despite many participants' drawing knowledge of HIV/AIDS from media sources, they felt that the media acted to misinform and, more critically, mislead the general public concerning the nature of the disease and its sufferers. And those affected by primarily, they felt that media articles influenced social opinion towards negative perceptions of HIV positive people. The following statements illustrate participants' beliefs regarding media information, which they felt was particularly damaging through the medium of television:

Participants believed that information through the media and especially television is rather harming than informing. However, it seemed that although the Greek scientific world and the public organisations dealt with HIV positive people's allowances in the better possible way, they did not manage to control the media world which according to participants' accounts, seemed to use People living with HIV for their benefit:

> *P: Hm…they have a subject whenever it suits them, if there is something new to say, let's say that they don't give understandable information, it is not convenient, I don't think that…there isn't any information, especially in Greece. And this…Greece is very good at issues like dealing with HIV positive people regarding medication, retirement and so on, allowances I mean…but as it concerns information, I think that we are far behind.* (Int3 p389: 510-515)

Once more, according to participants' reports media mislead general public's knowledge regarding HIV as the HIV positive people which were chosen to present their life stories were not a representative sample of the Greek HIV positive population:

> *A: Yes since then, where can you go today here? Everybody that happened to deal with this issue is decadence people that …. One out of two that presented (on TV.) let's say, one of them was taking drugs and in the end at some point he was found dead. Another one was saying that he was going to benches and I go with others (he means have sexual intercourse) so as to take them with me, in*

> *1993-1994, yes there were two incidents that appeared like this…I mean incidents that I remember and can tell you that they presented and were saying that stuff…and there was a whole situation about those.* (Int4 p3-4: 147-154)

In contrast to the above participants, who seemed to reject media as an information source whilst separating the scientific or public organisations' work regarding HIV information it was interesting to view the opinion of a participant who happened to work in the media world. The participant was not satisfied at all with the Greek scientific world and rewarded the media as an information source:

> *M: No mass media are doing a good job, they are doing their best. When you see all doctors in front of you getting paranoid, it's not…all this has to start from somewhere…*
>
> *R: What do you mean when you are saying paranoid?*
>
> *M: Eehhh…when I am saying this thing, it's when you are not saying that somebody next to you is doing unacceptable things…*
>
> *R: So, are we talking about wrong information?*
>
> *M: Of course, wrong, wrong…*
>
> *R: Which is happening due to some doctors?*
>
> *M: It happens due to carelessness, it happens due to carelessness, half of them are carelessness and half of them in order to take advantages from it.* (Int10 p15: 236-246)

The same participant though continued talking about a cultural phenomenon becoming predominant within Greece that refers to the propensity for lay explanations to develop in which non-experts claim expertise (such as medical knowledge of HIV infection) despite a lack of education in the area. As such, common discourses surrounding HIV tended to be misinforming and rather misleading. As a result, negatively toned yet inaccurate lay opinions were received as informed and powerful:

> *M: The experts of the topic, the experts, the experts, everyone in this country is an expert, anyone who wants is labelling himself as something, they make impressions, they show on TV…they show…the experts…*(Int10 p7: 319-321)

The scientific world was also rejected when the virus first appeared. The following participant happened to be one of the people living with HIV who got infected during the decade of 1980 where media were scaring people regarding HIV and Doctors did not know much about this new disease:

> *A: Yes, at that time this specific issue was like an atomic bomb which had exploded and was killing millions of people. There wasn't …any chance…there might weren't any solutions and all that fear of death and the rest*
>
> *R: Was this a creation of mass media?*
>
> *A: It was the mass media and some irresponsible doctors who were saying that yes we don't know, and maybe this and maybe the other* (Int4 p2: 70-76)

Therefore, although HIV positive participants seemed to prefer the mass media in order to receive information regarding HIV, according to their later reports they seemed to be rejecting it as they characterised it as misleading. However, people who worked for the media appeared to have a very different opinion regarding the misleading/ misinforming of media and especially television.

4.5 Public Attitudes

As far as the general public's opinion is concerned, participants' reports showed that one important factor that highly influenced people's opinion was the way they were perceiving issues such as HIV. Through the following excerpts, participants expressed their beliefs regarding the general public's opinion about HIV and HIV positive individuals and revealed the ways that they were dealing with those opinions. Such opinions and ways of HIV positive individuals' dealing with them are examined in the following sub-themes: general public's attitude, self-presentation, and labelling and stigmatisation.

General public's attitudes: The following participant described how people deny dealing with the actual issue of HIV, by receiving accurate information and helping HIV positive sufferers but instead they dramatize the situation so as to make themselves feel better as they are not HIV positive. In other words, seeing other people's misery, as they perceive being HIV positive, so as they can feel better or happier:

> *P: Yes, yes, that is the image that people want to show, they want to feel good by seing others suffer eeehh….through t.v. and through all that stuff they read from the papers, they want to see it everywhere, that something bad is happening near them but they are having a good time so this means that they are ok,with this way they feel secure. If they want it like this, let it be like this so that they feel that security. Some others take advantage from it though, well with their own way, (they say e.g.) look what happened to me, I was in the train and I saw somebody begging, things that are not real… so they continue this situation. Basically AIDS has a big difference from other diseases, basically when somebody is getting sick (gets infected) now that we (people) know that it is something (HIV) that somebody will get over with, we run towards him and help him and we say oh.. the poor guy. In contrast to that, the first years of AIDS everybody wanted to run away from it, nobody wanted to be close to him (to an HIV positive person), even one mother, I remember I saw her on t.v., when they asked her if her son was HIV positive she asked them to forgive her and was saying to take him away, she excommnunicated him, with that kind of beliefs that… that mother had…anyway…. Since then, AIDS came to a new …to another stage of a chronic disease where is controlable, anyway it's how I say it, the keep it frozen. But people's mentality hasn't changed, I mean that all this panic, all this drama is also because it is something sexually transmitted, a disease that is trasmitted through sex and in a quite unorthodox way …as it is in many people's minds.* (Int3 p396: 484-503)

Despite the several years that have passed since the early ages where HIV was first appeared, it seemed that HIV positive individuals still senced the rejection and the anger of general public that disaprooved the formers' lifestyle or sexual preferences. The following participant was reffering to his sexual life, and presented the general public's opinion for it, he explained the reasons that according to people, HIV positive individuals did not need any kind of support by them:

> *F: Because…people in general have a certain attitude towards those people who get infected with this virus, they believe that they (HIV positive people) get infected due to what they do, the hideous, disgusting, unbelievable and…they worth it so they don't need any sympathy, any understanding, any help…* (Int5 p2: 82-85)

It seemed that according to general public's opinion, homosexuality was identified with HIV and any homosexual activity was perceived as disgusting or hideous. Consequently, a homosexual individual infected with the HIV virus was confronted as a person whose actions were hideous or disgusting and not as a sick person who needed others help and support. Therefore, it seemed that general public was focusing on the actions that might consequence, the infection and not on the person that was actually infected.

Self presentation: The following participants seemed to assess people's attitude in greater depth; they did not differentiate themselves from general public, as the previous participants did. Instead, they believed that it was HIV positive individuals' mentality as well that influenced general public's opinion regarding HIV. In proportion to the way they wanted or needed to present themselves in general public, they would receive a certain attitude from them. Participants seemed to engage a self image management as they wanted to control the impressions that others had for them (Leary & Kovalski, 1990). According to the self image and the behaviour that participants presented they intended to affect social opinions around them. Self presentation became a way of life in some participants, as they tended to note other people's reactions and adjusted their self image to it in order to have the desired effect (Myers, 1999):

> *N: Hm hm...Yes, it's exactly like…and it...eehh…I believe that there are many times where we are more strict with ourselves, especially with the issue of HIV, I mean that we are more scared of how others are going to confront us and due to that we put ourselves at the back and the second thing is how we present it to people…*
>
> *R: Yes.*
>
> *N: If you feel good and you are not afraid eeehhh…the other cannot…I don't know…*
>
> *R: I have heard this several times…*
>
> *N: He (a random person) can't feel different, it is what we give to the other person, what he receives from us.* (Int6 p4: 185-193)

So the way that HIV positive individuals presented themselves had an impact on other people's attitude towards them:

> *P: The situation here in Greece is pleseant, in regards to the image that you present to the people, but still there are incidents where they (HIV positive individuals) complain..aahhh people don't come near me, they don't want me and all that stuff, well people do come close to us as long as we show them that we don't have a problem with that, if we saw them that we have a problem with this, then they never come close to us.* (Int3 pp399-400:671-675)

Another participant, had identified the above-mentioned people's attitude as he realised that people needed to know a degree of information about other's lives, so he chose the information that he wanted to give them, before they even asked him.

The participant decided to present himself in a way that his adjustment at the work environment would be better. He wanted to present himself with the better possible image to the external audience so as to control others' reactions (Myers, 1999). And according to the literature *"Some theorists have suggested that self-presentation involves not only people's attempts to manage the impressions others form about them, but also efforts to control their impressions of themselves as well"*(Greenwald & Breckler, 1985; Hogan, Jones, & Cheek, 1985; Schlenker, 1985; Leary & Kovalski, 1990, p: 34):

> *A: They know just because I have told them, they know about the other health problem of blood transfer and they know about it because I take personal days from work*
>
> *R: Could it be that you told them about the personal days or because you wanted to avoid more possible questions?*
>
> *A: Well this works for both of them…*
>
> *R: What do you mean?*
>
> *A: Well I give you something in order to cover something else.*
>
> *R: Yes…*
>
> *A: And I even trust you by saying to you something that I don't say to everybody, not to everybody, just a few, the ones who I share the office with…*
>
> *R: So you answer any possible questions…*

> *A: Exactly.*
>
> *R: Before they even ask..*
>
> *A: So with this way I show them that I trust them so there is no need for more..*
>
> *R: Why are you saying I trust? Do you believe that if we show trust to some people they tend to change their attitude?*
>
> *A: If we show them that we trust them they become more discreet.* (Int4 p8: 363-379)

Labelling and stigmatisation: According to Alonzo & Reynolds (1955) and Pryor et al. (1999) stigma is associated with HIV transmission mode, including multiple sex partners, especially among homosexual societies, and injected drug use. According to the following participant accounts, even nowadays people are still stigmatised or in other words negatively labelled when they are HIV positive. They felt ashamed for their sexual lifestyle and they have been placed by society into unacceptable groups. Consequently HIV positive people's everyday life was full of secrecy in regards to their health status, receiving medication and sexual preferences:

> *P: They are not informed, no they are not informed eehh…they find something hideous and of course the strange thing is not only like…just because is a sexual transmitted disease and lately it is exclusively a sexual transmitted disease, they have to justify their lives, anything that they do secretly, they have to show that there are some people where…they belong to specific groups, wrong in every aspect, I am not in that mood…and I have passed the stage of this shame or this stress, however there are a few that still have it, I have seen it at the group therapy, a lot of people feel it.* (Int3 p395: 417-423)

In other words, general public found HIV infection as something hideous, and according to the participant's report this happened due to the fact that HIV is a sexually transmitted disease but also due to little public education regarding the HIV virus. In addition to that, reported trends between 1991 and 1999 in the United States in regards to HIV had emerged that 48 per cent of the respondents believed that HIV positive people were responsible for their infection (Siegel & Lekas, 2002). It also noted that HIV positive individuals were stigmatised not only in the United States but universally, a fact that was depended on the culture of each country (Herek, 1999). For example

Herek (1999) also noted that fear and isolation of infected individuals was met more in developing countries where education and information about HIV was not adequate. Hence, HIV positive individuals' stigmatisation was met not only in developing countries but also in developed ones such as United States. In addition, the results of the above studies took place during the previous decade.

The present participant's accounts showed that even in the decade of the study stigma was still an issue for HIV positive population. However, the issue here was also how HIV positive people reacted towards the stigma that society had attributed to them. According to the participant, some people were internalising this belief and continued their lives by living in secrecy and guilt being always in a state to justify their choices or beliefs.

On the other hand, he had passed this stage as he reported. Indeed, according to the literature, it has been observed that many HIV positive individuals accept and internalise society's negative attitudes, and tend to experience feelings of shame and unworthy, or even maintain a secret identity in order to avoid a bad psychological consequence, whilst there are other HIV positive individuals who reject society's stigma and fight to change society's negative beliefs and attitudes (Siegel et al., 1998).

Labelling was not an issue only to homosexual HIV positive people; it was also to the heterosexuals. According to the following participant's accounts stigmatisation was inevitable even among people who had knowledge regarding HIV. In other words, when heterosexual individuals revealed their seropositivity they were immediately put into homosexual groups or prostitution, skills or actions that were considered unworthy or unacceptable by society:

> *Ch: Look, as far as HIV positiveness, I believe that it works like that…even among people who know that heterosexuals (HIV positive) are more and there are even more women, when you tell them that you are HIV positive their mind goes immediately that you are gay…*
>
> *R: ...or drugs…?*
>
> *Ch: Yes, prostitutes yes, and all that stuff, it is automatic when the others…it's like a label.* (Int7 p21-22: 1044-1050)

Labelling and stigma was not only an issue among homosexual groups but among heterosexual women as well. According to the above participant, inadequate public's education was not the only issue in HIV. People, who had information about the HIV virus and knew that it is not a disease found only among homosexual male individuals, expressed negative attitudes towards women as well. Literature adds, that even nowadays, general public still judge and stigmatise HIV positive peoples' attitudes that were never expressed for any other diseases during the years (Mc Donell, 1993).

HIV stigma was and unfortunately still is an issue for women especially, who according to the literature still face discrimination and labelled as dirty and undeserved (Lawless et al., 1996). And although during the years statistics showed that women were infected through ordinary heterosexual sex (Lawless et al., 1996), general public still stigmatise them as prostitutes, as the participant reported. However, public's attitudes are not the only ones that stigmatise women. Even among the scientific societies, the research studies regarding HIV and women tend to focus on specific groups such as sex workers whilst characterising them as a risk group of the general population, unfortunately very little has been studied about ordinary women living with the HIV virus (Hankins, 1995; Plant, 1990; Scambler & Smith, 1992; Lawless et al., 1996). For instance, the present participant had faced stigmatisation from women who labelled her as "gay" as she reported. The present participant commented on the fact that even women labelled her like that she was expecting more understanding from the females of the society that she was living. Unfortunately very little is known regarding HIV non positive females' attitudes towards HIV positive females and literature was not found in order to support and probably give an explanation on this matter. However, it is known that women are labelled as deviant and undeserving from society even if they infected with the virus through ordinary sex (Lawless et al., 1996).

According to participants' accounts general public's opinion was rather negative than sympathetic or compassionate. HIV was identified with sexual lifestyle or prostitution; actions unacceptable according to society's rules. Therefore, a possible revealing of participants' seropositivity ended defending themselves, whether they were or were not sharing this lifestyle. Most of the people around the world are familiar with the virus of HIV and have developed their own beliefs and opinions regarding this issue. Unfortunately many people have stigmatised HIV positive population perceiving them to be sinful, undeserved and responsible for their illness (Lazarus, 1999).

According to participants' reports sympathy was an attitude that was rarely experienced by them. Homosexuality, prostitution and "inappropriate", according to society's rules, were very common among general public's perceptions about HIV. HIV positive population felt stigmatised with a lifestyle that was not accepted from society. Some of the HIV positive individuals chose not to internalize these beliefs and continue their lives without guilt. However, some other HIV positive individuals had internalised general public's perceptions, and this explained their feelings of shame, guilt, unworthy and undeserved.

4.6 The HIV Journey: Perceptions of Viral Infection

The way that HIV positive individuals dealt with the virus was influenced by the way they perceived HIV. On the one hand, there were people who had experienced negative feelings in the past, when they were first diagnosed and still felt that way. On the other hand, there were people who also experienced negative feelings in the past but at the time of the study were more optimistic. Which one of those two, reported that they are more compliant? Why do some continue to report negative feelings and why do others adopt more positive perspectives? What happened in order to change negative to more positive feelings? What was the impact of all that on compliance with medication? Through the following paragraphs, participants' past and present feelings are presented in the following sub-themes: Past experiences (Negative psychological responses, risk taking actions, optimistic priority setting, punishment for sins and suicide) and present perspectives (pleasure, enjoying life, appreciation, personal development, depressed, religion and irresponsibility).

4.6.1 Past Experiences

According to some participants', the feelings that they experienced when they were first diagnosed were mostly negative. According to the literature, when people are confronted with stressful or negative events, they sometimes tend to give up or withdraw (Weiten & Lloyd, 1999). Those responses of apathy and inaction are usually associated with sadness and unhappiness (Weiten & Lloyd, 1999).

According to Selingman, (1974) and Weiten & Lloyd, (1999) and his theory about learning helplessness people like the abovementioned participants appear to experience passive behaviours produced by experiencing unavoidable and unwilling events (Hiroto

& Selingman, 1975). However, according to Selingman's, 1990 theory, learning helplessness is rather developed due to people's cognitive interpretation. And more specifically, helplessness usually occurs when people are experiencing aversive events in which they feel that they lose control and they usually exhibit a more pessimistic explanatory style (Selingman, 1990). During the following participants' accounts, issues of the abovementioned maladaptive coping patterns (Carver et al., 1993) are going to be examined:

Negative psychological responses: According to this participant's accounts feelings of helplessness, usefulness were experienced:

> *B: Then I generalised it and I felt useless, that I can't give at all, I had phobias that I will…I will…not be helped at all from medication, I was negative towards therapy, I didn't want to take them, I was afraid that I won't be able to work, that I'll be useless, that nobody would want me, I felt like I was nothing.* (Int1 p3: 129-132)

In addition, according to Carver et al., (1993), giving up and feeling helpless is highly associated with increased distress. In response to stress, people tend to pull back from other people and become preoccupied (Carver et al., 1993). In addition to the above, what is also expected from someone who has just being infected with HIV virus is experiencing agitation or other adverse psychological responses (Kessler et al., 1988). These might explain the following participant's preoccupation with doctors and anger towards them and towards the person that infected him with the virus, considering the fact that it was the participant's choice as well not to get protected:

> *B: Yes I felt very angry with myself too and…of course not with everyone that wasn't their fault, I felt it for the person that happened with and sometimes with doctors who made mistakes until they had the final result, which was positive.* (Int1 p2: 96-98)

Risk taking actions: The following participants had characterised themselves as a high risk group, due to their sexual preferences, and an HIV diagnosis was something that they were expecting. According to the literature, homosexual communities all over the world appear differences in sexual behaviour, social relationships and beliefs (Pontes et al, 1999). However, risk taking among homosexual individuals mostly appears in the developed countries such as the ones in America, Europe and Australia (Pontes et al., 1999). According to the participants' accounts of this study, individuals sometimes, even wanted or not caring of being infected from the virus. Through their reports they explained the reasons for such high risk taking behaviours:

> *G: I wasn't expecting it but I was believing that due to my free sexual relationships, I mean that I didn't have a stable one…a stable sexual partner, that it will happen to me at some point, it was impossible, I would certainly going to get infected with HIV or any other disease.*
>
> *R: So you had thoughts about it in the past?*
>
> *G: Yes, I was thinking about it, I was thinking about it, I was thinking about it intensively but there were times that with the…impulse, the madness of the feelings and the pleasure, you know when we have sex and all these that we feel when we have sex, all of us, I made a few unreasonable movements, I wasn't alone of course, it happened with my lov…* (lover's) *partner's consent…*
>
> *R: What do you mean?*
>
> *G: I mean without a condom yes, anyway I did some other…some other things too that …anyway….* (Int2 p1: 9-21)

The above participant was 27 years old when he was infected with the HIV virus. Literature related to high risk taking behaviours confirms that, "*gay men that engage in such actions report greater enjoyment in unprotected sex, report low communication skills with lovers and finally characterise themselves as high risk group for AIDS*" (Hays et al., 1990, p. 905).

By engaging risk taking actions, such as sexual intercourse without protection, the participants could continue living the lifestyle they enjoyed prior to diagnosis. In some cases, this involved a lifestyle in which pleasure was prioritised. One participant would not use any protection during sexual encounters nor would he reveal his HIV status, explaining that, for him, responsibility for infection lay in the hands of God or several coincidences rather than with himself:

> *G: Lets say that all these years, the coincidence, luck, the good God, the good health,my good health and the virus, he* (the sexual partner) *did not get infected,*

> *there were some coincidences...that is why he did not get infected.* (Int2 p6: 265-267)
>
> *G: "I say it, I confess it, I didn't do it for revenge, just because I was infected all humanity should get infected.*
>
> *R: No, this is another topic.*
>
> *G: Yes, I am completely…ehhhh…I can't say I am afraid of responibilities, that time I am spontaneous and I am more interested in the pleasure than.* (Int2 p6: 283-288)

Some of the reasons that might explain why homosexual individuals might engage in high risk sexual activities are: a) the young of their age where they seem to believe that since the AIDS cases are among men between 30-40, younger homosexual men tend to believe that HIV is an older age's problem b) young gay men might be less likely to communicate about low risk taking activities regarding sex and finally c) young gay men experience feelings of invulnerability, so they again tend to engage in high risk sexual activities (Hays et al., 1990). However, the participant also reported that the pleasure and the impulse of the moment was one factor that prompted him to engage high risk sexual activities. Hence, the age of the participant partially explained the reasons of the risk taking sexual activities that he was engaging. He knew that he would get infected with the HIV virus at a certain point of his life; however he was still not engaging some much safer sexual activities.

It seemed that the general public's opinion regarding high risk groups was also shared by homosexual individuals themselves. During the time of the diagnosis the following participant was in a relationship with another HIV positive male. Being into an emotional committed relationship could be another reason for engaging a risk taking sexual activity (Hays et al., 1990). Identification with the intimate partner may be the explanation of his high risk action:

> *P: Eehh.. because as a homosexual, I believe that everybody is prepared that something like that might happen to them, this is possibly how I was thinking about it, and there was a time that I even wanted to have it (HIV)…*(Int3 p387: 26-28)

When this participant was diagnosed with HIV virus did not receive any support from his intimate partner, he left from England, where he used to live and returned to Greece. He was no longer identified with his partner and his true feelings regarding the virus had started to appear. Feelings of helplessness and panic were his reaction:

> *P: I felt like losing the earth under my feet, I was in a bus looking at people and it seemed that they were moving very fast, and I didn't know where they were going, generally I felt panicked those first days, in fact when I came back here* (in Greece, he was in England) *it was October, it was my birthday, a good weather in Greece* (October is considered as a high temperature month) *and I covered myself with five blankets in order to avoid getting cold.* (Int3 p387: 60-66)

The following participant was also 30 years old when he found out that he was infected with the HIV virus. Again, the young of the age might be the reason that an individual might feel invulnerable as according to his reports although he knew that he was risking his health he somehow reassuring himself that "it would not happen to him":

F: Ok, eh…I didn't have any symptoms, I just did a check-up and I discovered it. So why I did that check-up…because I had dangerous sexual relationships, and I knew it and I was playing a Russian roulette…

R: What do you mean when you are saying Russian roulette?

F: Eh…anal sex without using protection, eh…and of course during the time of the intercourse I had a self-destructive tendency where people certain people don't understand danger and they think that it is something...that HIV or any other transmitted disease is not going to happen to them. Until the time that I was infected…I was infected with something ...well after every sexual intercourse my logic was saying to me that I had to have a check-up, it wasn't always…it was saying to me that I did something stupid again and anyway I had to have a check-up to see what was going on. (Int5 p1: 12-22)

Another participant was already under anti depressive therapy due to suicidal past behaviours. Psychopathology might be a further factor that pushed an individual to a self-destructive action like getting infected with a virus:

> *F: It was not that I had a certain love for sexual transmitted diseases, it was just that I didn't have…that I certainly wanted to deal with something like that in my life, it was just the less harmful, the easiest way to do something to myself without dying, because deep inside, very deep inside, I couldn't say that I wanted to die but I wanted to do something to myself so as to rationale the thought that everybody was against me, that everything was my fault so I had to punish myself, to rationale everything that had to do with that…like I said earlier on, on the other hand I wanted abstract other people's attention, I mean it was like calling for help* (Int5 p3: 104-113)

According to a previous study that took place in Columbia University in 1998 researching the psychological adjustment of women with HIV the researchers found that 53 per cent of infected women and 70 per cent of infected men were suffering from a psychiatric disorder prior to the HIV diagnosis (Siegel et al., 1998). A psychiatric disorder might explain the participant's risk taking actions and his ulterior aim to gain his close people's attention and love. Therefore, in the beginning participants reported that they were trying to get infected but when they actually did, they revealed that it was not death that they were seeking for. The first one reported that pleasure and impulse were more important than his health to him and through the pass of the years the inability to accept responsibility of one's own or others health emerged from his actions. Pleasure and spontaneity were rulling any sexual encounters and the continue of the lifestyle prior to the diagnosis was his priority.

The second one started to overprotect himself and the third one admitted that he wanted to abstract others attention. All of them were engaging in high risk sexual activities, each one of them for several and quite different reasons.

Optimistic priority setting: Prioritising several health problems that an individual might had, seemed to be helpful in aspects of dealing with the HIV virus. The following participant was infected from blood transfer as he was a haemophiliac; he was already in the hospital for that health problem when he was announced from the doctors that he was also HIV positive:

> *A: Fear, worry, stress, that there was a chance being a wrong result so I asked to recheck.*
>
> *R: Hm hm…*

> *A: Eh…I did the recheck and it was positive again, after a while I was cool, my interest was leaving the hospital, this was what I cared about, and then when I recovered and I didn't have the other health problem, I started looking at It (HIV) differently.* (Int4 p1:21-27)

The following two participants seemed to put priorities after the first shock of the diagnosis, in order to deal with the virus and move on with their lives. The question was what made them react like this, how they felt about themselves when they were diagnosed and what impact did all those had in regards to complying with medication. Unfortunately, no one of the rest participants referred to prioritising issues.

> *T: I felt bad, I felt bad…I wasn't expecting to get infected, I was a bit angry you know…well my husband might had it but if we were careful I wouldn't have a problem, do you understand?*
>
> *R: Yes*
>
> *T: After a while I realized what happened and I continued living.* (Int8 p 1-2: 48-53)

Some of them did not let themselves to experience any feelings; instead the organization of their thoughts in order to deal with the virus was their priority:

> *M: My mind was working all the time, what are we doing now! What are we doing now! By the way then I went to the doctor and he gave me…then it was azete (name of medication).* (Int10 p1: 38-39)

Punishment for sins: Another factor that influenced somebody's self-perception as an HIV positive individual was religion. Participants seemed to believe that they were punished for their sins. According to the literature, several people believe that HIV is the result of God's anger; some of them even believe that it is a punishment for their sins (Vlachos, 1994). However, according to orthodox religion God is not a punisher but a lover, he is not the one that punishes, it is people who self-punish themselves. In other words, the one that follows his sexual desires, in this case homosexuality, he then shoulders the consequences (Vlachos, 1994):

> *G: Well this influenced a lot my…my way of thinking and that god certainly did it, not as a punisher but as a teacher who wanted to show me that I lost my road*

> *and that I would have to stop this sexual intercourse, the sin with the meaning of…*
>
> *R: In quotes?*
>
> *G: My meaning of sin is missing the goal, sin in Ancient Greek means losing my goal, so for me it was exactly missing my goal, I mean that I lost my goal and if we say that a human's destination is to fall in love, to feel intimate with another person well I lost all that, sometimes I was changing sexual partners twice a day, and not only one, even two sexual partners.* (Int2 p2: 85-96)

Suicide: Depression is a one of the most common reactions to chronic illnesses (Taylor, 1990). According to DSM IV, (1994), the following participant is describing some of the symptoms of depression that he was experiencing when he was first diagnosed:

> *B: I was crying, I couldn't concentrate on my work…eehhh I had even thought of giving an end to my life, there was no point any more.* (Int1 p1: 30-32)

According to the previous reports, participants' perceptions of self being HIV positive appeared to be mostly negative, even though some of the participants admitted that for several reasons they even wanted to get infected. In the following paragraphs participants revealed their feelings and perceptions of self in present time. As time was passing by, participants went through several psychological, personal or physical changes and they finally came up to a point that some of them remained to their past perceptions of being HIV positive, but some others started viewing themselves from a quite different perspective.

4.6.2 Present Perspectives

Pleasure, enjoying life, appreciation: Although HIV is a major stressful event in somebody's life, there is evidence that people cope with it much better than they might be expected (Tayor, 1991). Therefore, in contrast to their previous accounts, participants seemed to have been adjusted to the fact that they are HIV positive and not only they did not perceive themselves as they used to in the past but they had also started to please themselves by enjoying and appreciating their life. According to a previous research (Holzemer et al, 1999), a high percentage of people start having a more positive perception of the quality of their life:

> *P: If you don't take it…eeehhh…and if you don't take it, and if it doesn't take you with it and you won't be…what happened to me and what a bad thing this is and be able to see the positive point of view, it has a positive point of view…you discover friends, you discover yourself better, you discover better relationships…you see life differently. For example I…what I will say might seem stupid or romantic but I remember we had gone for sailing with people from the centre of inspirational living….we were giving information to people (about HIV), it was sunset and I was on the boat, at the front, at the back…anyway I don't remember…*
>
> *R: Anyway and?*
>
> *P: I was looking at the sun disappearing into the sea, I was alone and I had sat there to read emm… I was thinking that, it was the first time that I realized that I might die and won't be able to see this thing again tomorrow, this was the first…of death. And I was thinking what a wonderful thing was that…something that all my life…I had traveled so much, I had seen so many things, but I had never felt something so deep inside me as that moment. Since then I am looking at everything, the leaves from the trees, the winter, the yellow leaves that fall of the trees on fall, May…the summer sunset in Santorini all that, they are very interesting, I am looking at everything in a different way.* (Int3 p393: 342-359)

At this point the participant realized that he did not want to miss anything as beautiful as the sunset for example. The shock or even the fear of death might explain his motivation to look around his environment and appreciate anything that would please him. According to his accounts although he had visited and seen several places, this might be the first time he actually observed something and actually enjoyed it.

Some of them were motivated to spend more time with or even started amusing themselves whilst doing things that pleasured them:

> *Ch: It made me meet myself, for example I go for yoga for once a month, I wasn't to do things that pleasure me, I mean that going for yoga or learning reicki (a type of yoga) or going... I was going anyway, to the theatre, shows and all that…* (Int7 p11:542-547)

The diagnosis and the shock of it also acted as a way to liberate them from anything that was restraining them:

> *Ch: I felt more the meaning of laughter, of joy, of games, I wasn't laughing, I wasn't shouting, I wasn't playing, now I can do anything that I hadn't done before.* (Int7 p12: 561-563)

Once more this liberation that the participant experienced had actually motivated her to seek quality in her life:

> *Ch: What personality has each one of us, what is he carrying, what does he have, well I believe that it is not something that…I don't know how to explain it when…my life, my personality, myself is…I feel that it had done good to me, even if this means traveling, I might had traveled without it ok? But I do it more with it..*
>
> *R: So you don't postpone them...now you are actually doing…*
>
> *Ch: I want to live every day; I want to do things every day.* (Int7 p13: 614-620)

The fear of the short time left had motivated them to find free time for themselves in order to enjoy their life:

> *G2: Because I did stuff, I did stuff, with the annual leave from the work, because I had more free time and my health got better, these helped me to have fun, to enjoy things that I wouldn't even dream.* (Int9 p8: 359-361)

Personal development: Individuals changed their perceptions of the everyday life by developing their personalities. According to participants' accounts the appreciation of simple things such as a beautiful morning, was something that they felt they owed to their health issue:

> *N: Yes, ok I bel…I believe that HIV…since I found out about HIV I have developed as a person…and it has also helped me to live life differently…*
>
> *R: yes…*
>
> *N:… to appreciate some things in a very different way*

> *R: Like?*
>
> *N: I mean…to give worth to things that I didn't before…especially the first period that I had found out I was giving worth to small things and I had started…(smiling) how can I say this…I felt like it was the first time that I was seeing them, a beautiful morning for example or a nice sunset or just a cup of coffee, small very things in which we don't always pay attention.* (Int6 p5: 219-230)

Dealing with a virus like HIV was heavy by itself; consequently unimportant issues of everyday life did not belong into their priorities:

> *Ch: More analytically… I used to be a closed person, I wasn't opening myself a lot, I wasn't talking about myself, it made me a more sociable person, I mean I speak I reveal, something which is good, keeping everything inside, locked, and not talking to anyone is making you carrying a lot and it is heavy. Revealing them by itself is easier…* (Int7 p11:533-537)

Taking care of themselves, whilst taking medication and following a healthy lifestyle became a habit which had actually made them taking also care of their inner selves:

> *Ch: It (HIV) made me love myself more and to tell you the truth you can't love other people if you don't love yourself first, I mean what this thing made me, was to reveal, to give…*
>
> *R: Yes…*
>
> *Ch: …to find myself…* (Int7 p12: 582-586)

And by saying taking care of their inner selves an HIV diagnosis operated as an awakening of self-development and a motivation for participants to look deep inside themselves:

> *P: Look in the…I was always interested in appearance, I always wanted somebody to appear good, sometimes though I wanted…to look who is beside me…besides appearance though I believe that I could reborn through a situation like this, I mean that…I want regeneration in my life…*(Int3 p393: 322-325)

Depressed: As it was already mentioned psychopathology was a factor that influenced participants' perceptions and consequently reactions in regards to dealing with HIV. The present participant was following anti-depressant therapy as he was diagnosed depressive before the HIV diagnosis:

> *F: …This bulimia is a sign of the serious depression that I have, lets say a word more…that makes it stronger…*
>
> *R: Do believe that you suffer from depression?*
>
> *F: Yes and quite serious…the symptoms I would say…the symptoms are pretty obvious now, my night insomnia, my bulimia and lots of others, and many thoughts and theories that I have in this stage. A lot of things that show how I am functioning in my everyday life…* (Int5 p12: 582-590)

Despite all the psychological problems, it seemed that an HIV positive individual is still trying to deal with HIV

> *F: Loads of us believe that we are powerless and weak but I would say that deep inside we all…if we think…*
>
> *R: That we have strength?*
>
> *F: If we think and if I personally think past times of my life where I dealt with…there is a question at the questionnaire, that I dealt with much more worse situations comparing to the ones that I live now in my everyday life and I coped with it.* (Int5 p27: 1291-1297)

Religion: Religion appears in present perspectives as well as according to the orthodox belief, through religion, people find tenderness, love and family. Religion and church heals people's personality, helps them deal with other people and society and finally helps people to find solutions in any problems they may have (Vlachos, 1994). The following HIV individual described how his religion helped him to deal with the disease and even avoid suicidal thoughts. It seemed that religion was a very powerful factor that helped some people to cope with their health situation:

> *B: I believe that what helped me was that I believe in another power, in god, that's it for me…I believe…I believe in god and I say that this power gave me…I mean it gave the courage to fight, I even believe that if didn't believe in god I*

> *wouldn't exist right now, I would have end my life, but just because I grew up with those beliefs and…I say…I always believed that things would get better and…another reason was that my mother believed too that he (god) will help me to deal with it eh…these were the basic reasons that made me say that I will fight it.* (Int1 p3: 139-145)

Irresponsibility: The following participant described his life as an HIV positive person who were coming to sexual intercourse with other men and did not use any protection.

> *G: Sometimes I am an irresponsible person, for reasons of irresponsibility nothing more, I am an irresponsible person, even…I even see it as a frivolity in any part of my character.* (Int2 p5: 241-244)

According to the findings, when HIV positive individuals were first diagnosed they experienced feelings of helplessness, anger or even expressed suicidal ideation and behaviors. However, some participants, had prioritized their needs in regards to health, and engaged new lifestyles in order to continue their lives. During the pass of time though, several participants' accounts had changed, appreciation of life and everyday pleasures occurred. The presence of a disease such as HIV motivated HIV positive individuals to develop their way of perceiving life issues or even liberated their personalities. Expectations on medication motivated participants to improve the quality of their lives. However, religion seemed to be a very powerful factor that highly influenced HIV positive individuals' perceptions regarding their health status and their mechanisms in dealing with it. Some of the participants, perceived God as a helper who motivated them to cope with the virus. On the other hand, some other participants perceived God as an entity that was motivating themselves to self-punishment and was waiting for them to regret for their actions, such as homosexual relationships. Apparently, those perceptions seemed to influence HIV positive individual's motivation to comply with antiretroviral therapy.

4.7 Chapter Summary

The findings of the qualitative part of being HIV positive in regards to the personal, social and cultural perspectives in Greece showed that since an HIV positive individual was diagnosed with the HIV virus was meeting difficulties in revealing one's health status as the fear of rejection was very strong according to the reports. In addition, revealing ones HIV positive status was confusing not only when it involved family members, but also friends or intimate partners.

On the other hand, participants’ accounts had showed that revealing their status might underpin emotional needs and expectations for changing relationships with their close people. As far as the experiences of HIV positive individuals whilst being HIV positive involved positive accounts when the participants were sharing their lives with another person who was informed about their health status. In this situation, participants were not stressed out with issues of receiving medication, revealing their status or afraid of being discovered. It was more helpful when they were sharing their lives with another HIV positive individual with which they could have mutual understandings in regards to experiences, fears or thoughts.

The need for the participants to form alliances especially in the work environment showed a positive impact on HIV positive people’s lives in regards to their feelings or ability to receive medication in public places such as work. Regarding the way that HIV positive individuals were choosing to receive information regarding HIV the most frequent method was the mass media. From which the information was rather misleading than informing, according to participants’ accounts. In spite of that though, according to participants’ accounts receiving information from contacting qualified people was less frequent.

As far as the feelings that HIV positive individuals were experiencing when they were first diagnosed, negative psychological responses and suicidal behaviours were very frequent. However, several participants’ accounts showed that through the pass of time those feelings had been replaced with change of perceiving life, personal development, appreciation of everyday situations and motivation in regards of improving their lives. Those participants’ attitudes towards HIV had changed and their willingness for more compliant behaviours was increased. On the other hand, some other individuals did not change their negative accounts either due to other diagnoses such as anxiety disorders, prior to HIV or wrong perceptions about religion in which their homosexual lifestyle was not accepted or inability to accept responsibility of one’s own health. Feelings of self-punishment were met and non-compliant behaviours were presented.

The next chapter presents the findings of compliance in relation to everyday life.

CHAPTER 5: COMPLIANCE IN THE CONTEXT OF EVERYDAY LIFE

5.1 Introduction

Continuing with the findings from the qualitative interviews and diary methodology, this chapter will explore issues related to compliance with medication in the context of everyday life. Specifically, thoughts and feelings concerning and the ways in which medical regimes fit into the everyday life of HIV positive individuals will be investigated. As in the previous chapter, both interviews and diary data have provided a more in-depth understanding of the experiences of participants through what the participants say they feel (interviews) and what they actually report they do (diaries).

This chapter presents the findings which resulted from a thematic analysis of the interview and diary data. Recurring and tangible themes are presented to enable an understanding of how compliance with medication is related the context of everyday life within Greek culture. Themes which emerged from the thematic analysis and which are presented in this chapter include:

- Experiencing HIV medication
- The practicalities of taking medication
- Ways of seeing compliance
- Doctors: Expectations and relationships

Each theme is divided into sub-themes through which similarities and differences across participants are explored. As far as the coding of interviews' quotations, each interview quotation will include the first letter of the participant's nickname, i.e. N: "..." and the first letter of the word researcher, i.e. R: "...". In regards to the diaries' quotations, they will be coded as M (number) for Male (number), i.e. M 1, and F (number) for Female (number), i.e. F 1.

5.2 Experiencing HIV Medication

Research suggests that antiretroviral therapy, as the principal medication for the treatment of HIV, can lead to the reduction of mortality among HIV positive individuals

(Palella et al., 1998). However, it has been proven that in order for the treatment to be effective in the long-term, there needs to be a high level of compliance from the individual (Penedo et al., 2003). Thus, the routine of taking HIV medication is an important factor in determining the health status and mortality of HIV positive individuals. The experience of taking HIV medication though is complex, as complying with antiretroviral therapy requires making lifestyle changes such as alcohol or food restrictions, and often results in unpleasant experiences such as side effects (Tucker et al., 2004).

The findings from the participants who participated in this study identified a number of negative experiences which were standing as barriers to taking HIV medication. Conversely, participants discussed facilitators within their everyday lives which acted as drivers for taking their antiretroviral therapy. In addition to barrier and facilitators, issues related to gender and identity emerged as factors which influenced their attitudes towards and likelihood of sustained use of HIV medication. There were also cross-cutting sub-themes discussed by participants which included: negative experiences of taking medication, barriers (acceptance of HIV and medication, present and future side-effects, associations with substance misuse, self-castigation, loss of freedom, meanings of HIV and medication in terms of gender and identity issues), positive experiences of taking medication, facilitators for taking medicine (supportive family members, the presence of supportive life partners).

5.2.1 Issues that make Taking Medication a Negative Experience, Barriers:

For many participants the action of taking HIV medication represented a negative and unpleasant experience. Taking HIV medication can have a significant impact upon HIV positive individuals inducing side effects, imposing complex drug-taking HIV regimes, and the stigma associated with HIV (Remien et al., 2003). Drawing upon the experiences of the participants themselves, these issues are explored in more detail in this section.

Acceptance of HIV and medication: Self-acceptance of an individual’s HIV positive status was one key concept associated with compliance. Participants reported being frustrated at having to continually take HIV medication, which together with the stress associated with living with the virus, challenged issues related to sense of self. This finding was supported by the literature which suggests that compliant or non-compliant behaviours amongst those individuals who are HIV positive is closely associated with the perception of one's self or the denial of self (Nam et al., 2008). For some participants, taking medication and drugs impacted on how strong and resilient they felt in themselves and undermine their ability to cope with the virus. Here, issues of frustration with medication were noted amongst participants:

> *P: I don't have the same strength, the same capabilities that I used to have then* (the first years of taking antiretroviral therapy)*, I feel that I don't have the same strength to cope with those now, and I feel that my organism has become…the toxins and all that stuff that it* (the organism) *could deal with in the past, and all that, all these ugly situations… that I don't have the same strength to deal with now. This is the main…with medication that annoys me, and of course the problem is that I live with the virus…my interactions…my sexual interactions have to be especially careful.* (Int3 p396:551-556)

The participant associated medication with the negative connotations of toxicity which is a term often used to describe damage to an organism. The quotation identifies the feelings of alienation that the participant felt towards his own body, and feelings of living with another presence in his body and which he could not accept. The participant went on to describing how the virus and the medication restricted his daily activities, including his sexual interactions. On one hand, the participant had to derive strength and willpower on a daily basis to cope with the symptoms of HIV and taking medication. In addition, he could not identify himself as a HIV positive individual as the quality of his sexual life was not corresponding to his expectations, which were restricted by the virus and medication. The participant felt controlled by the virus in what he did and how he behaved in his sexual life. This unwanted presence into individuals' bodies can make participants challenge their sexual identity, a notion which will be examined in the following pages. Not being able to accept a new sense of self (through adapting to live with the virus and taking medication) consequently led to feelings of hopelessness amongst participants as they lacked control of their lives. Inability to accept ones new sense of self also resulted for some in feelings of disgust as if they were in a constant state of conflict with the virus and their bodies. The routine of taking HIV medication seemed to take away participants' role of agency into their lives which were now led by the necessity of the HIV regimes. Established routines for taking medication also brought about restrictions amongst participants which brought about a sense of anxiety:

> M7: *I took my medication on time as a routine and with disgust…I went to my mother's* (house) *for lunch. My moves were a routine and full of anxiety.* (Diaries)

It seemed that the participant's denial on complying with medication resulted in a non-compliant behaviour when self-monitoring other aspects of their health:

> *F: Even now I cannot comply with medication; I can't even take the blood pressure medication on time, which has to be taken at some point during the morning (not at a specific time). I have transferred this time at some point during noon. Its ok, I still forget it, even if it is on a specific time.* (Int5 p.11:515-518)

For some participants, the action of taking medication represented a continuous realisation and a reminder that they were living with the virus, which brought about non-compliance. For example, for the following participant, medicating stimulated feelings of ''hurt'', as it was a constant reminder of living with the virus. Non-compliance presented one way of rejecting the medication as a way of challenging the reality of the situation, a form of denial and avoidance of his condition. This supports findings in the literature which suggests that denial constitutes a barrier which prevents the individual from accepting their condition and developing positive attitudes towards HIV and medication (Nam et al., 2008). Individuals within the current study who experienced feelings of denial demonstrated a tendency to stigmatise themselves, adopting negative attitudes as a form of punishing themselves for being HIV positive. Research indicated that when individuals struggle to accept their health status, they can adopt negative attitudes towards their condition and subsequently become unable to make the necessary lifestyle changes to cope with that condition (Nam et al., 2008):

> *F: So we have…a compliance problem, which exists anyway…*
> *R: yes…*
> *F: why is that…I can't think of a…that's what I am trying to think about now…*
> *R: what do you mean?*

> *F: one specific reason is that is a subconscious reaction or subconsciously a subconscious reaction eh…I don't want to say self*-destructive *oh! And supposing that if you don't take your treatment you are harming yourself, I don't mean to say that…*
> *R: a reaction of…?*
> *F: a reaction not to…to avoid remembering that I am sick, I am avoiding this, it hurts remembering that I am sick, even if the results of my check-ups are very good considering HIV.* (Int5 p11: 526-537)

Taking HIV medication also acted as a reminder of one's HIV positive identity, for example, the following female participant reports in her diary:

> F1: *I had my breakfast and got ready to go to work. I had my morning dose just after breakfast. No anxiety. My parents know, but I had the usual disappointment. It reminds me that I am HIV positive*. (Diaries)

Although emotionally supported by her family, this participant experienced disappointment resulting from the reminders evoked by taking medication. The reminders tended, for her, to overshadowed the support she was receiving from members of her family. However, this might not be the only issue, as family support could also reinforce the aloneness felt as the only person in the family who has the HIV virus. In this way, the presence of the family members during the taking of medication appeared to be detrimental to the following female:

> F2: *I was tired and I lay down. I ate something and took the last pill. I was with my family and brother, but for several reasons I felt so lonely. Very lonely!*

Present and future side-effects of taking medication: were a recurring issue, even amongst those participants who demonstrated high levels of compliance. According to Mehta et al. (1997) HIV positive individuals are often prevented from taking medication due to the side effects of the therapy. Undesirable side-effects were also a risk factor for non-compliance in chronically ill, elderly patients and HIV patients; major side-effects such as leukopenia, anaemia, transfusion, and gastrointestinal upset had led to decreased compliance (Mehta et al., 1997).

Although, antiretroviral treatments have progressed considerably over the years, recent studies have demonstrated that side effects can result in individuals choosing to stop taking the medication for a period of time. Remien et al. (2003) in a research conducted across four USA cities found that individuals who were HIV positive often stopped taking their medication due to the side effects experienced. Although HIV medication has been proven to combat the HIV virus and reduce the death rate of HIV positive individuals, the findings of the current study support those reported in Remien et al's study:

> M6: *I didn't wake up very well today. As soon as I had my morning coffee I had a feeling of nausea. I was alone at home. It was disgusting. I was so afraid to take medication. I feel like getting ill.* (Diaries)

The need for taking medication in order to deal with HIV virus caused the experiencing of such strong side effects and had produced intense anxiety. Here, the participant was experiencing trepidation accompanied by a fear of taking medication. In spite of feeling sick, he forced himself to take the medication even though he felt it was having a negative impact in terms of vomiting and sickness:

> M6: *I took my medication and trying not to vomit. I feel terrible.* (Diaries)

Here, being forced to endure the symptoms of the medications' side effects helps explain the negative feelings that this participant was experiencing. Non-compliant behaviours became a common reaction amongst participants who experienced side effects. In some cases this was a refusal to accept the short-term violation of the body which the drugs brought about:

> M4: *I woke up with a terrible pain in kidneys, I was very angry; I didn't even bother to take medication.* (Diaries)

Other participants failed to see the long-term positive impacts of antiretroviral therapy. Here, participants were more concerned about the negative impacts which the drugs were having on other aspects of their health:

> *P: Why should I take medication, I don't want them, and what are they doing? Anyway I don't believe that...that they are doing something good to me, they probably harm me, and new health problems will appear in future…*
> *R: Like what?*
> *P: I don't know, in my liver, kidneys, stuff like that.* (Int3 p397: 537-541)

Participants felt that taking medication was a continuous process, with no specific end date, and thus they found it difficult to look forward towards a time that they would no longer be taking medication. Participants felt unable to visualise a specific attainable goal and failed to visualise the long-term benefits of the disease. The meanings and understandings which participants attached to antiretroviral therapy informed the way that they understood, engaged and consequently complied with the medical treatment:

> *P: It's not like antibiotics, two weeks, a month of patience and then it's over, I won't take them again. Now, I will take them, and take them, and take them and I will wait for the moment that something will happen to me, I mean honestly I don't believe that…this will give me something(meaning that medication will not help him)…and this happens because I want something to happen to me, this may sound weird.* (Int3 pp398-399: 619-624)

The absence of a tangible goal and visible improvements has subsequently led many participants to question and re-consider their motives for taking anti-retroviral medication.

Associations with substance misuse: Participants with previous substance addictions also talked about how this impacted upon complying with HIV medication. Previous studies have shown that people with substance use problems have identified problems with HIV medication compliance as they find it difficult to incorporate new regimes into their current lifestyle and have negative perceptions regarding medication in general (Tucker et al., 2004). The following participant associated medication with previous substance problems, attaching negative connotations to carrying and taking drugs. Consequently, fear of being humiliated by being stopped by the police was a feeling that the participant was afraid of experiencing again:

> N: *Basically it reminds me other things; I mean it reminds me of…you know…drug use…*
>
> R: *Hm..*
>
> N: *Carrying some pills with me…eh…maybe I have a phobia that…the drug use is responsible for, I am thinking that if cops will stop me you know…some cops…I will have to explain to them and all that stuff, and from what I understand about their IQ…maybe they won't know what medication this is and what is it for…*
>
> R: *So you are making associations…*
>
> N: *Yes, and mostly this is what you know…that somebody sees me taking it (medication), where am I going to take them, I feel bad when people are looking at me taking you know five pills…*
>
> R: *Yes*
>
> N: *Eh...but that's the part it mostly hurts this hurts me the most…* (The fact that when he is taking medication in public, people and he himself are making associations with drugs)
>
> R: *Due to the drug use.*
>
> N: *Due to the drug use yes.* (Int6 p7:331-347)

The comments identify feelings of fear and suspicion resulting from how the participant believes society will perceive him, given his previous history of substance misuse. The fact the participant had to carry HIV medication every time he was leaving the house had resulted in a constant fear of him being misunderstood. Given his previous problems with substance misuse, the participant felt that taking medication was synonymous with taking drugs; it seemed that his perceptions regarding medication were highly influenced by his substance use problems.

Previous research undertaken by Tucker et al., (2004) investigated the relationships between mental health, drug use problems and non-compliance. It was found that mental health and present drug use problems were identified in non-compliant behaviours. This participant had a drug use problem in the past where he was associating hazardous drug use with antiretroviral therapy. The action of taking medication was reminding the participant of previous lifestyle activities and choices.

Self- punishment/castigation: According to participants' accounts, self–castigation was another feeling that participants were experiencing whilst being HIV positive and taking HIV medication. According to the findings of the research, religious beliefs were the main reason for such feelings.

The literature suggests that HIV stigma is strongly associated with certain religious beliefs such as the belief that HIV God's punishment for all the people who are not following the word of God (Zou et al., 2009). One participant had already characterized himself as "inexcusable" for being forgetful and for not taking his HIV medication on time. He claimed he was not receiving his medication. According to this participant's accounts during interviews, he believed that he was HIV positive as a consequence of God's will. He, interpreted this as a sign that he should ''…walk again on the right road of heterosexuality'' and stop being a homosexual with multiple partners. Therefore, heterosexuality and monogamy are interpreted as twin righteous paths according to the participant's beliefs regarding God's will. Hence, according to the participant he is characterising himself as inexcusable for not complying with medication according to the doctors' prescriptions.

On the other hand, his non-compliant behaviour is interpreted by him as a castigation of his "sinful" body for not "walking on God's road". The participant has perceived his body as a sinful. This refers to orthodox religion's beliefs where all people, even HIV positive people, can regret their actions and return to God's will in spite of their diseases (Vlachos, 1994). A cry for help was shown by the participant's use of capital letters in the diary whilst characterizing himself as non-compliant. Issues of self-punishment and feelings of desperation were evident when the individual was either taking medication late or not at all (the following quotations come from the same person who participated in all three stages of the current research, questionnaires, interviews and diaries. This is something that is known by the researcher as the current participant wrote his name on the printed data and game his name during the interview process although it was clearly explained to him that all the above processes were strictly anonymous):

> *R: So you have lived a quite lonely life* (in past), *and then you had a life that…*
> *G: Very much…*
> *R: …that the church would not accept?*

> *G: No way, me neither anyway*
>
> *R: So neither would you…*
>
> *G: Yes, me neither, but I finally reconsider my views about all these and I say that it is not the place that consecrates the person and helps holiness, it is the way of living and maybe through people I might find God. And I was really seeing him through them (*the sexual partners) *even during sex, in spite of all the guilt, the insecurity, my thoughts.* (Int2 p9: 426-435)

Hence, feelings of guilt and insecurity possess this participant during the time that he is enjoying his sexual encounters. And after the sexual action he did not comply with his HIV medication as he stated as he took his medication later than it was supposed to be taken (considering the fact that antiretroviral therapy must be taken in specific hours during the day):

> M8: *I slept with my partner, and woke up quite late, around 13:00pm. I took my medication when I was in the bathroom, but I was quite late, at 15:00pm. INEXCUSABLE!! FORGETFUL!! At 16:00pm we decided to go to the super market and then went to our friend's country house to spend the weekend.* (Diaries)

> M8: *I came back home, I had a shower, chatted on the phone, I relaxed while watching TV, at 01:00am I took my medication and slept. Unfortunately, I don't have a specific time that I take my medication and I can't find a reason why I am doing it. Although I know that it may have a negative consequence on medication and the progress of my health, I am still doing it. I AM INEXCUSABLE!!!* (Diaries)

This particular participant began to question himself about the moral reasons for not taking medication:

> *M8: We woke up late. Around 12:00. I completely forgot it and didn't take medication!!! (Morning dose). Maybe because I was with my partner, all the time. Basically I believe that it was carelessness, or maybe I am just a bit apathetic when it concerns health issues. Is this a kind of self-punishing?*

The participant understood that his behaviour was detrimental to his health, in spite of that though he was not changing his behaviour:

> G: *Yes yes, there is an interpersonal relationship with God, there is an ideological, an ontological probably, an ontological relationship with God eh…it is not…it is not that I see God as a punisher at that point…or a judger of what I am doing.*
> *R: Hm hm*
> *G: Probably as a judger of what I am doing, I just see him* (God) *as a great lover if you can understand my way of thinking, I mean eh…I see him through me, the sum of my psychosomatic existence and* (I see him) *through the person that I am having sex with…*
> *R: Yes*
> *G: And I am thinking about several things from the holy bible during that point, let's say you can't make fun of the saints let's say or me* (meaning God) *it is either me* (God) *that you will love or devil which is your flesh.* (Int2 p3: 126-137)

A possible explanation of the participant's moral questions of why he was not complying with the medication might be that the unwillingness to change a non-compliant behaviour derived from the associations that this participant was making regarding God and Devil. He was interpreting his flesh or else his body as the devil that enjoyed a type of pleasure that was not accepted by God. On the other hand, God became a judge who was judging his actions during the sexual encounters. The participant was seeing God through himself or through his sexual partner during that time, and as he earlier stated he was overwhelmed by feelings of guilt for his actions and insecurity for his soul. Hence, by not engaging a compliant behaviour he was punishing this flesh/body. So, by taking HIV medication the participant was not following the road he thought God was trying to show him. This explained why he was disappointed in himself at the exact point at which he was actually taking his medication:

> M8: *I went to the theatre with a friend, around 20:30 in the evening. She doesn't know about AIDS. Around 23:00 the performance was over and I went back*

> *home after a while. Alone. I took my medication after a while and after reading a bit, I slept. Nothing special.....apathetic????* (Diaries)

Loss of freedom: Participant diaries provided valuable insights into barriers to compliance. Some participants felt that many treatment regimes forced them to abandon pleasant activities such as smoking, overeating, drinking, oversleeping or even fail to remember taking medication, issues which acted as barriers to HIV positive individuals' compliance. This finding supports research which suggests that such restrictions make individuals feel as if they are losing control of their lives (Taylor, 1991). The findings of this study showed that HIV positive individuals were experiencing feelings of being trapped, as they felt that taking medication curtailed their freedom to undertake everyday things such as oversleeping. The following participant was annoyed by the fact that he had interrupted his sleep in order to take medication. The participant's freedom to enjoy a morning in bed or eat whenever he was hungry was lost and as a result perceived taking medication as an obstacle in his life:

> M3: *I took medication 15 minutes later because I didn't want to wake up. I had breakfast although I did not want to eat because I feel better when I have food in my stomach. Medication is a nightmare; they are an obstacle to my freedom to do whatever I want.* (Diaries)

> M7: *I took my medication whilst being very anxious because they stand as an obstacle to my freedom not to get up from bed.* (Diaries)

The following participant had gone out to a restaurant to celebrate his birthday and chose not to take his medication. Perceiving the taking of medication as a responsibility which brought about unpleasant thoughts and feelings, the participant chose to enjoy his evening and retain his sense of personal freedom by not complying with the medication:

> M4: *I went out to a restaurant and had a very nice time with my friends. I didn't take the night dose*. (Diaries)

Taking medication often caused anxiety as it restricted freedom to undertake activities which participants had previously took for granted. In some cases, the routine of taking medication restricted individuals' flexibility and spontaneity, leading to increased worry and anxiety:

> F1: *I was one hour late for medication. I was a bit anxious because I usually wake up early during the weekend (8:00 am the latest), but today I didn't… I usually don't stay up so late though. It was an unexpectedly interesting night out last night! I was also a bit anxious about the house, how will I find time to tide it up?* (Diaries)

Hence, within the context of losing one's freedom, the complexity of the medication regimes and the restrictions that this brought about were some of the reasons that HIV positive individuals did not comply with medication.

According to participant diaries, the regime of taking medication was often disrupted by oversleeping:

> M5: *I woke up at 14:15pm and I suddenly got out of bed when I realised that it was too late to take my morning dose. I just had a coffee*. (Diaries)

Some participants reported that forgetfulness was a factor in complying with medication:

> F2: *I was quite anxious, I forgot to take medication with me, and I wouldn't take them on time then.* (Diaries)
>
> *M6: Did I take medication? I don't remember.* (Diaries)

Restrictions upon individual freedom through the constraints brought about by regularly taking the medication, coupled with the practical difficulties of maintaining a medication routine acted resulted in feelings of frustration and anxiety which acted as a barrier to compliance with HIV medication. As before mentioned several times, we are moving on with the meanings of HIV and medication in terms of gender and identity issues.

Meanings of HIV and medication in terms of gender and identity issues: Meanings of HIV and medication also had gender implications amongst participants. Here, being a HIV positive female had confounded the expectations of the culturally accepted female form. Dubish, suggested that "*the female body is considered from societies as the family symbol of honesty and purity"* (Dubish, 1986, p.211 in Best, 2003). Hence, females were perceived from the society as the pure and honest bodies that would also meet the expectations to bring and raise life within the family. These expectations brought about tensions for female participants who believed that having HIV compromised experiences of motherhood and developing intimate relationships. HIV positive women participants perceived their body as deviant as they could not meet the male expectation of health and purity:

> *Ch: Generally I would really want to have a family to have a child, I know that I can and I know that there also all the circumstances and the presumptions ...but have a chlid on your own, I want to have a husband too.*
> *R: Yes*
> *Ch:Yes lets say that we are having a child just for having a child, to bring it to our world and say what…*
> *R: You want all the…*
> *Ch: All the package…*
> *R: All the package…*
> *Ch: But the truth is that lately I ….have this feeling that dissapointment that nothing will happen in this field, I don't know…I see…I see…even the steps I take, my tries, my attempts, that I did…where are they? Where did they take me to? It is not so easy to go out and say that I will have a relationship, you always hope that…oh! Maybe it wasn't ment to be…and you don't, I mean that I want to feel a bit like a woman three or four times a year, to go out…and play.* (Int7 p15: 720-736)

For some female participants, being unable to experience motherhood and develop an intimate relationship with the opposite sex challenged their perceptions of their femininity. These restrictions were difficult for participants to accept given that they felt physically able and well. Not being accepted in this way generated feelings of alienation and loneliness:

> F2: *I feel terrible. I wish I was with someone…* (Sex partner) *I feel so lonely. I don't know if it finally worth to continue this way. If you can't live like other people… Sometimes I feel inferior to others. I am also disappointed by the fact that I will probably end up alone in life and I will never become a mother. Well…this could happen even without HIV. I don't know what is wrong, is it HIV or me? I know nothing! I am confused!* (Diaries)

The participant reported that she was experiencing feelings of powerlessness as she was prevented from making the same choices other females do due to HIV. Being unable to experience motherhood and ''live up to'' what is expected of a female and her role in society might explain her feelings of inferiority. Consequently, she believed that she would remain unfulfilled as according to her beliefs she could never be able to support this gendered role. This led to feelings of inferiority as she questioned her sense of place within society within the context of her sexual identity. Greek females are raised with the idea of having a family and bearing children. Even nowadays in Greece, the females are considered as the maintenance of family purity; hence, a possible contamination of the female is considered as dangerous for the whole family (Dubish, 1986; Best, 2003). Therefore, it is rather ironic that a mother is the primary educator of the Greek family's children (Attitudes, 2000; Best, 2003).

In summary, participants' experiences identify a number of issues which acted as barriers to taking HIV medication. These included feelings of violation of the physical body through the act of intoxicating the body, the lack of freedom and choice arising from a prescriptive medication routine. All represented negative experiences which acted as barriers to taking medication. However, there were certain issues which acted as facilitators to taking HIV medication; these issues are going to be explored during the following section.

5.2.2 Issues that make Taking Medication a Positive Experience, Facilitators:

There were certain circumstances where taking medication could be less unpleasant and was even characterized as a positive experience by some participants. In this section participants' experiences regarding the support of their family members or their life partners are examined as a facilitator for taking medication. In Greece, "*the family* *system appears to have different patterns compared to other countries"* (Sachpersoglou & Bor, 2001, p. 117). In Greece, the family network is considered as a solid institution and the members of it are supposed to share each other problems, stand by them and support them in stressful situations (Sachpersoglou & Bor, 2001). Indeed, Sachpersoglou & Bor's, (2001) showed that HIV positive individuals in Greece receive a large amount of psychological support from friends or life partners as well, who are considered part of that wider notion of the "family".

Supportive family members: For some participants, medication was taken in the company of a family member. These experiences revealed that when participants took their medication with their family around, they reported fewer negative feelings than those who took their medication alone. Although, the act of taking medication was nevertheless an unpleasant experience for all, the process was perceived as more positive when supported by family members:

> F2: *Today I woke up at 8:00; I had breakfast and then my morning dose. I was with my parents at home. I felt very good. It makes me feel so nice when I manage to wake up early*. (Diaries)

> F2: *I woke up early for a Saturday. I had my breakfast, and then I had a bath and took my medication, I was with my parents at home, I felt very good*. (Diaries)

The support of family members appeared to be beneficial to HIV positive individuals in terms of taking medication. However, the presence of a supportive life partner could strengthen this action even more. During the following section participants reveal the feelings they experience when their life included not only the support of family members but also supportive life partners.

The presence of supportive life partners: The presence of a life partner was a positive resource for participants in terms of emotional support and companionship. Participants reported feelings of happiness, joy and relaxation whilst spending time with the life partner. The emotional support of a life partner allowed the act of taking medication to be a more positive experience than when experiencing the activity alone:

> M5: *I woke up at 11:15 and took my medication. At 12:30 I had my breakfast, I was listening to some music while I was reading a book. I was with my partner at home, I was relaxed.* (Diaries)

> M5: *My boyfriend came back home and had dinner together. We then chatted a bit hugging each other whilst lying on the bed. I took my medication at midnight. I was happy, relaxed and cheerful.* (Diaries)

The presence of a supportive life parnter provided the conditions for relaxation, tenderness, affection, love and security:

> *T: It felt nice, I felt like I had somebody to support me again, and I felt secure again, which I had lost…*
> *R: You mean the security given from a man…?*
> *T: Companionship, not just a man because I could have some guy…*
> *R: When I say a man…I don't mean just a sexual relationship…*
> *T: A man that ….this happen slowly, slowly because you can't be…you understand immediatelly what the other person is…*
> *R: Definitely…*
> *T: A security, without knowing why, and I wasn't even sure that it will last that long.*
> *R: Yes.*
> *T: Because he had different ideas, and I couldn't reach his ideas.*
> *R: Yes, did the fact that he is HIV positive played an important role?*
> *T: Yes yes.*
> *R: Which was the difference?*
> *T: It was…nobody else would stay with me, because I had somebody else and he left.* (Int8 p10:463-478)

As explored in chapter 4, section 4.3 (Intimate relationship attachment), it was more helpful when the intimate partner was also HIV positive, the two HIV positive partners could support each other emotionally and practically, share their experiences and understandings of being HIV positive and being under antiretroviral therapy.

In summary, the findings reported in this section showed that barriers to taking HIV medication were generated through physical feelings of tiredness and weakness as a result of taking the medication. For others, taking medication was highly associated with substance misuse and feelings of humiliation when taking medication in public. However, the company of supportive family members or intimate partners brought about feelings of joy, happiness and security which acted as a facilitator for HIV positive participants to take medication.

In addition, the availability of loved ones was counteracted by feelings of inadequacy within some participants, especially in how they felt they were perceived within society and by others. Here, cultural issues relating to motherhood and perceptions of the ‘‘wholesome’’ and ‘‘pure’’ female were tensions which led to participants feeling alienated and excluded. Nevertheless, taking medication did not involve only psychological barriers or facilitators for taking HIV medication. Everyday life practicalities, such as the impact of certain activities that HIV positive individuals had, was another issue that participants had to deal with when they had to take medication.

5.2.3 The Practicalities of Taking Medication

The following findings reveal the ways in which HIV positive people accommodate antiretroviral therapy in their everyday life. Specifically, this section examines the practicalities of taking medication and the impact that activity has upon lifestyle and habits. It also examines the social, place, temporal and spatial contexts which were perceived important factors when participants were taking their medication. Participants were asked about medication regimes and the ways in which they impacted upon everyday routines and the impact this had on compliance. The following sub-themes are presented in this section: routine, social context (taking medication in public, place context (taking medication at home), temporal context (taking medication at spare time, taking medication at night time) and spatial context (unexpected events and compliance, priorities).

Routine: Some participants revealed that the act of taking antiretroviral medication was a fundamental part of their everyday routine. According to the National Aids Manual (1996) when HIV positive individuals assume control of managing their disease, then they feel more in control of their lives. It has been stated that when people are in control of their lives or else their own motivation, thought process, and patterns of behaviour, they manage situations more effectively whilst overcoming self-doubts and reaching self-protective actions (Diclemente & Peterson, 1994). The findings from the present research showed that when participants failed to incorporate taking medication into their everyday routine, then they tended to forget to take the medication. Those who were more consistent in taking medication were more likely to incorporate taking their medication into their everyday schedule, typical routines and work patterns:

> M8: *After cooking and tasting the food I took medication after 12:00 as usual without any significant feelings.* (Diaries)

Other participants needed to be more specific and rigid about taking medication, where it became an established part of their day:

> F3: *21:00 medication, dinner at home, just before I go out,* (felt) *absolutely nothing, routine.* (Diaries)

This was more difficult for individuals who did not have an established routine. Here, the activity of taking medication was more complex and not always successful:

> *A: Ok now I practically, I struggle more during the weekends, I have my schedule during weekdays, I wake up this time, that time I'll be at the office, that time I will…*
> *R: So you have your schedule…*
> *A: I make it yes, but it's different in weekends.* (Int4 p8-9:398-403)

Changes and disruptions to routines and daily structures often had implications upon compliance:

> *A: Yes, that is what is happening now, however now due to my job I am complying the rest of the days. When I wasn't working I wasn't…*
> *R: When you were not working?*
> *A: Yes.* (Int4 p9:433-436)

The experiences of participants' suggested that compliance was something that they struggled to adhere to during the weekends when their everyday routines were disrupted:

> *A: I have scheduled them, but it changes during the weekend.* (Int4 p.9:403)

> *A: I will sleep a bit more, I will have lunch another time than the usual one, I will change the time that I will go out, I will even go out at night, it is different because….I do struggle (to take medication) during the weekend. (Int4 p.9:405-406)*

Other participants made the necessary changes to their lives and to their schedules to accommodate taking medication:

> *N: Look, I usually take my medication on time, for example I might not take it once or twice or the most three times a month….if go out one night, I will take it a few hours later or just for one day not at all. I discussed this though with my doctor, so I changed my time schedule and I take my medication at noon where I am always at home.* (Int 6 p 8: 362-366)

These necessary changes that participants had made were not related only to their everyday schedules but also to their need for privacy from the watch of strangers when medication had to be taken. It seems that the inventing of routine was not only a way of dealing with everyday habits and schedules; it was also a way to deal with the unpleasantness of taking medication in public, as according to one participant's statement, public venues for taking medication would place him in a position to explain the reasons for taking medication and hence opening himself up to potential hostile reactions. In this case, private venues were important:

> *G: I came up to a point that I got used to it, it became a routine to me…the use of medication, so I knew that… that time…I invented …according to my habits lets say, I had invented a routine that was convenient for me, I was combining the time that I had to take medication with the time that I would be alone where nobody would ask me why I was taking medication.* (Int9 p.10: 490-495)

However, in developing established routines, participants also felt that they lost some control over their own lives. In some ways the regularity of taking medication forced an unwanted routine upon them. Some participants reacted negatively to this as the habitual activity of taking medication was a continuous psychological reminder of having HIV:

> *P: Yes, yes this thing with medication, I remember when I was completing the questionnaire…I realised that taking medication is a routinized movement that makes me feel disgust, I just try not to think about it all the time.* (Int3 p397: 533-535)

For some participants, the act of taking medication acted as a reminder which subsequently impacted on pleasure that they derived from the activity that they were undertaking medication:

> *M7: I took medication on time as a routine and then had dinner. I was apathetic without any pleasure but without having any deep* (important) *thoughts about medication.* (Diaries)

For most participants, taking medication was simply a boring, repetitive activity that had forced the participant to engage in a routine that had to be followed. Feelings of tiredness appeared as HIV positive individuals' lives were rotating around medication. In this way medication became the start and the end of every day instead of just being the path towards a better quality of life. Hence, the psychological consequences could be quite profound, as in cases when taking medication was described as a long-term psychological burden which they struggled to accept as part of everyday life:

> *P: The problem now is that I am in a routine, a routine….this is not the point…if I wanted to send a message it would be…to have a…that I will have to take medication every day, which I am already doing for quite a few years, this is tiring, every day starts with it, and it ends according to the time that I have to take my medication and then eat.* (Int3 p398: 614-618)

The inflexibility and long-term nature of the medical routine led to some participants feeling as if their future lives were already mapped out. Feelings of helplessness came to the surface, where HIV positive individuals could perhaps feel not only that they had once more lost control of their lives, in fact that they were under somebody else’s control who was outlining their lives.

The following participant, referred to his life as ‘‘frozen’’ as if he was lifeless and helpless. A possible self-cutting of medication could once again give meaning to his life. The participant was possibly aware of the result of stopping the medication as he was mentioning that crying was something that gave him the chance to experience strong feelings in the past. Therefore, he was aware of the negative consequences into his life after stopping HIV medication. Nevertheless, he was willing to experience them in order to take himself out of this medical routine:

> *P: But yes, maybe inside you, the biggest cries, the strongest emotions originate through something very strong...*
> *R: Something strong...?*
> *P: I need something strong…in my case, medication made* (my life) *look like a frozen thing, I have to throw it away from me because I can’t…*
> *R: Throw what?*
> *P: Eh...I don’t know, to take it completely out of me, to stop thinking about it, even this small part of it that I have inside me now, this has to go as well, it bothers me.* (Int3 p.399: 652-659)

In other cases taking medication interrupted daily leisure activities and disrupted work tasks:

> M7: *I took medication exactly on time; I had dinner and watched TV. I was with my partner at home. The fact that I had to stop the film in order to take medication annoyed me. I took them as a routine.* (Diaries)

> M7: *I took medication around 9:00 – routine- I had breakfast- because I had to eat, I feel better this way about medication- I went out to buy a magazine and then wrote one of my stories on my pc. I said: medication again, I have to eat again so early.* (Diaries)

In summary, some participants reported that an imposed routine could be beneficial in regards to compliance, enabling them to incorporate medication into their work schedule or everyday habits. However, some HIV positive individuals struggled to comply with medication during the weekends where their habits or time schedules were less structured and more spontaneous. For others, a routine was tiring and unpleasant as they were forced to interrupt leisure activities or other tasks. Furthermore, the long-term nature of the routine challenged notions of control within people's lives; where many felt that their lives were being dictated by the medication regime.

Diaries were a valuable method for capturing participants' activities, at the time and the place they were taking the antiretroviral therapy whilst exploring the reflections on these activities. In the following section, participants reported on the actions they were doing whilst taking medication in regards to contexts of place, temporal, social, and spatial.

Situational context: Situational context referred to the situation that the individuals were into when they were taking their HIV medication. What feelings and thoughts were caused to the participants whilst being in a certain situation, and how these influenced their compliance with antiretroviral therapy? The situational context several times involved public or crowded places such as their work or a coffee shop. However, there were only a few participants that were actually complying with medication whilst being in situational contexts as the following:

> F1: (I took medication)...*At work.*
> M9: *I took medication at work.*
> M8: (I took medication)*... At work's coffee shop.*
> F2: *I had launch at office and then took my medication.*
> F2: *I ate a salad* (at work) *and started taking pills (totally 3).* (Diaries)

Perhaps public environments such as workplace or coffee shops were perceived as visible places where HIV positive individuals should have to confront others about taking medication. This might give an explanation on the small number of participants who were actually complying in spite of the situational context they were into.

Nevertheless, there were other everyday life situations that although seemed unimportant, nevertheless impact upon compliance. Unexpected events and brought about difficulties in taking medication:

> M9: *I took half of my medication because I got back home late from work and had to eat dinner later* (evening pills). (Diaries)

The change of emotional context due to unexpected events could also result not taking medication properly, or in this instance almost forgetting to take medication:

> M6: *I took my car for service at a garage. I was furious with the amount of money I had to pay just for changing car oils. I cooked and took medication; I almost forgot to take those.* (Diaries)

The participant had to put aside any changes in his mood that caused a strong negative feeling so as to take medication. Therefore, although he was trying to fit medication into his everyday life, the unexpected event at the garage occupied his mind and, as a result, he forgot to take his medication. Hence, everyday life's unexpected incidents could cause non-compliant behaviours within HIV positive individuals.

Place context: The place context referred to the places where participants were when they were taking their medication. Taking a morning dose of medication at the home was common amongst participants, organising their time before they began their workday. According to the literature the home is usually considered as the place that occupiers fulfil their objective functions such as shelter, support, access and use, but also represents meanings related to the tenant's experiences and personality (Oswald et al., 2006; Stedman, 2002; Proshansky, Fabian, & Kaminoff, 1983):

> M4: *I was drinking coffee and around 10:00am I took my medication and went to work.* (Diaries)
> F2: *I had a shower, had breakfast, and took morning pill. Got ready for work.* (Diaries)

When not working or during the weekends participants were spending much more time at home. Their home was usually the place where they were taking their antiretroviral therapy:

> M5: *I woke up at 11:15am and took my medication. At 12:30am I had my breakfast, listened to music while reading a book.* (Diaries)

> M8: *After cooking launch and tasted my food I took my medication after 12:00am as usual.* (Diaries)

> F2: *I woke up early for a Saturday. I had my breakfast, and then I had a bath and took my medication.* (Diaries)

> M9: *Evening pills in my room.* (Diaries)

Being at home around the people who knew about their HIV positive status seemed to make taking medication much easier:

> M5: *I was chatting with my sexual partner's mother. I took my medication at 00:15am.* (Diaries)

> M5: *I woke up at 12:00 and took my medication while watching TV with my boyfriend.* (Diaries)

> M5: *My boyfriend came back home, we had dinner together and chatted a bit while holding each other in bed. I took my medication at midnight.* (Diaries)

> M7: *I took my medication (*at the centre of inspirational living, where he is volunteering) *as a routine and had dinner.* (Diaries)

> M6: *When you are at home it is easier to take them* (medication)*, but when you are out, you are a bit anxious just in case you are going to be seen taking medication.* (Diaries)

It seems that participants' homes were a popular place for taking medication. According to previews literature, *"The concept of meaning of home is used to cover subjectively meaningful habits, social contacts, evaluations, goals, values, cognitions and emotions of a person in relation to their home"* (Sixsmith, 1986; Oswald & Wahl, 2005; Moore, 2000; Marcus, 1995; Manzo, 2005; Oswald et al., 2006, p. 190).

Consequently, *"the meaning of home describes the accumulation of a range of place attachment processes, operating when people form affective, cognitive, behavioural and social bonds to a particular setting"* (Brown & Perkins, 1992; Oswald et al., 2006p. 190). Hence, perhaps the supportive environment and sometimes the privacy of the home, depending on the needs that each participant had is an explanation of such a choice.

Priorities: The issue of prioritisation was also raised as an important factor when discussing compliance. Some participants prioritised more entertaining and pleasant activities before the activity of taking medication:

> M8: *Unfortunately, I took my medication 3 hours later. I took them at 03:00am when I got back home.* (Diaries)

Other participants managed to regularly take medication even if this was incorporated into a hectic and unplanned lifestyle:

> F1: *Its 10:30, I just woke up. Last night's "hi"* (to my friends) *became a complete night out. I came back home at 5:30 am. I eat my breakfast quickly so as to take medication.* (the participant took her medication at the same time that she used to take it all week) (Diaries)

According to the experiences of participants, the action of taking medication was often undertaken in several places such as work, the home or other public places. However, as HIV positive individuals reported in this and in the previous section, the support of their partners, friends and family provided a supportive environment for them to take medication. Taking medication when spending time at home provided more privacy and incorporating the activity into enjoyable activities made taking the action of taking medication less serious or prescriptive. However, maintaining a regular routinized medical routine often led to participants feeling inhibited, restricting notions of freedom and choice as they felt they were being encouraged to live formal and structured lives.

5.3 Ways of Seeing Compliance

According to the literature, compliance is a behaviour that is highly dependent on personal experiences, intentions and beliefs about medication and its effectiveness (Remien et al., 2003). Treatment issues, such as side-effects, decision-making, medical practicalities, support issues and numerous other factors can define people's willingness and intention to adopt compliant behaviours (Remien et al., 2003).

This section will examine the thoughts, feelings and intentions of participants in relation to compliance and the development of compliant/non-compliant behaviour. The sub-themes that are going to be examined in this section are: amount of drug treatment and finally reputation.

Amount of HIV drug treatment: Nowadays, antiretroviral therapy decreases HIV/AIDS symptomatology, slows down HIV production and stops people from becoming ill for much more time (Aggleton, 1989). In certain cases, the participants of the current study reported that antiretroviral therapy impacted negatively on aspects of their compliant behaviour. Consequently, several participants failed to engage in full compliance. In some cases, the number of pills that had to be taken and the frequency of the medication doses were reasons for failure to. A fact that is also supported by previews literature in which the numerous pills that are required for a combination HIV therapy are considered as one of the most powerful barriers of compliance. These pills are usually taken multiple times per day along with taking care of the doses timing in concurrence with food or fluids intake (Chesney et al., 2000):

> *B: Yes…yes it had an impact on my psychological state, after a few years though I started taking five pills daily, which I am still doing. This medication helped me a lot psychologically speaking, because I was saying that its different taking five pills per day than taking twelve.* (Int1 p6: 294-297)

The decrease of the numerous pills had empowered the participant's compliant behaviours. Participants felt inhibited in respect of the outlook of their life with the number of pills they had to take. When the number decreased they had started feeling mentally positive as they associated taking fewer pills with an improvement in their condition. The decrease of the number of pills needed to be taken motivated HIV positive individuals to engage into a more positive outlook of their lives:

> *A: It was until 96—97 where my therapy changed, it was then that I took the cocktail and things (in regards to health) became stable, and I started looking at it and with a very…that there is life and you can do several things.* (Int4 p6: 249-251)

Visibility: A number of participants reported that they feared being seen by colleagues taking medication. According to participants' accounts taking medication in front of other people was difficult for them as they were concerned that they might need to justify what medication they were taking and why they were taking it. As such, their rights to privacy of taking medication led to feelings of discomfort. Hence, in order to avoid those feelings of discomfort and awkwardness non-compliant behaviours might occur. This issue prevented the following participant from taking medication at work where she did not want to be seen by a colleague:

> M4: *I was in a public place with associates. I wasn't feeling very good. I had medication with me.* (Diaries)

In order to conceal the fact that she was taking medication and thereby keep her HIV status private, the participant refused to comply with medication whilst in the office. Here, the participant revealed her fear that colleagues were seeing her taking it:

> F2: *Too much work at the office, with my colleagues. Nothing special; I don't take medication at the office.* (Diaries)

> F2: *I never take medication at work, I am afraid if anybody will see me taking it.* (Diaries)

The participant reflected upon an occasion when she did take medication within the workplace. This caused the participants feelings of stress as she was preparing all day in order to find an excuse and justify herself in the case challenged by a colleague:

> F2: *I got ready for work. I took the rest of the pills with me because I will have to eat launch at there* (at work). *I am good. I've decided not to get stressed again. If they see me, it doesn't mean that they are going to know why I am taking them* (medication) *for. It can be anything(whoever has the fly…)* (it is a Greek saying which means that if you know something and you do not want to reveal it, you are afraid that just because you know it, other people will find out too). *I am a bit stressed. I could take antibiotics though.* (Diaries)

The participant felt that in some way she was deceiving her work colleagues, a deceit which resulted in feelings of anxiety. The participant was awaiting a chance within the day which allowed her take the medication and was constantly on edge waiting for the opportunity:

> F2: *I had lunch at office. I took the second pill. I was very anxious, until I managed to find the chance to take it. I didn't want to be seen by anybody.* (Diaries)

Complying or non-complying with antiretroviral therapy were usually an issue when participants were among people who did not know about their HIV positive status. However, those participants were constantly dealing with feelings of shame or guilt when they were taking their medication in front of others:

> F1: *In the beginning I was with only one of my colleagues and managed to take the first pill (relaxed). When I was about to take the second pill another colleague entered the room and started talking to me. I was holding it in my hand and at the moment he was not looking at me, I took it. I didn't want him to see me; I was thinking that I would probably find the right moment to take it. I don't believe that he would make any comments but I wasn't feeling comfortable to take my medication while he was talking to me. I was thinking that the pill was blue and it would look like a Viagra! I believe that nobody saw me, as soon as I took it, I forgot it. It didn't bother me at all later.* (Diaries)

Conversely, the participant felt more able to take her medication when she was in an environment which was comfortable and familiar to her:

> F2: *I was tidying up the house and took the rest of my medication. I was with my parents and brother. I was good, didn't have a problem at all.* (Diaries).

The environment and the people they were surrounded by were key predictors of compliance. For some participants, however, being surrounded by close friends did not increase their likelihood of taking medication. This occurred where participants had taken the choice not to inform their friends that they were HIV positive. Here, incorporating medication within shared activities became more difficult and disrupted medication routines:

> M8: *I got back home around 19:00; I chatted with my partner and made plans about the weekend. We arranged to spend it at a friend's house on the countryside so as to relax a bit and enjoy nature with good company. I was thinking about this a bit; I had to find a way to take my medication in front of my friends. I just let it go; I would have to deal with it at that point. Then I went out for a drink with some friends. Unfortunately I took my medication quite late. At 03:00 am, after I got back home.* (Diaries)

This deceit was often a preoccupation for participants, which impacted on their well-being through increased anxiety levels:

> M8: *I was anxious whether he would see me* (taking HIV medication) *but fortunately it doesn't last long, just for a few seconds, so this relaxes me a bit. What worries me is that at some point he might discover the pills in the fridge and ask me what are those for and why I am taking them.* (Diaries)

In summary, this section has presented a number of important factors in the development of compliant and non-compliant behaviours amongst individuals with positive HIV. A key factor was being surrounded by friends and family, which provided a support network where they felt more able to take medication. Additionally, the environment was seen by participants as crucial to compliance. A comfortable, familiar and secure environment, such as the home, provided participants with a setting where they felt they would not be confronted about taking the medication. Other environments, such as the workplace or other public places, were seen as more visible spaces – meaning they were more likely to be challenged by others.

5.4 Doctors: Expectations and Relationships

Participants reflected upon the relationship that they had developed with their doctors, discussing their expectations from the doctor-patient relationship and the impact that this had on compliance. Participants defined what they felt constituted an effective relationship with their doctor, identifying issues of trust and reciprocity in addition clinical and practical support.

The experiences of participants indicated that the doctor can play a significant role in bringing about compliance through the way sin which they communicate and interact with their patients. Here, participants suggested that the doctors role become more expansive, to incorporate psychological and emotional support alongside medical decision-making. The sub-themes that are going to be examined in this section include: building trust and reciprocity and the identified need for psychological support.

Building trust and reciprocity: Some of the participants reported that they had a close relationship with their doctors. Here, participants reported being more satisfied with their doctors when the doctor spent a longer period of time talking to them in consultation, enabling the opportunity to build trust between the patient and doctor. For individuals who are HIV positive this development of trust was seen as crucial, given that the doctor was often the individual who was most closely associated with the health and well-being status of the individual. Subsequently, strong doctor-patient relationship generated feelings of stability for the participant, a stability which was predicated upon shared memories and events between the doctor and patient:

> *R: In general do you talk with your doctor?what kind of relationship do you have(with the doctor)?*
> *A: We used to talk more when I wasn't working, now I go there for a while and we don't…just the check up…*
> *R: Yes, what about your relationship?*
> *A: They are good*
> *R: So you don't have any problem with him?*
> *A: Ok, we are together for many years, together we went through difficult situations, now we are stable.* (Int4 p10: 447-454)

On the other hand, although the restriction of time was understandable from participants, their need to build a caring relationship still existed. The small amount of time that doctors spend with their patients is a matter that has been examined in past studies as well and according to doctor's reports, they do not spend enough time with patients as their time schedule is very busy and some of them do not feel comfortable enough in order to ask personal information of patients' personal lives (Yee, 2003):

> *Ch: I understand that Doctors' time is not much and I am not saying that it is definitely has to create a relationship, perhaps it cannot happen for several reasons, although I would really want it…*
> *R: I could not consider it as bad or judging wanting to have a better relationship with the Doctor.*
> *Ch: Well you know a Doctor has…so many patients, I don't know how a relationship could be created, considering the matter of time.* (Int7 p8: 362-368)

For the participant, the development of a friendly and co-operative relationship with a qualified doctor was fundamental to the stability and security of the individual. However, there were differing expectations amongst participants about what they expected from the doctor-patient relationship. The following participant felt that the role of the doctor should be primarily be as ‘‘expert’’ and ‘‘scientist’’, distancing themselves from developing close or personal relationships with tehir patients. Here, the doctor was seen as an individual to make clinical decisions when in need of assistance:

> *R: So, everything is good with medication..*
> *T: Yes, I am doing good, I'm doing good.*
> *R: What about doctors?*
> *T: With doctors yes, I do what they say and I am doing good, I don't have any problem.*
> *R: Hm hm, good for you.*
> *T: If there is something wrong I go there and , guys this happened to me…(laughter)…come to us.*
> *R: To the doctors?so there is great understanding and good behaviour, right?*
> *T: Yes, yes.* (Int8 p13: 627-635)

Other participants who did not report a close and personal relationship with their doctor nevertheless identified the important role that the doctor can play in providing help and support in the decision-making process. In the following example this helped directly with compliance, where the information supplied by the doctor re-iterated the importance of taking HIV medication to the individual:

> *R: Apart from those, if you can find a psychologist s/he helps, as doctors help too, like the example you gave me a while ago regarding non complying with medication…*(where the doctor and the psychologist cooperated)
> *F: Eh…yes…*
> *R: I suppose that you talk about it with your psychologist or your doctor…*
> *F: Yes, with my psychologist, with the doctor…em…well basically I have told it to the doctor too…but he can't say a lot to me, he can't be authoritarian towards me regarding this issue…ok and he is quite…quite young in age and a bit distant to all this Professor thing…*
> *R: Hm hm…*
> *F: Which is very common in Greece*
> *R: Yes…*
> *F: He is not arrogant, eh…we referred to the issue of me receiving my medication late once or twice, or that some times I may just forget it…and he simply told me make sure…he said I understand, that there are several reasons that make this happen…when you will realise that it is important is…and even this realisation is important enough of why you should do it.* (Int5 p 23: 1122-1140)

A doctor who was being visited very ocassionally, needed to be seen as a friend in order to inspire reciprocity and security to the HIV positive individuals. The need for a comfortable environment seemed to have detrimental importance for certain HV positive individuals as a comfortable and friendly environment within a doctor's surgery was a place that participants would want to visit. However, when comfortability and reciprocity did not exist between a doctor and a patient, a visit to the doctor's office was becoming a negative and an obligatory experience:

> *Ch: Hm…I don't know, because the last one and a half year that I have another doctor and the relationship is totally typical, and when I say typical I mean ok I*

> *go there, he sees me, he asks me how I am eh…you I want…our contact is every now and then…*
> *R: Yes…*
> *Ch: I feel a bit…lets say, the first times that I was visiting a doctor I used to give him sweets so as to to feeel an environment like…you know like going to a…*
> *R: Friend?*
> *Ch: To a friend and give him something…*
> *R: Yes.*
> *Ch: And I did the same thing to the new doctor and it seemed that he found it a bit strange, it was my need of course, it was covering my issues but I want to feel that I go somewhere you know…somewhere that I feeel comfortable, not somewhere that they force me to go.* (Int7 p7: 342-355)

This participant felt that there was a need to participate in the decision-making process alongside doctors. Research indicates that HIV positive individuals who wish to be involved in their medical therapy are more eager to receive HIV related information and become more engaged as a result (Marelich & Erger, 2004). This explained the participant’s desire to participate in formalised meetings and conferences regarding HIV related medical issues:

> *R: Yes, needs that others might have too?*
> *Ch: To tell you the truth I had always wanted to…for example once a month doctors are gathering to talk about several medical issues, doctors from several hospitals, and they say their opinion. I would really want every now and then to participate in an open meeting, above the limitations of the hospital, the visiting to the doctor and the check-ups.* (Int7 p7: 377-382)

Previous research identifies that certain attitudes of doctors (i.e. being distant) towards HIV positive people had been received as refusal to care from the behalf of the doctors (Frank, 1986, Gerbert et al, 1991 in Robinson, 1998). Hence, for other participants, having a distant and clinical relationship with the doctor could result in mistrust and feeling unwanted. Some participants felt that there was a perceived lack of empathic concern and compassion from the doctor, resulting from a demeanour described by the following participant as ‘‘cold’’ and ‘‘careless’’:

> *B: Yes, he understands me, the doctor that I have now, not the previous ones, not all of them, they were kind of cold and careless, some of them…*
> *R: Hm hm…*
> *B: And this was bothering me a lot psycholocally speaking, because I felt that since they had made a vowel to Hipocrates and themselves they were supossed to feel good with what they provide. They should make fun of themselves first and then the rest since they really wanted to help another person. And in this specific situation it is a patient, not only the…but this is bad in both ways, because if the other one is careless and he is just doing the typical stuff so as to finish and then say next and wants to stand up and leave he makes you feel that he is seeing you as a worm, that you are not valuable to him, he just wants to do his job and that's it, next. It was giving me the impression that I was in a house with prostitutes and when ever they were waiting for the other to come so as the next customer would come in, that's how I was feeling.* (Int1 p14: 656-668)

According to negative accounts reported during the interview, participants could feel that the doctor was "making fun'' of them when the time they spend together was deemed to be insufficient for the doctor to really understand their situation. The participant above associated visiting the doctor with visiting a prostitute's house in which the doctor was perceived as the prostitute. Hence, the doctor's careless, unfriendly and hastily attitude associated him with a prostitute's attitude in to the participan's mind. The small ammount of time and the doctor's typical attitude and the abovementioned assciations caused feelings of invaluability to the participant.

Additionally, due to the fact that illness usually involves emotions such as emotional uncertainty, fear and anxiety, patients are considered as sensitive to and attentive of the verbal and non-verbal communication they experience when visiting the doctor's office (Morgan, 2003). By looking attentive or encouraging, doctors can provide patients with positive feedback and facilitate their participation in the decision-making process. Conversely, when doctors engage a distant role, patients tend to leave the doctor's office without actually describing their problems and end up with more unanswered questions (Morgan, 2003). The doctor's clinical approach brought about feelings of not being vaued on the participant as he regarded himself as another number and not a patient. The uncomfortable and unfriendly envorinment was not fullfilling the patient's expectations and resulted stability issues to the participant as long as anxiety symptoms:

> *B: There were cases where I was not sleeping or eating just because of that, because I felt that that I wasn't sure whether I had a standard doctor, and this was hurting me, the fact that I couldn't open myself to any of those for more specific issues. I mean…it is not just doing your check up and that's it, the typical, it is psychology too, it is a basic issue for the patient.* (Int1 p11:533-537)

Need for psychological support: HIV positive individuals felt that there was a requirement for emotional and psychological support when living with HIV. Even in those circumstances where there were close personal relationships between the doctor-patient, the necessary time for such meetings was not enough. Participants felt that they needed support and somebody to discuss their fears, thoughts or feelings with. They felt such discussion was fundamental to their well-being but often reported they were unsupported in this respect. There was a requirement for this kind of support from a trained professional who was not within their networks of support (friends and family):

> *B: At this point I am satisfied considering the fact that we talk a bit more than we used to do in past.*
> *R: Hm…*
> *B: But not so much, as it concerns psychology, things are typical again* (meaning that he does not receive the psychological support he needs) (Int1 p11-12: 546-549)

Psychological and emotional components were identified as key needs for participants to feel a sense of overall well-being. According to the literature, the constant use of counselling provides HIV-positive individuals' care improvement and should be supported at all healthcare settings. HIV counselling is regarded as effective and efficient in encouraging patients to carry out medical care advice (Eichler et al., 2002). The following participant characterised his therapy as incomplete. The medical support for taking HIV medication did not seem enough for an HIV positive individual as there were several other factors, such as anxiety, fear or stigma that s/he had to deal with. The combination of the medical along with the psychological support seemed to be the detrimental for HIV positive individuals. The absence of the HIV positive individuals' psychological support seemed to have negative impacts on the overall attitudes towards the medical care:

> *R: However, is there any psychological support over there* (at the hospital)*?*
> *B: No, it does not exist and this is very bad…*
> *R: Would you like to have any?*
> *B: They used to have in the beginning but not anymore, yes I would like to have..*
> *R: Hm*
> *B: A patient's psychological state is very important, if (doctors) are not capable of providing something in all fields then it would be better if there was nothing at all, instead of providing half of it, if it is half then it never ends.*
> *R: So there is something missing…*
> *B: Something is missing, either you do it all or you do not do anything, it is like a missing part.*
> *R: Yes.*
> *B: It is like an unfinished puzzle, you are trying to finish it but it never ends, a part is missing.* (Int1 p12: 557-571)

Dealing with the HIV virus was accomplished more dynamically when psychological help was provided. Although, the following participant was dealing with the virus without any psychological help for several years, his engagement to psychotherapy seemed to be satisfactory for the improvement of his care:

> *A: I started to change slowly since 2000 and then…ok I had started psychotherapy and then on 2002 I visited the CIL, things changed in a more dynamic way.*
> *R: That is what I am going to ask you now, whether you went through all this by yourself or you had support…*
> *A: Slowly yes by myself, but in certain cases, especially the latest years I had support, but I was by myself until 96-97.* (Int4 p11-12: 543-549)

Trust, understanding, empathy, friendliness and non-judgemental attitudes were expectations that HIV positive individuals felt they wanted from their doctors. Given that the development of a caring relationship between doctor-patient more compliant behaviours (Taylor, 1991) this need could be considered as very important. Consequently, the solution of combining medical and psychological support was essential to the well-being of HIV positive individuals but was unsupported through existing care mechanisms.

5.5 Chapter Summary

Medication was a fundamental aspect of the everyday life of participants living with HIV, in terms of developing established routines and incorporating the action of taking medication at home, in public places and in the workplace. For all participants this involved adapting their life and daily routines to ensure that medication was taken and established routines ensured that they took their medication on time. For others, who led more flexible lives, taking medication was often a burden which interrupted pleasant and enjoyable leisure activities.

Moreover, structured and inflexible medication routines led to participants feeling disempowered, as if they were losing control of their lives and its structure. For some this led to feelings of frustration and subsequent non-compliance. Furthermore, for many the routine of taking medication brought about the realisation that medication would be a part of them for the rest of their lives. However, visibility was an issue that was actually causing non-compliant behaviours as participants wanted to avoid exposing themselves in respect to their health to public. Conversely, participants felt more comfortable when they were taking medication within a familiar environment such as their home. Hence, in terms of complying behaviours, even though medication could actually not involve numerous pills, rights to privacy and visibility were still issues in HIV positive individuals’ minds.

Conversely, the presence of supportive family members or intimate partners acted as facilitators to medication compliance, as their support seemed resulted in feelings of joy and happiness which made many participants feel more comfortable and relaxed when taking medication. The environment was also a facilitator in compliance. When taking medication in places where participants had more privacy or being supported by family or intimate partners, it was easier and less stressful. However, for others, the support of family and friends was not always enough. HIV had also influenced participants’ perceptions according to their gender and sexual identities.

HIV positive individuals experienced feelings of helplessness as due to society's stereotypes and their masculine or feminine roles had been lost. Male participants could no longer have the strong roles that society had placed them to have and females felt abnormal or deficient as not only they could not continue the generation through motherhood but also had been positioned by society as a source of infection. Participants' self-esteem was influenced and feelings of guilt or blame were experienced.

However, compliance was not only dependent on a supportive family and environment. The doctor-patient relationship was also seen as a key determinant in the likelihood to take medication. Some participants, who had developed trustful relationships with their doctors, and received understanding, empathy and a non-judgemental attitude from their doctor, were subsequently more likely to comply with medication. However, doctors did not always have the time to develop such relationships with individuals, leading participants to feeling devalued. Participants revealed that medical support was not sufficient to support some of the less tangible indicators that are important to their health and psychological well-being, recommending the need for more qualified psychological support.

The next chapter presents the quantitative analyses based on variable categories.

CHAPTER SIX: DESCRIPTIVE ANALYSIS OF FACTORS

The previous chapter presented the findings of the thematic analysis of the interviews and diaries data. In this chapter descriptive analysis of all the factors arising from the quantitative research is presented. After examining the responses given by the 80 respondents (in total 800 = 10%), the data were coded and entered into a data file so that there would be statistically analyzed. The first step of the analysis procedure was to organize the questions based on the variables categories, as they were presented at the theoretical part of the present study. Then, the information was entered concerning each variable.

The *aim* here was to provide descriptive information about the five factors, as they described in chapter 3: 1) Demographic/ lifestyle factors; 2) Social–cultural factors; 3) Health and health care factors; 4) Psychological factors and 5) Medications factors

For every single question the frequencies, the percentages and the descriptive statistics (mean and standard Deviation (SD)) are presented so as to explain the trends revealed in the responses. Also, for the various variables categories Cronbach's alpha coefficient was estimated in order to examine whether there was an internal consistency in each category, so as to say whether the questions were related to each other.

6.1 Results

Before the analysis of each factors' category it is important to note that according to the responses of the participants more than half of them 53.7%, (n = 42) were diagnosed HIV between 1990 and 1999, 16.3% (n = 13) were diagnosed between 1983 and 1989, and 30% (n = 25) were diagnosed between 2000 and 2005. Only one (1.3%) participant started treatment between 1983 and 1989.

6.1.1 Demographic and Lifestyle factors

Information regarding the lifestyle of HIV positive participants is presented in this section. Information on demographic characteristics has already been presented in chapter 3 (section3.7.4).

In more detail data analysis using descriptive statistics (average value and standard deviation) was conducted to answer the question:

- *What sorts of lifestyles do people with HIV live?*

Results are presented on table 6.1

Table 6.1: Lifestyle Information

	n	%
Consumption of alcohol		
No	45	56.3
Yes	35	43.8
How much do you drink approximately per day?		
0	74	92.5
1	2	2.5
2	2	2.5
3	1	1.3
4	1	1.3
How much do you drink approximately per week?		
0	41	51.3
1-5	33	41.3
6-10	2	2.5
11-15	2	2.5
16-20	1	1.3
21-25	0	0
26-30	1	1.3
Do you smoke?		
No	31	38.8
Yes	49	61.3
How many cigarettes do you smoke on average per day?		
0	31	38.8
1 - 10	9	11,5
11 - 20	12	15.1
21 - 30	10	12.6
31 - 40	13	16.3
41 - 50	2	2.5
51 - 60	3	3.8

From Table 6.1, results indicated that 43.8% (n = 35) of the sample reported that they consumed alcohol and 56.3% (n = 45) declared that they did not. Additionally, the majority of the sample (92.5%, n = 74) did not drink alcohol every day and only 7.5% of the sample reported that they drink at least one glass of alcohol every day. Also the majority of the sample (51.3%, n = 41) reported that they did not drink alcohol every week. Specifically, 41.3% (n = 33) drinks 1 to 5 glasses of alcohol every week, 2.5% (n = 2) drinks 6 to 10 glasses of alcohol every week, 2.5% (n = 2) drinks 11 to 15 glasses every week, 1, 3% (n = 1) drinks 16 to 20 glasses of alcohol every week and 1.3% (n = 1) drinks 26 to 30.

Furthermore 61.3%, (n = 49) of the sample were smokers and the rest 38.8% (n = 31) were not. In terms of amount of cigarettes smoked, 11.5% (n = 9) of the sample did not smoke more than 10 cigarettes per day, 15.1%, (n = 12) of the sample smoke 11 to 20 cigarettes and 12.6% (n = 10) were relatively heavy smokers at 21 to 30 cigarettes per day. Heavy smokers constituted 22.5%, (n = 18) of the sample that smoke more than 30 cigarettes per day and less than 60. In detail, 16.3% (n = 13) smoke 31 to 40 cigarettes per day, 2.5 (n = 2) smoke 41 to 50 cigarettes per day and 3.8% (n = 3) smoke 51 to 60 cigarettes per day (Table 11).

In summary, many of the participants consumed alcohol, however, not on a daily basis. Also, many of the participants smoked and most of them smoked many cigarettes per day, on average 27, 59 per day. Based on the above, it could be said that the HIV positive people in Greece *do not have a healthy lifestyle*. This is according to the findings of other researchers (Rotheram-Borus et al., 1997), who reached to the conclusion that many HIV positive individuals do not change their risk related habits such as drinking alcohol, a fact that consequences the reduction of healthy lifestyles and their co-operation with medical care system. Further examination of the Greek lifestyle habits is presented in section 8.3.1 Lifestyle and socio-demographic information.

6.1.2 Socio-cultural Factors

The aim of this section is to understand the socio-cultural positioning of HIV/AIDS sufferers.

6.1.2.1 Perceived Severity

In this section the results concerning the beliefs of HIV positive participants regarding HIV in Greece are presented.

- Data analysis using descriptive statistics (average value and standard deviation) was conducted in answer the research question:
- *What are respondents' beliefs about the HIV?*

In details, perceived severity consisted of two items adapted from an established scale of Aversa and Kimberlin (1996) indicating the extent to which HIV positive individuals perceived HIV virus (Aversa & Kimberlin, 1996). The perceived severity scale consisted of two items requiring the participant to respond to the statement ‘For me HIV/AIDS is...’ by marking one of five numbers between two sets of opposites: ‘Not Serious/Serious’ and ‘Mild/Severe.’ The responses ranged from 1, low perceived severity of HIV, to 5, high perceived severity (Aversa & Kimberlin, 1996).

Analysis of respondents showed that 81.3% (n = 65) of the participants believed that their HIV situation was serious or very serious, a further 5.0% (n = 4) believed that their HIV situation was not so serious and the remaining 10% (n = 8) believed that their HIV situation was moderately serious. A very small percentage (3.8%) of the respondents thought that their condition was not serious (n = 3). As such, the majority of the sample believed that their condition was serious or quite serious. Moreover, 50% (n = 40) of the sample reported that their HIV status was severe or quite severe while 26.2% (n = 21) believed that their situation was not severe or not so severe. The remaining 23.8% (n = 10) reported that their situation was average (see Table 6.2).

Table 6.2: Perceived severity

For me HIV AIDS is…	n	%	Mean	SD.
Not serious	3	3,8	4,35	1,092
2	4	5,0		
3	8	10,0		
4	12	15,0		
Serious	53	66,3		
Mild	12	15,0	3,39	1,410
2	9	11,3		
3	19	23,8		
4	16	20,0		
Severe	24	30,0		

SD = Standard deviation

6.1.2.2 Perception of the Position of HIV Positive People within Society

The results concerning the perception of the position of HIV positive people within the Greek society are presented in this section.

Data analysis using descriptive statistics (average value and standard deviation) was conducted in answer the research question:

- *What is the perception of the position of HIV positive people within society?*

In order to measure HIV positive individuals' attitudes to HIV and sexuality a scale of ten items was designed. The scale was separated in two sections indicating HIV and sexuality in general public's and HIV positive individuals' opinion. The scale's reliability was high α = 0.62, which means that there was internal correlation between items.

For questions 3, 4, 6, 7 & 8 the minimum value was 1 = Strongly disagree and the maximum 4 = Strongly agree. For the rest of the questions there was a reversal in coding so as to achieve the best possible reliability of the answers (the recoding was 4=1, 3=2, 2=3, 1=4). It must be noted that in Table 6.3 the wording of the questions is opposite to that presented in the questionnaire so as to facilitate the presentation of the results.

Table 6.3: Perception of the position of HIV positive people within society

	n	**Min.**	**Max.**	**Mean**	**SD.**
1. To be an HIV positive individual is not a bad thing	80	1	4	2.19	1.06
2. Being homosexual is acceptable in our society	80	1	4	2.20	0.86
3. Sexual identity is not important in nowadays	80	1	4	2.54	0.91
4. Being promiscuous is acceptable by today's standards	80	1	4	2.40	0.87
5. HIV positive individuals will not die younger	80	1	4	2.56	0.87
6. HIV positive individuals are likely to have long term relationships	80	1	4	2.40	0.85
7. HIV positive individuals are not a great danger for the spreading of HIV virus	80	1	4	2.59	0.92
8. Being HIV positive motivates me to take care of myself more	80	1	4	3.36	0.60
9. I take care of myself well	80	1	4	3.19	0.78
10. HIV positive don't put other peoples' health in danger	80	1	4	3.14	0.87
ATTITUDES TO HIV & SEXUALITY	80	1,70	3,50	2.65	0.41

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

The average value of the variable that concerned the health beliefs, susceptibility was (M = 2.65; SD = 0.41) which means that the majority of sample did not agree with the statements. The perception of the respondents did not seem to be favorable towards the position of HIV positive people within society. This occurred because the responses of all items were on the average closer to the negative response and particularly to questions 1 and 2, namely: *''To be an HIV positive individual is not a bad thing''* (M = 2.19; SD = 1.06), *''Being homosexual is acceptable in our society''* (M = 2.20; SD = 0.86). The answers concerning HIV positive individuals' opinion were more positive and in particular *''Being HIV positive motivates me to take care of myself more''* (M = 3.36; SD = 0.60), *''I take care of myself well''* (M = 3.19; SD = 0.78), *'’HIV positive don't put other peoples' health in danger''* (M = 3.14; SD = 0.87).

6.1.2.3 Support Network

In more detail data analysis using descriptive statistics (average value and standard deviation) was conducted to answer the following research questions:

What is the level of social support that HIV positive people have?

- *Who supports the participants emotionally?*
- *Who supports the participants practically?*
- *Who supports the participants financially?*
- *Who supports the participants for taking their medication?*
- *Who understands the participants the best?*
- *Who mostly accepts the participants?*

Social support was measured with two scales; the first one was Cohen and Hoberman's (1983) -Interpersonal Support Evaluation List (ISEL-12). ISEL – 12 is a short version of ISEL that measures participants' perceptions of the perceived availability of social support (Cohen & Hoberman, 1983). A supplementary social support scale which indicated who provides social support was specially designed for the current research through the literature review and piloted since ISEL-12 did not provide such information. The second scale was designed by the researcher considering the pilots and the literature review.

In particularly, the items regarding the social support of the sample had a different minimum value (0.58) and maximum value (3.00). All other questions had a minimum value of 0 dans (0 = definitely false, 3 = definitely true). In questions 1, 2, 7, 8, 11 and 12 there was a reversal so as to achieve a reliable Cronbach's alpha index (the recoding was 3 = 0, 2 = 1, 1 = 2, 0 = 3). The scale reliability was 0 .84, which means that there was a high internal correlation between items (Table 6.4).

Table 6.4: Social Support from the environment

SOCIAL SUPPORT	n	Min.	Max.	Mean	SD
1. If I wanted to go on a trip for a day(for example to the country or mountains), I wouldn't have a hard time finding someone to go with me	80	0	3	1,79	1,099
2. I don't feel that there is no one I can share my most private worries and fears with	80	0	3	1,98	1,079
3. If I were sick, I could easily find someone to help me with my daily chores.	80	0	3	2,04	0,934
4. There is someone I can turn to for advice about handling problems with my family.	80	0	3	2,24	0,875
5. If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me.	80	0	3	2,19	0,858
6. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.	80	0	3	2,33	0,978
7. I do often get invited to do things with others.	80	0	3	2,30	0,933
8. If I had to go out of town for a few weeks, it wouldn't be difficult to find someone who would look after my house or apartment (the plants, pets, garden e.t.c.)	80	0	3	1,89	1,006
9. If I wanted to have lunch with someone, I could easily find someone to join me.	80	0	3	2,29	0,830
10. If I was stranded 10 miles from home, there is someone I could call who could come and get me.	80	0	3	2,04	1,037
11. If a family crisis arose, it wouldn't be difficult to find someone who could give me good advice about how to handle it	80	0	3	1,94	1,083
12. If I need some help in moving to a new house or apartment, I wouldn't have a hard time finding someone to help me	80	1	6	1,93	1,065
SOCIAL SUPPORT	80	0,58	3,00	2.0771	0,595

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

In general, the answers of the participants were not very positive. This is proven by the fact that all items' average value of the variable that concerned the social support was (M = 2.08, SD = 0. 595) (close to two) which means that the level of social support was not so high. In particular, the more positive answers concern questions 6,7 & 9– ‘‘When I need suggestions on how to deal with a personal problem, I know someone I can turn to’’ (M = 2.33, SD = 0.978), ‘‘I do often get invited to do things with others’’ (M = 2.30, SD = 0. 933) and ‘‘If I wanted to have lunch with someone, I could easily find someone to join me’’ (M = 2.29, SD = 0. 830) and the more negative ‘‘If I wanted to go on a trip for a day (for example to the country or mountains), I wouldn't have a hard time finding someone to go with me’’ (M = 2.79, SD = 1.099).

As far as the second scale that indicated who provided social support the following was found according to Table 6.5: The 0 standed for negative response and 1 for positive. The general pattern for all the cases was friends and family in the first two places (usually with this order) and sexual partner and work colleagues in the last two (usually with this order).

Table 6.5: Type and Source of Support (A)

		Min.	Max.	Mean	SD.
Emotional support from partner	80	0	1	0,33	0,471
Emotional support from family	80	0	1	0,51	0,503
Emotional support from friends	80	0	1	0,65	0,480
Emotional support from work colleagues	80	0	1	0,10	0,302
Practical support from partner	80	0	1	0,25	0,436
Practical support from family	80	0	1	0,55	0,501
Practical support from friends	80	0	1	0,63	0,487
Practical support from work colleagues	80	0	1	0,10	0,302
Financial support from partner	80	0	1	0,13	0,333
Financial support from family	80	0	1	0,56	0,499
Financial support from friends	80	0	1	0,39	0,490
Financial support from work colleagues	80	0	1	0,05	0,219
Social support from partner	80	0	1	0,15	0,359
Social support from family	80	0	1	0,44	0,499
Social support from friends	80	0	1	0,71	0,455
Social support from work colleagues	80	0	1	0,16	0,371
Support for taking medication from partner	80	0	1	0,15	0,359
Support for taking medication from family	80	0	1	0,44	0,499
Support for taking medication from friends	80	0	1	0,71	0,455
Support for taking medication from work colleagues	80	0	1	0,16	0,371
Understanding from partner	80	0	1	0,26	0,443
Understanding from family	80	0	1	0,54	0,502
Understanding from friends	80	0	1	0,68	0,471
Understanding from work colleagues	80	0	1	0,10	0,302
Acceptance from partner	80	0	1	0,30	0,461
Acceptance from family	80	0	1	0,61	0,490
Acceptance from friends	80	0	1	0,71	0,455
Acceptance from work colleagues	80	0	1	0,16	0,371

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

Specifically, the emotional support came most often from friends (65%), family members (51.3%) sexual partners (32.5%) and work colleagues (10%). There was a similar order found for the practical support. So, again friends (62.5%) provided the most practical support, followed by family (55%), the sexual partner, for those who have one, (25%) and lastly work colleagues (10%). Moving on to the financial support there was a small change in the first two positions. So friends came in second position (38.8%), in the first position there was the family (56.3%), in the third position the sexual partner (12.5%) and in the last the work colleagues (5%).

In terms of social support the friends (71, 3%) came in the first position, the family (43.8%) came in second position, the work colleagues (16.3%) came in the third position and the sexual partner (15%) came in the last. 42.5% of the participants reported that they received support for taking medication from their family and 31.5% from their friends. It was also found that some of the participants received support from their sexual partners (21.3%) and work colleagues (1.3%). As far as the issues of understanding friends came first (67.5%) and family second (53.8%). Consequently, sexual partner was in the third position (26.3%) and in the last came the work colleagues (10%).

In regards to acceptance the pattern did not change. So, in the first place there were friends (71.3%) and in the second the family (61.3%) followed by the sexual partner (30%) and the work colleagues in the last position (16.3%) (Table 6.6).

Table 6.6: Type and Source of Support (B)

Type of support		Partner	Family	Friends	Work colleagues
Emotional support	**%**	32,5	51.3	65.0	10.0
	N	26	41	52	8
Financial support	**%**	12.5	56.3	38.8	38.8
	N	10	45	31	31
Practical support	**%**	25.0	55.0	62.5	10.0
	N	20	44	50	8
Understanding	**%**	26.3	53.8	67.5	10.0
	N	21	43	54	8
Acceptance	**%**	30.0	61.3	71.3	16.3
	N	24	49	57	13
Social support	**%**	15.0	43.8	71.3	16.3
	N	12	35	57	13
Support for taking medication	**%**	21.3	42.5	37.5	1,3
	N	17	34	30	1

6.1.3 Health and Health Care Factors

This section presents the health of HIV positive individuals, as well as the doctor-patient relationship.

6.1.3.1 General Health

The aim here was to examine the HIV positive individuals' general health status, physiological and psychological health influencing compliance to the medical treatment regimes. In other words the exploration was focused upon the impact of the participants' general health status to compliance with the medical treatment.

In more detail data analysis was conducted to answer the research question below:

- *What is participants' Physiological and Psychological health status?*

The general health of participants was measured using the General Health Questionnaire (GHQ). Goldberg designed the General Health Questionnaire in 1972 and several shortened versions of this have since been produced. In the current study, the (GHQ12) was used. The questions had a different and lower maximum value (2.25) while all the other questions had the value three (3 = much less than usual) and additionally a different and higher minimum value (1) whiles all the other questions had the value 0 (see Appendix 2). The scale reliability was 0.78, which means that there was a high internal correlation between items. In general, the responses of the participants were quite positive. This was proven by the fact that all items' average value of the variable that concerns the level of general health was (M = 0,997, SD = 0. 459) (close to one) which means that the general health status was good.

Table 6.7: General health status

Have you recently:	**N**	**MIN.**	**MAX.**	**MEAN**	**STD. DEV.**
1. been able to concentrate on what you are doing?	80	0	3	1,05	0,673
2. lost much sleep over worry?	80	0	3	1,11	0,941
3. felt that you are playing a useful part in things?	80	0	3	0,91	0,766
4. felt capable of making decisions about things?	80	0	3	1,06	0,769
5. felt constantly under strain?	80	0	3	1,24	0,860
6. felt you couldn't overcome your difficulties?	80	0	3	1,05	0,860
7. been able to enjoy your normal day to day activities?	80	0	3	1,21	0,867
8. been able to face up to your problems?	80	0	3	1,00	0,656
9. been feeling unhappy or depressed?	80	0	3	0,86	0,964
10. been losing confidence on yourself?	80	0	3	0,79	0,951
11. been thinking of yourself as a worthless person?		0	3	0,48	0,856
12. been feeling reasonably happy, all things considered?	80	0	3	1,21	0,822
General health status	80	0	2.25	0.99	0.459

6.1.3.1 Health Status

In order to be more detailed data analysis was conducted to answer the following research question:

- *What is participants' health status?*

The health status of the participants was measured using the SF-36, (Brazier et al., 1992). The minimum value was 1 = Poor and maximum was 5 = Excellent.

Table 6.8 shows the results of health status obtained from the responses of respondents. The table shows that their health status was good. This is proven by the fact that responses on average run around answer was *'good'* and the deviation from this value was equal to 1 (M = 3.20; SD = 1.072).

Table 6.8: The participants' beliefs for their health status

HEALTH STATUS	**n**	**Min.**	**Max.**	**Mean**	**SD**
In general would you say your health is…	80	1	5	3,20	1,072

Min = minimum; Max = maximum; SD = Standard deviation; n = number

6.1.3.2 Experienced Symptoms

In this section the information concerning the symptoms of HIV positive participants are presented.

Data analysis was conducted to answer the research questions below:

- *What HIV symptoms do respondents experience?*

The experience of symptoms was measured using the HIV-Related Symptoms checklist (SSC-HIV) (Holzemer et al., 1999). The 26-item SSC-HIV is a reliable measure (Cronbach alpha ranged from 0.72 to 0.82) available to use in studies related to symptoms of HIV positive population (Holzemer et al., 1999). Even in the present study, the values of Cronbach alpha were high.

Specifically, in order to express the various symptoms / problems the respondents were asked: *"below there is a list of potential problems that you may be experiencing today. If you have the problem, rate the degree of intensity which best describes the extent of the problem; and responded on a scale of 0-3 whereby blank= 0, mild=1, moderate=2, severe=3"*

According to the results HIV respondents suffered most from the following symptoms:

Table 6.9: Symptoms that participants experience (n = 80)

	Mean	SD		Mean	SD
Muscle aches	.51	.86	**Day sweats**	.31	.76
Weakness	.58	.89	**Night sweats**	.49	.87
Painful joints	.54	.94	**Loose stools**	.55	.86
Fatigue	.78	1.03	**Diarrhea**	.48	.90
Dry mouth	.54	.91	**Gas/bloating**	.87	1.13
Thirsty	.43	.81	**Abdominal pain**	.33	.71
Difficulty concentrating	.49	.79	**Shortness of breath at rest**	.30	.75
Depression	.63	.95	**Wheezing**	.21	.61
Memory loss	.56	.84	**Shortness of breath**	.36	.73
Fear/worries	.71	1.03	**Nausea**	.27	.59
Anxiety	.96	1.18	**Vomiting****	.19	.45
Disorientation	.38	.66	**Lack of appetite**	.26	.63
Fever*	.13	.33	**Chills****	.14	.38

All symptoms have zero minimum value and the value of 3 as maximum, n = 80
**1 as a maximum value, no one gave an answer above 1*
*** 2 as a maximum value, no one gave an answer above 2*

All the mean values of the variables were less than 1 (the average value of the likert scale that we use is 2 = moderate) which means that respondents tended to experience only mild health symptoms at the time of this research. Among these health symptoms, the respondents experienced mostly anxiety (M = 0.96; SD = 1.18) gas/bloating (M = 0.87; SD = 1.13) and fear / worries (M = 0.71; SD = 1.03) Contrary, the symptoms they experienced less was fever (M = 0.13; SD = 0.1333), chills (M = 0.14; SD = 0.38) and vomiting (M = 0.19; SD = 0.45).

6.1.3.3 Anxiety and Depression

The results concerning the degree of anxiety and depression are presented in this section.

A more detail data analysis using descriptive statistics (average value and standard deviation) was conducted to answer the following research question:

- *What are the anxiety and depression status?*

To measure anxiety and depression the Hospital Anxiety and Depression scale (HADS) was used (Zigmond & Snaith, 1983) and dividing the outcome by 14 -the number of the questions-). The HADS scale was designed to measure anxiety and depression in general medical patients.

In order to achieve high reliability there was a reversal of the questions. The scale reliability was 0.86, which means that there was a high internal correlation between items. The questions had a different and lower maximum value (2.07) while all the other questions had a value of 3 (0 means high level of anxiety and 3 low level of anxiety). In addition, the average value of the variable that concerned the level of anxiety and depression was 0.86 (close to one) which means that the level of the anxiety and depression was high (Table 6.10).

Table 6.10: The degree of participants’ anxiety and depression (n = 80)

ANXIETY AND DEPRESSION	Mean.	Max.	Mean	SD
I don’t feel tense or “wound up”	0	3	1,08	0,759
I still enjoy the things I used to enjoy	0	3	0,69	0,851
I don't feel frightened as if something awful is about to happen	0	3	1,11	0,871
I can laugh and see the funny side of things	0	3	0,63	0,905
Joyful thoughts go through my mind	0	3	1,13	0,832
I don't feel cheerful	0	3	1,10	0,756
I can sit at ease and feel relaxed	0	3	1,16	0,719
I feel as if I am turned on	0	3	1,01	0,787
I get sort of frightened feeling like "butterflies" in the stomach	0	3	0,55	0,692
I take care my appearance	0	3	0,73	0,968
I don't feel restless as if I have to be on the move	0	3	1,00	0,811
I look forward with enjoyment to things	0	3	0,64	0,971
I don't have sudden feelings of panic	0	3	0,78	0,826
I can enjoy a good book or radio or TV programme	0	3	0,40	0,805
LEVELS OF ANXIETY AND DEPRESSION	**0**	**2.07**	**0,856**	**0,502**

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

6.1.3.4 Experiences and Perception of Health Care

Results concerning the experiences and perceptions of health care are presented in this section.

Hudson’s (1982) Adherence Attitude Inventory (AAI) was used to indicate the relationship between the respondents and their care providers. The scale reliability was high 0.85, which means that there was a high internal correlation between the items.

Data analysis was conducted to answer the following research question:

- *What are respondents’ experiences and feelings about healthcare?*

Specifically, 7 several questions concerning respondents’ experiences of and feelings about health care provision were posed in the questionnaire. The minimum value was 1 = None of the time, and maximum value was 7 = All of the time. Results are presented in Table 6.11.

Respondents perceived that they were well informed about planning to fit the medication dosing schedule into their personal routine (M = 5.43; SD = 1.868).

Furthermore they thought that the medical provider promotes the participation of the respondents in taking decisions about their medicine (M = 4.94; SD = 2.064) and understands how difficult it is for someone to follow this medical regime (M = 4.79; SD = 1.947).

In addition, respondents reported that the medical provider wanted to know about the problems that respondents experienced in order to take their medication effectively (M = 5.63; SD = 1.687) as well as asked all the appropriate questions so as the respondents were enabled to take their medication correctly (M = 5.86; SD = 1.597). Moreover the respondents reported that the medical provider asked if they could handle any possible side–effects of their medication (M = 5.64; SD = 1.759)

The healthcare questions were combined together and subject to a mean value in order to identify a healthcare provision construct. The construct ‘health care provision achieved the mean score of 5.31 (SD=1.36) which indicated that the level of health care was more than average.

Table 6.11: The respondents' experiences and feelings about healthcare (n = 80)

My medical provider...	Min.	Max.	Mean	SD
1. makes sure that I have a plan for fitting the medication dosing schedule into my personal routine	1	7	5.43	1.868
2. wants me to participate in making decisions about my medicine	1	7	4.94	2.064
3. understands how difficult it is to follow my medication regimen	1	7	4.79	1.947
4. wants to know what problems I have that make it hard to take my medications	1	7	5.63	1.687
5. understands my personal life and why it is hard for me to take my medications	1	7	4.86	2.036
6. makes time for me to ask all the questions I need about my medications	1	7	5.86	1.597
7. asks me if I can handle any possible side-effects of my medication	1	7	5.64	1.759
HEALTH CARE	**1**	7	5.305	1.363

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

6.1.3.5 Satisfaction with the Healthcare

The results concerning the participants' satisfaction with the healthcare are presented in this section.

Health care satisfaction items were adapted from the Patient Satisfaction Questionnaire (Ware et al., 1983; Bogart et al., 2004).

Data analysis was performed to answer the research question below:

- *How satisfied are respondents with the health care they have received?*

Participants' satisfaction of health care provision was measured on a scale of 1-5 where 1= strongly disagree and 5 = Strongly agree. From Table 6.12, it can be seen that respondents reported being generally satisfied with the medical care that they had received (M = 4.23; SD = 0.88) as they felt they had someone to help them if needed (M = 3.89; SD = 1.16) even though they suggested medical care could be improved (M = 3.87; SD = 1.10). In general, this means that the respondents were satisfied, but they also believed that they could be more satisfied, because they could not always reach someone for help.

Table 6.12: Satisfaction with health care

	Min.	**Max.**	**Mean**	**SD.**
1. I am very satisfied with the medical care I Receive	1	5	4.23	0.88
2. If I have a medical problem, I can reach someone for help without any problem	1	5	3.89	1.16
3. There are things about the medical care I receive that could be better	1	5	3.87	1.10

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

6.1.4 Psychosocial Factors

This section presents the results of psychological factors such as self-esteem, coping strategies, locus for control, personality characteristics and life satisfaction.

6.1.4.1 Self Esteem

The results concerning the degree of self-esteem are presented in this section.

Data analysis was carried out to answer the research question:

- *What is their perceived level of self-esteem?*

Self-esteem was measured with the Self-Esteem Scale (SES). Rosenberg's (1986) Self-Esteem Scale (SES) is widely used as a uni-dimensional measure of self-esteem

(Robinson et al., 1991). SES is used to measure the self-esteem of the participants which according to the literature review and pilots plays an important role in HIV positive individuals lives (Kelly and Lawrence, 1988) and may be implicated in compliance to medication.

The measurement of self-esteem degree was achieved 10 questions (items). For questions 1,2,4,6 and 7, the minimum value was 1 = Strongly disagree and the maximum was 4 = Strongly agree. For the rest of the questions there was a reversal so as to achieve maximum reliability of the responses. In must be noted that in Table 6.13, the wording of the questions is the opposite of that presented in the questionnaire so as to facilitate the presentation of results. The reliability of the scale was 0.63, which means that there was internal correlation between items.

The average deriving of the sum of all items was (M = 1.98; SD = 0.386). This means that the degree of self-esteem was average. This was attributed from the negative responses to questions 3,5,7 and 8, namely '*All in all, I am inclined to feel that I am a success'* (M = 0.76; SD = 0.860), '*I have a lot of things to be proud of'* (M = 1.80; SD = 0,960), '*On the whole, I am satisfied with myself'* (M = 1.99; SD = 0,720) και '*I have a lot of respect for myself'*(M = 1.50; SD = 0,886). This was opposite to the conclusion reached by Taylor (1991) who found out that when diagnosed with HIV an individual deals a lot with self-esteem issues compared to individuals who are not HIV positive.

Table 6.13: The degree of participants' self-esteem (n = 80)

SELF ESTEEM	**Mean.**	**Max.**	**Mean**	**SD**
1. I feel that I am a person of worth, at least on an equal plane with others	1	4	2,63	0,663
2. I feel that I have a number of good qualities	1	4	2,36	0,641
3. All in all, I am inclined to feel that I am a success	1	4	0,76	0,860
4. I am able to do things as well as most other people	1	4	2,44	0,777
5. I have a lot of things to be proud of	1	4	1,80	0,906
6. I take a positive attitude toward myself	1	4	2,28	0,616
7. On the whole, I am satisfied with myself	1	4	1,99	0,720
8. I have a lot of respect for myself	1	4	1,50	0,886
9. I don't certainly feel useless at times	1	4	2,04	0,934
10. There isn't a moment that I think I am no good at all	1	4	2,10	0,936
SELF ESTEEM	*1.00*	*2.70*	*1.98*	*0.386*

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

6.1.4.2 Coping Strategies

This section presents the results of participants' coping strategies when facing various problems.

Data analysis was conducted to answer the research question below:

- *What are participants' coping strategies?*

Coping Strategies were measured with (CPS). The measurement was performed using 14 questions (items). For all of the items, the minimum value was 1 = Strongly disagree and maximum was 5 = Strongly agree. The reliability of the scale was a = .67, which means that there was internal correlation between items.

Table 6.14: Participants' coping strategies (n = 80)

COPING STRATEGIES	Mean.	Max	Mean	SD
1. I find that I can better face up to dealing with a difficult situation if I remind myself that I have already solved many other problems in my life.	1	5	4,14	0,689
2. I never give up, even when the odds are stacked against me.	1	5	3,96	0,920
3. If I have a problem, I try to find something else to do to help take my mind off it.	1	5	3,15	1,202
4. I try to adapt to difficult situations rather than fight against them.	1	5	2,66	1,043
5. In difficult situations I seek support in my faith.	1	5	3,64	1,235
6. I try to find out about all sides of a problem.	1	5	4,13	0,802
7. If I have any problems, I look to others for help and support.	1	5	3,34	1,158
8. I react in different ways to problems: Sometimes I am down and then I am up and full of energy again.	1	5	3,98	0,842
9. I tend to give in when there is a problem and to let things take their own course.	1	5	2,18	1,111
10. It is often the case that I can't solve the problems that I have. Then I become depressed and can't see any point to my life.	1	5	2,24	1,094
11. I find it easier to deal with any problems I have by remembering that there are always others who are far worse off than me.	1	5	3,86	1,028
12. I often wish that someone else would solve my problems for me.	1	5	3,05	1,272
13. If I have any problems I try to take it with a sense of humour.	1	5	3,74	1,209
COPING STRATEGEIS	*2.54*	*5.00*	*3.38*	*0.474*

Min = minimum; Max = maximum; SD = Standard deviation; n = number

The questions regarding the coping strategies of the sample (this question was constructed by adding all the questions and dividing the outcome by 13 - the number of the questions) had a different and higher minimum value (2.54). Additionally, the average value of the variable that concerned the level of coping strategies was (M =

3.39; SD = 0.474 (close to three) which means that the level of coping strategies was slightly good (Table 6.14).

This is attributed mostly to the negative questions and in particular '*I tend to give in when there is a problem and to let things take their own course'* (M = 2.18; SD = 1.111), *'It is often the case that I can't solve the problems that I have. Then I become depressed and can't see any point to my life'* (M = 2.24; SD = 1,094).

6.1.4.3 Locus of Control

The results concerning HIV positive individuals' locus of control are presented in this section.

Data analysis was performed to answer the following research question:

- *What is participants' locus of control?*

Table 6.15: The degree of participants' locus of control (n = 80)

LOCUS OF CONTROL	Min.	Max.	Mean	SD
1. If my condition worsens, it is my own behaviour which determines how soon I will feel better again.	1	6	4,33	1,290
2. As to my condition, what will be will be.	1	6	3,93	1,376
3. If I see my doctor regularly, I am less likely to have problems with my condition.	1	6	4,46	1,405
4. Most things that affect my condition happen to me by chance.	1	6	3,29	1,371
5. Whenever my condition worsens, I should consult a medically trained professional.	1	6	4,84	1,152
6. I am directly responsible for my condition getting better or worse.	1	6	4,63	1,173
7. Other people play a big role in whether my condition improves, stays the same, or gets worse.	1	6	3,31	1,539
8. Whatever goes wrong with my condition is my own fault.	1	6	3,61	1,547
9. Luck plays a big part in determining how my condition improves.	1	6	3,15	1,519

10. In order for my condition to improve, it is up to other people to see that the right things happen.	1	6	2,90	1,523
11. Whatever improvement occurs with my condition is largely a matter of good fortune.	1	6	2,58	1,456
12. The main thing which affects my condition is what I myself do.	1	6	4,80	1,237
13. I deserve the credit when my condition improves and the blame when it gets worse.	1	6	3,79	1,507
14. Following doctor's orders to the letter is the best way to keep my condition from getting any worse.	1	6	5,11	1,158
15. If my condition worsens, it's a matter of fate.	1	6	2,38	1,496
16. If I am lucky, my condition will get better.	1	6	2,75	1,627
17. If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.	1	6	4,08	1,474
18. The type of help I receive from other people determines how soon my condition improves.	1	6	3,49	1,458
LOCUS OF CONTROL	*2.44*	*6.00*	*3.74*	*0.654*

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

Participants’ locus of control was measured with Form C of the Multidimensional Health Locus of Control (MHLC) scale. The MHLC instrument was developed and validated by Wallston and Wallston and colleagues and used to measure health locus of control beliefs. The MHLC measures three dimensions of locus of control beliefs: (1) ‘‘internal’’, (2) ‘‘chance’’ external, and (3) ‘‘powerful others’’ external beliefs about who or what is responsible for the respondent’s health status (Aversa & Kimberlin, 1996). Form C of MHLC scales show concurrent and construct validity as they were moderately stable over time (Wallston et al., 1994).

The measurement was performed using 18 questions (items). For all of the items, the minimum value was 1 = strongly disagree and the maximum was 6 = Strongly agree.

The reliability of the scale was 0.78, which means that there was internal correlation between items.

In Table 6.15 are the questions pertaining to the variable locus of control. This variable was constructed by adding the individual questions and dividing the outcome by total number of questions. The scores for the sample had a minimum value (2.4) and maximum value (6.00). Additionally, the average value of the variable that concerned the level of locus of control was (M = 3.74; SD = 0.654) (close to four) which means that the level of locus of control was good

This can be attributed mostly to the fact that negative questions had been given to few of the items and in particular to 11,15 and 16 *‘‘Whatever improvement occurs with my condition is largely a matter of good fortune’’* (M = 2.58; SD = 1.456), *‘‘If my condition worsens, it's a matter of fate’’* (M = 2.38; SD = 1.496) and *‘‘If I am lucky, my condition will get better’’* (M = 2.75; SD = 1.627) and to moderate answers for questions 4,7 and 18.

6.1.4.4 Personality Characteristics

The role of personality characteristics in HIV/AIDS has received limited consideration (Penedo et al., 2001). This section presents the results of the personality characteristics of the HIV participants of the study.

- In more detail data analysis using descriptive statistics (average value and standard deviation) was conducted to answer the research question:
- *What are participants’ personality characteristics?*

Measurement of personality was undertaken with the use of the Ten Item Personality Inventory (TIPI). The TIPI is a ten item measure of the “Big-Five” personality domains (Gosling et al., 2003). It consists of two items per scale and measures Extraversion, Agreeableness, Conscientiousness, Emotional Stability, and Openness to Experience (Gosling, et al., 2003). All the items had a minimum value of 1 (1 = strongly disagree, 7 = strongly agree). The scale reliability was quite low a= .37, which means that the internal correlation was low.

From Table 6.16 can be observed that the characteristic with the higher average value was *‘Sympathetic, Warm’* (M=5.51, SD=1.638), followed by another characteristic *‘‘open to new experiences, complex’’* with an average value of (M=5.19, SD=1.949). Additionally the characteristic with the lower average value was *‘‘Disorganized, careless’’* (M = 2.71, SD = 1.924), and above that, was the characteristic of critical – quarrelsome with an average value of (M = 3.54, SD = 1.828). Furthermore the characteristic with the higher value of variance was *‘‘Conventional, uncreative’’’* (M = 4.00, SD = 2.187), which means a higher degree of variation in the answers and the characteristic with the lowest variance was *‘‘Sympathetic, Warm’’* (SD 1.638) which means a low degree of variation of the answers for this particular characteristic.

Table 6.16: The respondents’ personality characteristics (n = 80)

characteristics	Min.	Max.	Mean	SD
○ Extroverted, enthusiastic	1	7	4,80	1,951
○ Critical, quarrelsome	1	7	3,54	1,828
○ Dependable, self-disciplined	1	7	4,00	1,821
○ Anxious, easily upset	1	7	4,56	2,128
○ Open to new experiences	1	7	5,19	1,949
○ Reserved, quiet	1	7	4,86	1,791
○ Sympathetic, warm	1	7	5,51	1,638
○ Disorganised, careless	1	7	2,71	1,924
○ Calm, emotionally stable	1	7	4,61	1,984
○ Conventional, uncreative	1	7	4,00	2,187

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

Additionally, some more comments can be added regarding the personality traits. So from table 6.17 it can be observed that not all of the questions had the same minimum and maximum value. The question considering the extraversion characteristic had a different and lower maximum value (6.5) while all the other questions had the value 7 and additionally for the characteristics of agreeableness and conscientiousness there were different and higher minimum values (2.5 and 2 respectively) while all the other questions had the value 1.

The agreeableness characteristic came first among the others with an average value of (M = 4.98, SD = 1.209), followed by conscientiousness with an average value of (M = 4.64, SD = 1.273). Last among the five characteristics there was extraversion with an average value of (M = 3.96, SD = 1.439). It should be mentioned though that the average value of the seven points of the likert scale was 4. Furthermore, the variance of the above five characteristics did not appear fairly similar to other variations.

Table 6.17: The respondents' personality characteristics (GROUPING)

characteristics	Min.	Max.	Mean	SD
○ Agreeableness	2.50	7.00	4.98	1.209
○ Conscientiousness	2.00	7.00	4.64	1.273
○ Openness to experiences	1.00	7.00	4.59	1.488
○ Emotional Stability	1.00	7.00	4.02	1.525
○ Extraversion	1.00	6.50	3.96	1.439

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

6.1.4.5 Life Satisfaction

The results participant's life satisfaction, are presented in this section.

In more detail data analysis was conducted to answer the research question below:

- *What is participants' life satisfaction?*

In order to measure HIV positive individuals' life satisfaction Cantril's Ladder of Life was used (Bernard, 2000). The Ladder of life is a self-anchored scale with which participants were asked to state their level of satisfaction with life on a scale of one to ten.

The measurement was performed using 1 question (items). The minimum value was 1 = worst life I could expect to have and the maximum was10 = Best life I could expect to have.

The average value for the variable that concerned the level of life satisfaction was 6.65 which means that the majority of the sample was satisfied with their life. This can be seen more clearly if the frequencies in Table 6.18. So, 76.2% of the sample responded with a value above 5 and 12.5% responded with a value equal to 5. Only 11.3% of the sample ranked their life with values equal to 3 and 4. Hence, only a small proportion of the sample reported as being dissatisfied with their life, while the best life a patient could expect to have, referred to life circumstances for those who were already HIV positive.

Table 6.18: The degree of participants' life satisfaction

	n	%	Mean	SD
3	5	6,3	6,65	1,639
4	4	5,0		
5	10	12,5		
6	13	16,3		
7	18	22,5		
8	24	30,0		
9	5	6,3		
Best life I could expect to have	1	1,3		

6.1.5 Medication Factors

Participants' thoughts about taking medication, their beliefs about the effectiveness of the medication and their compliance and commitment to the medication are presented in this section.

6.1.5.1 Beliefs about HIV Medication

The measuring of participants' perceptions regarding medication benefits was undertaken with the use of nine items adapted from an established scale of Aversa and Kimberlin (1996) indicating the benefits and barriers of antiretroviral therapy according to HIV positive individuals' perceptions (Aversa & Kimberlin, 1996).

Data analysis was conducted to answer the research questions:

- *What are patients' beliefs about HIV medication and about taking medication?*
- *What are respondents' thoughts and feelings about HIV and medical treatment?*

In order to establish patient's beliefs about taking HIV medication a set of nine questions asked regarding the dangers, costs, convenience, simplicity, helpfulness, comfort, importance, usefulness and effectiveness of using HIV medication. Respondents answered on a scale of 1-5 and the results are given in Table 6.19.

Table 6.19: The respondents' beliefs about HIV medication (n = 80)

I find HIV medication...	Min.	Max.	Mean	SD
dangerous	1	5	3.72	1.201
expensive	1	5	2.30	1.657
inconvenient	1	5	3.36	1.371
complicated	1	5	3.72	1.368
distressing	1	5	3.20	1.504
harmful 1-5	1	5	4.03	1.283
unimportant	1	5	4.70	.753
useless	1	5	4.78	.656
ineffective	1	7	4.55	.810

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

Results show that medication was considered as very helpful (M = 4.03; SD = 1.283), important (M = 4.70; SD = 0.753), worthwhile (M = 4.78; SD = 0.656), and effective (M = 4.55; SD = 0.810). Positive scores also indicated that respondents considered medication as safe (M = 3.72; SD = 1.201), convenient (M = 3.36; SD = 1.371), simple to take (M = 3.72; SD = 1.368), and comforting (M = 3.72; SD = 1.368), However, medication was considered expensive (M = 2.30; SD = 1.657).

In summary the majority of HIV positive respondents believed that HIV medication contributed to their life positively with the only major drawback reported being its high cost.

6.1.5.2 Feelings about HIV Medication

Data analysis was conducted to answer the research questions:

- *What are patients' feelings about HIV medication and about taking medication?*

Respondents also were asked to describe their feelings about taking HIV medication. In order to measure that, Positive and Negative Affect Scale (PANAS) was used (Watson et al., 1988).

It was using a set of 20 descriptors. These were rated on a scale of 1-5 whereby 1 = very slightly, 2 = a little, 3 = moderately, 4 = quite a lot, 5 = extremely. Table 6.20 gives the results of this analysis.

Table 6.20: The respondents' feelings about taking HIV medication (n=80)

Taking HIV medication makes me feel…	Mean	SD	Taking HIV medication makes me feel…	Mean	SD
interested	3.25	1.43	**irritable**	1.90	.98
distressed	2.42	1.20	**alert**	3.08	1.34
excited	1.75	1.14	**ashamed**	1.64	.97
upset	1.63	1.01	**inspired**	1.63	1.17
strong	3.36	1.11	**nervous**	2.04	1.19
guilty	1.76	1.11	**determined**	3.74	1.17
scared	1.78	1.10	**attentive**	4.05	1.01
hostile	1.30	.74	**jittery**	1.84	1.11
enthusiastic	1.97	1.33	**active**	3.12	1.28
proud	2.00	1.41	**afraid**	2.09	1.19

SD = Standard deviation

This shows that respondents were feeling interested (M = 3.25; SD = 1.43), strong (M = 3.36; SD = 1.11), alert (M = 3.08; SD = 1.34), attentive (M = 4.05; SD = 1.01), determined (M = 3.74; SD = 1.17), and active when taking HIV medication (M = 3.12; SD = 1.28), indicating a positive disposition towards medication usage. Conversely, few respondents reported feeling distressed, excited, upset, guilty, scared, hostile, enthusiastic, proud, irritable, ashamed, inspired, nervous, jittery or afraid when taking their medication.

6.1.5.3 Thoughts about Taking Medication

Several questions concerning respondents' cognitive thinking and self-efficacy were posed in the questionnaire. The Attitude Adherence Inventory (AAI) was used. The minimum value is 1 = None of the time and the maximum value is 7 = All of the time. In the question 1-14 there was a reversal. The results for the presented are in Table 6.21.

Respondents demonstrated high level of cognitive thinking and self-efficacy. More specifically questions regarding their cognitive functioning and self-efficacy about taking medication had a minimum value = 1.38 and maximum value = 7.00. All the other questions had a minimum value of 1. The average value of the variable that concerned thoughts about taking medication was 5.92 (more close to six) which means that the majority of the sample replied that most of the time their cognitive functioning and their feelings of self-efficacy regarding taking their medication were high (Table 6.21). This indicates that respondents were able to remember issues and tasks regarding compliance with medication and also believed in their ability to fully comply with their medication. This is mostly because of the positive answers given to questions 1 to 10. It must be noted that most of the negative answers had been given to the question ‘When I take my HIV medication it doesn't remind me that I am HIV positive’ (M = 4.20; SD = 2.20). However, this deviation from the average was high which means that the medication recalled problems to some of the participants, while others they do not.

Table 6.21: The participants’ thoughts about the HIV medication (n = 80)

	Min.	Max.	Mean	SD
1. In the afternoon, I don't have a hard time remembering if I took my early dose of medication	0	7	6.29	1.15
2. I haven't forgotten whether I have taken my medication, even while I am in the middle of doing it.	0	7	6.13	1.19
3. I don't often have trouble remembering to get refills for my medication on time.	0	7	6.45	1.08
4. I don't forget to talk to my medical provider about side-effects of my medication.	0	7	6.36	1.14
5. I want to take my medication and i don't forget to take it	0	7	6.35	1.02
6. I may loose track of time but I don't take my medication late or not at all	0	7	6.10	1.22
7. I don't have any problem remembering to take my medications with me when I leave home.	0	7	5.71	1.36
8. I don't fear that I am not capable of taking my medication, as I should.	0	7	6.33	1.39
9. I feel confident that I will be able to keep making the effort to take this medication for ever	0	7	6.14	1.52
10. I feel confident that I'll be able to follow the medication plan	0	7	6.38	1.16
11. I find it possible to follow the food restrictions with my medications.	0	7	5.73	1.54
12. I don't have any trouble taking my medications on time	0	7	5.49	1.61
13. In the past, I haven't had any trouble taking medication when I had no physical symptoms	0	7	5.58	1.77
14. Things don't get in the way of my taking my medication as prescribed	0	7	5.93	1.27
15. When I take my HIV medication it doesn't remind me that I am HIV positive	0	7	4.20	2.20
16. When I take my HIV medication I feel I am benefiting my quality of life	0	7	5.64	1.77
TAKING MEDICATION	**1.38**	**7.00**	**5.92**	**0,902**

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

6.1.5.4 Effectiveness of Medication

Susceptibility of HIV positive individuals' feelings of vulnerability and whether to stop receiving antiretroviral therapy was measured by a three item scale adapted from an established scale of Aversa and Kimberlin (1996) indicating the consequences of stopping HIV medication (Aversa & Kimberlin, 1996).

The minimum value was 1 = Strongly disagree and the maximum value was 5 = Strongly agree. The results for the effectiveness are presented in Table 6.22.

Table 6.22: The participants' beliefs for the effectiveness of medication (n=80)

If I stopped taking my antiretroviral medication I would…	**Min.**	**Max.**	**Mean**	**SD**
1. Develop AIDS sooner	1	5	4.22	1.08
2. Develop AIDS symptoms and associated diseases sooner	1	5	4.25	1.01
3. Get sicker sooner	1	5	4.31	1.26
EFFECTIVNESS OF MEDICATION	**1.00**	**5.00**	**4.26**	**0,95**

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

It is clear from the results presented in Table 6.22, that the effectiveness of medication was quite high since the average deriving from the sum of all three items was quite close to strongly positive (M = 4.26; SD = 0.95).

6.1.5.5 Commitment to Medication

Results concerning participants' commitment to the medication are presented in this section.

Seven items were used to measure commitment to the HIV medication. The minimum value was 1 = None of the times and 7 = All of the time. The results are presented in Table 6.23.

Table 6.23: The participants' commitment to medication (n = 80)

	Min.	Max.	Mean	SD
1. I am determined to do whatever it takes to take my medication in schedule.	1	7	5.93	1.49
2. I follow all the food restrictions that come with my medication no matter how hard it is.	1	7	5.50	1.71
3. I am determined to take my medications even if there is no way to have privacy (i.e. in front of friends, family, co-workers).	1	7	5.36	2.02
4. I take my medication even if I don't feel well.	1	7	6.21	1.30
5. I am determined to stick with a plan to help me remember to take my medication as prescribed.	1	7	5.84	1.75
6. I learn as much as I can about my medications so I can take them exactly as prescribed.	1	7	5.70	1.62
7. I am committed to taking my medication even if it tastes bad or is hard to swallow.	1	7	6.01	1.66
COMMITMENT TO MEDICATION	**2.00**	**7.00**	**5.79**	**1.10**

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

It is clear from the results, that the degree of commitment was high, since the average deriving from the sum of all seven items was close to strongly positive (M = 5.79; SD = 1.10)

6.1.5.6 Compliance with HIV Medication

Results concerning the degree that participants complied with the medication are presented in this section. The Attitude Adherence Inventory (AAI) was used to measure compliance to the medication. The results for compliance with medication are presented in Table 6.24.

Table 6.24: Compliance with HIV medication

	n	%	Mean	SD
I have taken all of my medication as prescribed so far today				
Yes	72	90.0	1.20	0.68
No	4	5.0		
Can't remember	0	0.0		
To the best of my recollection	4	5.0		
I took all of my medication as prescribed so far yesterday				
Yes	72	90.0	1.21	0.71
No	3	3.8		
Can't remember	1	1.3		
To the best of my recollection	4	5.0		
I took my medication as prescribed in the past week				
Yes	64	80.0	1.54	1.12
No	2	2.5		
Can't remember	1	1.3		
To the best of my recollection	13	16.3		
I took all of my medication as prescribed in the past month				
Yes	54	67.5	1.83	1.27
No	4	5.0		
Can't remember	4	5.0		
To the best of my recollection	18	22.5		
Total compliance with medication	**80**	**100.0**	**1.44**	**0,78**

Min = minimum; Max = maximum; M=mean; SD = Standard deviation; n = number

From the Table it can be seen that the majority of the sample, 81.88% [(90% + 90% + 80% + 67.5%)/4] of the four questions presented in Table 6.24 reported that they comply with their HIV medication regime. When asked about compliance with medication in the near past (today and yesterday) 90% of respondents indicated that they had fully complied. Compliance levels fell when respondents reported behaviour in the past week and the lowest frequency of respondents' compliance over the past month (67.5%).

It is clear from the results presented in Table 6.24, that the compliance rate was quite high, since the average deriving from the sum of all four items was quite close to strongly positive (M = 1.44 (1.20 + 1.21 + 1.54 + 1.83)/4; SD = 0.78 (0.68 + 0.71 + 1.12 + 1.27)/4).

6.2 Chapter Summary

The findings of this chapter showed that most of the respondents were diagnosed between 1990 and 1999 (53.7%) and less were diagnosed between 2000 and 2005 (30%) and even fewer between 1983 and 1989 (16.3%). The socio-cultural positioning included their perceptions about being HIV positive within the Greek socio-cultural system as well as the perceptions about medication and aspects of their health and health care. Participants acknowledged themselves as people who suffer from a serious disease and believe that being HIV positive is a negative issue for the society that worsens if the positive diagnosis is accompanied by homosexuality.

The general approach on the matter enforced the HIV positive individuals to care for themselves more than they used to before the diagnosis and against all odds they seemed to be successfully coping with the virus itself as well as with the attitudes they experienced from society. In terms of the health care provided participants seemed to be generally satisfied although they could find more than one ways to improve it. This could mean either that the HIV positive individuals had settle for a healthcare system they know they cannot change or that they found a way to make themselves heard in regards to their real needs.

In terms of medication the participants were facing very few problems with side effects at the time of the research so they showed that they were coping well. Though it should be mentioned that the findings could alternate if the time of the study was different and the participants were facing problems with medication. In regards to cognitive functioning, the findings showed that respondents felt able to remember issues regarding taking HIV medication. In terms of self-efficacy, the results indicated that respondents succeeded in complying with medication in the past and believed in their ability to comply with their therapy at the time of the research.

In addition, respondents realised that if they stopped taking medication that would probably result their health decline indicating their feelings of vulnerability to HIV and dependence on medication. Respondents’ feelings towards HIV medication were generally positive. They regarded taking medication as beneficial, with the only major drawback being the high cost of medication. At this point it should be mentioned that although respondents considered medication expensive, it is provided to them by the government free of charge.

At this point the aim was to investigate the psychosocial factors that influence compliance to medication/treatment regimes amongst HIV/AIDS positive individuals. The main topics of the investigation were the impact that lifestyle, support network, self-esteem, anxiety and depression, quality of life and coping strategies have towards compliance.

According to the findings, in regards to the participants' lifestyle information, most of them either did not consume alcohol or they consumed small amounts of it and most of them smoked. This showed certain levels of addiction to substances (alcohol and cigarettes) that could exist either before or after the diagnosis.

In terms of the support provided to the participants, a categorisation of the main support areas was conducted into six categories, social, practical, financial, support for taking medication, understanding and finally acceptance. According to the findings most of the given support was provided by friends and family as they appeared to be in the first two places in the questionnaires less support was given by sexual partners and colleagues who appeared mostly in the last two places.

In terms of the participants' general health, the findings showed that it was in good levels; the perceptions regarding their health status appeared to be in good levels as well as in comparison to the health status of the general population and the perceptions they had about their health before the HIV diagnosis. As mentioned in previous chapters this outcome could be alternate if the time of the study was different and the participants were found to deal with numerous side effects of medication. In contrast the participants' levels of anxiety and depression were increased compared to their perceived levels before the diagnosis.

Furthermore the findings showed that participants' coping strategies, locus of control and self-esteem were in good and satisfactory levels. The findings also showed that the participants were quite satisfied with their lives even after the HIV diagnosis.

Findings suggested that if the levels of anxiety and depression were excluded, the rest of the psychosocial factors that had been measured would generally be in good levels since the diagnosis of the virus.

The following chapter refers to the factors associated with compliance, correlations of the findings and finally the regression analysis including the variables that will derive after the correlations.

CHAPTER SEVEN: PREDICTORS OF COMPLIANCE WITH HIV MEDICATION REGIMES

In chapter 6 the descriptive analysis of all the factors arising from the quantitative data in the present study were presented. This chapter will refer to the way in which the main factors: 1) Demographic/lifestyle; 2) Socio–cultural; 3) Health and healthcare; 4) Psychosocial and 5) Medications influence compliance to medication/treatment regimes amongst HIV/AIDS positive individuals.

7.1 Research Questions

The research questions that are addressed in this chapter are organized into 5 themes. These are presented in detail below:

1. Demographic and lifestyle factors

- *What is the relationship between compliance with HIV medication and*
    - Gender?
    - Age?
    - Income?
    - Smoking?
    - Drinking alcohol?
    - Sexuality?

2. Social – cultural factors

- *What is the relationship between compliance with HIV medication and*
    - Perception of the position of HIV positive people within society
    - Perceived severity
    - Practical support?
    - Financial support?

    - Social support?
    - Support for taking medication?
    - Understanding for taking medication?

3. Health and health care factors

- *What is the relationship between compliance with HIV medication and*

    - General health
    - Health status?
    - Level of anxiety and depression?
    - Experienced symptoms?
    - Experiences and perception of health care
    - Satisfaction with healthcare?

4. Psychosocial factors

- What is the relationship between compliance with HIV medication and
    - Self-esteem?
    - Coping strategies?
    - Locus of control?
    - Personality traits?
    - Life satisfaction

5. Medication factors

- What is the relationship between compliance with HIV medication and
    - Thoughts about taking medication?
    - Feelings about taking medication?
    - Effectiveness of medication
    - Commitment to HIV medication?

Finally, this chapter explores which of the factors listed above are most predictive of compliance with HIV medication?

7.2 Methods

Full details of the methods employed to gather data for this study can be found in Chapter 3 (section 3.7). To reiterate, in total 80 people (10% of the 800 patients that was the population target) who were HIV positive completed the questionnaire used to gather the data. This questionnaire comprised a number of well know scales. Details of these scales can be seen in Chapter 3 and they are summarised below in Table 7.1.

Table 7.1: Variables investigated and measures used in the questionnaire

1.Demographic & Lifestyle	2. Social - Cultural	3.Health & health care	4.Psychosocial	5.Medication	Compliance
	(i)Persives severity (PANAS)	(i) General Health (GHQ).	(i) Personality(TIPI),	(i) Belief (scale of Aversa and Kimberlin)	(i) self reporting of compliance
	(ii)Perseption (a scale of ten items	(ii) Health status (SF-36)	(ii) Self esteem (SES),	(ii) Feelings (PANAS)	(ii) Separate parts of Attitude Adherence Inventory (AAI)
	(i) Social support (ISEL12)	(iii)Experienced symptoms (SSC-HIV) A	(iii) Coping Strategies (CPS),	(iii)Thoughts (AAI)	
		(iv)Anxiety and Depression(HADS)	(iv) Locus of control (MHLC),	(iv)Effectiveness (scale of Aversa and Kimberlin)	
		(v)Experiences and perception of health care (AAI)	(v) Life satisfaction (Ladder Scale),	Commitment (self reporting)	
		(vi) Satisfaction with health care, (PSQ)			

In addition, two more scales, designed through pilot trials and the literature review, were used so to measure the sources of social support, attitudes to HIV and sexuality. In these, higher scores indicated that respondents felt they were coping better with respect to each measure.

7.3 Data Screening and Analysis

Initially screening of the data took place to ensure the data did not have any missing values or wrong coding. Firstly, a missing data count was performed indicating that the only variable with lower rates of completion was the income variable (with 4 people not completing this). Secondly, the data was tested for normality to enable the selection of appropriate statistical tests (Field, 2005). The Kolmogorov Smirnov test was used to determine if the variable representing compliance with medication, (the dependent variable) was normally distributed.

As can be seen in Table 38 (Appendix 3) ‘compliance with HIV medication’ was not normally distributed. A finding confirmed by the Kolmogorov-Smirnov test which indicated that the data for this variable significantly differed from a normal distribution (Kolmogorov-Smirnov $p < 0.0001$). In such case the use of non-parametric tests like Mann Whitney, Spearman’s rho or Kruskal Wallis depending on what we were intending to do were indicated.

Mann Whitney is a non-parametric test equivalent to the t- test that indicating whether two independent samples are from the same population; the Kruskal Wallis test is a generalization of Mann Whitney’s test. It is the non-parametric equivalent to a one-way ANOVA that tests whether several independent samples are from the same population and assumes that the underlying variable has a continuous distribution. These non-parametric tests require an ordinal level of measurement.

Additionally, for any correlation that was made with the variable ‘compliance with HIV medication’ the non-parametric Spearman coefficient was used rather than the parametric Pearson Product Moment coefficient. Spearman’s coefficient is commonly used as a nonparametric measure of correlation between two ordinal variables or when the data have violated parametric assumptions (Field, 2005) such as non–normal distribution. Finally linear regression was used in order to establish the influence of factors on compliance with HIV medication. Linear regression is the estimation of the linear relationship between a dependent variable and one or more independent variables or covariates.

7.4 Results

This analysis begins with the presentation of the relationships between the variables listed above and compliance to medication. Descriptive analysis for all variables has already been presented in chapter 6.

7.4.1 Factors Associated with Compliance with HIV Medication use

Prior to entering variables into the regression model, correlations were conducted to identify those variables that were associated with compliance to aid selection of appropriate variables for the analysis.

7.4.1.1 The Association between Compliance, Demographic and Lifestyle Factors

In this section the existence of significant differences among different groups of the demographic and lifestyle factors relating to compliance with HIV medication were investigated. For this purpose Mann Whitney & Kruskal Wallis tests were used. In regards to gender there was no significant statistical difference between compliance with HIV medication and males /females (n = 80, Z=-0.863, p = 0.388).Compliance did not significantly differ according to sexual orientation either for homosexuals, bisexuals or heterosexuals ($\chi 2$ = 2.598, df = 2, p = 0.273) or according to alcohol consumption between those people that reported drinking alcohol and those that did not (n = 80, Z=-1.552 p = 0.121).

Furthermore compliance did not significantly differ (Mann Whitney) according to smoking between participants that smoke cigarettes and participants that did not (n = 80, Z=-0.119, p = 0.905). Finally, there was not significant correlation between compliance with HIV medication and income (rho = -0,025, p > 0.05, n = 76). So, in this group of participants, sex, sexual orientation, alcohol use, smoking and income were not found to be related to compliance with HIV medication. According to the literature, non-compliance to HIV therapy is not consistently associated with demographic characteristics (Eldred et al., 1997; Morin and Moatti, 1996; Singh et al., 1996; Chesney et al., 2000)

7.4.1.2 The Relationship between Compliance and Social Support

In order to examine the relationship between social support and compliance with HIV medication Mann Whitney test was selected. Social support has five different sub groups, social support, support from partner, support from family, support from friends and support from colleagues. Mann Whitney test was used for each sub group since in regards to social support, patients with social support were examined towards patients without social support. The same applied for the other four sub groups.

Mann Whitney U tests showed that the compliance levels of the participants who reported that they received social support from their partner (n = 80, Z=-1.524, p = 0.128), family (n = 80, Z=0.318, p = 0.318), friends (n=80, Z=-0.748, p = 0.458,) or work colleagues (n = 80, Z=-0.565 p = 0.572), did not significantly differ from those who reported that they did not receive such social support.

In regards to emotional support, Mann Whitney U test showed that participants who received emotional support from their partner and those that did not receive such support significantly differed in their reported levels of compliance (n = 80, Z=-2.552, p = 0.011). HIV patients with emotional support from their partner reported that they complied more with their HIV medication regimen (M =1.95, SD = 0.122, M is the average value of compliance) in comparison to HIV patients with no emotional support from their partner (M =1.69, SD = 0.472).

Mann Whitney U analyses (for each case, partner, family friends, colleagues the Mann Whitney was used separately,) showed that participants that get emotional support from their family (n = 80, Z=-0.817, p = 0.414), friends (n = 80, Z=-0.364, p = 0.716) and colleagues (n = 80, Z=-0.396, p = 0.692) did not report significantly different levels of compliance with their HIV medication regimen than those who did not receive such support. So, the practical support from the family did not appear to be related to compliance with HIV medication.

Practical support from (for each case, family friends, etc. the Mann Whitney was used separately) the respondents' family did appear to be related to compliance with HIV medication (n = 80, Z=-2.764 p = 0.006). However, those who received practical support (M = 1.67, SD = 0.480) indicated lower compliance levels than those who did not (M = 1.90, SD = 0.262). A Mann Whitney U test showed that compliance levels did not significantly differ between participants that reported receiving practical support from their partner (n = 80, Z=-1.718, p = 0.086), their friends (n = 80, Z = -0.251, p = 0.802) and work colleagues (n = 80, Z=-0.396, p = 0.657) and those that did not.

Financial support did not appear to be related to compliance levels with Mann Whitney U tests showing that those who did not receive financial support from their partner (n = 80, Z=-1.190, p = 0.234), their family (n = 80, Z=-0.548, p = 0.583), their friends (n = 80, Z=-0.654, p = 0.513) or their work colleagues (n = 80, Z=-1.381, p = 0.167) did not have different compliance levels than those who did.

Support for taking medication did not appear to be related to compliance levels with Mann Whitney U tests showing that those who received support for taking their medication from the partner (n = 80, Z=-1.811, p = 0.07), from friends (n = 80, Z=-1.411, p = 0.158), work colleagues (n = 80, Z=-0.938, p = 0.348) did not significantly have different compliance levels than those who did not.

However, support for taking medication appeared to be related to compliance levels with Mann Whitney U tests showing that those who received support for taking their medication from the family (n = 80, Z=-2.061, p = 0.039) had different compliance levels than those who did not.

So, support for taking the medication from the family was related to compliance with HIV medication. Moreover, there was a higher degree (Table 84, Appendix 4) of compliance for HIV medication (M = 1.86, SD = 0.296) for those that did not receive support for taking their medication from the family comparing them with those that received this type of help (M = 1.66, SD = 0.510)

Understanding appeared to be related to compliance levels with Mann Whitney U tests (Table 7.3), showing that those who received understanding from the partner (n = 80, Z = -2.270, p = 0.023) had different compliance levels than those who did not. That means that understanding from the partner may be related to compliance with HIV medication. Moreover taking under consideration that HIV patients with understanding from the partner indicated higher compliance rate with HIV medication (M = 1.95, SD = 0.127) than HIV patients with no understanding from the partner (M = 1.79, SD = 0.343).

However, understanding did not appear to be related to compliance levels with Mann Whitney U tests showing that those who received understanding from the family (n = 80, Z=-1.022, p = 0.307), from friends (n = 80, Z=-0.142, p = 0.882) and work colleagues (n = 80, Z=-1.167, p = 0.243) did not significantly differ in their compliance levels than those who did not.

However, acceptance did not appear to be related to compliance levels with Mann Whitney U tests (Table 12) showing that those who received acceptance from the family (n = 80, Z = -1.462, p = 0.144), from friends (n = 80, Z=1.458, p = 0.145) and work colleagues (n = 80, Z=-1.679, p = 0.093) did not significantly differ in their compliance levels than those who did not.

Furthermore, there was not significant correlation between compliance with HIV medication and the attitude to HIV & sexuality (rho = 0,177, p =0.116, n = 80). The same applies between perceived severity and compliance with HIV medication (rho=0.055, p=0.631, n=80 & rho=0.022, p=0.847, the perceived severity includes two questions).

7.4.1.3 The Relationship between Compliance and Health Factors

The association between compliance with HIV medication and health factors is going to be presented in this section. There was no statistical significant relationship found between compliance and the health variables.

Table 7.2: Relationship between compliance and health factors (n = 80)

Spearman's rho	General Health	Levels of anxiety and depression	Health care	Health status	Compliance with HIV medication
General Health	1.000				
Levels of anxiety and depression	.687**	1.0			
Health care	-.096	-.064	1.0		
Health status	.077	-.043	.015	1.0	
Compliance with HIV medication	-.202	-.128	.104	.096	1.0

**** Correlation is significant at the .01 level**

Also all types of symptoms such as muscle aches and weakness were checked as to whether they related to compliance with HIV medication. This investigation was conducted for each one of the symptoms.

Table 7.3: Relationship between compliance and experienced symptoms (n = 80)

Symptoms	Compliance with HIV medication (r values)
Muscle aches	.214
Weakness	-.044
Painful joints	.113
Fatigue	-.108
Dry mouth	.151
Thirsty	.136
Difficulty concentrating	-.029
Depression	.038
Memory loss	-.008
Fear/worries	-.037
Anxiety	-.134
Disorientation	.001
Fever	.104
Chills	.122
Day sweats	.142
Night sweats	.110
Loose stools	-.117
Diarrhea	.003
Gas/bloating	.111
Abdominal pain	.011
Shortness of breath at rest	-.015
Wheezing	-.023
Shortness of breath with activity	.084
Nausea	-.104
Vomiting	.054

**** Correlation is significant at the .01 level (2-tailed).**

*** Correlation is significant at the .05 level (2-tailed).**

The above Table clearly shows that there was no significant correlation between the symptoms and compliance with HIV medication.

The investigation of satisfaction with health care and its relation to compliance with HIV medication follows. This investigation was done for each one of the three components of satisfaction with health care.

Table 7.4: Relationship between compliance and satisfaction with health care (n=80)

Spearman's rho	Compliance with HIV medication	I am very satisfied with the medical care I receive	If I have a medical problem, I can reach someone for help without any problem	There are things about the medical care I receive that could be better
Compliance with HIV medication	1.000			
I am very satisfied with the medical care I receive	.281(*)	1.000		
If I have a medical problem, I can reach someone for help without any problem	.153	.669(**)	1.000	
There are things about the medical care I receive that could be better	-.288(*)	-.276(*)	-.062	1.000

**** Correlation is significant at the .01 level (2-tailed).**

*** Correlation is significant at the .05 level (2-tailed).**

Table 7.4, shows that there was a statistical significant low positive correlation between the variables ‘compliance with HIV medication’ and ‘I am very satisfied with the medical care I receive’ (rho = 0.250, p = 0.025). This means that when there was an increase in the level of satisfaction of medical care received then there was an increase in the level of the variable ‘compliance with HIV medication’. Additionally, there was a statistical significant low negative correlation between the variables ‘compliance with HIV medication’ and ‘there are things about the medical care I receive that could be better’ (rho = -0.314, p = 0.005).

7.4.1.4 The Relationship between Compliance and Psychosocial Factors

This section presents the association between compliance with HIV medication and psychosocial factors.

Table 7.5: The relationship between compliance and psychosocial factors (n = 80)

Spearman's rho	Compliance with HIV medication	Self Esteem	Coping Strategies	Locus of control	Attitudes to HIV and sexuality
Compliance with HIV medication	1.000				
Self Esteem	.244(*)	1.000			
Coping Strategies	-.122	-.179	1.000		
Locus of control	-.138	-.064	.452(**)	1.000	
Attitudes to HIV and sexuality	.167	.178	.101	.129	1.000

**** Correlation is significant at the .01 level (2-tailed).**

*** Correlation is significant at the .05 level (2-tailed).**

In the Table 7.5 above a statistically significant weak positive correlation was observed between the variables ‘compliance with HIV medication’ and ‘self-esteem’ (rho = 0.244, p =0.029).

In this section personality traits were checked as to whether they related to compliance with HIV medication.

Table 7.6: The relationship between compliance personality characteristics (n = 80)

Spearman's rho	1	2	3	4	5	6	7	8	9	10	11
1. extroverted, enthusiastic	1										
2. Critical, quarrelsome	.139	1									
3. dependable, self-disciplined	-.032	.264*	1								
4. Anxious, easily upset	.069	.240*	.375**	1							
5. Open to new experiences, complex	.336**	-.050	-.012	-.058	1						
6. Reserved, Quiet	-.194	.096	.252*	.339**	-.286*	1					
7. Sympathetic, Warm	.184	-.097	-.037	.101	.368**	.095	1				
8. Disorganised, careless	-.288*	.082	-.011	.114	-.275*	.250*	-.237*	1			
9. Calm, emotionally stable	-.024	-.174	.054	-.087	-.168	.112	.238*	-.081	1		
10. Conventional, uncreative	.076	-.072	.118	.154	-.118	.424**	.038	.085	.055	1	
11. Compliance with HIV medication	.235(*)	.080	.041	-.054	.255*	-.046	.231*	-.261*	.121	-.040	1

**** Correlation is significant at the .01 level (2-tailed).**

*** Correlation is significant at the .05 level (2-tailed).**

Table 7.6, shows that there was a statistically significant low positive correlation between ‘compliance with HIV medication’ and ‘open to new experiences’ (r = 0.222, p = 0.047). Additionally, there was a statistical low negative correlation between the variables ‘compliance with HIV medication’ and ‘disorganized’ (r = -0.265, p = 0.018).

7.4.1.5 The Relationship between Compliance and Medications Factors

The association between compliance with HIV medication and medication factors will be investigated in this section.

Table 7.7 shows that there was a statistically significant moderate positive correlation between ‘compliance with HIV medication’ and ‘thoughts about taking medication’ rho = (r = 0.57, p < 0.01). There was a statistically significant low positive correlation between compliance and commitment to medication (r = 0.349, p < 0.01).

Table 7.7: The relationship between Compliance and medications factors (A) (n=80)

Spearman's rho	Thoughts about taking medication	Commitment with HIV medication	Compliance with HIV medication
Thoughts about taking medication	1.0		
Commitment with HIV medication	.573**	1.0	
Compliance with HIV medication	.325**	.349**	1.0

**** Correlation is significant at the .01 level (2-tailed).**

*** Correlation is significant at the .05 level (2-tailed).**

Feelings about taking HIV medication were investigated as to whether they related to compliance with HIV medication. This investigation was conducted for each one of the feelings about taking HIV medication reported. The findings are presented below.

Table 7.8: The relationship between Compliance and medications factors (B) (n=80)

	Compliance with HIV medication (r values)
Taking HIV medication makes me feel interested	.242*
Taking HIV medication makes me feel distressed	-.193
Taking HIV medication makes me feel excited	.176
Taking HIV medication makes me feel upset	-.204
Taking HIV medication makes me feel strong	.060
Taking HIV medication makes me feel guilty	-.100
Taking HIV medication makes me feel scared	-.169
Taking HIV medication makes me hostile	.014
Taking HIV medication makes me feel enthusiastic	.083
Taking HIV medication makes me feel proud	.213
Taking HIV medication makes me feel irritable	-.057
Taking HIV medication makes me feel alert	.028
Taking HIV medication makes me feel ashamed	-.198
Taking HIV medication makes me feel inspired	.191
Taking HIV medication makes me feel nervous	-.062
Taking HIV medication makes me feel determined	.065
Taking HIV medication makes me feel attentive	.134
Taking HIV medication makes me feel jittery	-.179
Taking HIV medication makes me feel active	.111
Taking HIV medication makes me feel afraid	-.147

**** Correlation is significant at the .01 level (2-tailed).**

*** Correlation is significant at the .05 level (2-tailed).**

Table 7.8 shows that there was a statistical significant low positive correlation between the variable ‘compliance with HIV medication’ and the variable ‘Taking HIV medication makes me feel interested’ (rho = 0.242, p=0.030, n = 80)

Below benefits of medication were investigated as to whether they related to compliance with HIV medication. This investigation was conducted for each one of the benefits of HIV medication.

Table 7.9: The relationship between Compliance and medications factors (C) (n=80)

	Compliance with HIV medication (tailed values)
I find HIV medication...(dangerous 1-5 safe)	.059
I find HIV medication...(expensive 1-5 inexpensive)	-.043
I find HIV medication...(inconvenient 1-5 convenient)	.124
I find HIV medication...(complicated 1-5 simple)	.092
I find HIV medication...(distressing 1-5 comforting)	.163
I find HIV medication...(harmful 1-5 helpful)	.121
I find HIV medication...(unimportant 1-5 important)	.244*
I find HIV medication...(useless 1-5 worthwhile)	.137
I find HIV medication...(ineffective 1-5 effective)	.136

**** Correlation is significant at the .01 level (2-tailed).**

*** Correlation is significant at the .05 level (2-tailed).**

Table 7.9 presents the results of correlational analyses of the relationship between compliance and medication factors. Table 7.9 shows that there was a statistical significant low positive correlation between the variable ‘compliance with HIV medication’ and the variable ‘I find HIV medication (unimportant 1-5 important)’ (rho = 0.244^{*}, p = 0.029).

7.4.1.6 Summary of Factors Associated with Compliance

According to the results, the participants of the present study who were more likely to comply with their HIV medication regimes, tended to be more open, organized people, and with higher self-esteem levels. These people believed that taking their medication was important and were interested in and committed to their medication regimes and thought about taking medication more often.

They tended to be more satisfied with the health care they received and believed that health care support was available when they required it. In regards to support related factors, those who had an understanding partner and also did not have support to take their medication from their family were more likely to comply to their medication regimes.

7.4.2 Predicting Compliance with HIV Medication use

A linear regression analysis was conducted to determine the relative influence of specific predictor variables on the criterion dependent variable ‘compliance with HIV medication’. Some of the variables were included in the model as they were found to correlate significantly with the variable ‘compliance with HIV medication’. These were: (i) open to new experiences; (ii) disorganized; (iii) I am very satisfied with the medication I receive; (iv) there are things about the medical care I receive that could be better; (v) self-esteem; (vi) commitment to the medication; (vii) thoughts about HIV medication; (viii) taking HIV medication makes me feel interested; (ix) I find HIV medication (unimportant 1-5 important). Some other variables that were not significantly correlated with the variable ‘compliance with HIV medication’ were also included as they were regarded as important in previous studies (Penedo et al., 2003). These were (i) extroverted; (ii) sympathetic.

The degree of correlation was low for all of them, except of the variables: cognitive thinking and self-efficacy. Furthermore there were some additional quantitative variables called dummy variables (emotional support from partner, practical support from family, support taking medication from family, understanding from partner and acceptance from partner). These variables were also included since the analysis indicated that they affected compliance to HIV medication.

Additionally, another reason why some of the above variables were included in the present model was the theoretical information that was found, regarding what factors influence compliance with HIV medication. Variables such as locus of control, susceptibility, severity, benefits/barriers of medication (Aversa & Kimberlin, 1996), social support, depression (Safren et al., 2001), communication with doctors (Taylor, 1991), side effects (Remien et al., 2003) were some of the factors that according to past literature were influencing compliance to medication (see chapter 2 for more details).

Bearing all these in mind, an explanatory linear regression model was built. From the three stepwise methods (forward, backward and stepwise) a backward method was chosen. Also the natural logarithm for the dependent variable was used in order to have a positive intercept.

If the goodness of fit is looked upon, the R-Squared value (0.586) and the R-Adjusted (0.569) were moderate which meant that the explanatory variable explained 58.6% of the variation of the dependent variable. The Durbin Watson value = 1.85 was very satisfactory. The coefficient for the variables ‘cognitive functioning” and “self-efficacy” was 0.151, for the variable open to new experiences 0.04014 and for the variable support for taking medication from family -0.08204. All the coefficients were statistical significant since their p-values were less than 0.05. Additionally it did not appear to have a multicollinearity problem (since the mean value of all the VIF values were close to one) and the residuals did not deviate from the normal distribution significantly (Appendix 5, Graph 1).

The model had the following form:

Compliance with HIV medication = e ^ (-0.488) * e^0.151(‘‘cognitive functioning” and “self-efficacy”) * e^0.04014 (open to new experiences)*e^ [-0.08204 (support for taking medication from family)]
or
Ln (**Compliance with HIV medication**) = (-0.488) + 0.151(‘‘cognitive functioning” and “self-efficacy”) +0.04014 (open to new experiences)-0.08204 (support for taking medication from family)

Table 7.10: Model Summary

	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics					Durbin-Watson
Model					R Square Change	F Change	df1	df2	Sig. F Change	
12	,765	,586	,569	,14695	-,009	1,659	1	74	,202	1,850

Dependent Variable: Ln (Compliance)

Table 7.11: Model Summary

	Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
	B	Std. Error	Beta			Tolerance	VIF
(Constant)	-,488	,115		-4,249	,000		
Open to new experiences, complex	4,014E-02	,009	,353	4,563	,000	,951	1,051
Cognitive functioning and self efficacy	,151	,019	,613	8,018	,000	,971	1,030
Support for taking medication from family	-8,204E-02	,035	-,181	-2,377	,020	,979	1,021

A Dependent Variable: Ln(Compliance)

7.5 Chapter Summary

After the completion of the analysis, the following results can be drawn:

The majority of the sample showed compliance with antiretroviral therapy since the average value of this variable was 1.78. The personality questionnaire showed that the characteristic with the lower average value was “disorganised, careless” (2.71). In addition, the characteristic “critical, quarrelsome” came with an average value of 3.54. The characteristic with the higher variation of responds was “Conventional, uncreative” (2.187) and the characteristic with the lowest variance was “Sympathetic, Warm” (1.68) which indicated a low degree of variation in the answers for this particular characteristic.

It was also found that the impact of lifestyle (alcohol and smoking) on compliance with HIV medication was not significant since (n = 80, Z=-1.552 p = 0.121) and (n = 80, Z=-0.119, p = 0.905) respectively and the same applied for the influence of the gender and sexual orientation since (n = 80, Z=-0.863, p = 0.388)) and (X2 = 2.60, df = 2 and Asymptotic significance = 0.273) respectively.

Moreover, the income was not related to compliance of HIV medication (rho = -0,025, p > 0.05). Also, it was found that the average value of the variable that concerned social support was 2.08 (close to two) which indicated that the level of participants' social support was good. Additionally, no relationship was established between social support and compliance with HIV medication (r ho= 0,187, p > 0.05).

The source from which participants draw social support, cane firstly from friends and family (usually with this order) and secondly from the sexual partner and work colleagues (usually with this order). It was found that the emotional support from the partner was related to compliance with HIV medication (p = 0.011), as individuals with emotional support from the partner indicated higher compliance with HIV medication (M=1.95) towards HIV patients with no emotional support from the partner (M=1.65).

Also, the practical support from the family was related to compliance with HIV medication (p = 0.006), as HIV patients with practical support from the family indicated lower compliance with HIV medication (M=1.53) towards HIV patients with no practical support from the family (M=1.90).

In addition, HIV medication compliance was related with the support for taking medication from the family (p = 0.039). It was also indicated that there was a higher degree of HIV medication compliance (M=1.86) for those that did not receive support for taking their medication from the family comparing to those who received this type of help (M=1.48). As far as the understanding from the partner, it was related to compliance with HIV medication (p = 0.023), as participants with understanding from the partner indicated higher compliance with HIV medication (M=1.95) towards participants with no understanding from the partner (M=1.79).

Finally, acceptance from the partner was related to compliance with HIV medication (p = 0.023), as participants with acceptance from the partner indicated higher compliance with HIV medication (M=1.94) towards participants with no acceptance. Furthermore, a low positive correlation was found between ‘‘compliance with HIV medication’’ and ‘‘self-esteem’’ (rho = 0.24, p =0.029.). This suggests that when there was an increase in the level of self-esteem then there was also an increase in the level of the variable ‘‘compliance with HIV medication’’. Additionally, to this correlation there was a moderate positive correlation between the variables ‘‘compliance with HIV medication’’ and ‘thoughts about taking medication’’(rho = 0.53, p =0.000..). This implies that when there was an increase in the level of thoughts about taking medication consequently there was an increase in the level of the variable ‘‘compliance with HIV medication’’. Of course there was a low positive correlation between compliance and commitment to medication (rho = 0.39, p =0.000..).

In addition, there was a low negative correlation between ‘‘compliance with HIV medication’’ and ‘‘disorganized’’ (rho = -0.27, p =0.018) suggesting that if the level of disorganization increased then the level of compliance decreased.

There was also a low positive correlation between ‘compliance with HIV medication’ and the level of “satisfaction with medical care received” (rho = 0.250, p = 0.025). This meant that when there was an increase in the level of participants’ satisfaction medical care of the received, then there was an increase in the level of the variable ‘‘compliance with HIV medication’’. Furthermore, there was a low negative correlation between the variables ‘‘compliance with HIV medication’’ and ‘‘There are things about the medical care I receive that could be better’’ (rho = -0.314, p =0.005).

There were not any significant correlations between symptoms and compliance with HIV medication. However, there was a low positive correlation between ‘‘compliance with HIV medication’’ and ‘‘Taking HIV medication makes me feel interested’’ (rho = 0.24, p =0.0029). No other correlation existed between any feeling and compliance with medication. The same result existed between the variable ‘‘compliance with HIV medication’’ and the variable ‘‘I find HIV medication (unimportant 1-5 important)’’ (rho = 0.24, p = 0.030).

Finally, the regression analysis led to a model, which explained the 58.6% of the variation of the dependent variable (compliance with HIV medication) by using the thoughts about taking medication (Cognitive functioning and self-efficacy), open to new experiences and support for taking medication from family as exploratory variables.

Support for taking medication from family had a negative impact to compliance with HIV medication. Thoughts about taking medication had the greatest (positive) impact followed by the variable open to new experiences (half of the impact that thoughts have and tripled comparing with the variable: support for taking medication from family).

During the following chapter both quantitative and qualitative findings in regards to the individual factors that affected compliance with antiretroviral therapy as well as the strengths and implications of these findings in relation to people living with HIV are going to be discussed.

CHAPTER EIGHT: DISCUSSION

8.1 Introduction

The aim of this study was to gain an insight into how certain factors influence compliance with HIV medication within the cultural context of Greece. Great emphasis was given to the social, cultural, psychological factors that may result to compliant or non-compliant behaviors and special attention was paid to the HIV positive individuals' perspective. In contrast to past studies which examined individualized factors that influenced compliance with antiretroviral therapy, the present study examines a combination of these factors and analyzed the impact they may have on HIV positive individuals' compliance with HIV medication.

This discussion will first revisit the aims and objectives of the research, and then summarize the empirical quantitative results and the qualitative findings. This will be followed by an integration of both qualitative and quantitative findings, pulling out the meaning of the data. Here, the overall findings will be presented in relation to their correspondence with, and differences from past studies. Elaborations of existing knowledge will also be presented whilst taking into consideration social, cultural, psychological, everyday life factors, as well as gender/ identity factors. The chapter will continue with a presentation of new insights developed within the current study and will move on to a methodological critique and suggestions of the implications of the work. Recommendations for future research will also be examined and the chapter will end with a section on final conclusions of the current study.

8.2 Aims and Objectives

To recap, the aims of the current study are:

1. Examine the psychosocial factors influencing compliance to medication/treatment regimes amongst HIV/AIDS positive individuals.
2. Explore the ways in which issues of identity and gender may influence compliance to medication/treatment regimes.
3. Explore the ways in which compliance to medication impacts on the everyday life of HIV/AIDS individuals.
4. Explore how the relationship between health care professionals and people living with HIV impacts on compliance.
5. Understand the socio-cultural positioning of HIV/AIDS sufferers, and how such positioning influences compliance to medication.

6. Examine participants' general health status.

8.3 Discussion of the Main Findings

The main findings will be discussed under six areas. In each one of these areas the findings of the current study will be discussed, structured according to the aims and objectives of the research. The empirical findings arising within the current study are compared and contrasted with those presented in past literature.

8.3.1 Lifestyle and Socio-demographic Information

Participants' lifestyle information indicated that the amount of the alcohol consumed was low. On the other hand, the levels of smoking were high, considering the fact that as mentioned above Greece has the highest smoking rate in Europe (Vardavas & Kafatos, 2006). This means that the results derived from the present study are in agreement with those of Rotheram-Borus et al. (1997) who observed that HIV positive individuals African Americans and Latinos do not change their alcohol and smoking habits.

In the current study the compliance was not affected by the gender, the sexual activity, the age, the income or the profession. *"As is common throughout the compliance literature, non-compliance to HIV therapy is not consistently associated with demographic characteristics"* (Eldred et al., 1997; Morin and Moatti, 1996; Singh et al., 1996; Chesney et al., 2000, p.1602). In contrast to the findings of the current study, Penedo et al., (2003) examined gender, age, ethnic group, level of education, employment status and income in American men and women living with HIV and undertaking HIV medication. It should be noted, however, that ethnic group was not examined in the current study as all the participants were Greek citizens, which means that there was no ethnic variation. As it was before mentioned all participants were carefully chosen in regards to their ethnic group so as to avoid cultural issues. In addition, another study by Gordillo et al., (1999) that examined HIV positive individuals of an HIV institution in Madrid that were undertaking HIV medication, indicated that the educational level was associated with medical compliance. Unfortunately, educational level was not investigated in the present study and this can be considered as a methodological limitation. Therefore, it is difficult to compare the findings of the present study with those of Gordillo et al's.

8.3.2 Psychosocial Factors

In order to compare the empirical findings, on the following Table (8.2), a summary of the psychosocial factors associated with HIV medication compliance are presented and then discussed within the following paragraphs.

Table 8.1: Key Quantitative: Psychosocial factors

CHAPTER LEVEL, TITLE	**FINDINGS**
Chapter 6, level 6.1.4, Psychosocial factors	
Self esteem	• The degree of self-esteem was average
Coping Strategies	• The level of coping strategies was slightly good
Locus of Control	• The level of locus of control was good.
Personality characteristics	• The characteristic with the higher average value was 'open to new experiences, complex' with an average value of. The characteristic with the lower average value was 'Disorganized, careless' and above that was the characteristic of critical – quarrelsome.
Life satisfaction	• Only a small proportion of the respondents were reported being dissatisfied with their life, while the best life a patient could expect to have referred to life circumstances for those who were already HIV positive.
Satisfaction with the healthcare	• Respondents were satisfied, but they also believed that they could be more satisfied, because they could not always reach someone for help
Chapter 7, level 7.4.1.4, The association between compliance and Psychosocial factors	
Association with compliance	• When there was an increase in the level of self-esteem then there was an increase in the level of 'compliance with HIV medication'

8.3.2.1 Personality

According to the findings of the present research, there was no correlation between the variables ''compliance with HIV medication'' and ''extroverted, enthusiastic'' (indicating extraversion).

Earlier work of Penedo et al., (2003) indicated that, high scores of extroversion and contentiousness were associated with a better overall function, sexual functioning, life satisfaction and HIV mastery. Additionally, high scores of extroversion were associated with less financial, medical, disclosure worries and sexual functioning. However, although earlier work indicated that extroversion is a personality trait that is highly associated with several areas of an HIV positive person's life. The present study did not show such a fact.

In addition, findings of the present study showed that there was also a high correlation between compliance with HIV medication and openness to new experiences, which indicated that HIV positive individuals (that they had accepted their condition) were open to take any medication that could improve their health status together with their quality of life. On the other hand, there was a negative correlation for the variables ‘‘compliance with HIV medication’’ and ‘‘disorganized’’ which indicated that if the level of disorganization increased then the level of compliance decreased. In contrast to the study of Penedo et al. that indicated that personality traits were not directly associated with compliance to HIV medication, the present study indicated that openness to new experiences and disorganization were directly associated with compliance to antiretroviral therapy (Penedo et al., 2003). The characteristic of disorganization was an aspect of the personality that existed even before the diagnosis, or appeared after the diagnosis as the individuals could not adopt to the new lifestyle.

The present study showed that when an HIV positive person was open to new experiences s/he appeared to be taking medication as prescribed whereas when an HIV positive person was disorganized s/he seemed to not be taking medication as prescribed. In order to substantiate these findings, further research is required to clarify the relationship between personality characteristics and compliance.

8.3.2.2 Quality of life/Life satisfaction

The present study indicated that HIV positive individuals' considered that they enjoyed a good quality of life, as the majority of participants responded that they were satisfied with their lives. According to the research of Penedo et al. (2003) the quality of life was highly associated with compliance to HIV medication. On the other hand, the research of Gordillo et al. (1999) indicated that although the HIV positive individuals' lifestyle was been improved by the behaviour of the later and their doctors, it was not associated to compliance with medication. The current study also did not find that compliance was related to quality of life.

In terms of explaining, the reasons for HIV positive individuals being satisfied with their lives may be that the HIV, once diagnosed, they developed personalities through changing perceptions, setting new life priorities, following healthy lifestyles and enjoying life experiences that were not enjoying or else appreciating at the same degree as in the past, such as enjoying a wonderful morning, travelling and so on.

8.3.2.3 Self Esteem

The study indicated that the correlation between compliance with medication and self-esteem was weak but indicated that higher levels of self-esteem were associated with higher levels of compliance with medication. This means that when there was an increase in the level of self-esteem then there was an increase in the level of the variable ‘‘compliance with HIV medication’’. Studies have shown that psychosocial factors such as self-efficacy, self-esteem, resilience and commitment are related to compliance with medication (Catz et al., 2000; Chesney et al., 2000a; Giffordet al., 2000; Moatti et al., 2000; Spire 2002).

Additionally, the present research has identified that certain HIV positive individuals have showed optimistic behaviours. This finding agrees with previous research as self-esteem and optimism have been associated in several health situations (Anderson, 2000). In the present study it was observed that when HIV positive individuals appeared to have high levels of self-esteem they also had optimistic views regarding health or life issues, consequently they showed increased levels of compliance with medication.

It may be that when individuals experience low levels of self-esteem, they are not motivated towards self-protection and engage in risky behaviors such as taking multiple sexual partners, heavy use of alcohol or illegal substances. In contrast, HIV positive individuals with high self-esteem perceived fewer threats associated with HIV in comparison to HIV positive individuals with low self-esteem; as self-esteem was a strong predictor of emotional distress and threats associated with HIV. Apparently, high levels of self-esteem in association with optimistic views are very important because the individual manages to deal better with HIV virus (Nyamathi et al., 1993; Anderson, 2000).

8.3.2.4 Anxiety and Depression

According to the present research participants exhibited high levels of anxiety and depression. They explained that their anxiety and depression levels had increased significantly compared to levels experienced before diagnosis. This finding agrees with that of Safren et al., (2001) who reported that:

"Greater depressed mood was associated with poorer adherence. These findings highlight the importance of provider or counsellor awareness of psychological and psychiatric difficulties among patients with HIV; these variables appear to affect adherence outcomes" (*Safren et al., 2001 p.* 1159).

According to Kelly et al., (1998, p. 412), "*there is a link between psychiatric disorder, lifetime history of injection drug use, psychological adjustment patterns, and family history of attempted suicide. The significant role of HIV-negative status as a discriminating factor for a lifetime history of suicide attempt may indicate the effect of recruitment bias or perhaps an effect of fear of acquiring HIV infection".*

Also Mehta et al. (1997, p.1667) stated that *"major depression is the most commonly cited psychiatric problem among HIV-infected individuals. It has been suggested that active psychiatric intervention should be an important component in the effective management of HIV-infected patients".*

In contrast to the above findings, the present research observed that there was no correlation between anxiety and depression and compliance with HIV medication. There was one case (in the qualitative findings) where the HIV positive individual was diagnosed with depression and did not take his medication as he should have, but again the individual was diagnosed even before the illness and his compliance with HIV medication was as irregular as the compliance with the medication for depression as well as any other health issues such as cholesterol.

8.3.2.5 Coping

In regards to coping with the HIV virus, the findings of the present study suggest that its level was good. In other words, HIV positive individuals appeared to have high levels of coping strategies.

The present thesis has demonstrated that in several situations HIV positive individuals' adopted certain coping strategies. Here ''coping strategies'' mean the development of certain personality aspects such as sense of humor, adaptation to difficult situations or the development and analysis of different points of view regarding this particular problem. Furthermore, HIV positive individuals have found and adopted other coping strategies such as ''faith'', use of support network or even destiny. Also, the HIV positive shares coping strategies and belief systems when developing a relationship with the doctor (Morgan, 2003).

It is believed that coping with HIV usually plays a significant role in compliance with medication (Aversa & Kimberlin, 1996). In addition, Singh et al., (1999, p. 829) stated that*: Individuals who confronted the stress with problem-solving and behaviour-modifying approaches were significantly more likely to be adherent than those who coped by denial or who utilized emotions to create meaning out of dismal situations.*

At last, in the present study there was no evidence that link the coping strategies with the compliance to HIV medication.

8.3.2.6 Influence of Support Network

In the present study, the influence of the support network that the HIV positive individuals had was also examined. Taking under consideration the Greek cultural context whereby anything “unhealthy” tends to be socially isolated, we could then see that the participants received more support from those they had closest relationships even before they were diagnosed as HIV positive.

In terms of explaining the support network is being characterized by its size, its homogeneity, the density of the network and the members of it. Additionally, some other characteristics of it are the contact of network ties, the emotional closeness and stability (Ashida, 2005; Israel & Antonucci, 1987; Rounds & Israel, 1985).

The most important factor that proved to affect compliance with medication in the present research was the existence of the supportive and understanding life partner. That means that when emotional support from the life partner existed the HIV positive individuals were taking their medication as they were supposed to. This may be because the nature of social support increased psychological health and self-esteem along with promoting immune function and decreasing isolation and stress in HIV positive people (Barroso, 1997; Heckman et al., 1997; Kylma & Vehvilainen- Julkunen, 1997; Nunes et al., 1995; O’ Neill&Kenny, 1998; McCormick et al., 2001).

According to the literature, a good support network seemed to influence HIV positive individuals’ longer survival (Reillo, 1990). An Italian study had showed that low support network scores were associated with low CD4 cell counts (Solano et al., 1991). Additionally a study in Chicago showed that HIV positive individuals who were involved with the gay community of the area and consequently had a support network appeared to have a longer survival time (Caumartin et al., 1991). A study of Catania

(1992) in San Francisco had showed that in west cultures HIV positive individuals were receiving support from family members, friends, societies that they belong. Additionally, Catania’s study showed that HIV positive individuals tend to seek for support especially when coping with issues such as death. However, the research of Catania indicated that HIV positive individuals were seeking for support from family members when there was a positive situation such as a good blood test result (Catania, 1992).

According to the findings of the present study and the past literature, it seems that support network had a significant role in HIV positive individuals’ lives. Not only did HIV positive individuals seek for support network for help but it seemed that it influenced the formers health status, such as the Italian study of Solano et al. (1991), but also their survival time (Caumartin et al., 1991). On the other hand, although family was considered as a support network the study of Catania (1992) showed that in west societies it is only when “the news were good” HIV positive individuals shared it with their families.

Hence, the next major factor that was examined was the support coming from the family. In the present study, a significant statistical difference was observed between practical support and support for taking medication with compliance to HIV medication. In terms of practical support from the family the present study showed that there was a difference between those that received practical support from their family and the ones that did not. Moreover, it should be taken under consideration that there were individuals who received practical support from the family but showed lower compliance, which means that the family affected them in a negative way.

Also, when talking about family support, the study have showed that when the family gave support to the HIV positive individuals for taking their medication, the later did not comply as they should. According to Taylor (1991) HIV positive who had social support managed to tolerate side-effects and to adjust to their medication.

According to the literature in regards to the Greek family, it is composed of family members and also extended family members such as, in laws, relatives and family friends. These are the ones that are supposed to show concern and take care of any person that might be in need (Georgas, 1991). However, this picture changed over the last decades especially in urban areas and more specifically in Athens. According to the study of Georgas (1991) although the family relationships and family obligations were still functional, there was an overall change of the youngest family members from collectivist to individualist values. A possible explanation for this may be the change of structure of the Greek family. During the past decades the family was characterized as patriarchic were the father was the breadwinner and the mother was the housekeeper. The breadwinner father had an authoritarian behaviour and was the one that was taking the family decisions. However, during the last decades this structure changed in urban areas as the youngest family members rejected the authoritarian role of the father. Along with the rejection of the fathers' authoritarian roles there might was a rejection of several family values as well (Georgas, 1991). Although this topic would be very interesting to investigate, during this research it was not possible to expand on it, however, it would be interesting to look into the reasons in future research.

Additionally, in other cultures such as North America and Western Europe it was observed that there was a change in the dynamics of the family system as well. Both partners' roles and child-parent relations had been changed and the values of the family had been affected (Cliquet, 2003). Consequently, the family system of these societies became more vulnerable, less stable but more satisfying over the last decades (Cliquet, 2003). In terms of explaining, over the last decades the family involved less family siblings and more female participation in family issues. However, according to the literature if there is a health issue within the family, the American and western Europe societies show less responsibility and support in contrast to the Mediterranean regions that show greater support due to stronger family bonds that they still appear to have (Reher, 1998).

It seems that the family dynamics has been changed in several cultures over the last decades, the partner roles have changed especially in West and Mediterranean societies as well. Consequently, in both cultures the family values have been affected. However, according to the literature despite the weakening of the traditional family functions it seems that it is a human need to make efforts and continue investing in families (Alexander, 1979; Cliquet, 2003).

The present study's findings showed that the diagnosis of HIV was the reason for some participants to form stronger bonds with existing friends. Also, the findings had showed that the participants that received social support from friends and the ones that did not appeared not to have differences regarding the levels of compliance. Moreover, participants that received financial or/and social support from work colleagues also appeared not to have differences in the reported levels of compliance. Moreover, in the study of Mehta et al. (1997, p. 1667), they observed that *"higher perceived social support was not found to be significantly associated with compliance".* In contrast to that, the literature indicates that "*mutually supportive relationships, religion, miracles, and work, all provide a sense of hope that promotes coping skills, positive lifestyle choices, and self-esteem in people with HIV"* (Hall, 1994; McCormick et al., 2001, p. 60).

8.3.2.7 Locus of Control

"The locus of control construct refers to an individual's expectancy for control (internal locus of control), or lack of control (external locus of control) over health outcomes" (Aversa & Kimberlin, 1996, p. 208). In the current study, participants' felt locus of control was high. Here, locus of control primarily concerned the ability of the individuals to control their condition, i.e. the ability of the HIV positive individuals to determine how soon they would feel better again or the need for someone else's help in order to feel better.

"Studies using health related locus of control have shown that patients who express strong 'powerful others' orientation and those who express more internal orientation tend to be more compliant than individuals oriented to chance locus of control (Aversa & Kimberlin, 1996, p. 208). In contrast to that, the present study has shown no correlation between locus of control and compliance with HIV medication.

8.3.3 Issues of Identity and Gender that may Influence Compliance to Medication/treatment Regimes

The difference between sex and gender is well defined. *''Whereas 'sex' describes a biological distinction between men and women, 'gender' is a social construct that differentiates the power, roles, responsibilities, and obligations of women from that of men in society''* (Who, 2002; Turmen, 2003, p.411). The quantitative findings of the present study found no correlation between gender and identity issues and compliance with HIV medication. Similarly, the qualitative findings of the current study (interviews and diaries) also indicated that issues of gender and identity were not important in regards to whether or not a person was compliant with medication. In other words, some issues that were identified in the findings, were HIV positive individuals' thinking and feelings in regards to HIV and medication which although did not seem to be directly associated with compliance at the time of the study could possibly be used as the ways to identify the reasons that empowered the compliance of other participants of the study.

The experience of stigma associated with being HIV positive was an important gender issue that arose in this study. Unfortunately, this was an issue for women especially, who still face discrimination and social labeling as ‘‘dirty’’ and ‘‘undeserving’’ (Lawless et al., 1996). Participants, males and females often reported living in secrecy and guilt, having continuously to justify their choices and beliefs. The study has revealed at the time of the research, in Greece, HIV was still identified with promiscuous sexual lifestyles or prostitution and that these remain socially classified as actions which are unacceptable according to social norms and morals. Therefore, revelation of HIV positive status could consequently result in the need for self-defense on the part of HIV positive individuals regardless of their participation in socially rebutted lifestyles and lifestyle choices.

Additionally, the absence of companionship caused feelings of abnormality and deficiency for some of the women who took part in this study. When this concerned loss of sexual relations as well as loss of a partner to share their lives with, women described loss of their sense of femininity, their female identity and even tended to generalise this deficiency in other aspects of their lives. Moreover, *“HIV positive people are often expected not to have sex or only to have sex with other positive people. The notion of pleasure rarely comes into it, especially for women, because there are cultural barriers to discussing sex within either relationships or communities”* (Bell et al., 2007, p. 116). Therefore, when the women participating in this study were not able to find another HIV positive man, they preferred not to form any sexual or intimate relationship at all. According to past literature, *“…the sexuality of men and women with HIV is diminished by the fear of infecting others and being infected, as well as guilt, anger and ill health resulting in negative physical and psychological effects on sexual desire”* (Shapiro 2007, p. 82).

This study also indicated that taking HIV medication impacted on women’s feelings of powerlessness as they felt they could not make the same choices that other females did. Therefore, whilst taking medication, and being unable to experience motherhood, also caused them feelings of inferiority. Consequently, they believed that they were unable to find a life partner as according to their beliefs they could not support their gender role of becoming mothers. These women experienced their body as abnormal and as they could not fulfill their expectation of having a body which was going to continue the generation.

Men on the other hand, were concerned about rejection when attempting to attract a female partner and felt that this was due to their inherent weakness or their HIV positive status. In line with past literature, men can present themselves as healthy and contented, when in fact they are experiencing pain, depression or anxiety (Liu, 2005). In contrast with women though, men in the current study showed more willingness to develop intimate relationships, albeit they were still quite cautious.

Evidence suggests that HIV positive males and females have the right to form families and experience parenthood (Bell et al., 2007). However, the findings of the current study suggested that both men and women were discouraged to do so. According to the literature, being HIV positive does not mean that parenthood is forbidden; however HIV positive individuals do not always have the necessary information regarding this matter and are often pressured by families and communities to give up the idea of reproduction (Bell et al., 2007). As mentioned in the beginning of this section, although issues such as the above did not directly affect compliance with HIV medication, it appeared that when such issues as intention to develop intimate relationships or to become parents provided participants with the motivation to comply with medication. In addition, when participants actually had an intimate partner or in case parenthood was not an issue, feelings of happiness, joy and relaxation were experienced. The capability of participants’ sharing their thoughts or feelings with an intimate partner who was also HIV positive did not result negative feelings such as deficiency but actually seemed to empower compliance with medication.

However, according to the findings of the current study, in contrast to females, the male participants did not express any intention to become parents. This might happen due to the small number of heterosexual male participants or due to the limitation of the study requesting the marital status of the participants. However, the current research could not further investigate this issue. Therefore, such an issue would be very interesting to be examined in future studies.

8.3.4 Medicalization of Everyday Life for HIV/AIDS Individuals

Table 8.2: Key Quantative: Medication factors

CKAPTER LEVEL, TITLE	**FINDINGS**
Chapter 6, level 6.1.5, Medication factors	
Beliefs about HIV medication	• Medication was believed to be very helpful, important, worthwhile, effective, safe, convenient, simple to take and comforting, but expensive
Feelings about HIV medication	• Respondents were feeling interested, strong, alert, attentive, determined and active in their use of HIV medication indicating a positive disposition towards medication usage. Few respondents reported feeling distressed, excited, upset, guilty, scared, hostile, enthusiastic, proud, irritable, ashamed, inspired, nervous, jittery or afraid when taking their medication.
Thoughts about taking medication	• The majority of the sample replied that most of the time their cognitive functioning and their feelings of self-efficacy regarding taking their medication were high.
Effectiveness of medication	• The effectiveness of medication was quite high
Commitment to medication	• The degree of commitment to medication was high
Compliance with HIV Medication	• The compliance rate was quite high
Chapter 7, level 7.4.1.5, The association between compliance and medication factors	
Association with compliance	• When there was an increase in the level of the thoughts about taking medication then there was an increase in the level of ‘compliance with HIV medication’. • When there was an increase in the level of commitment to medication then there was an increase in the level of the ‘compliance with HIV medication’. • There was a positive correlation between the ‘compliance with HIV medication’ and the ‘Taking HIV medication makes me feel interested’ • There was a positive correlation between the ‘compliance with HIV medication’ and the ‘I find HIV medication unimportant

This study has identified numerous factors that made compliance to medication and coping with medication quite a difficult issue in HIV positive individuals’ everyday life. In addition, several negative experiences appeared to act as barriers to compliance. On the other hand, a number of factors, particularly positive experiences, performed as facilitators to the integration of medicalization in everyday life.

The key issue was that the majority of HIV positive participants believed that HIV medication contributed to their life positively with the only major drawback reported as high cost. Analysis of respondents’ feelings about taking medication indicated that actively taking medication was linked to feelings of strength, alertness, determination, attentiveness and activity. Taking medication did not make HIV positive people feel guilty, scared, hostile, enthusiastic, irritable, ashamed, jittery or inspired. In other words taking medication has proved to be associated with positive feelings. It was in this sense that positive experiences achieved through taking medication could, in themselves, motivate compliance. However, past study proved that when HIV positive individuals take medication that requires abandoning enjoyed activities then they feel that they have lost control over their environment or their lives (Taylor, 1991).

The qualitative findings pointed to the negative consequences and expectations of HIV positive individuals experiences of side effects linked to medication as well as fears of future side effects could be problematic for compliance. Despite the fact that quantitative data did not highlight any significant medication related symptoms at the time that the research was taking place. However, the qualitative findings showed that when individuals experienced even few medication related symptoms, such as trying to take antiretroviral therapy when already ill due to side effects, they struggled and felt confused. According to past studies, side effects such as dizziness, withdraw and more are indeed risk factors for non-compliant behaviours. Additionally, considering the fact that antiretroviral therapy may result in adverse side effects in the future such as pancreatitis, peripheral neuropathy, lactic acidosis, metabolic complications and so on (Piliero, 2003), HIV positive individuals actually engaged in non-compliant behaviours (Mehta, Moore & Graham, 1997).

Consequently, illness and the gaining of HIV positive status were seen as a punishment for their choice of a homosexual lifestyle. In this sense, an illness like HIV could be seen as a ‘‘just’’ punishment. Hence non-compliant behaviours became their transportation to self-castigation of their bodies. This notion of bodily punishment for ill deeds has its roots in Greek philosophy. According to the history of illness, ironically the Greeks were one of the earliest civilizations that identified body functioning in health and illness.

Hippocrates was the first who developed a humoral theory about illness in 377 B.C. which was then expanded by Galen. This theory posited that the body was divided into four fluids: blood, black bile, yellow bile and phlegm, and when a person was ill those fluids were imbalanced. The treatment of any illness involved the restoring of the fluids’ balance (Taylor, 1991). Through the passing of the decades, and during the middle Ages, mysticism and demonology adopted these theories into new beliefs, where illnesses were God’s punishment for evil actions. The cure for such illnesses was the punishment of the body (Taylor, 1991).

Later in years, and while Christianity was becoming the main religion, the cure for such illnesses was left upon prayers to God; hence, religious concepts intervened in medical knowledge and therapy issues. Consequently, “*…physicians’ actions were absorbed by priests and medical therapies became indistinguishable from religion”* (Taylor, 1991, p. 4). Therefore, considering the above historical retrospection of illness and therapy it is not surprising that several residues are still left in certain Greek reasoning around health and illness, religion and action. And when people, according to religious ideation, engage in societally “unacceptable” actions such as homosexuality, theories of the 80’s that HIV is the illness of the homosexuals mix with earlier concepts of religiosity to create the possibility that self-castigation actions might occur to cure the body through punishment rather than through medical help. However, believing in God did not necessarily result in non-compliant behaviours, as several individuals did have faith in God and continued taking their HIV medication as prescribed, whilst using their faith so as to find strength to cope with the illness.

Another issue that arose through the current research in terms of understanding how taking medication fits into everyday life concerned the loss of one’s freedom to enjoy anything pleasant without the interruption of taking antiretroviral therapy. This was an important factor that acted as an obstacle to medication compliance in the participants in this study. Hence, a possible interruption of pleasant activities could result non-compliant behaviours. Apparently, the literature suggests that when individuals feel that their autonomy has been lost or limited by external factors, such as taking medication, they tend to experience anger that may result in attempts to regain freedom (Brehm, 1966; Brehm & Brehm, 1981; Taylor, 1991). In other words, when individuals’ freedom is threatened they can actually engage in non-compliant behaviours so as to gain back their freedom.

Additionally, associations with past substance misuse (there were no current substance misuses among the study sample) could promote non-compliant behaviours as individuals identified taking HIV medication with past habits of taking other chemical substances. Present substance misuse issues are highly associated with non-compliant behaviors (Tucker et al., 2004). Taking this argument further, the current research suggested that even past substance misuse habits could be associated with taking HIV medication in regards to carrying or taking pills in public.

A very important influence in an HIV positive individuals' life concerned being reminded of their HIV positive status. However, on an everyday level, this constant reminder could create feelings of deficiency which then had consequences for gendered identity. This New medical treatments have given new social roles to HIV positive individuals, in terms of work opportunities, development of intimate relationships and motherhood (Siegel & Lekas, 2002).

According to Siegal and Lekas, (2002) HIV positive individuals can live with HIV and keep on being productive on their work, have intimate relationships or experience motherhood. The current study suggested that motherhood and intimacy are issues that many women face every day. Although, new medication allows female HIV positive individuals to experience motherhood, by decreasing the chances of transmitting the virus to the fetus (Siegel & Lekas, 2002), many HIV positive women that took part in the current study still felt unable to experience an intimate relationship and consequently motherhood, as these women strongly coupled the development of intimate relationship with possible motherhood with the result of feeling deficient.

Additionally, certain individuals organized their lives around HIV by becoming members of NGO's and associated only with other HIV positive individuals whereas there were other HIV positive individuals who wanted to minimize and normalize the illness (Siegel & Lekas, 2002). Considering the above, the individuals who want to live their lives through normalizing the illness as much as they can, and identify themselves as healthy individuals, are drawn back as taking medication on everyday basis results in the reminding of their ill identities (Siegel & Lekas, 2002).

On the other hand, the support of a life partner could result in positive feelings and the patient considered taking HIV medication a positive experience and consequently non-compliant behaviours were less likely to occur. Paradoxically, the support of the family was not enough for compliant behaviours to occur. In general, when HIV positive individuals found support, they tended to achieve better compliance as they could hope for a more optimistic future which would include the maintenance of a relationship or the beginning of a family (Nam et al., 2008).

Individuals, who have supportive partners, especially when couple focused support for compliance is provided, are more likely to comply (Remien et al., 2005). Here, partners who attend medical appointments where they both can cooperate with the doctor and understand what is involved in taking medication and why this is important in maintaining health, then HIV positive individuals tend to comply more(Remien et al., 2005)..

8.3.5 The Relationship between Health Care Professionals and HIV Patients

Table 8.3: Key Quantative: Health and Health care factors

CKAPTER LEVEL, TITLE	**FINDINGS**
Chapter 6, level 6.1.3, Health and Health care factors	
General Health	• The general health status was good.
Health status	• Health status was good
Experienced symptoms	• The respondents faced mostly anxiety, gas/bloating, and fear/worries. Contrary, the symptoms they faced less was fever, chills and vomiting
Anxiety and Depression	• The level of the anxiety and depression was high
Experiences and feelings about healthcare	• The level of health care was very good:
Satisfaction with the healthcare	• Respondents were satisfied, but they also believed that they could be more satisfied, because they could not always reach someone for help
Chapter 7, level 7.4.1.3, The association between compliance and Health and Health care factors	
Association with compliance	• There is no relationship between compliance and the health variables explored, symptoms • When the level of satisfaction of medical care is high there is an increase in the level of compliance with HIV medication

Empirical findings of the current research showed that HIV positive individuals were generally satisfied with the medical care they received. However, there were things that needed to be changed in order to achieve an even better health care provision. This is discussed below in relation to the doctor-patient relationship.

Although numerous studies have examined the doctor patient relationship for a variety of chronic illnesses, little attention has been paid to the relationship between doctors and HIV positive patients (Marelich & Erger, 2004). According to the literature, compliance is an issue affected by the relationship between the health care provider and the patient (Marelich & Erger, 2004).

According to Parson's health care model (Morgan, 2003) there are four types of doctor and patient relationships; the paternalistic style, the relationship of mutuality, the consumerist relationship and the relationship of default. The paternalistic relationship involves a doctor centred relationship where the doctor is the dominant person and has control of the doctor – patient meeting. The relationship of mutuality describes equal roles of both the doctor and the patient, where both parties exchange ideas and suggestions regarding the patient's therapy. The third type is the consumerist relationship, characterized by the reversion of the power relationships with the patient taking the dominant role. Finally, there is the relationship of default where patients adopt a passive role no matter the doctor's attitude. It appears that the HIV positive individuals' responses of this study in regards to the relationships they have with their doctors agreed according to Parson's model. Nevertheless, the current study extended this model further by suggesting a new role model where the doctor adopts the role of expert friend who can help with his/her knowledge.

In addition, the findings of the present study suggested that although at the time of the study the majority of the HIV positive individuals were generally satisfied with their doctors (questionnaires), most of them were not satisfied in the past (interviews and diaries). This was especially evident for those HIV individuals when they had a paternalistic doctor-patient relationship where they were just following the doctor's medical orders. They were also unsatisfied even when they had a mutual relationship with their doctors, where although they participated in therapy decisions, the fact that they did not have a friendly relationship alongside the mutual one, resulted in some level of mistrust. Finally, when HIV positive participants in the current study reported having relationships of default they felt helpless or even humiliated.

Hence, although the findings of the current study agreed with the role modeling that literature suggests; and even though the majority of the participants were satisfied with their relationships with doctors according to the questionnaire results, the interviews indicated that those same HIV positive individuals had past experiences that resulted negative feelings and non-compliant behaviours due to unsatisfactory relationships with the health care providers.

Hence, considering the fact that relationships between doctors and patients represent particular forms of power and status relationships and taking into account that HIV positive participants held expectations of friendly relationships and not any of the above mentioned ones (according to the four role modeling) the current study suggests that the uniqueness of these individuals was not corresponding to the power and status relationships that doctors have with other patients that suffer from other chronic illnesses. This contrasts with past studies that suggest that power and status are key defining aspects of the relationship between health care providers and patients (Marelich & Erger, 2004). Apparently, the participants of this study needed another model of relationship with doctors which involved the doctor acting as a friend first and an expert second in order to share knowledge with them.

Another issue that impacted on HIV positive people’s health care satisfaction was the time spent with their doctors. The doctor and patient consultations usually average about six minutes, however this depends on the variation of each patient’s issue. Therefore the actual length of each consultation may vary from two to twenty minutes (Morgan, 2003). According to the literature *“Pressure of time encourages a more tightly controlled doctor-centred consultation with less attention paid to the social and psychological aspects of a patient’s illness*” (Morgan, 2003, p.56). As a result, during a consultation it is more likely to issue prescriptions than identify and work on the patient’s psychological problems. (Howie et al 1992; Morgan, 2003).

The findings of the current study identified the same issue with regard to health care satisfaction. HIV positive individuals were not satisfied with the time spent with their doctors and sometimes they even felt humiliated as they compared their doctors with prostitutes and themselves with clients who were visiting. Moreover, many felt they did not have enough time to talk about their health issues with their doctors. With only five to fifteen minutes meetings in which they reported on their health progress, much was not brought to the consultation such as their fears, talk about any possible medication side effects and advice seeking on several issues that mattered to their health. Interestingly, participants understood the difficulty of spending more time with their doctors and suggested that the support of a psychologist who would cooperate with their doctor might provide for psychological and counseling needs.

Unfortunately, psychological support could not be provided to all HIV positive individuals in Greek public hospitals and organizations (Greek citizens do not have to pay for public sector services as help is provided from health insurance without any cost) as the number of psychologists that work in public sectors was and still is limited in relation to the number of HIV positive patients.

8.3.6 The Socio-Cultural Positioning of HIV/AIDS Sufferers, and how such Positioning Influences Compliance to Medication.

Table 8.4: Key Quantative: Socio – cultural factors

CKAPTER LEVEL, TITLE	**FINDINGS**
Chapter 6, level 6.1.2, Socio – cultural factors	
Severity	• Most participants believed that their health status was serious or near serious. Half of the participants believed that their personal health condition was severe or near severe and described their health as fair or poor.
Perception of the position of HIV positive people within society	• Being HIV positive was a negative issue for the society
Support Network	• Support network provided the following types of support: • Friends, family, sexual partner, colleagues
Chapter 7, level 7.4.1.2, The association between compliance and Social support	
Association with compliance	• Individuals with acceptance from the partner indicated higher compliance with HIV medication

Within the following section, the participants' perceptions about the position of HIV positive people within society and how these perceptions might underpin compliance to medication, will be presented and discussed

Although, the majority of participants believed that their health status was serious or close to serious, approximately half of them believed that their situation was severe or close to severe and they considered their health as fair or poor. Being HIV positive was considered as something rather negative within the Greek society. Moreover, in Greece, participants felt that being labeled both HIV positive and a homosexual was more unacceptable since this was socially designated as disgusting. Therefore HIV and homosexuality were, and most importantly are perceived as, a negative issue; as an illness that comes as punishment and as an opportunity to feel pity for the people that are different within society.

Social relationships and attitudes were influenced from the Greek cultural context of isolating anything designated "unhealthy". As such the stigmatization of HIV positive individuals was keenly felt amongst the sample. Apparently, *"…a person's conception* *of reality, fear and danger, abnormality and stigma, health and beauty may be very individual, this perception, to a large extent, is culturally patterned"* (Ferrante, 1988, p. 224; Huber & Gillaspy, 1998 p. 195).

Fear of stigmatization and rejection meant that revealing ones positive status was an issue that some HIV positive individuals had to consider quite carefully and led to an evaluation of Greek society as ''unfriendly''. On the other hand, revealing ones status was a completely different issue for others. They would either use their HIV status to change relationships in ways consistent with felt emotional needs or in order to assert their independence and clearly state that any kind of support would be needed from family members or from partners and friends.

However, according to the findings of the present study, HIV positive individuals successfully coped with being HIV positive as well as with all the possible negative attitudes towards them. According to the literature, HIV positive individuals who are members of several societies' groups such as sports clubs or have strong family bonds tend to comply better with medication (Nam et al., 2008). The HIV positive participants of the current study did not refer to any society's groups or clubs that they were members of, but they did referred to the support they received from their family members, friends and life partners.

Apparently, the empirical findings indicated that specifically the emotional support and the support for taking medication from life partners increased compliance behaviours. Therefore, even though HIV positive individuals perceived that they lived in a "hostile" society that rejects them and stigmatizes them, the support of the people they were close to such as life partners, played a far more important role in HIV positive people's compliance than the society in general. It may was that the buildup of strong bonds in their relationships and the formation of alliances enhanced the participants' coping mechanisms and leading to compliance with medication.

Despite being faced with the reality and the difficulties of being an HIV positive individual within Greek society, HIV acted as a motivational factor in order for them to care for themselves more than they used to before the HIV diagnosis. As Siegel & Lekas, (2002) have argued, many HIV positive individuals engage in self-care strategies with the expectation to prolong their lives, control their symptoms and slow disease progression.

Continuing with the reasons that some HIV positive individuals managed to cope with the diagnosis, it should be mentioned that several HIV positive individuals reported that they experienced negative feelings such as anger, helplessness, suicidal thoughts or feeling punished for sins at the time of the diagnosis. However, whilst living with the illness, their present perspectives changed to setting priorities, such as the development of self or the gaining of strength through religious beliefs. This new way of seeing life and setting priorities, apparently changed the HIV positive individuals' perceptions regarding their sense of self-value, self-esteem and self-image. Adopting a positive and satisfying self-image acted as a coping mechanism against those negative attitudes that HIV positive individuals experienced when they were first diagnosed. On the other hand, those HIV positive individuals that did not manage to set new priorities faced depression, often acted irresponsibility and tended towards risk taking actions.

According to the empirical findings of the current study and the findings from previous research, the ability of one's health status acceptance was a factor that enabled HIV positive individuals to overcome fear of stigma (Maman et al., 2003; Nam et al., 2008). Conversely, some individuals did not accept their HIV positive status and consequently continued to experience fear of stigmatization, feel depressed or continued to engage in risk taking actions. Additionally, individuals who accepted their health status were more likely to experience support from their environment, in contrast to others who appeared to have met difficulties first with revealing their status and second with sharing their fears. *Apparently, sharing ones secret and enjoying the support of a confidant leads to sharing ones reality of the diagnosis that makes it harder to deny one's status. A confidant who conveyed messages of hope are important in developing the will to live positively for the future and managing lifestyle changes that promote medication compliance* (Nam et al., 2008, p. 307). However, the findings of the current research suggest that when HIV positive individual, accept their health status, manage to overcome the fear of stigmatization and rejection and finally achieve a more positive look to the future, then setting new life priorities comes into the limelight.

8.3.7 General Health Issues

Additionally, the results of the GHQ12 showed that the overall mental health status of the participants was good.

Hence, the current study suggested that when HIV positive individuals perceived that their physical and mental health was good, they might not feel the need to take their medication as prescribed.

The quantitative data showed high compliance levels while qualitative data reflecting everyday life showed many instances of non-compliance. Hence, the current study suggests that although participants realized that they did suffer from a chronic illness, their perceptions regarding their health status and their compliance behaviours might resulted to unwanted outcomes. That means that if HIV positive individuals perceived their health levels as good and if they also believed that if not taking medication as prescribed once or twice a week, as the qualitative results indicated, was a compliant behaviour, then we have a number of false perceptions. Consequently, HIV positive individuals' perceptions regarding their health levels and compliance issues may as well lead to non-compliant behaviours that the HIV positive individuals did not actually realize.

8.3.8 Contribution to Knowledge (new insights)

Understanding compliance from the above mentioned different perspectives was complex and indicated that the need for further research is needed to clearly identify the role different factors play in compliance to medication amongst HIV positive people. Many of the studies examining compliance have employed quantitative methodologies, which identified the factors that influence individuals' non-compliance (Remien et al., 2003). However, such studies failed to provide an in-depth understanding of the ways that living with HIV and taking medication was located within the psychological, social and cultural context of everyday life and relationships. In contrast to past studies which identified individualized factors, the present research placed more emphasis on a holistic approach to the psychological, social and cultural context that makes compliance/non-compliance understandable from the HIV positive peoples' perspective.

The present study aimed to explore the psychosocial factors and their influence on HIV positive individuals' beliefs in today's Greek society; and examined in depth the underpinning motives of the factors' power that leads People living with HIV to cope or not with the above mentioned psychosocial factors. At the same time, the underpinning motives of the factors' power that lead to complying or not with medication in order to deal with their physiological changes are also investigated.

As far as the medicalization into everyday life is concerned, the literature indicates that there are contradictory beliefs regarding the fitting of HIV medication into everyday life. Furthermore, limited literature was available at the time of the study concerning HIV/AIDS medication and its relation to everyday life and the quality of it (Penedo et al., 2003). The present study explored the issue of fitting medication into everyday life and identified its impact on individuals' social relationships and quality of life.

The findings of the current study suggest that although phenomenologically, medicalization in everyday life seemed to be an evitable issue (according to the study's quantitative results), the HIV positive individuals' everyday life did not support such a thing (qualitative results). In other words, considering the fact that Greek HIV positive individuals were living with the fear of stigmatization, fitting medication into their everyday habits was not very easy.

Additionally, although the current study supports past literature's findings that indicate that taking medication becomes a helpful routine for HIV positive individuals, it also addresses the negative impacts of this routine to the infected individuals' lives. Therefore, although HIV positive individuals add HIV medication into their everyday routine, this same routine might become unpleasant and actually trap HIV positive individuals into a situation that they cannot avoid. This everyday life routine was reminding HIV positive individuals of their health status. Inevitably, such an issue had an impact on their genders and identities.

Every time that medication was taken, several negative feelings such as deficiency feelings became another everyday aspect of their lives. Both, males and females (as the findings did not indicate any differences in regards to gender issues) were trying to defend their roles either by trying to remain strong (for males) or deal with the fact that they would not experience motherhood (for females). Consequently, such issues were causing even stronger feelings of deficiency and several times loneliness as certain HIV positive individuals, either males or females, were not able to defend those roles and they actually chose to extend this loneliness. Apparently, taking medication did not seem to be an easy issue for female and male HIV positive participants of the current study.

Additionally, medicalization in everyday life was actually difficult in regards to medication symptoms or else side effects. Past literature indicated that experiencing side effects is highly related to non-compliant behaviours. The current study managed to explain why side effects are actually related to non-compliant behaviours. Apparently, when HIV negative individuals happen to feel sick due to a random reason (i.e. gastrointestinal problems) they have the choice of not eating or doing anything that makes them feel worse. On the other hand, HIV positive individuals were not lucky enough as to have such a choice. Instead, they had to take HIV medication or force themselves to eat in spite of the medication related health problems. Such pressure though might not be effective and it might lead to non-compliant behaviours.

As far as Socio cultural positioning is concerned, *"It has been well documented that Greece is only recently becoming more progressive on issues of sex education and contraception, and the fear of HIV/AIDS precipitates much of this change"* (Best, 2003, p.2). Additionally, open discussions regarding sexuality still remain a taboo issue outdoors or indoors within Greece, an issue that is highly related to the public conception of HIV and AIDS (Best, 2003, p.3). In regards to the social and cultural issues related to HIV, past literature indicates that events, actions, attitudes and beliefs are mediated by historical and cultural factors of each country (Huber & Gillaspy, 1998 p. 195). Therefore, past literature managed to identify the perceptions that mediated from the social and cultural positioning of each country. However, it did not explain how such perceptions might influence HIV positive individuals' willingness to comply with antiretroviral therapy along with the socio-cultural positioning and its influence on medical compliance among HIV positive individuals in Greece. Whilst the current study supports most previous findings on the socio-cultural factors and their vast influence to medical compliance among HIV positive people, the present study expands these findings by examining how such position influences compliance with antiretroviral therapy.

Firstly, the current study suggests that the support of family members was not always helpful. The Greek family is a "solid system" in which the members of it share each other's problems and the one might expect to count on other's help (Sachperoglou & Bor, 2001). Nevertheless, the current study indicated that although the family system is as described in the literature, there are certain situations where individuals do not want this support. If they have it, they actually show lower compliance levels. Therefore, it is suggested that several individuals want to liberate themselves from the family system and might actually use the HIV diagnosis so as to assert their independence and state that emotional or practical support is not needed. Therefore, the current study suggests a further examination on the family system and its impact on HIV positive individuals, as it is clearly not very helpful any more.

Additionally, the current findings indicate that information from the mass media is misleading and most of the times misinforming. Apparently, the general public's attitudes and positioning towards the HIV virus and HIV positive individuals is highly influenced by the mass media. According to the findings, in contrast to other European countries, the Greek mass media not only they do not give the appropriate scientific information as to clear the picture around the virus, but instead they use HIV and confront HIV positive individuals as members of a lower social status so as to increase their ratings. In addition, the findings of the present study indicated that certain HIV positive individuals managed to cope with a diagnosis of HIV and taking medication through rejecting the general socio- cultural positioning of Greece.

Finally, the current research supports past literature that indicates that bad relationships with doctors and limited time appointments usually lead to non-compliant behaviors. The underlying reasons of such behaviors were examined within the present study. According to the present study limited time appointments and non-friendly doctors might lead certain feelings, such as rejection or even humiliation. HIV positive individuals were seeking for friendly and closer relationships with doctors (such as sharing more personal information) and when such relationships were not accomplished, non-compliant behaviours were occurring. Finally, the findings of the current study strongly addressed the need for psychological support within the Greek health care system that is very rarely provided. Although, Greek HIV positive individuals seek for closer and friendlier relationships with doctors they do understand that this cannot be evitable all the time. Hence, they strongly express the need for a psychologist who could co-operate with the medical team in regards to the patient's better possible biological and psychological well-being.

Past studies examined certain factors responsible for non-compliant behaviours; hence, up until now there were certainly a number of reasons influencing compliant or non-compliant behaviours. However, none of the past studies examined all these factors from the HIV positive individuals' perspectives. Hence, the current study aimed to examine these reasons from the HIV positive individuals' point of view, by letting their voice to be heard through interviews' procedures. Additionally, the current study aimed to examine HIV positive individuals' everyday life through their daily personal reports (diaries) and actually compare the above findings with the quantitative ones (questionnaires), having as an overall aim to examine all these findings from every possible perspective. Table 8.6 presents the summary of the key findings of the qualitative study. However, as all studies, the present one had its limitations which are going to be presented in the following section.

Table 8.5: Key qualitative findings

TITLE	**FINDINGS**
Revealing HIV status	HIV positive individuals tended not to reveal their HIV status either due to a fear of a possible rejection from family, friends and life partners or because they had felt rejected in the past. When they did reveal their status this was in order: To change relationships in ways consistent with felt emotional needs Assert their independence And claim that emotional support was not needed from family members
HIV and social networks	Social relationships were influenced reflecting the Greek cultural context of isolating those who are deemed to be "unhealthy" For some others HIV was the reason for developing closer relationships with existing friends. Forming alliances made some friendship bonds stronger. The maintenance of an intimate relationship allowed HIV positive people to enjoy supportive emotional, practical relationships supplying them with a degree of courage and happiness.
Knowledge/ lack of awareness and justification of HIV status	Most of the participants received information about HIV post diagnoses, usually from the doctors and/or the mass media. Past substance misuse experiences resulted in denial of any information regarding the virus The mass media were perceived to misinform/mislead the general public and HIV positive individuals themselves by emphasizing negative perceptions. Some people did not receive any information at all probably due to gender issues within their families
Public attitudes	Cultural mentality influenced the general public's attitudes towards HIV positive individuals and HIV. The way that HIV positive individuals were presenting themselves, i.e. a negative or a positive self-image was also a reason for positive or negative public's attitudes. Labelling and stigmatisation was an issue that all HIV positive individuals were experiencing regardless of any positive self-image
The HIV journey: perceptions of viral infection *Past experiences*	HIV positive individuals were first diagnosed, they experienced situations such as: learned helplessness, anger, being prepared for such a diagnoses due to constant engaging in risk taking actions, feeling being punished for their sins such as homosexual behaviours , suicidal thoughts optimistic priority setting due to suffering numerous illnesses aside from HIV
Present perspectives	HIV positive people adjusted to their health status and actually perceive it as a way to: gain pleasure, enjoying and appreciate life enhance their personal development through changing perceptions and enable the setting of new life priorities and healthy lifestyles Some others found ways to help themselves and deal with HIV through: religion, which offered acceptance and tenderness Some other HIV positive people did not manage to adjust to their health status

	and were still experiencing: depression irresponsibility issues such as engaging into numerous sexual relationships without informing partners about their HIV positive status
Doctors, expectations and relationships	Participants' expected to build a close and friendly relationship with their doctors. When this relationship was as expected and participants were participating in therapy decisions, compliance was better. Time spend with the doctor was an issue that influenced compliance as well. Apparently, participants expected to spend more time with their doctors Medical support was not enough as the need for psychological support was highly expressed
gender and identity issues	Women especially, faced discrimination and were more likely to feel labeled as dirty and undeserving The absence of companionship caused feelings of abnormality and sexual deficiency for some women. This sexual deficiency had contributed to a sense of lost feminine identity which permeated many different aspects of their lives. HIV medication contributed to women's feelings of powerlessness as, according to their beliefs, they could not make the same life choices that other women could. Being unable to experience motherhood also caused feelings of personal and social inferiority. Men on the other hand, identified themselves as weak in addition to facing rejection from women due to their HIV positive status. In contrast with women, men were more willing to try further so as to finally form an intimate relationship although they were relatively cautious in this respect. HIV positive men and women tended to live in secrecy and guilt, having to justify their choices and beliefs

8.4 Methodological Critique

8.4.1 Design

One methodological limitation of the current study was the design of the elicitation questionnaires. According to these findings, participants were receiving support (social, practical, support for taking medication, understanding and acceptance) from the family, friends, sexual partner and colleagues. However, the marital status of the participants was not defined. Therefore, when participants were referring to the support that they were receiving from their family, it was not clarified whether their family was their parents or their life partners. Therefore, while the study identified that participants received support from their family, however, the detail of this was not investigated, hence it was difficult to ascertain which member of the family provided support to individuals with HIV.

8.4.2 Data Collection

Due to the fact that the research took place in Greece, and the only period that the researcher could be in Greece was during summer, the data collection had several limitations, including the use of a convenient sample. During the period of the research some possible participants were on summer vacations while others were not interested in completing a questionnaire, a diary or participating in an interview (as confided to the researcher via personal contact). As a consequence, and due to the need of the data collection, it was difficult to ensure that quotas for age, sex, years of being infected with the HIV, or years of undertaking antiretroviral therapy were fulfilled. Instead, the only criteria for collecting the data were that the participants were HIV positive, undertaking HIV medication and of Greek ethnicity. Consequently, the majority of the sample consisted of males, especially homosexual males. The number of females participating was small and thus insufficient to sustain more complex statistical analysis. Hence, the small amount of female participants did not allow extracting as much information as would be sufficient to shed light on their view point.

A further issue according to participant accounts was the length of the questionnaire. In terms of explaining, there were a number of possible participants who were just *"bored"* as they reported to complete such a long questionnaire, this issue reasoned participants' non-participation. Moreover, some did not want to take the questionnaire home as not all their family members were informed regarding their HIV positive status. Also, they were afraid that informed family members might find the questionnaire and read the given answers. Due to these reasons, the period that the collection of data occurred and the length of the questionnaire and the fear of some HIV positive population that their secret will be revealed another limitation occurred; the small sample size. Only ten per cent of the HIV positive individuals that were asked to participate at the research had actually participated (80 participants out of 800). As a consequence of that perhaps the small sample size might affected the generalizability of the study's findings (Breakwell et al., 2000).

Another limitation of the current research was the fact that the sample was derived from the same geographical (urban) area in Greece. Participants' accounts and questions rose during the progress of the research and involved urban issues. In terms of explaining, perhaps if the HIV positive individuals were from rural areas they would have had different things to report as it is more possible to face social exclusion as they are not protected by anonymity. For example, at the beginning of the interview process there were participants who would introduce themselves to the researcher and would confide that they descended from rural areas and moved to Athens (the city were the research took place) after their HIV diagnosis so as to "vanish in the crowd".

8.4.3 Data Analysis

Finally, another methodological critique would be the difficulty in combining qualitative and quantitative data. Although a mixed methods' study can be advantageous for exploring complex research questions, during the progress of the analyses, the large extent and the richness of the data was rather difficult to bring into a coherent story.

8.5 Practical Implications of the Work

The study findings have implications for the work of medical staff, psychologists, voluntary workers, family members and HIV positive people themselves concerning current ways of thinking about and facing HIV. The following sections will present the better possible actions that all the above mentioned groups of people could do so as to deal with HIV and HIV positive people. The following section will review these implications for each group below.

8.5.1 Doctors

According to the findings of the study, participants' reported several times that doctors were not approachable enough and the time spent with them was very limited. It should also be considered that there were times where participants did not feel as people who were suffering from an infection; instead they felt as if they were subjects for statistics. Therefore, the practical implications of this work in regards to doctors could be that the former could be more approachable to HIV positive individuals as well as spend more time with them so as seropositive patients could talk about their fears or thoughts with them.

It would also be important that the HIV positive individuals could participate in their therapy decisions and be treated first and foremost as people and second as people that suffer form an illness; according to the findings HIV positive individuals do not want to be treated as subjects for statistics or just as people with an illness and therefore such behaviours could act as a facilitator in regards to compliance with their medical treatment. When doctors' spend the time to get to know their patients more, then consequently they have the opportunity to work with the patients' family members, by informing the latter about the virus and their patient's practical and physical needs. That networking could lead to a more overall approach to the HIV positive individual, the provided support could be more effective and that could result to a more compliant behaviour towards medication.

8.5.2 Psychologists

Seeing other related health professions, and according to the opinions gathered from the participants, psychologists could also treat HIV positive individuals as human beings, instead of subjects that would form statistics and would give them answers for their researches. They could actually approach them in a more humane way and take on to their actual roles as professionals who can offer understanding and support. Also psychologists could expand the “working together” and relate to the patients’ family members in terms of a more inclusive approach. However, it should be considered that psychologists would only be able to provide advice regarding the mental and psychological status of the patient including their fears, thoughts and emotional needs and would not provide any form of medical advice to the family members.

8.5.3 Voluntary Workers

Volunteering could also be benefited from this work. Similar actions to the above mentioned ones could also be performed by voluntary workers. Volunteers from various NGOs could organize their work and stay focused on their goal of dealing with HIV positive individuals primarily as human beings and then as people who are facing this particular illness.

8.5.4 Family

The present study could also change the current way that family members are dealing with HIV positive individuals. The family members may benefit from counseling sessions with professionals so as to receive further information on how HIV positive individuals would like to be treated, what their needs are and what type of support they do want from their family. In addition, family counseling sessions could also be beneficial to the family members so as to learn how to live with an HIV positive individual, come to terms with the new given situation and face their own fears and thoughts. According to the findings of this study, HIV positive individuals reported that either their family members were overprotective or they did not pay the needed attention on what the HIV positive individuals were going through. The briefing of the family members could result to a better comprehension of HIV positive individuals' needs and result to more understanding attitudes and behaviours.

8.5.5 People themselves

When an individual is diagnosed with the HIV infection, their way of engaging with living with HIV would be through the collection of information about the virus itself followed by the collection of information regarding their own new health status. The next step would be the seeking for medical and psychological support, so as to understand the changes of their everyday life and begin to cope with them as well as learn how to make informed choices about their health. However, there is a possibility that while reading this study, some HIV positive individuals might actually find others that share similar experiences to their own and may find better coping mechanisms.

Also, given the information on medical support, they could be encouraged to seek better medical care if the one they already have is not satisfactory enough and actually begin counseling sessions so as to share their fears, needs or thoughts. Another benefit could be that the HIV positive individuals might see that asking for help either from medical staff or from family members could be proved to be beneficial, as many of the participants in the current study admitted that it can be done and actually help while trying to cope with HIV and continue living as normal people.

The most important achievement though would be that the study would help HIV positive individuals realize that studies such as the present one, might worth in regards to answering questions they themselves might have had. Additionally, the researcher not only did not treat the participants as numbers but as human beings who need and can in fact have a voice into the world of science.

8.6 Recommendations for future research

The present thesis examined how compliance to antiretroviral therapy is affected by psychosocial factors, socio-cultural positioning, gender and identity issues, relationship with health care professionals, their general health status and their coping mechanisms with regards to taking medication as a part of their everyday life.

The data collection involved elicitation questionnaires, face to face semi- structured interviews and diaries. The findings provided a global picture of the topic and gave useful information for health psychology. However, during the progress of the study new questions were raised and hopefully they will be answered in future studies. These new questions are presented on the following sections

8.6.1 Understanding the Impact of Marital Status

The qualitative findings showed that participants talk about the importance of their family in their lives as the family members seemed to provide them with emotional and practical support they need. Drawing upon the research findings regarding the family's support, further research should examine the way that marital status impacts on compliance. It may be useful to compare individuals who are not married or without a lifelong relationship and individuals who are living with a life partner or are married and the impact this has on compliance to antiretroviral therapy.

8.6.2 Understanding High-Risk Behaviours

In addition, the qualitative findings also showed that several participants were behaving carelessly before the HIV diagnosis, by engaging in high risk behaviours and lifestyles, whilst knowing that an infection such as HIV was possible. It would be interesting to examine the reasons why some individuals behave in such ways. In addition, it may be useful to investigate the reasons why they wanted to be infected and what expectations they might have from getting infected with a terminal disease. Furthermore, future studies should examine why individuals with HIV feel shocked and depressed when they are actually diagnosed as HIV positive when in fact they were seeking such a diagnosis.

8.6.3 The Unique and the Ordinary Patient

Furthermore, future research could examine in more depth the reasons why some HIV positive individuals want to be treated as unique patients, confide all their thoughts, fears and even personal information to medical staff while some other HIV positive individuals want to be treated as ordinary patients. Considering the fact that, the findings of the present study showed that relationships with medical staff are connected to compliance with medication, it would be interesting to examine what are the underlying issues of needing to feel unique or ordinary, and search out for more answers in regards to relationship with the medical staff and compliance with medication. In other words, although literature supports the theory of the unique and the ordinary patient, and indeed the findings of the present research correspond to it, the question that arises is regarding the underlying reasons why HIV positive people express different needs in the ways of approach by medical staff.

8.6.4 Religious Theories

According to the findings of the current research there are religious concepts that intervene with medical knowledge and therapy issues. Homosexuality and HIV are associated and become “unacceptable” actions that need to be punished. Consequently, non-compliant behaviours are a way for HIV positive individuals, to punish themselves for their sinful actions. However, there are certain HIV positive individuals that support other religious theories (the most common) where God is not a punisher and whilst using their faith they manage to find strength and cope with the illness. Considering the fact that Greece is a country that its culture is highly related to religion, a research regarding the religious views of the Greek society and its impact on therapy issues would be a very interesting field for further research.

8.6.5 Family and Support

According to the findings of the present study, there were certain individuals who received practical support from the family but show lower compliance, which may suggest that the family is affecting them in a negative way. Also, when talking about family support, the study has shown that when the family gives support to the HIV positive individual for taking HIV medication, the latter is not complying as s/he should. According to the literature, the Greek family is considered as a “solid” institution in which all family members are supposed to share each other’s problems (Sachperoglou & Bor, 2001). The study of Sachperoglou & Bor, (2001) examined the disclosure of HIV and social support in Greece, and indicated that the fathers of the Greek family are the ones who show lower levels of support compared to brothers/ sisters and mothers. Additionally to the previous literature, the findings of the present research indicate that the support of the Greek family is not helpful as it is expected it to be. Therefore, agreeing with the previous literature further research should focus on the communication patterns of the Greek family system and its supportive actions in order to examine what might have occurred.

8.7 Summary of Conclusions

The aim of the present study was to gain an insight into how certain factors might influence compliance with HIV medication within the cultural context of Greece. It aimed to give an in depth understanding of how psychosocial, cultural factors along with the everyday life and gender/ identity issues are located into the lives of HIV positive individuals who are under antiretroviral therapy. Great emphasis was given to the social, cultural, psychological factors that may result to compliant or non-compliant behaviours and special attention was paid to the HIV positive individuals' perspective.

In contrast to past studies which identified individualized factors, the present research gave more emphasis on a holistic approach to the psychological, social and cultural context that makes compliant or non-compliant behaviours understandable seen from the HIV positive peoples' perspective.

In this section the final conclusions of the current study together with the answers to the hypothesis of this research are going to be presented. The structure of the following section is going to be presented according to the numbering of the thesis objectives as mentioned at the beginning of this chapter.

Objective a: Examine the psychosocial factors influencing compliance to medication/treatment regimes amongst HIV/AIDS positive individuals

The psychosocial factors explored in the current research involved lifestyle and demographic information, personality, quality of life, self-esteem, anxiety and depression, coping, social support and finally locus of control. The above psychosocial factors were chosen according to past literature (section 2.6, literature review) that was associated with compliance to HIV medication.

Lifestyle/demographic information

From the survey it was observed that there was a significant difference between the number of males and females that participated. Moreover, the majority of the sample was homosexual and had a full time job. In terms of occupation, there was a variety of professions like teachers, salesmen, painters, trainers, translators, self-employed. The income per month was a normal salary within the Greek context. The participants' amounts of alcohol consuming proved to be in low levels. On the other hand, the levels of smoking were high; however, the participants were smoking even before they were diagnosed as HIV positive. At this point, it has to be mentioned, like in previous sections, that the lifestyle and demographic information was not related to compliance with HIV medication.

Self esteem

The level of participants' self-esteem was in rather high levels. Participants seemed to feel equal with other individuals that were not infected with the HIV virus. With regards to the influence of self-esteem on compliance with HIV medication the current study indicated that when the level of self-esteem was increased, the level of compliance with medication was also increased.

Anxiety and depression

Participants' levels of anxiety and depression were presented in high levels. The HIV positive individuals that participated in this research explained that their anxiety and depression levels increased significantly compared to the levels experienced before diagnosis. However, the findings of the present research did not show any correlation between anxiety and depression and compliance with HIV medication. In other words, even though participants' appeared to experience high levels of anxiety and depression they continued to take their medication. There was only one case where an HIV positive individual was diagnosed with depression and did not take his/her medication as s/he was supposed to, but again this individual was diagnosed with depression even before the illness and his compliance with HIV medication was as irregular as the compliance with the medication for depression as well as other health issues (i.e. cholesterol).

Coping

The findings of the present study suggested that participants generally coped well with their HIV status. HIV positive individuals showed satisfactory levels of coping strategies such as the development of certain personality aspects i.e. sense of humor or other coping strategies i.e. faith in god, use of support network or even destiny. However, there were also certain individuals that used avoidant coping strategies, with the result of becoming depressed and with low self-esteem. In spite of the above findings though, the present study did not find any link between the coping strategies and compliance to HIV medication.

Social support

One of the most important findings of the present study was the influence of the support network that the HIV positive individuals had. The examined support was divided in seven categories: emotional, practical, financial, social, support for taking medication, understanding and acceptance. The most important factor that proved to affect compliance with medication was the existence of the supportive and understanding life partner. That means that when emotional support from the life partner existed the HIV positive individuals were taking their medication as they were supposed to.

Another major factor was the support from the family. In this type of support, there was a difference between practical support and support for taking medication with compliance to HIV medication. In terms of practical support from the family the study had showed that there was a difference between people that received practical support from their family and those that did not. Moreover it should be taken under consideration that there were individuals who received practical support from the family but showed lower compliance. As mentioned before, it was not possible to expand on this topic in this research. In regards to the support from friends, the findings of this study indicated that the there was no difference in compliance between those who had support from friends and those that did not.

Finally, participants that received financial or/and social support from work colleagues also appeared not to differ in the reported levels of compliance. Therefore, when support was given from life partners, compliance with HIV medication was increased. On the other hand, when support was given from family members, compliance was not as high as it was for HIV positive individuals that were not receiving any family support. This last statement does not mean that family support indicated lower compliance; instead it meant that when family was not supporting participants levels compliance were higher.

Locus of control

In this study, locus of control was relatively high amongst participants as they felt able to control their condition, i.e. the ability of the HIV positive individuals to determine how soon they will feel better again or the need for someone else’s help in order to feel better again. The present study showed no correlation between locus of control and compliance with HIV medication.

Objective b: Explore the ways in which issues of identity and gender may influence compliance to medication/treatment regimes

Gender and identity

According to the quantitative findings gender and identity issues were not correlated with compliance with HIV medication. However, although the qualitative findings have supported the above quantitative findings suggesting that issues of gender and identity were not an issue in relation to compliance with medication; the qualitative findings suggest that compliance might be indirectly associated with gender and identity empowerment for compliance with HIV medication. In other words, although the findings suggested that gender and identity issues were not directly associated with compliance at the time of the study, they apparently managed to empower the compliance of other participants of the study.

Objective c: Explore the medicalization of everyday life for HIV/AIDS individuals

Medicalization in everyday life

According to the findings of the present study, there are numerous factors that make medicalization and coping with medication difficult in HIV positive individuals' everyday life.

Other factors (i.e. supportive environment) act as facilitators or positive experiences in the individuals' medicalization in everyday life.

In spite of the negative or positive experiences that HIV positive individuals might have, the majority of the respondents believe that in general HIV medication contributes to their life positively as it is also linked to feelings of strength, alertness, determination, attentiveness and activity. "*Here it should be stressed that in Greece, all people, including migrants regardless of whether they have legal or illegal residence status, have free access to all state hospitals, health care centres and other health care services. Moreover, all people living with HIV/AIDS are entitled to receive treatment with all the new therapeutic agents free of charge*" (Ballas, 2000, p. 82; Best, 2003, p.5).

In general taking medication has proved to be associated with positive feelings in the current study. As far as experiencing side effects in everyday life, according to the quantitative findings, HIV positive individuals did not experience significant medication related symptoms at the time that the research was taking place. In contrast, the qualitative findings indicated that individuals experience a few present side effects (i.e. vomiting) as well as fears of future side effects (i.e. cholesterol).

Additionally, the qualitative findings showed that when individuals experienced even these few, medication orientated symptoms they struggled and felt confused, as they were trying to take antiretroviral therapy when they were already ill due to side effects. Another issue that appeared to have an impact on the medicalization of participants' everyday life was religion, especially as it related to "unacceptable" actions such as homosexuality. Another difficulty that an HIV positive individual met in everyday life was the loss of one's freedom to enjoy pleasant activities or experiences. Hence, taking medication became the action that interrupted HIV positive individuals' pleasant habits and in these circumstances non-compliant behaviours could occur.

Finally, the findings of the current study indicated that associations with past substance misuse (there were not any present substance misuses among the sample of the study) could cause non-compliant behaviours as individuals identify taking HIV medication with past habits of taking other chemical substances. Moreover, the up to date literature suggested that present substance misuse actions were related to non-compliant behaviours, but nothing was mentioned regarding the relationship of past substance misuse actions and present actions related to compliance with HIV medication.

Objective d: Explore how the relationship between health care professionals and people living with HIV impacts on compliance

Relationships with doctors

The current study suggests that HIV positive individuals were generally satisfied with the medical care they received. However, the participants of the present study expressed that there were things that needed to change so to achieve an even better health care system. In other words, according to Parson' health care model (Morgan, 2003) there are four types of doctor and patient relationships; the paternalistic, the relationship of mutuality, the consumerist relationship and the relationship of default.

The findings of the current study agreed that there were power and status issues within the health care setting as well as the four modeling roles that were mentioned above. In addition, the findings of this study implies that although at present time the majority of the HIV positive individuals were in general satisfied with their doctors (questionnaires), most of them have not been satisfied in the past (interviews and diaries). Hence, the findings of this study agreed with the role modeling that literature suggested (Morgan, 2003); and even though the majority of the participants were satisfied with their relationships with doctors (according to the questionnaire results).

The interviews indicated that those same HIV positive individuals had past experiences that resulted to negative feelings and even non-compliant behaviours due to unsatisfactory relationships with the health care providers. Moreover, even the ones that appeared to be generally satisfied with the services of their health care providers they made suggestions so as to improve their relationships, as they were sometimes feeling frustrated and annoyed with their doctors. This is in contrast with past studies that observed that power and status were the key points of the relationship between the health care providers and patients (Marelich & Erger, 2004).

Apparently, this group of people needed another model of relationship with doctors that would involve the person first and then the doctor who would be adopting the role of an accepting friend that exchanges knowledge with them. Additionally, HIV positive individuals were not satisfied with the time spent with their doctors and sometimes they even felt humiliated as they identified their doctors as “the working women” and themselves as “the clients” who were visiting. Hence, it was the meet of less time than needed with the occurrence of several negative feelings that resulted to the fact that participants felt that they did not have enough time to talk about their health issues with their doctors.

HIV positive individuals in the current research were able to understand the difficulty in spending more time with their doctors and suggested that the support of a psychologist who would cooperate with their doctor might be the answer to such an issue. Unfortunately, the psychological support cannot be provided to all HIV positive individuals in Greek public hospitals and organizations as the number of psychologists is not efficient in relation with the number of HIV positive patients (as mentioned above, Greek citizens do not have to pay in public sectors as any help is provided to them from their health insurance for free).

Objective e: Understand the socio-cultural positioning of HIV/AIDS sufferers, and how such positioning influences compliance to medication.

The present study also examined the perceptions of the position of HIV positive people within society and how these perceptions might underpin to compliance. Although, the majority of participants believed that their health status was serious or close to serious. About half of the participants believed that their situation was severe or close to severe their health as fair or poor. Additionally, the HIV positive individuals in this study appeared to have feelings of vulnerability in the case of stopping receiving medication. As far as being an HIV positive person within the Greek society the current study suggests that it has proved to be something rather negative. Moreover, whilst being HIV positive and a homosexual was even heavier and unacceptable for the Greek society, as the participants of the current study perceived it.

Empirical findings showed that the Greek cultural mentality identified homosexuality with HIV and additionally any homosexual activity was perceived as unacceptable. Therefore HIV and homosexuality were seen as negative by the Greek society. Social relationships and attitudes were consequently influenced from the Greek cultural context of isolating anything “unhealthy”; hence being HIV positive was perceived as a negative issue for society. The next issues that HIV positive individuals had to deal with was labeling and stigmatization; issues that according to the findings would usually arise after such a diagnosis.

In spite of the above, revealing ones status into this same society was a completely different issue for some other individuals. Some individuals were either using HIV in order to change relationships in ways consistent with felt emotional needs, or for asserting independence and clearly stating that not any kind of support was needed from family members or from partners and friends. However, no matter how negative the perceptions of the Greek society are, HIV positive individuals were successfully coping with being HIV positive as well as with all the possible negative attitudes towards them within the Greek society. The findings of the present research indicated that the emotional support and the support for taking medication from life partners increased compliant behaviours.

Therefore, even though HIV positive individuals perceived that they live in a “hostile” society that rejects them and stigmatizes them, the support of people close to them, such as life partners, played a positive role in HIV positive people's compliance. Building stronger bonds in their relationships and forming alliances was another way of the successful coping of the participants of the current study Additionally, for the participants themselves, although being HIV positive was a rather difficult situation whilst living in the Greek society, HIV acted as a motivation factor in order for HIV positive individuals to care for themselves more than they used to before the HIV diagnosis. That was when satisfaction of HIV medication and commitment to it intervened and empowered HIV positive individuals' compliant behaviours.

According to the present study, what followed was the change of some individuals' present perspectives where medication became a tool for remaining healthy and new life priorities and healthy lifestyles were set. In contrast to the above, certain HIV positive individuals did not manage to set new priorities or deal with any negative thoughts and attitudes as they still experienced past negative issues (from when they were first diagnosed) such as depression, irresponsibility and risk taking actions.

The literature indicates that the reason for changing ones present perspectives is the ability of one's health status acceptance that enables HIV positive individuals to overcome fear of stigma (Maman et al., 2003; Nam et al., 2008). However, the current research came to add that although when accepting one's health status, overcome the fear of stigma and rejection and look positively for the future, then a new setting of life priorities that involves compliance to medication as well could come into the limelight.

Objective f: Examine participants' general health status

The overall results of the participants' level of health, was the same as usual for the majority of the respondents. The examination regarding participants' health level of this research was not responding to their actual health level but it was responding to the way that HIV positive participants perceived their health status. The majority of the participants considered that their health status was good, although this might not have been true as their medical records might have indicated different results (unfortunately, there was not any access to participants' medical records so as to compare perceptions and actual health levels, due to confidentiality issues).

Additionally, the results of the GHQ12 showed that the overall health of the participants was in good levels as well. Hence, the current study suggested that when HIV positive individuals perceived that their physical and mental health were both in good levels they might not feel the need to take their medication as prescribed. Considering that when one feels ill s/he would be seeking for therapy so as to feel better, the participants in the current study would not feel ill and consequently they might not feel that they needed medication that much. Additionally, according to the participants' compliance responses in quantitative methods, they showed high compliance levels. However, in regards to the findings, the small sample size should be taken under consideration (see section 8.4.2 Data collection).

On the other hand, the qualitative methods that examined HIV positive individuals' everyday life, participants' responses showed that they did not take their medication as prescribed. Hence, the current study suggests that although participants realized that they did suffer from a chronic illness, their perceptions regarding their health status and compliance behaviours might consequence unwanted results.

CHAPTER NINE: REFLEXIVITY

9.1 The Concept of Reflexivity

The meaning of the term “reflexivity” can vary considerably. According to Alvesson & Skoldberg (2000, p. 245) *“Reflection means thinking about all the conditions for what one is doing, investigating the way in which the theoretical, cultural and political context of individual and intellectual involvement affects interaction with whatever is being researched”*. Throughout this thesis it has been argued that the objective stance of the researcher cannot always be attained and that subjectivity and the social positioning of the researcher is important to consider. In this respect, a reflexive analysis is offered in this chapter in order to help situate this study thus enabling the reader to more comprehensively evaluate the work and its value within the academic domain.

Since reflexivity can be interpreted as an activity to *“break away from a frame of reference and to look at what it is not capable of saying”* (Alvesson & Skoldberg, 2000, p. 246), this reflexive analysis acknowledges that scientific knowledge or science itself is a part of our everyday human activity and activity that a scientist does has validity and meaning just as every human activity does (Steier, 1991). According to Steier (1991), “*nothing has a meaning on its own” (p.54).* Meaning does not come only through seeing or observing, but also through interpretation of evidence provided (Steier, 1991).

The researcher interprets the research process, data and analysis, their values are part of the reasons they conduct a study and they progress their work within a context of meaningful relationships which in themselves colour their research decisions. As such, a fuller understanding of this research and its conclusions can only develop through a firm location of the work within a reflexive analysis in which the supervisory relationships, work with participants and attendant power relationships are exposed in the way they shaped the research. Finally, the impact of the research on my own feelings of security and sense of self are provided.

9.2 The Topic of the Study

The reason why this area caught my attention is difficult to explain. My motivation was in part inspired by the prolonged reference of media to the gay society when I was still an adolescent. “The gay disease”, “Death”, “Gays are paying for their sins” and all these expressions were clearly heard in the news. I found it quite unfair that such judgemental attitudes were prevalent and thought they might be instrumental in preventing gay people from enjoying life to its full. In my young mind and full of expectations, I wanted to change the world. Through the passage of time I realised I could not change the world but indeed I could do something small in order to enhance insight into this problem, especially at a psychological and social level. So I decided to go to university and study Psychology while bearing in mind that I could repeatedly draw on the knowledge I would have gained from my studies to help people discriminated against in their lifestyle choices.

This initial drive lead me to undertake a PhD concerning research focused on HIV/AIDS since previous PhD students advised me that I should choose a topic of personal interest to myself. This left me with many decisions to make, as a variety of topics were available to be chosen from, reflecting my own life experiences, feelings or thoughts. But was this the main purpose of undertaking a PhD? I have wondered several times if I should remain detached from my personal interests and possibly avoiding personal answers or be more deeply involved in helping to resolve burning social issues. I decided that working on issues concerning HIV/AIDS would simultaneously address both my own personal interests and pressing social concerns.

My interest in compliance to medical regimes began when I first started working as a volunteer with HIV positive people and I became aware of the problems surrounding compliance to medication. Among people with HIV I observed a need or thirst for life which was in direct contradiction to their chosen way of living, impacting on their compliant behaviours. This was the compelling issue which motivated my application to study in this area.

9.3 The Beginning of the Research

My choice of this topic was not always well understood among my family, friends and colleagues in Greece and some found my decision objectionable. I received discouraging comments such as “Are you obsessed with diseases or death?” or “How can you spend so much time reading about HIV?” In the beginning, I tried to emphasise the significant role of HIV/AIDS research but unfortunately I could still see their knowing, full of disapproval facial expressions. Despite their smiles of consent, I was quite certain that they had not understood a word of what I had said and were totally oblivious to my proposal. I detected an unwillingness to understand that created barriers to creating the evidence base from which the lives of those with HIV could be improved.

I realised that it had become a matter of “them and us”. It was then when I realised that during the whole process of my work I had to be as non-judgemental as possible and make my participants feel equal to me. I had to gain the trust of my participants so that they would give me a fuller picture of their experiences (Louis & Barton, 2002). Nevertheless, this was not the only time that my reality met with the problem of separation between “them and us”. During the first steps of my study, I realised that the judgment of “them” was replaced by the knowledge of the supervisory team and my willingness to receive this knowledge. It was obvious that the reflection of my thoughts would help me to understand my position towards the supervisory team (Steier, 1991).

9.4 Reflections on Supervision

It seems that one of the greatest difficulties that people face in their daily interactions with others is the understanding, interpretation and reflection of the alternate feelings and thoughts involved and exchanged continuously between them. During a person’s effort to identify himself, this “self” can be compared with an exterior reality. Moreover, what is thought as real in the exterior world is then adapted to define what is real in the interior world of each person (Journal of Neosience, 2005).

The main aim of this chapter is the exploration of my personal reflections on my relationship and my position regarding the supervisory team during the period of designing the research of the PhD I am currently undertaking. The chapter will first introduce the purpose of reflexivity based on the existing literature review and then reflections depicting the first steps of the research process will follow. The next sections will revolve around the reflections on different cultural and social backgrounds between the supervisory team and me. The positions of each one of us according to where I placed the supervisory team and myself in this relationship. In recognition of the above the final part of this chapter will examine/analyse/explore the relationship between the participant and researcher which will be contrasted with the relationship between the supervisory team and the researcher

9.5 My Position towards the Different Social and Cultural Background between the Supervisory Team and the Researcher

In terms of my relationship with the supervisory team, there were many times that I was concerned with issues of our different cultural and social backgrounds. According to Louis & Barton (2002), a researcher can position him/herself in the research in a context of cultural, social and identity factors. As for social background, I could say that I interpreted this in terms of social knowledge in the context of society. I contrasted the established knowledge that the supervisory team possessed, to my relative lack of research experience. Therefore, I positioned them above me, having in mind that they were the ones who should make all the decisions regarding my research. Consequently, I automatically positioned myself at the place of a student instead the one of a researcher, something that later made me feel quite helpless. This fact made me realise that I was indeed placing myself into an imaginary social construct but instead of framing this in terms of upper or middle class I used “upper and middle knowledge”. At this point, I would agree with Louis & Barton (2002), who argued that “*historical, political, social and cultural factors position people even before they were born*” (p.3).

It seemed to me that for some reason I was in the constant need to place myself below the supervisory team and in consequence to place myself above my research participants. That was my reality and it did not satisfy me at all because, I wanted to co-operate with my participants on equal terms. A year after the begging of the study the setting of an agenda for our team meetings with me leading the discussions was decided.

A certain mechanism that the supervisory team proposed so as to help me overcome the subordinate role I had adopted. Nothing could feel scarier than this at that point. I felt like stealing somebody else's work that I had to memorize and present. I felt guilty for something I had not done; in fact I managed to convince myself that I could never make it. And the time that I had to present in the first of these meetings had arrived.

It reminded me of a time that I was in high school and it was my turn to be orally examined at the day's lesson in chemistry (a lesson that I particularly disliked). I was a fourteen year old girl again, who was standing in front of the whole classroom and deal with the fact that had not understood the lesson once more. The supervisory team was expecting me to start talking about the meeting's topic and I was recalling high school's memories. It was really difficult for me to speak in English at that moment; I could not remember even the simplest words.

That was the moment that the supervisory team started to talk to each other about my study. I felt like I was saved, during their talk I had the time to make myself feel better. And I managed to do it; I remembered them constantly saying to me that this research was mine and that nobody could support it as much as I could. It was only a few seconds that I managed to repeat this to myself in my mind. I had to make it and I did it. I still do not know if I performed well but somehow I managed to change from simply following the supervisory team's instructions to owning the research.

Moreover, I was pre-occupied by questions regarding the different cultural background within the team since I was coming from a less scheduled oriented culture/mentality. In terms of explaining, the Greek population does not usually take under consideration the seriousness of a deadline or the time of an appointment. Consequently, when I had to meet medical staff or participants regarding the progress of my research this could either not happen or happen later than it was supposed to. Additionally, considering the fact that the beginning of the research took place during the summer I was aware that most of the medical staff or the participants will not be available during the whole season.

Having that fact in mind I knew that the collection of my data will delay. Therefore, when I had to present the progress of my work such as approaching medical staff or participants so as to collect data, I had to consider factors that the supervisory team appeared to take for granted. It was very difficult for me to explain a situation like this to the supervisory team which belonged to a culture very well known as formal and strict with schedules. As expected our different sense of reality and how it was represented was my main concern (Alvesson & Skoldberg, 2000).

Given the above differences, I felt I needed to bring our worlds closer together and at the same time express myself in a coherent and cohesive way so as to resolve situations like the above. Being able to understand all ideas presented by the supervisory team without letting our cultural differences stand as a barrier to our relationship was my intention. As postmodernists argue, we should all pay attention to two aspects of representation, the construction of our particular reality and how well this reality is captured and interpreted (Alvesson & Skoldberg, 2000).

In the following section I will reflect on the multiple realities I faced as a researcher and the challenges this posed for the research enterprise I was engaged in.

9.6 Participants

I had numerous questions each time I was meeting each one of the participants. Did they offer me their genuine experiences, thoughts, feelings or were their motivations for participation clouding the version of the reality they were exposed to? Were the numbers analysed through the questionnaires or the words they spoke in interviews and wrote in diaries more authentic? Numerous questions crossed my mind once data collection was complete. Considering the fact the research took place in Greece, the cultural context between the participants and myself was similar. I could understand their expressions, the issues they struggled with and the situations they were not comfortable with. There were several times that we did not need to explain everything to each other, one facial expression was enough.

My work as a researcher was very fulfilling. I could actually understand from their perspective issues such as social rejection. I had seen it happening; maybe I had contributed to that sense of rejection at some point in their lives. But it was not as simple as it seemed to be; I never expected to meet someone and hear them describe how they were intentionally infecting other people. As I listened carefully, trying to be objective, trying not to judge I realised that just sharing the same culture was not enough. I had to stand in front of him as a researcher, not as a human being who was furious with the way the participant was describing what he was doing.

At that moment I considered as more proper to hide my feelings, my thoughts, remain calm without making any facial expression. I knew I had the strength and the knowledge to do it, but still I wanted to leave this person, not due to any fear; there was not any fear at all. The participant destroyed my sense of understanding, the reality I had built up during my work with people with HIV. I was fighting with my sense of a non-judgemental world which would embrace all those people who were suffering from a disease like HIV. But my participant was unfair; his actions were unfair to other people.

I was there listening to him, unable to do anything about it. I was not there to judge or give advice; I was there to collect information in order to understand how to improve the lives of people with HIV. Still, this made me feel so selfish, but I knew I did not have a choice. I wanted to end the interview very quickly; I did not want to look at him anymore. I was angry; how he could be so unfair when I was fighting unfairness? I could not listen to him anymore. But it is not in the best interests of a researcher to think that way so as not to miss out on understanding very different, but still legitimate perspectives; a researcher should, instead, continue to collect as much information as possible from such a valuable source. I was then able to transform my negative feelings to positive ones involving feeling lucky that he confided in me, giving me the opportunity to collect this research evidence and present it to others through the medium of my thesis. He related that he was not complying with medication, he did not take his medication as prescribed due to religious issues, he was harming other people, he talked as freely as a researcher would wish, providing excellent material to discuss with my supervisors.

However, I thought again of me as a student and not as a researcher and ended the interview as soon as I could have gained some valuable information. Maybe my supervisors would be disappointed but I was a student, my excuse seemed perfect. I now know that I actually managed to hide my feelings yet three years later this experience is still annoying me. And I know it is still annoying me, as from all of the participants, I chose to write about this specific participant. Indeed, even as I reflect on this experience for the current chapter, I am conscious of reading quickly and sparingly through this interview transcript, almost reliving the experience in the process. And I am still writing about him, hoping that now that I revealed all my thoughts, I can finally stop being hampered with what happened that day. However, I will always be the researcher who used the student role in order to avoid a difficult situation and that specific participant will always be the one who severely challenged my reality. That reality of mine in which I was "fighting" HIV, whilst being on the same side with HIV positive people became overwhelmed by emotions against HIV.

9.7 Power-Relations: Participants-Researchers vs Researchers-Supervisory Team

At this point, it is again important to emphasise "how important it is to consider what we think we know as real or rational" (Journal of Neosience, 2005). The way we perceive our relationships is a part of our sense of reality, which as I think about it; influences many of our interactions. Whilst considering the fact that the researcher creates a certain relationship with the participants for the best accomplishment of the research, in the same way this same relationship may occur between the researcher and the supervisory team. Louis & Barton, (2002) believed that on the subjectivity and reflexivity and working with participants from poor urban schools, they arrived at the following conclusion concerning power relations in research. *"They did and I listened"* (Louis & Barton, 2002, p.5). Louis and Barton, (2002) were attempting to understand the complex lives of the poor minority in this area, as long as try to establish and maintain relationships within and out of schools. Louis was confused about the responsibilities she held as a researcher, as well as a person who cares about the lives of those people and also a person who wants to listen.

I mention this research because it depicts my confusion when striving to separate my responsibilities as a student and researcher as well. I was using my knowledge in order to approach my participants and seek more information from them, in the same way, the supervisory team was using its knowledge to motivate and guide me for the better progress of my work. It was then when I realised that indeed almost everything depended on a particular reality we had constructed in order to guide our interactions.

My supervisors were expecting me to significantly progress my work and I was expecting to gather necessary information from participants. At the same time, I was offering participants a chance to rethink their experiences, clarify them and reflectively provide it to me (Colombo, 2003). In the same way, the supervisory team and I were rethinking our knowledge reflectively for the best accomplishment of the research. Whilst reviewing all the above, I came to my first question; did the supervisory team and I build up a certain relationship for the best interest of science? Moreover, what about those moments of uncertainty?

There were many times that I felt quite unsure about my work or even about my relationship with my supervisors. Was that science too or did my sense of reality set up the conditions where I felt I was trapped into it without being able to really see what was happening? I was considering the fact that I did not know their thoughts about our relationship. Perhaps I could assume that the times that I felt so unsure about the progress of my work were synonymous with those moments when the supervisory team and I had different expectations for the process and the progress of the work, and of course our relationship as supervisors and student.

Nevertheless, participants within, just as in the case of supervision are considered to be thinking individuals that affect the situation which we are referred (Soros, 1994). We were thinking individuals, too. Accordingly, our thoughts, feelings and actions were influencing the situation, which at that point was our relationship. Maybe this was our common reality, through our knowledge we were all influencing the situation or else our relationship.

Nonetheless, I should be the first one who would use all this knowledge and influence the situation as a researcher and not as a student. At this point I would like to make reference to Burr’s (1995, p.8, cited in Colombo, 2003) statement that “Knowledge is therefore seen as not something that a person has, but as something that people do together”. This would require the constant awareness of my position in research regarding supervision so as to be able to understand and develop my abilities as a researcher by using the knowledge on offer by the supervisory team.

9.8 Reflections on the “HIV Testing”

HIV, even the sound of it is scary. How would it feel like to be HIV positive? How would it feel like to hear a stranger saying to you that you are or you are not HIV positive? What does it feel like waiting in a reception area to learn the test results? And finally, how much courage does it need to go through all the above? Several questions were running through my mind at the beginning of this research. I could not fully understand how it felt to be a HIV positive individual since this was not something I had personally experienced. At least that was what I believed at that time. That was the time that I realised that I could not be a hundred per cent sure that I was HIV negative unless I was tested for HIV.

I was a 27 year old then, heterosexual, sexually active female that did not always practice safe sex. I had always engaged in long term relationships but there were a couple of times that I did not use the necessary protection for myself and my partner. How could I be so sure that I was not HIV positive then? I decided to have an HIV test. I was thinking about it for several days as I was trying to prepare myself for any possible result.

People say that when you are afraid of something it will happen to you, and I was afraid of HIV. I had already identified it with several negative issues such as stigma, fear, isolation, loneliness, unfairness, deficiency; it was a final countdown to death for me. These ceaseless considerations were dominating my mind. I found thousands of reasons to avoid testing myself; I was denying any possibility of a positive result.

It was then when I realised that I was aligning myself with my participants, I was not different at all, in fact I was avoiding something that they had dared to do and managed to live with the results. How could a person like me who was terrified even of the idea of getting tested, do research on something as emotive as HIV that other people were living with. Furthermore they might expect that my research actually helps to improve their lives by providing understandings around medication compliance. It was then when I finally decided to do the HIV test and booked an appointment. The big day arrived, and there I was sitting in a doctor’s office being asked about my sexual life.

I was shy and felt like trying to defend myself when I was listening questions such as “have you ever taken money for sex”? I thought: How can they ask me these questions, isn’t it obvious that I am not that kind of person? Is this what they think about me? Do they feel sorry for me? Numerous questions crossed my mind during the interview.

After that I went to another room and a nurse came to take blood from my arm. I thought that she felt sorry for me and I was trying to show her that I was a happy person rather than one to be pitied; "If she saw me smiling she would not think that I was infected" I thought. My torture had finished and when I went back home I realised what happened; I finally understood how it feels to be tested, how it feels to understand or even falsely suspect that others feel sorry for you. I was a researcher who was challenging social beliefs but at the same time I was a part of that same society. I wanted to make clear to the medical staff that I was not HIV positive, that I was "healthy", so that they will/ would not pity me. What I felt about all these HIV positive people, I felt sorry for them; all my fears were based on my beliefs about HIV.

Results day arrived, so I called the diagnostic centre to learn the results. After giving the necessary information, the nurse told me that there was something wrong with the results. What she meant was that there was something wrong with the paper work but what I understood was that there was something wrong with the blood test results. It felt like an eternity waiting to hear what was wrong with me. After a while, the nurse announced the negative result to me but I had to double or even triple check what she was saying. I felt that I was not able to understand what she was saying as she was talking to me in English. She did not say a difficult or an unknown word to me, it was me that I was not sure about what I was able to understand even though I could clearly hear that I was HIV negative.

After the end of this process I realised that I was glad with what I did. Not only did I feel lucky with the result, considering the fact that I was not very careful with my partners, but I was also glad that I finally managed to experience some of the feelings that my participants had experienced in the past. It was then when I felt ready to move on with the interviews, as from that point I would be able to understand/share some of the participants' experiences. It was then that I appreciated the lesson that my participants had taught me, I could never do research on something that I would have only experienced through textbooks. From that point, I was into the topic of my study and actually managed to examine issues from my participants' point of view.

9.9 The End of the Research

Nearly ten years after the beginning of the research and I am still here in front of my computer writing about it. I am so tired, and I wonder if I actually “fought” HIV? Did I actually learn anything from this journey? Did I help people? Is my research worth something? Was I wiser then when I was excited about it, and full of energy, thinking that I could actually do something to help HIV positive people? Am I wiser now that I am so tired without any energy, caring only about the end of this research? My reality has changed, my whole world has changed, I am not a student any more, and I am a researcher, a working person that needs a break from all this reading.

In the beginning I had talked about “them and us”, it was “them” that could not understand my need to research on HIV and it was “us” who knew, who could understand the meaning of this research. Now, it is just “us”, there are not two categories any more, now it is one category. I am one of “them” and they are one of “us”. Now I know that they just could not understand; the people who were asking me why I chose this topic did not actually have the same knowledge as me, I was there to give them the answers. I am one of “them” because there are issues that I do not understand either and I am still asking questions, and hoping others can provide the answers. We are exchanging information, without belonging to any categories. I cannot avoid wondering whether this is happening because I became more mature or because I feel tired of “fighting” about HIV positive people’s rights. No, I am not tired of fighting for my ideals and my beliefs.

It is not a matter of maturity either, it is exchange of information, I am here to give some answers, satisfactory or not, good or bad. I don’t know if I managed to do ‘good’ research, I really do hope that in my own way I managed to contribute to scientific knowledge, to think about possible questions and find the best possible answers. I was not fighting for HIV or for HIV positive people; I was fighting for science; that was my goal. I do not know if this research will ever help anyone. I do know though that “it is the journey that matters” (Kavafis, 1911), because I learned things, I discussed issues; I exchanged thoughts, beliefs, knowledge, I met people who revealed their thoughts and fears to me and I met other people and I analysed all this information and presented it for the benefit of expanding knowledge in this area. While I am writing these lines I realise that I am not that tired either, I am satisfied for every little thing that I did so far, for what I have learned alongside my supervisors, from the people who participated in this research, for everyone who helped me to achieve this goal and gave me the chance to make this journey and give just a little something to science. I will always remember this journey.

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Appendices

Appendix 1: Reliability Analysis

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****** Method 1 (space saver) will be used for this analysis ******
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Personality

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  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
                Mean         Variance       Item-            Alpha
              if Item        if Item        Total           if Item
              Deleted        Deleted     Correlation        Deleted

Q1            39.6375        47.0188        .1799            .3283
Q3            40.4375        59.4391       -.2533            .4855
Q5            39.2500        44.1646        .2963            .2766
Q7            38.9250        49.9943        .1279            .3504
Q9            39.8250        49.1082        .0934            .3651
Q2NEW         39.9750        51.7209        .0221            .3905
Q4NEW         41.0000        47.0886        .1378            .3467
Q6NEW         41.3000        43.9089        .3591            .2565
Q8NEW         39.1500        43.3696        .3382            .2585
Q10NEW        40.4375        46.4264        .1486            .3418


Reliability Coefficients

N of Cases =     80.0                    N of Items = 10

Alpha =    .3701
```

Health

```
 ****** Method 1 (space saver) will be used for this analysis ******



  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
                Mean         Variance       Item-            Alpha
              if Item        if Item        Total           if Item
              Deleted        Deleted     Correlation        Deleted

Q11           10.9250        26.8551        .4510            .7729
Q12           10.8625        25.4872        .4295            .7740
Q13           11.0625        27.5530        .2878            .7865
Q14           10.9125        27.7517        .2608            .7889
Q15           10.7375        26.8290        .3238            .7843
```

```
Q16            10.9250        24.7538        .5711          .7586
Q17            10.7625        25.4492        .4863          .7677
Q18            10.9750        27.3665        .3873          .7781
Q19            11.1125        24.6834        .5052          .7653
Q20            11.1875        24.3315        .5566          .7593
Q21            11.5000        27.0127        .3043          .7862
Q22            10.7625        24.9176        .5924          .7573


Reliability Coefficients

N of Cases =     80.0                    N of Items = 12

Alpha =    .7886
```

Levels of anxiety and depression

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 ****** Method 1 (space saver) will be used for this analysis ******



  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
                Mean        Variance       Item-            Alpha
              if Item        if Item       Total           if Item
              Deleted        Deleted    Correlation        Deleted

Q24            10.9125        43.1948        .5644          .8563
Q25            11.3000        41.5544        .6497          .8512
Q26            10.8750        42.5665        .5346          .8576
Q27            11.3625        42.0821        .5537          .8566
Q28            10.8625        42.6517        .5573          .8564
Q29            10.8875        44.1264        .4683          .8610
Q30            10.8250        43.0323        .6203          .8540
Q31            10.9750        44.0247        .4555          .8616
Q32            11.4375        44.0973        .5257          .8585
Q33            11.2625        42.2973        .4904          .8607
Q34            10.9875        43.5062        .4896          .8600
Q35            11.3500        44.2557        .3256          .8707
Q36            11.2125        41.5872        .6694          .8503
Q37            11.5875        43.5112        .4939          .8597


Reliability Coefficients

N of Cases =     80.0                    N of Items = 14

Alpha =    .8670
```

Self Esteem

```
 ****** Method 1 (space saver) will be used for this analysis ******

  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)
Item-total Statistics

               Scale          Scale      Corrected
               Mean          Variance      Item-              Alpha
              if Item        if Item       Total             if Item
              Deleted        Deleted    Correlation          Deleted

Q38           17.2625        12.9049        .3394              .6014
Q39           17.5250        13.0373        .3268              .6043
Q40           19.1250        16.7184       -.3549              .7411
Q41           17.4500        12.1241        .4129              .5829
Q42           18.0875        12.1315        .3186              .6033
Q43           17.6125        12.8986        .3808              .5958
Q44           17.9000        11.8380        .5256              .5617
Q45           18.3875        11.4302        .4586              .5678
Q46           17.8500        11.0658        .4868              .5583
Q47           17.7875        11.9922        .3230              .6025
Reliability Coefficients

N of Cases =     80.0                    N of Items = 10

Alpha =    .6324
```

Coping Strategies

```
****** Method 1 (space saver) will be used for this analysis ******

  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean          Variance      Item-              Alpha
              if Item        if Item       Total             if Item
              Deleted        Deleted    Correlation          Deleted

Q48           39.9125        35.9543        .1899              .6612
Q49           40.0875        36.4606        .0621              .6783
Q50           40.9000        31.3823        .3838              .6323
Q51           41.3875        31.7340        .4406              .6251
Q52           40.4125        32.8783        .2538              .6558
Q53           39.9250        37.5892       -.0238              .6848
Q54           40.7125        33.1695        .2615              .6536
Q55           40.0750        33.5386        .3848              .6378
Q56           41.8750        30.8196        .4817              .6165
Q57           41.8125        32.8884        .3119              .6451
Q58           40.1875        32.6606        .3643              .6373
Q59           41.0000        29.9747        .4599              .6171
Q60           40.3125        33.5593        .2125              .6626

Reliability Coefficients

N of Cases =     80.0                    N of Items = 13

Alpha =    .6660
```

Locus of control

```
 ****** Method 1 (space saver) will be used for this analysis ******

  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)

Item-total Statistics

               Scale          Scale      Corrected
               Mean         Variance       Item-              Alpha
              if Item        if Item       Total             if Item
              Deleted        Deleted    Correlation          Deleted

Q61           63.0750       129.6146        .2516              .7815
Q62           63.4750       124.7335        .3920              .7724
Q63           62.9375       124.2112        .3989              .7719
Q64           64.1125       126.9112        .3201              .7773
Q65           62.5625       132.3505        .1884              .7846
Q66           62.7750       130.5310        .2524              .7811
Q67           64.0875       126.5112        .2828              .7805
Q68           63.7875       120.4479        .4664              .7665
Q69           64.2500       122.7215        .4055              .7713
Q70           64.5000       125.4430        .3199              .7777
Q71           64.8250       121.0829        .4827              .7657
Q72           62.6000       131.0785        .2142              .7835
Q73           63.6125       120.5948        .4776              .7658
Q74           62.2875       128.4353        .3389              .7762
Q75           65.0250       122.0500        .4353              .7691
Q76           64.6500       123.6481        .3422              .7764
Q77           63.3250       122.3487        .4342              .7692
Q78           63.9125       122.0049        .4514              .7680


Reliability Coefficients

N of Cases =     80.0                    N of Items = 18

Alpha =    .7844
```

Health care

```
 ****** Method 1 (space saver) will be used for this analysis ******



  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean         Variance       Item-              Alpha
              if Item        if Item       Total             if Item
              Deleted        Deleted    Correlation          Deleted

Q80           31.7125        71.1188        .5230              .8509
Q81           32.2000        66.8203        .5926              .8424
Q82           32.3500        67.9772        .6017              .8401
```

```
Q83           31.5125        66.5062        .7899           .8151
Q84           32.2750        64.8601        .6732           .8294
Q85           31.2750        72.0753        .6069           .8400
Q86           31.5000        70.2278        .6023           .8398


Reliability Coefficients

N of Cases =     80.0                    N of Items =  7

Alpha =    .8570
```

Satisfaction with health care

```
 ****** Method 1 (space saver) will be used for this analysis ******


  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)

Item-total Statistics

               Scale          Scale      Corrected
               Mean         Variance       Item-            Alpha
              if Item        if Item       Total           if Item
              Deleted        Deleted    Correlation        Deleted

Q87            7.7625         2.4619        .1847          -.1054
Q88            8.1000         1.3570        .3801          -.9608
Q89            8.1125         3.3163       -.1939           .7027


Reliability Coefficients

N of Cases =     80.0                    N of Items =  3

Alpha =    .1530
```

Social support

```
 ****** Method 1 (space saver) will be used for this analysis ******


  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean         Variance       Item-            Alpha
              if Item        if Item       Total           if Item
              Deleted        Deleted    Correlation        Deleted

Q90           23.1375        41.6391        .5808           .8240
Q91           22.9500        40.7316        .6672           .8167
Q92           22.8875        48.7087        .1153           .8565
Q93           22.6875        45.3062        .4254           .8356
Q94           22.7375        44.6264        .4988           .8309
Q95           22.6000        43.4582        .5172           .8292
```

```
Q96            22.6250        42.9715         .5918           .8239
Q97            23.0375        44.4922         .4155           .8369
Q98            22.6375        43.2214         .6575           .8209
Q99            22.8875        42.1011         .5878           .8236
Q100           22.9875        43.6074         .4405           .8356
Q101           23.0000        41.6203         .6063           .8219


Reliability Coefficients

N of Cases =     80.0                    N of Items = 12

Alpha =    .8420
```

Attitudes and sexuality

```
 ****** Method 1 (space saver) will be used for this analysis ******


  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
                Mean        Variance       Item-           Alpha
              if Item        if Item       Total          if Item
              Deleted        Deleted    Correlation       Deleted

Q109           24.3750        13.6551         .2898           .5991
Q110           24.3625        13.6771         .4094           .5693
Q111           24.0250        14.8095         .1978           .6186
Q112           24.1625        15.0239         .1879           .6195
Q113           24.0000        13.5190         .4317           .5637
Q114           24.1625        14.9479         .2070           .6150
Q115           23.9750        14.3791         .2573           .6049
Q116           23.2000        14.9975         .3603           .5894
Q117           23.3750        13.7563         .4605           .5615
Q118           23.4250        15.0070         .1895           .6192


Reliability Coefficients

N of Cases =     80.0                    N of Items = 10

Alpha =    .6219
```

```
****** Method 1 (space saver) will be used for this analysis ******
_
```

Thoughts about taking medication

```
  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean          Variance      Item-            Alpha
              if Item         if Item      Total           if Item
              Deleted         Deleted    Correlation       Deleted

Q123          88.4875       186.9872        .6376           .8892
Q124          88.6500       184.9139        .6775           .8877
Q125          88.3250       186.4500        .7046           .8877
Q126          88.4125       190.2201        .5359           .8921
Q127          88.4250       184.8044        .8116           .8854
Q128          88.6750       183.0829        .7217           .8862
Q129          89.0625       178.0593        .7228           .8849
Q130          88.4500       183.1620        .6161           .8890
Q131          88.6375       176.9935        .7206           .8848
Q132          88.4000       180.3443        .8538           .8826
Q133          89.0500       181.2886        .5943           .8897
Q134          89.2875       176.8150        .6737           .8865
Q135          89.2000       182.8456        .4674           .8957
Q136          88.8500       182.4582        .7073           .8864
Q137          90.5750       186.0196        .2924           .9084
Q138          89.1375       205.6391       -.0080           .9151


Reliability Coefficients

N of Cases =     80.0                    N of Items = 16

Alpha =    .8971



****** Method 1 (space saver) will be used for this analysis ******
_



  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean          Variance      Item-            Alpha
              if Item         if Item      Total           if Item
              Deleted         Deleted    Correlation       Deleted

Q123          37.1000        33.3316        .7338           .8925
Q124          37.2625        32.6771        .7532           .8902
Q125          36.9375        33.7809        .7541           .8909
Q126          37.0250        35.9234        .5253           .9139
```

```
Q127           37.0375         32.9479         .8884            .8787
Q128           37.2875         31.5745         .8280            .8815
Q129           37.6750         31.5892         .6503            .9063


Reliability Coefficients

N of Cases =     80.0                    N of Items =  7

Alpha =    .9074
```

Self-efficacy

```
****** Method 1 (space saver) will be used for this analysis ******
_


  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean          Variance      Item-             Alpha
              if Item         if Item      Total            if Item
              Deleted         Deleted   Correlation         Deleted

Q130           35.2250         46.3791         .6001            .8537
Q131           35.4125         43.1062         .7193            .8373
Q132           35.1750         45.8930         .7921            .8346
Q133           35.8250         45.2854         .5807            .8569
Q134           36.0625         42.8188         .6763            .8435
Q135           35.9750         44.1513         .5286            .8686
Q136           35.6250         46.2880         .6834            .8445


Reliability Coefficients

N of Cases =     80.0                    N of Items =  7

Alpha =    .8672
```

Health beliefs, Susceptibility

```
 ****** Method 1 (space saver) will be used for this analysis ******



  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean          Variance      Item-             Alpha
              if Item         if Item      Total            if Item
```

```
              Deleted        Deleted    Correlation        Deleted

Q139           8.5625         3.5657        .8567           .9053
Q140           8.5375         3.8467        .8429           .9132
Q141           8.4750         3.9234        .8839           .8840



Reliability Coefficients

N of Cases =     80.0                    N of Items =  3

Alpha =    .9315
```

Feelings about medication

```
 ****** Method 1 (space saver) will be used for this analysis ******


  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean         Variance       Item-            Alpha
              if Item        if Item       Total            if Item
              Deleted        Deleted    Correlation        Deleted

Q151A         43.0875        99.4226        .2581           .7920
Q151B         43.9125       100.5366        .2843           .7886
Q151C         44.5875        96.8277        .4751           .7769
Q151D         44.7125        99.5492        .4083           .7816
Q151E         42.9750       106.2019        .0608           .8007
Q151F         44.5750        98.3741        .4203           .7804
Q151G         44.5625       100.7302        .3103           .7868
Q151H         45.0375       103.9859        .2852           .7884
Q151I         44.3625        97.9809        .3437           .7852
Q151J         44.3375        98.1252        .3128           .7878
Q151K         44.4375        98.5277        .4817           .7780
Q151L         43.2625        95.1074        .4562           .7773
Q151M         44.7000        99.9089        .4099           .7817
Q151N         44.7125        98.3087        .3921           .7819
Q151O         44.3000        96.5671        .4655           .7773
Q151P         42.6000        98.5215        .3855           .7823
Q151Q         42.2875       101.3973        .3163           .7864
Q151R         44.5000        95.8987        .5320           .7737
Q151S         43.2125       102.1188        .1961           .7947
Q151T         44.2500        97.3291        .4323           .7794



Reliability Coefficients

N of Cases =     80.0                    N of Items = 20

Alpha =    .7928
```

Malaise/Weakness/Fatigue

```
 ****** Method 1 (space saver) will be used for this analysis ******
```

```
  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
                Mean         Variance       Item-            Alpha
              if Item         if Item       Total           if Item
              Deleted         Deleted    Correlation        Deleted

Q152           2.8500        13.1165        .6615           .8461
Q153           2.7875        12.4479        .7431           .8315
Q154           2.8250        11.6905        .8365           .8129
Q155           2.5875        12.8024        .5545           .8683
Q156           2.8250        12.7285        .6742           .8436
Q157           2.9375        14.0087        .5448           .8645



Reliability Coefficients

N of Cases =     80.0                    N of Items =  6

Alpha =    .8677
```

Confusion/Distress

```
 ****** Method 1 (space saver) will be used for this analysis ******


  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
                Mean         Variance       Item-            Alpha
              if Item         if Item       Total           if Item
              Deleted         Deleted    Correlation        Deleted

Q158           3.2375        14.8163        .6728           .8715
Q159           3.1000        14.2177        .6243           .8786
Q160           3.1625        14.6441        .6567           .8732
Q161           3.0125        12.6201        .8008           .8487
Q162           2.7625        12.0568        .7523           .8621
Q163           3.3500        15.0405        .7948           .8611



Reliability Coefficients

N of Cases =     80.0                    N of Items =  6

Alpha =    .8861
```

Fever /Chills

```
 ****** Method 1 (space saver) will be used for this analysis ******
```

```
  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
                Mean         Variance      Item-            Alpha
              if Item        if Item       Total           if Item
              Deleted        Deleted    Correlation        Deleted

Q164            .9375         2.9454        .6122           .7479
Q165            .9250         2.8551        .5859           .7424
Q166            .7500         1.7848        .6922           .6465
Q167            .5750         1.5133        .6917           .6791



Reliability Coefficients

N of Cases =     80.0                    N of Items =  4

Alpha =    .7697
```

Gastrointestinal discomfort

```
 ****** Method 1 (space saver) will be used for this analysis ******


  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
                Mean         Variance      Item-            Alpha
              if Item        if Item       Total           if Item
              Deleted        Deleted    Correlation        Deleted

Q168           1.6750         3.9437        .5462           .5166
Q169           1.7500         4.8481        .2204           .7242
Q170           1.3500         3.2177        .5030           .5482
Q171           1.9000         4.3696        .5614           .5332



Reliability Coefficients

N of Cases =     80.0                    N of Items =  4

Alpha =    .6561
```

Shortness of breath

```
 ****** Method 1 (space saver) will be used for this analysis ******



  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
                Mean        Variance       Item-            Alpha
              if Item        if Item       Total           if Item
              Deleted        Deleted    Correlation        Deleted

Q172            .5750         1.5133        .6996           .7976
Q173            .6625         1.6948        .8248           .6961
Q174            .5125         1.6454        .6343           .8585


Reliability Coefficients

N of Cases =     80.0                    N of Items =  3

Alpha =    .8439
```

Nausea/Vomiting

```
 ****** Method 1 (space saver) will be used for this analysis ******



  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
                Mean        Variance       Item-            Alpha
              if Item        if Item       Total           if Item
              Deleted        Deleted    Correlation        Deleted

Q175            .4500          .9089        .5603           .6720
Q176            .5375         1.1125        .6081           .6474
Q177            .4625          .8340        .5771           .6602


Reliability Coefficients

N of Cases =     80.0                    N of Items =  3

Alpha =    .7435
```

Commitment to medication

```
****** Method 1 (space saver) will be used for this analysis ******



  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean         Variance       Item-            Alpha
              if Item        if Item       Total           if Item
              Deleted        Deleted    Correlation        Deleted

Q182          34.6250        44.0348        .6587           .7327
Q183          35.0500        43.1367        .5871           .7429
Q184          35.1875        42.7872        .4699           .7713
Q185          34.3375        48.9859        .4736           .7669
Q186          34.7125        44.2834        .5112           .7585
Q187          34.8500        42.9392        .6476           .7319
Q188          34.5375        49.6441        .2954           .7982



Reliability Coefficients

N of Cases =     80.0                    N of Items =  7

Alpha =    .7855
```

Compliance with HIV medication

```
****** Method 1 (space saver) will be used for this analysis ******



  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean         Variance       Item-            Alpha
              if Item        if Item       Total           if Item
              Deleted        Deleted    Correlation        Deleted

Q178           4.5750         7.1842        .5937           .7948
Q179           4.5625         6.9581        .6350           .7789
Q180           4.2375         4.6897        .7942           .6751
Q181           3.9500         4.6557        .6478           .7819

Reliability Coefficients

N of Cases =     80.0                    N of Items =  4

Alpha =    .8116


****** Method 1 (space saver) will be used for this analysis ******
```

```
  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean         Variance       Item-            Alpha
              if Item        if Item       Total           if Item
              Deleted        Deleted    Correlation        Deleted

Q123          37.1351        34.6938        .7311           .8937
Q124          37.2703        34.1177        .7588           .8906
Q125          36.9459        34.9285        .7642           .8908
Q126          37.0676        37.3241        .5207           .9152
Q127          37.0676        34.2282        .8859           .8799
Q128          37.2838        32.6992        .8334           .8819
Q129          37.7432        32.6318        .6537           .9072


Reliability Coefficients

N of Cases =     74.0                    N of Items =  7

Alpha =    .9081


****** Method 1 (space saver) will be used for this analysis ******
_


  R E L I A B I L I T Y   A N A L Y S I S   -   S C A L E   (A L P H
A)


Item-total Statistics

               Scale          Scale      Corrected
               Mean         Variance       Item-            Alpha
              if Item        if Item       Total           if Item
              Deleted        Deleted    Correlation        Deleted

Q130          35.2432        46.1318        .5685           .8505
Q131          35.4595        42.6627        .6947           .8332
Q132          35.2297        44.9191        .7765           .8287
Q133          35.9189        43.6372        .5843           .8494
Q134          36.0946        42.3060        .6559           .8388
Q135          36.0946        42.3608        .5350           .8617
Q136          35.6892        44.6829        .7031           .8345


Reliability Coefficients

N of Cases =     74.0                    N of Items =  7

Alpha =    .8618
```

Appendix 2: Tables

TABLE 1: What is your age?

N	Valid	80
	Missing	0
Mean		43.28
Median		43.00
Std. Deviation		10.068
Minimum		22
Maximum		72

TABLE 2: What medical condition do you have?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		2	2.5	2.5	2.5
	Bad	3	3.8	3.8	6.3
	Best	7	8.8	8.8	15.0
	Good	44	55.0	55.0	70.0
	Medium	5	6.3	6.3	76.3
	Normal	1	1.3	1.3	77.5
	Not Good	1	1.3	1.3	78.8
	Quite Good	3	3.8	3.8	82.5
	Stable	1	1.3	1.3	83.8
	Very Good	13	16.3	16.3	100.0
	Total	80	100.0	100.0	

TABLE 3: When were you diagnosed?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	JAN 83	1	1.3	1.3	1.3
	JAN 85	3	3.8	3.8	5.0
	OCT 85	1	1.3	1.3	6.3
	JAN 86	1	1.3	1.3	7.5
	FEB 87	1	1.3	1.3	8.8
	MAY 87	1	1.3	1.3	10.0
	JAN 88	1	1.3	1.3	11.3
	JUL 88	1	1.3	1.3	12.5
	AUG 88	1	1.3	1.3	13.8
	JAN 89	1	1.3	1.3	15.0
	FEB 89	1	1.3	1.3	16.3
	JAN 90	1	1.3	1.3	17.5
	FEB 90	1	1.3	1.3	18.8
	NOV 90	1	1.3	1.3	20.0
	JAN 91	1	1.3	1.3	21.3
	FEB 92	3	3.8	3.8	25.0
	JUL 92	1	1.3	1.3	26.3
	OCT 92	2	2.5	2.5	28.8
	NOV 92	2	2.5	2.5	31.3
	JAN 93	2	2.5	2.5	33.8
	AUG 93	1	1.3	1.3	35.0
	JAN 94	1	1.3	1.3	36.3
	APR 94	1	1.3	1.3	37.5
	AUG 94	1	1.3	1.3	38.8
	NOV 94	1	1.3	1.3	40.0
	MAR 95	1	1.3	1.3	41.3
	JUN 95	2	2.5	2.5	43.8
	JUL 95	1	1.3	1.3	45.0
	SEP 95	1	1.3	1.3	46.3

OCT 95	1	1.3	1.3	47.5
DEC 95	2	2.5	2.5	50.0
JAN 96	1	1.3	1.3	51.3
APR 96	1	1.3	1.3	52.5
MAY 96	1	1.3	1.3	53.8
NOV 96	1	1.3	1.3	55.0
DEC 96	3	3.8	3.8	58.8
JAN 97	1	1.3	1.3	60.0
MAR 97	1	1.3	1.3	61.3
JAN 98	2	2.5	2.5	63.8
AUG 98	1	1.3	1.3	65.0
DEC 98	1	1.3	1.3	66.3
JAN 99	1	1.3	1.3	67.5
MAR 99	1	1.3	1.3	68.8
APR 99	1	1.3	1.3	70.0
JAN 00	2	2.5	2.5	72.5
APR 00	1	1.3	1.3	73.8
MAY 00	1	1.3	1.3	75.0
DEC 00	1	1.3	1.3	76.3
JAN 01	3	3.8	3.8	80.0
MAR 01	1	1.3	1.3	81.3
MAY 01	2	2.5	2.5	83.8
AUG 01	1	1.3	1.3	85.0
DEC 01	1	1.3	1.3	86.3
JAN 02	1	1.3	1.3	87.5
JUL 02	1	1.3	1.3	88.8
APR 03	1	1.3	1.3	90.0
JUL 03	1	1.3	1.3	91.3
MAY 04	1	1.3	1.3	92.5
NOV 04	1	1.3	1.3	93.8
JAN 05	2	2.5	2.5	96.3

	APR 05	1	1.3	1.3	97.5
	JUL 05	1	1.3	1.3	98.8
	OCT 05	1	1.3	1.3	100.0
	Total	80	100.0	100.0	

TABLE 4: When did you start taking HIV medication?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	JAN 83	1	1.3	1.3	1.3
	NOV 90	1	1.3	1.3	2.5
	JAN 92	2	2.5	2.5	5.0
	FEB 92	1	1.3	1.3	6.3
	APR 92	1	1.3	1.3	7.5
	AUG 92	2	2.5	2.5	10.0
	JAN 93	2	2.5	2.5	12.5
	MAR 93	1	1.3	1.3	13.8
	MAY 93	1	1.3	1.3	15.0
	DEC 93	1	1.3	1.3	16.3
	JAN 94	1	1.3	1.3	17.5
	APR 95	1	1.3	1.3	18.8
	OCT 95	1	1.3	1.3	20.0
	NOV 95	1	1.3	1.3	21.3
	JAN 96	5	6.3	6.3	27.5
	FEB 96	1	1.3	1.3	28.8
	MAR 96	1	1.3	1.3	30.0
	APR 96	1	1.3	1.3	31.3
	MAY 96	1	1.3	1.3	32.5
	AUG 96	1	1.3	1.3	33.8
	DEC 96	1	1.3	1.3	35.0
	JAN 97	5	6.3	6.3	41.3
	FEB 97	1	1.3	1.3	42.5
	MAR 97	1	1.3	1.3	43.8

	MAY 97	1	1.3	1.3	45.0
	JUL 97	1	1.3	1.3	46.3
	OCT 97	1	1.3	1.3	47.5
	DEC 97	1	1.3	1.3	48.8
	JAN 98	3	3.8	3.8	52.5
	OCT 98	2	2.5	2.5	55.0
	JAN 99	1	1.3	1.3	56.3
	MAY 99	1	1.3	1.3	57.5
	SEP 99	1	1.3	1.3	58.8
	JAN 00	1	1.3	1.3	60.0
	APR 00	1	1.3	1.3	61.3
	MAY 00	1	1.3	1.3	62.5
	JAN 01	5	6.3	6.3	68.8
	MAR 01	1	1.3	1.3	70.0
	JUN 01	1	1.3	1.3	71.3
	AUG 01	3	3.8	3.8	75.0
	OCT 01	1	1.3	1.3	76.3
	NOV 01	1	1.3	1.3	77.5
	MAR 02	2	2.5	2.5	80.0
	AUG 02	1	1.3	1.3	81.3
	JAN 03	1	1.3	1.3	82.5
	JUN 03	1	1.3	1.3	83.8
	NOV 03	1	1.3	1.3	85.0
	AUG 04	1	1.3	1.3	86.3
	JAN 05	2	2.5	2.5	88.8
	FEB 05	1	1.3	1.3	90.0
	JUL 05	4	5.0	5.0	95.0
	AUG 05	1	1.3	1.3	96.3
	SEP 05	1	1.3	1.3	97.5
	OCT 05	2	2.5	2.5	100.0
	Total	80	100.0	100.0	

TABLE 5: What is your sex?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Female	17	21.3	21.3	21.3
	Male	63	78.8	78.8	100.0
	Total	80	100.0	100.0	

TABLE 6: How would you rate your sexual identity?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Homosexual	42	52.5	52.5	52.5
	Bisexual	11	13.8	13.8	66.3
	Heterosexual	27	33.8	33.8	100.0
	Total	80	100.0	100.0	

TABLE 7: Do you drink alcohol?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	45	56.3	56.3	56.3
	Yes	35	43.8	43.8	100.0
	Total	80	100.0	100.0	

Table 8: How much do you drink approximately per day?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	74	92.5	92.5	92.5
	1	2	2.5	2.5	95.0
	2	2	2.5	2.5	97.5
	3	1	1.3	1.3	98.8
	4	1	1.3	1.3	100.0
	Total	80	100.0	100.0	

Table 9: How much do you drink approximately per week?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	41	51.3	51.3	51.3
	1	8	10.0	10.0	61.3
	2	12	15.0	15.0	76.3
	3	6	7.5	7.5	83.8
	4	4	5.0	5.0	88.8
	5	3	3.8	3.8	92.5
	7	2	2.5	2.5	95.0
	14	2	2.5	2.5	97.5
	20	1	1.3	1.3	98.8
	28	1	1.3	1.3	100.0
	Total	80	100.0	100.0	

Table 10: Do you smoke?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	31	38.8	38.8	38.8
	Yes	49	61.3	61.3	100.0
	Total	80	100.0	100.0	

Table 11: How many cigarettes do you smoke on average per day?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0	31	38.8	38.8	38.8
	1	1	1.3	1.3	40.0
	3	1	1.3	1.3	41.3
	4	1	1.3	1.3	42.5
	5	1	1.3	1.3	43.8
	6	3	3.8	3.8	47.5
	10	2	2.5	2.5	50.0
	15	5	6.3	6.3	56.3
	20	7	8.8	8.8	65.0

	25	3	3.8	3.8	68.8
	30	7	8.8	8.8	77.5
	40	13	16.3	16.3	93.8
	50	2	2.5	2.5	96.3
	55	1	1.3	1.3	97.5
	60	2	2.5	2.5	100.0
	Total	80	100.0	100.0	

Table 12: Do you work?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Unemployed	29	36.3	36.3	36.3
	Part-time	15	18.8	18.8	55.0
	Full-time	36	45.0	45.0	100.0
	Total	80	100.0	100.0	

Table 13: What is your occupation?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid		37	46.3	46.3	46.3
	Architect	2	2.5	2.5	48.8
	Artist	1	1.3	1.3	50.0
	Businessman	1	1.3	1.3	51.3
	Cashier	1	1.3	1.3	52.5
	Computer	1	1.3	1.3	53.8
	Doctor	1	1.3	1.3	55.0
	Driver	1	1.3	1.3	56.3
	Ex driver	1	1.3	1.3	57.5
	Journalist	1	1.3	1.3	58.8
	Nutritionist	1	1.3	1.3	60.0
	Own business	1	1.3	1.3	61.3
	Painter	1	1.3	1.3	62.5

	Private sector	1	1.3	1.3	63.8
	Private Sector	9	11.3	11.3	75.0
	Public Sector	6	7.5	7.5	82.5
	Retirement	6	7.5	7.5	90.0
	Salesman	2	2.5	2.5	92.5
	Secretary	1	1.3	1.3	93.8
	Teacher	3	3.8	3.8	97.5
	Trainer	1	1.3	1.3	98.8
	Translator	1	1.3	1.3	100.0
	Total	80	100.0	100.0	

Table 14: What is your income?

N	Valid	74
	Missing	0
Mean		852.65
Median		765.00
Std. Deviation		453.329
Minimum		400
Maximum		2500

Table 15: Personality traits

	N	Minimum	Maximum	Mean	Std. Deviation
Sympathetic, Warm	80	1	7	5.51	1.638
Open to new experiences, complex	80	1	7	5.19	1.949
Reserved, Quiet	80	1	7	4.86	1.791
extroverted, enthusiastic	80	1	7	4.80	1.951
Calm, emotionally stable	80	1	7	4.61	1.984
Anxious, easily upset	80	1	7	4.56	2.128
Conventional, uncreative	80	1	7	4.00	2.187
dependable, self-disciplined	80	1	7	4.00	1.821
Critical, quarrelsome	80	1	7	3.54	1.828
Disorganised, careless	80	1	7	2.71	1.924
Valid N (listwise)	80				

TABLE 16: Major personality dimensions

	N	Minimum	Maximum	Mean	Std. Deviation
Agreeableness	80	2.50	7.00	4.9875	1.20908
Conscientiousness	80	2.00	7.00	4.6438	1.27337
Openness to experiences	80	1.00	7.00	4.5938	1.48855
Emotional Stability	80	1.00	7.00	4.0250	1.52594
Extraversion	80	1.00	6.50	3.9688	1.43937
Valid N (listwise)	80				

TABLE 17: General health

	N	Minimum	Maximum	Mean	Std. Deviation
Have you recently been able to conscentrate on what you are doing?	80	0	3	1.05	.673
Have you recently lost much sleep over worry?	80	0	3	1.11	.941
Have you recently felt that you are playing a useful part in things?	80	0	3	.91	.766
Have you recently felt capable of making decisions about things?	80	0	3	1.06	.769
Have you recently felt constantly under strain?	80	0	3	1.24	.860
Have you recently felt you couldn't overcome the difficulties?	80	0	3	1.05	.870
Have you recently been able to enjoy your normal day to day activities?	80	0	3	1.21	.867
Have you recently been able to face up your problems?	80	0	3	1.00	.656
Have you recently been feeling unhappy or depressed?	80	0	3	.86	.964
Have you recently been loosing confidence on yourself?	80	0	3	.79	.951
Have you recently been thinking of yourself as a worthless person?	80	0	3	.47	.856
Have you recently been feeling reasonably happy, all things considered?	80	0	3	1.21	.822
Health	80	.08	2.25	.9979	.45988
Valid N (listwise)	80				

Table 18: In general would you say that your health is...

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	**Poor**	3	3.8	3.8	3.8
	Fair	19	23.8	23.8	27.5
	Good	28	35.0	35.0	62.5
	Very good	19	23.8	23.8	86.3
	Excellent	11	13.8	13.8	100.0
	Total	**80**	**100.0**	**100.0**	

Table 19: Your levels of anxiety and depression

	N	Minimum	Maximum	Mean	Std. Deviation
I don't feel tense or "wound up"	80	0	3	1.08	.759
I still enjoy the things I used to enjoy	80	0	3	.69	.851
I don't feel frightened as if something awful is about to happen	80	0	3	1.11	.871
I can laugh and see the funny side of things	80	0	3	.62	.905
Joyful thoughts go through my mind	80	0	3	1.12	.832
I don't feel cheerful	80	0	3	1.10	.756
I can sit at ease and feel relaxed	80	0	3	1.16	.719
I feel as if I am turned on	80	0	3	1.01	.787
I get sort of frightened feeling like "butterflies" in the stomach	80	0	3	.55	.692
I take care my appearance	80	0	3	.73	.968
I don't feel restless as if I have to be on the move	80	0	3	1.00	.811
I look forward with enjoyment to things	80	0	3	.64	.971
I don't have sudden feelings of panic	80	0	3	.77	.826
I can enjoy a good book or radio or TV programme	80	0	3	.40	.805
Levels of anxiety and depression	80	.00	2.07	.8563	.50206
Valid N (listwise)	80				

Table 20: Your self-esteem(SES)

	N	Minimum	Maximum	Mean	Std. Deviation
I feel that I am a person of worth, at least on an equal plane with others	80	0	3	2.62	.663
I feel that I have a number of good qualities	80	0	3	2.36	.641
All in all, I am inclined to feel that I am a success	80	0	3	.76	.860
I am able to do things as well as most other people	80	0	3	2.44	.777
I have a lot of things to be proud of	80	0	3	1.80	.906
I take a positive attitude toward myself	80	0	3	2.28	.616
On the whole, I am satisfied with myself	80	0	3	1.99	.720
I have a lot of respect for myself	80	0	3	1.50	.886
I don't certainly feel useless at times	80	0	3	2.04	.934
There isn't a moment that I think I am no good at all	80	0	3	2.10	.936
Self Esteem	80	1.00	2.70	1.9888	.38681
Valid N (listwise)	80				

Table 21: Coping Strategies

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
I find that I can better face up to dealing with a difficult situation if I remind myself that I have already solved many other problems in my life	80	2	5	4.14	.689
I never give up, even when the odds are stacked against me	80	2	5	3.96	.9 20
If I have a problem, I try to find something else to do to help take my mind out off it	80	1	5	3.15	1.202
I try to adapt to difficult situations rather than fight against them	80	1	5	2.66	1.043
In difficult situations I seek support in my faith	80	1	5	3.64	1.235
I try to find out about all sides of a problem	80	1	5	4.12	.802
If I have any problems, I look to others for help and support	80	1	5	3.34	1.158
I react in different ways to problems: sometimes I am down and then I am up and full of energy again	80	2	5	3.97	.842
I tend to give in when there is a problem and to let things take their own course	80	1	5	2.17	1.111
It is often the case that Ican't solve the problems that I have. Then I become depressed and can't see any point to my life	80	1	5	2.24	1.094
I find it easier to deal with any problems I have by remembering that there are always others who are far worse off than me	80	1	5	3.86	1.028
I often wish that someone else would solve my problems for me	80	1	5	3.05	1.272
If I have any problems I try to take it with a sense of humor	80	1	5	3.74	1.209
Coping Strategies	80	2.54	5.00	3.3885	.47417
Valid N (listwise)	80				

Table 22: Locus of control

Descriptive Statistics

	N	Minimum	Maximum	Mean	Std. Deviation
If my condition worsens, it is my own behavior which determines how soon I will feel better again	80	1	6	4.33	1.290
As to my condition, what will be will be	80	1	6	3.92	1.376
If I see my doctor regularly, I am less likely to have problems with my condition	80	1	6	4.46	1.405
Most things that affect my condition happen to me by chance	80	1	6	3.29	1.371
Whenever my condition worsens, I should consult a medically trained professional	80	2	6	4.84	1.152
I am directly responsible for my condition getting better or worse	80	2	6	4.63	1.173

Other people play a big role in whether my condition improves, stays the same or gets worse	80	1	6	3.31	1.539
Whatever goes wrong with my condition is my own fault	80	1	6	3.61	1.547
Luck plays a big part in determining how my condition improves	80	1	6	3.15	1.519
In order for my condition to improve, it is up to other people to see that the right things happen	80	1	6	2.90	1.523
Whatever improvement occurs with my condition is largely a matter of good fortune	80	1	6	2.57	1.456
The main thing which affects my condition is what I myself do	80	1	6	4.80	1.237
I deserve the credit when my condition improves and the blame when it gets worse	80	1	6	3.79	1.507
Following doctor's orders to the letter is the best way to keep my condition from getting worse	80	1	6	5.11	1.158
If my condition worsens, it's a matter of fate	80	1	6	2.38	1.496
If I am lucky, my condition will get better	80	1	6	2.75	1.627
If my condition takes a turn for the worse, it is because I have not been taking proper care of myself	80	1	6	4.08	1.474
The type of help I receive from other people determines how soon my condition improves	80	1	6	3.49	1.458
Locus of control	80	2.44	6.00	3.7444	.65422
Valid N (listwise)	80				

Statistics

Table 23: How satisfied you are with your life?

N	**Valid**	80
	Missing	0
Mean		6.65
Median		7.00
Mode		8
Std. Deviation		1.639
Minimum		3
Maximum		10
Percentiles	**25**	6.00
	50	7.00
	75	8.00

Table 24 Health Care

	N	Minimum	Maximum	Mean	Std. Deviation
My medical provider makes sure that I have a plan for fitting the medication dosing schedule into my personal routine	80	1	7	5.43	1.868
My medical provider wants me to participate in making decisions about my medicine	80	1	7	4.94	2.064
My medical provider understands how difficult it is to follow my medication regimen	80	1	7	4.79	1.947
My medical provider wants to know what problems I have that make it hard to take my medications	80	1	7	5.63	1.687
My medical provider understands my personal life and why it is hard for me to take my medications	80	1	7	4.86	2.036
My medical provider makes time for me to ask all the questions I need about my medications	80	1	7	5.86	1.597
My medical provider asks me if I can handle any possible side-effects of my medication	80	1	7	5.64	1.759
Health care	80	1.86	7.00	5.3054	1.36339
Valid N (listwise)	80				

Table 25: **Satisfaction with health care**

	N	Minimum	Maximum	Mean	Std. Deviation
I am very satisfied with the medical care I receive	80	1	5	4.23	.886
If I have a medical problem, I can reach someone for help without any problem	80	1	5	3.89	1.169
There are things about the medical care I receive that could be better	80	1	5	3.87	1.107
Valid N (listwise)	80				

Table 26: Social Suport from the environment

	N	Minimum	Maximum	Mean	Std. Deviation
If I wanted to go on a trip for a day(for example to the country or mountains), I wouldn't have a hard time finding someone to go with me	80	0	3	1.79	1.099
I don't feel that there is no one I can share my most private worries and fears with	80	0	3	1.98	1.079
If I were sick, I could easily find someone to help me with my daily chores	80	0	3	2.04	.934
There is someone I can turn to for advice about handling problems with my family	80	0	3	2.24	.875
If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me	80	0	3	2.19	.858
When I need suggestions on how to deal with a personal problem, I know someone I can turn to	80	0	3	2.33	.978

I do often get invited to do things with others	80	0	3	2.30	.933
If I had to go out of town for a few weeks, it wouldn't be difficult to find someone who would look after my house or apartment (the plants, pets, garden e.t.c.)	80	0	3	1.89	1.006
If I wanted to have lunch with someone, I could easily find someone to join me	80	0	3	2.29	.830
If I was stranded 10 miles from home, there is someone I could call who could come and get me	80	0	3	2.04	1.037
If a family crisis arose, it wouldn't be difficult to find someone who could give me good advice about how to handle it	80	0	3	1.94	1.083
If I need some help in moving to a new house or apartment, I wouldn't have a hard time finding someone to help me	80	0	3	1.93	1.065
Social Support	80	.58	3.00	2.0771	.59560
Valid N (listwise)	80				

Table 27: **Who provides your social support?**

		No	**Yes**
Emotional support from partner	**Count**	54	26
	%	67.5%	32.5%
Emotional support from family	**Count**	39	41
	%	48.8%	51.3%
Emotional support from friends	**Count**	28	52
	%	35.0%	65.0%
Emotional support from work colleagues	**Count**	72	8
	%	90.0%	10.0%
Practical support from partner	**Count**	60	20
	%	75.0%	25.0%
Practicalsupport from family	**Count**	36	44
	%	45.0%	55.0%
Practical support from friends	**Count**	30	50
	%	37.5%	62.5%
Practical support from work colleagues	**Count**	72	8
	%	90.0%	10.0%
Financial support from partner	**Count**	70	10
	%	87.5%	12.5%
Financial support from family	**Count**	35	45
	%	43.8%	56.3%
Financial support from friends	**Count**	49	31
	%	61.3%	38.8%
Financial support from work colleagues	**Count**	76	4
	%	95.0%	5.0%

Social support from partner	**Count**	68	12
	%	85.0%	15.0%
Social support from family	**Count**	45	35
	%	56.3%	43.8%
Social support from friends	**Count**	23	57
	%	28.8%	71.3%
Social support from work colleagues	**Count**	67	13
	%	83.8%	16.3%
Support for taking medication from partner	**Count**	63	17
	%	78.8%	21.3%
Support for taking medication from family	**Count**	46	34
	%	57.5%	42.5%
Support for taking medication from friends	**Count**	50	30
	%	62.5%	37.5%
Support for taking medication from work colleagues	**Count**	79	1
	%	98.8%	1.3%
Understanding from partner	**Count**	59	21
	%	73.8%	26.3%
Understanding from family	**Count**	37	43
	%	46.3%	53.8%
Understanding from friends	**Count**	26	54
	%	32.5%	67.5%
Understanding from work colleagues	**Count**	72	8
	%	90.0%	10.0%
Acceptance from partner	**Count**	56	24
	%	70.0%	30.0%
Acceptance from family	**Count**	31	49
	%	38.8%	61.3%
Acceptance from friends	**Count**	23	57
	%	28.8%	71.3%
Acceptance from work colleagues	**Count**	67	13
	%	83.8%	16.3%

Table 28: **Attitudes to HIV and sexuality**

	N	Minimum	Maximum	Mean	Std. Deviation
In most people's opinions to be an HIV positive individual isn't a bad thing	80	1	4	2.19	1.057
In most people's opinions being homosexual is acceptable in our society	80	1	4	2.20	.863
In most people's opinions sexual identity is not important in nowdays	80	1	4	2.54	.913
In most people's opinions being promiscuous is acceptable by today's standards	80	1	4	2.40	.866
In most people's opinions HIV positive oindividuals willn't die younger	80	1	4	2.56	.869
In most people's opinions HIV positive individuals are likely to have long term relationships	80	1	4	2.40	.851
I believe that HIV positive individuals are not a great danger for the spreading of HIV virus	80	1	4	2.59	.924
I believe that being HIV positive motivates me to take care of myself more	80	1	4	3.36	.601
I believe that I take care of myself well	80	1	4	3.19	.781
I don't believe that HIV positive individuals put other people's health in danger	80	1	4	3.14	.868
Attitudes to HIV and sexuality	80	1.70	3.50	2.6562	.41272
Valid N (listwise)	80				

Table 29: For me HIV/AIDS is...

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	**Not serious**	3	3.8	3.8	3.8
	2	4	5.0	5.0	8.8
	3	8	10.0	10.0	18.8
	4	12	15.0	15.0	33.8
	Serious	53	66.3	66.3	100.0
	Total	**80**	**100.0**	**100.0**	

Table 30: For me HIV/AIDS is...

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	**Mild**	12	15.0	15.0	15.0
	2	9	11.3	11.3	26.3
	3	19	23.8	23.8	50.0
	4	16	20.0	20.0	70.0
	Severe	24	30.0	30.0	100.0
	Total	**80**	**100.0**	**100.0**	

Table 31: Patient's thoughts about taking their medication

	N	Minimum	Maximum	Mean	Std. Deviation
In the afternoon, I don't have a hard time remembering if I took my early dose of medication	80	1	7	6.29	1.150
I haven't forgotten whether I have taken my medication, even while I am in the middle of doing it	80	1	7	6.1 3	1.195
I don't often have trouble remembering to get refills for my medication on time	80	1	7	6.45	1.078
I don't forget to talk to my medical provider abour side-effects of my medication	80	1	7	6.36	1.139
I want to take my medication and i don't forget to take it	80	1	7	6.35	1.020
I may loose track of time but I don't take my medication late or not at all	80	1	7	6.10	1.218
I don't have any problem remembering to take my medications with me when I leave home	80	1	7	5.71	1.460
I don't fear that I am not capable of taking my medication, as I should	80	1	7	6.32	1.394
I feel confident that I will be able to keep making the effort to take this medication for ever	80	1	7	6.14	1.516
I feel confident that I'll be able to follow the medication plan	80	1	7	6.37	1.162
I find it possible to follow the food restrictions with my medications	80	1	7	5.73	1.542
I don't have any trouble taking my medications on time	80	1	7	5.49	1.615
In the past, I haven't had any trouble taking medication when I had no physical symptoms	80	1	7	5.57	1.770
Things don't get in the way of my taking my medication as prescribed	80	1	7	5.92	1.271
When I take my HIV medication it doesn't remind me that I am HIV positive	80	1	7	4.20	2.196
When I take my HIV medication I feel I am benefiting my quality of life	80	1	7	5.64	1.766
Thoughts about taking medication	80	1.38	7.00	5.9234	.90215
Valid N (listwise)	80				

`Table 32 :` Health beliefs, Susceptibility

	N	Minimum	Maximum	Mean	Std. Deviation
If I stopped taking my antiretroviral medication I would develop AIDS sooner	80	1	5	4.22	1.079
If I stopped taking my antiretroviral medication I would develop AIDS symptoms and associated diseases sooner	80	1	5	4.25	1.013
If I stopped taking my antiretroviral medication I would get sicker sooner	80	1	5	4.31	.963
Health beliefs, Susceptibility	80	1.00	5.00	4.2625	.95569
Valid N (listwise)	80				

`Table 33:` Beliefs about HIV medication, benefits

	N	Minimum	Maximum	Mean	Std. Deviation
I find HIV medication...(dangerous 1-5 safe)	80	1	5	3.72	1.201
I find HIV medication...(expensive 1-5 inexpensive)	80	1	5	2.30	1.657
I find HIV medication...(inconvenient 1-5 convenient)	80	1	5	3.36	1.371
I find HIV medication...(complicated 1-5 simple)	80	1	5	3.72	1.368
I find HIV medication...(distressing 1-5 comforting)	80	1	5	3.20	1.504
I find HIV medication...(harmful 1-5 helpful)	80	1	5	4.03	1.283
I find HIV medication...(unimportant 1-5 important)	80	1	5	4.70	.753
I find HIV medication...(useless 1-5 worthwhile)	80	1	5	4.78	.656
I find HIV medication...(ineffective 1-5 effective)	80	1	5	4.55	.810
Valid N (listwise)	80				

`Table 34:` Feelings about HIV medication

	N	Minimum	Maximum	Mean	Std. Deviation
Taking HIV medication makes me feel interested	80	1	5	3.25	1.428
Taking HIV medication makes me feel distressed	80	1	5	2.42	1.199
Taking HIV medication makes me feel excited	80	1	5	1.75	1.142
Taking HIV medication makes me feel upset	80	0	5	1.63	1.011
Taking HIV medication makes me feel strong	80	1	5	3.36	1.105
Taking HIV medication makes me feel guilty	80	1	5	1.76	1.105
Taking HIV medication makes me feel scared	80	1	5	1.78	1.102
Taking HIV medication makes me hostile	80	1	4	1.30	.736
Taking HIV medication makes me feel enthusiastic	80	1	5	1.97	1.331
Taking HIV medication makes me feel proud	80	1	5	2.00	1.405
Taking HIV medication makes me feel irritable	80	1	4	1.90	.976
Taking HIV medication makes me feel alert	80	1	5	3.08	1.339

Taking HIV medication makes me feel ashamed	80	1	5	1.64	.971
Taking HIV medication makes me feel inspired	80	1	5	1.63	1.173
Taking HIV medication makes me feel nervous	80	1	5	2.04	1.185
Taking HIV medication makes me feel determined	80	1	5	3.74	1.166
Taking HIV medication makes me feel attentive	80	1	5	4.05	1.005
Taking HIV medication makes me feel jittery	80	1	5	1.84	1.119
Taking HIV medication makes me feel active	80	1	5	3.12	1.277
Taking HIV medication makes me feel afraid	80	1	5	2.09	1.182
Valid N (listwise)	80				

`Table 34:` **Feelings about HIV medication**

	N	**Minimum**	**Maximum**	**Mean**	**Std. Deviation**
Taking HIV medication makes me feel interested	80	1	5	3.25	1.428
Taking HIV medication makes me feel distressed	80	1	5	2.42	1.199
Taking HIV medication makes me feel excited	80	1	5	1.75	1.142
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Taking HIV medication makes me feel jittery	80	1	5	1.84	1.119
Taking HIV medication makes me feel active	80	1	5	3.12	1.277
Taking HIV medication makes me feel afraid	80	1	5	2.09	1.182
Valid N (listwise)	80				

Table 35: Symptoms					
	N	Minimum	Maximum	Mean	Std. Deviation
Muscle aches	80	0	3	.51	.857
Weakness	80	0	3	.58	.897
Painful joints	80	0	3	.54	.941
Fatigue	80	0	3	.78	1.031
Dry mouth	80	0	3	.54	.913
Thirsty	80	0	3	.43	.808
Difficulty concentrating	80	0	3	.49	.795
Depression	80	0	3	.63	.946
Memory loss	80	0	3	.56	.840
Fear/worries	80	0	3	.71	1.034
Anxiety	80	0	3	.96	1.174
Disorientation	80	0	3	.38	.663
Fever	80	0	1	.13	.333
Chils	80	0	2	.14	.381
Day sweats	80	0	3	.31	.756
Night sweats	80	0	3	.49	.871
Loose stools	80	0	3	.55	.855
Diarrhea	80	0	3	.48	.900
Gas/bloating	80	0	3	.87	1.129
Abdominal pain	80	0	3	.33	.708
Shortness of breath at rest	80	0	3	.30	.753
Wheezing	80	0	3	.21	.610
Shortness of breath with activity	80	0	3	.36	.733
Nausea	80	0	3	.27	.595
Vomiting	80	0	2	.19	.453
Lack of appetite	80	0	3	.26	.631
Valid N (listwise)	80				

Table 36: Compliance with HIV medication

	N	Minimum	Maximum	Mean	Std. Deviation
I have you taken all of my Medication as prescribed so far today	80	.00	2.00	1.8500	.47998
I took all of my medication as prescribed so far yesterday	80	.00	2.00	1.8625	.44277
I took all my medication as prescribed in the past week	80	.00	2.00	1.7750	.47667
I took all of my medication as prescribed in the past month	80	.00	2.00	1.6250	.58190
Compliance with HIV medication	80	.00	2.00	1.7781	.41145
Valid N (listwise)	80				

Table 37: Commitment to medication

	N	Minimum	Maximum	Mean	Std. Deviation
I am determined to do whatever it takes to take my medication in schedule	80	1	7	5.92	1.491
I follow all food restrictions that come with my medication no matter how hard it is	80	1	7	5.50	1.714
I am determined to take my medications even if there is no way to have privacy(i.e. in front of friends, family, co-workers)	80	1	7	5.36	2.020
I take my medication even if I don't feel well	80	1	7	6.21	1.299
I am determined to stick with a plan to help me remember to take my medication as prescribed	80	1	7	5.84	1.753
I learn as much as I can about my medications so I can take them exactly as prescribed	80	1	7	5.70	1.618
I am committed to taking my medication even if it tastes bad or is hard to swallow	80	1	7	6.01	1.657
Commitment to medication	80	2.00	7.00	5.7929	1.09999
Valid N (listwise)	80				

Appendix 3:Tables

Table 38: Checking Normality

		Compliance with HIV medication
N		80
Normal Parameters	Mean	1.7781
	Std. Deviation	.41145
Most Extreme Differences	Absolute	.380
	Positive	.295
	Negative	-.380
Kolmogorov-Smirnov Z		3.400
Asymp. Sig. (2-tailed)		.000

a Test distribution is Normal.
b Calculated from data.

Table 39: Sex & Compliance with HIV medication

	What is your sex?	N	Mean Rank
Compliance with HIV medication	Female	17	44.09
	Male	63	39.53
	Total	80	

Table 40: Chi – square

	Compliance with HIV medication
Chi-Square	.745
df	1
Asymp. Sig.	.388

a Kruskal Wallis Test
b Grouping Variable: What is your sex?

Table 41: Sexual orientation & Compliance with HIV medication

	How would you rate your sexual identity?	N	Mean Rank
Compliance with HIV medication	Homosexual	42	43.65
	Bisexual	11	39.41
	Heterosexual	27	36.04
	Total	80	

Table 42: Chi square

	Compliance with HIV medication
Chi-Square	2.598
df	2
Asymp. Sig.	.273

a Kruskal Wallis Test
b Grouping Variable: How would you rate your sexual identity?

Table 43: Alcohol & Compliance with HIV medication

	Do you drink alcohol?	N	Mean Rank
Compliance with HIV medication	No	45	43.46
	Yes	35	36.70
	Total	80	

Table 44: Chi square

	Compliance with HIV medication
Chi-Square	2.409
df	1
Asymp. Sig.	.121

a Kruskal Wallis Test
b Grouping Variable: Do you drink alcohol?

Table 45: Smoking & Compliance with HIV medication

	Do you smoke?	N	Mean Rank
Compliance with HIV medication	No	31	40.82
	Yes	49	40.30
	Total	80	

Table 46: Chi square

	Compliance with HIV medication
Chi-Square	.014
df	1
Asymp. Sig.	.905

a Kruskal Wallis Test
b Grouping Variable: Do you smoke?

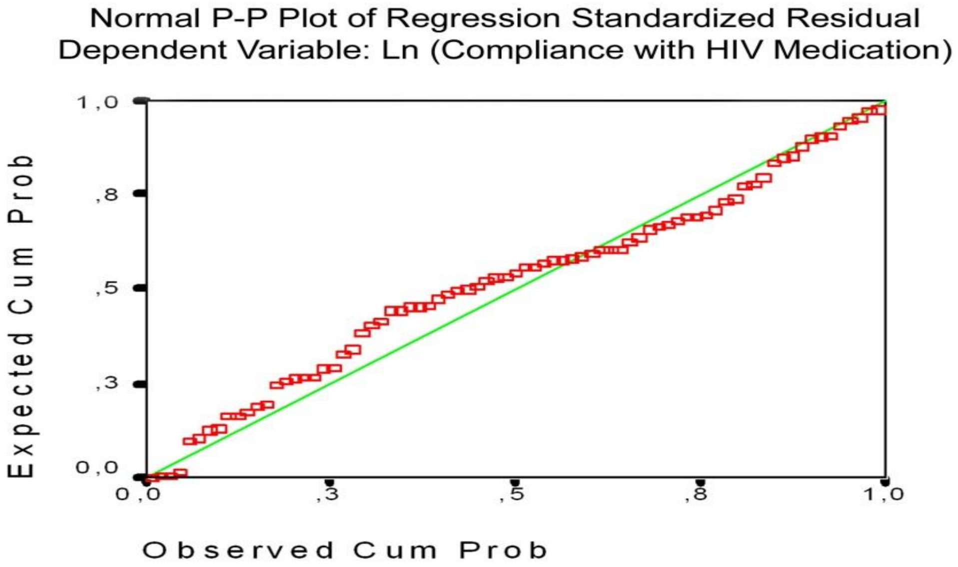
Appendix 4: Tables

Table 47: Emotional support from partner & Compliance with HIV medication

					Statistic	Std. Error
Compliance with HIV medication	Emotional support from partner	No	Mean		1.6944	.06430
			95% Confidence Interval for Mean	Lower Bound	1.5655	
				Upper Bound	1.8234	
			5% Trimmed Mean		1.7505	
			Median		2.0000	
			Variance		.223	
			Std. Deviation		.47252	
			Minimum		.00	
			Maximum		2.00	
			Range		2.00	
			Interquartile Range		.5000	
			Skewness		-1.669	.325
			Kurtosis		2.420	.639
		Yes	Mean		1.9519	.02410
			95% Confidence Interval for Mean	Lower Bound	1.9023	
				Upper Bound	2.0015	
			5% Trimmed Mean		1.9712	
			Median		2.0000	
			Variance		.015	
			Std. Deviation		.12287	
			Minimum		1.50	
			Maximum		2.00	
			Range		.50	
			Interquartile Range		.0000	
			Skewness		-2.676	.456
			Kurtosis		7.053	.887

Appendix 5: Graphs

Graph 1



Appendix 6: Questionnaire for quantitative survey

Section 1: Your Personality

In this section, I will ask you questions regarding your personality (TIPI)

Here are a number of personality traits that may or may not apply to you. Please write a number next to each statement to indicate the extent to which you agree or disagree with that statement. You should rate the extent to which the pair of traits applies to you, even if one characteristic applies more strongly than the other.

Strongly disagree	Moderately disagree	Disagree a little	Neither agree nor disagree	Agree a little	Moderately agree	Strongly agree
1	2	3	4	5	6	7

1. _
_
_

___Extroverted, enthusiastic
2. ______Critical, quarrelsome
3. ______Dependable, self-disciplined
4. ______Anxious, easily upset
5. ______Open to new experiences, complex
6. ______Reserved, quiet
7. ______Sympathetic, warm
8. ______Disorganised, careless
9. ______Calm, emotionally stable
10. ______Conventional, uncreative

Section 2:Your Health

In this section and its subsections, I will ask you questions about your physiological and psychological health.

Section 2a: Your general health(GHQ12)

We want to know how your health has been in general over the last few weeks. Please read the questions below and each of the four possible answers. Circle the response that best applies to you.					
Have you recently:					Official Use
11. been able to concentrate on what you are doing?	0: Better than usual	1: Same as usual	2: Less than usual	3: Much less than usual	
12. lost much sleep over worry?	Not at all	No more than usual	Rather more than usual	Much more than usual	
13. felt that you are playing a useful part in things?	More so than usual	Same as usual	Less so than usual	Much less than usual	
14. felt capable of making decisions about things?	More so than usual	Same as usual	Less than usual	Much less than usual	
15. felt constantly under strain?	Not at all	No more than usual	Rather more than usual	Much more than usual	
16. felt you couldn't overcome your difficulties?	Not at all	No more than usual	Rather more than usual	Much more than usual	
17. been able to enjoy your normal day to day activities?	More so than usual	Same as usual	Less so than usual	Much less than usual	
18. been able to face up to your problems?	More so than usual	Same as usual	Less than usual	Much less than usual	
19. been feeling unhappy or depressed?	Not at all	No more than usual	Rather more than usual	Much more than usual	
20. been loosing confidence on yourself?	Not at all	No more than usual	Rather more than usual	Much more than usual	
21. been thinking of yourself as a worthless person?	Not at all	No more than usual	Rather more than usual	Much more than usual	
22. been feeling reasonably happy, all things considered?	More so than usual	Same as usual	Less so than usual	Much less than usual	

Section 2b: Your Health status(SF-36)

Health Status	This question asks you for your views about your health. This information will help to keep track of how you feel and how well you are able to do your usual activities. Answer the question by marking the answer as indicated. If you are unsure about to answer a question, please give the best answer you can.					
	1: Poor	2: Fair	3: Good	4: Very good	5: Excellent	Official Use
23. In general would you say your health is…	O	O	O	O	O	

Section 2d: Your levels of anxiety and depression(HADS)

Please read each item below and underline (circle) the reply which comes closest to how you have been feeling in the past week					
24. I feel tense or “wound up”	1: Most of the time	2: A lot of the time	3: From time to time, occasionally	4: Not at all	Official Use
25. I still enjoy the things I used to enjoy	1:Definitely as much	2:Not quite as much	3:Only a little	4:Hardly at all	
26. I get a sort of frightened feeling as if something awful is about to happen	1:Very definitely and quite badly	2:Yes but not too badly	3:Alittle but it doesn’t worry me	4:Not at all	
27. I can laugh and see the funny side of things	1:As much as I always could	2:Not quite so much now	3:Definitely not so much now	4:Not at all	
28. Worrying thoughts go through my mind	1:A great deal of time	2:A lot of time	3:From time to time but not too often	4:Only occasionally	
29. I feel cheerful	1: Not at all	2: Not often	3:Sometimes	4:Most of the time	
30. I can sit at ease and feel relaxed	1:Definitely	2:Usually	3:Not often	4:Not at all	
31. I feel as if I am slowed down	1:Nearly all the time	2:Very often	3:Sometimes	4:Not at all	
32. I get sort of frightened feeling Like “butterflies” in the stomach	1:Not at all	2:Occasionally	3:Quite often	4:Very often	
33. I have lost interest in my appearance	1:Definitely	2:I don’t take so much care as I should	3:I may not take quite as much care as ever	4:I take as much care as ever	
34. I feel restless as if I have to be on the move	1:Very much indeed	2:Quite a lot	3:Not very much	4:Not at all	
35. I look forward with enjoyment to things	1:As much as I ever did	2:Rather less than I used to	3:Definitely less than I used to	4:Hardly at all	
36. I get sudden feelings of panic	1: Very often indeed	2: Quite often	3: Not very often	4: Not at all	
37. I can enjoy a good book or radio or TV programme	1:Often	2:Sometimes	3:Not often	4:Very seldom	

Section 2c: Your self-esteem(SES)

Below is a list of statements dealing with your general feelings about yourself. If you STRONGLY AGREE, circle SA. If you AGREE with the statement, circle A.. If you DISAGREE, circle D. if you STRONGLY DISAGREE, circle SD

	1:Strongly Disagree	2:Disagree	3:Agree	4:Strongly Agree	Official Use
38. I feel that I am a person of worth, at least on an equal plane with others	**S D**	**D**	**A**	**S A**	
39. I feel that I have a number of good qualities	**S D**	**D**	**A**	**S A**	
40. All in all, I am inclined to feel that I am a failure	**S D**	**D**	**A**	**S A**	
41. I am able to do things as well as most other people	**S D**	**D**	**A**	**S A**	
42. I feel I do not have much to be proud of	**S D**	**D**	**A**	**S A**	
43. I take a positive attitude toward myself	**S D**	**D**	**A**	**S A**	
44. On the whole, I am satisfied with myself	**S D**	**D**	**A**	**S A**	
45. I wish I could have more respect for myself	**S D**	**D**	**A**	**S A**	
46. I certainly feel useless at times	**S D**	**D**	**A**	**S A**	
47. A times I think I am no good at all	**S D**	**D**	**A**	**S A**	

Section 2 e: Your coping strategies (CPS)

"The following statements describe how other people act in difficult situations. When you think about the recent past, you may remember problems and difficult situations, you had to deal with. Please try to remember these situations. To what extent do each of these statements apply to your thinking and acting in those difficult situations?"You may choose between 'strongly disagree', 'disagree', 'neutral' - that is, a statement might be partly true and partly not - 'agree' or 'strongly agree'. Please choose the category which – in your opinion - best applies to you."

	1: Strongly Disagree	2:Disagree	3: Neutral	4: Agree	5: Strongly Agree	Official Use
48. I find that I can better face up to dealing with a difficult situation if I remind myself that I have already solved many other problems in my life.	1	2	3	4	5	
49. I never give up, even when the odds are stacked against me.	1	2	3	4	5	
50. If I have a problem, I try to find something else to do to help take my mind off it.	1	2	3	4	5	
51. I try to adapt to difficult situations rather than fight against them.	1	2	3	4	5	

52. In difficult situations I seek support in my faith.	1	2	3	4	5	
53. I try to find out about all sides of a problem.	1	2	3	4	5	
54. If I have any problems, I look to others for help and support.	1	2	3	4	5	
55. I react in different ways to problems: Sometimes I am down and then I am up and full of energy again.	1	2	3	4	5	
56. I tend to give in when there is a problem and to let things take their own course.	1	2	3	4	5	
57. It is often the case that I can’t solve the problems that I have. Then I become depressed and can’t see any point to my life.	1	2	3	4	5	
58. I find it easier to deal with any problems I have by remembering that there are always others who are far worse off than me.	1	2	3	4	5	
59. I often wish that someone else would solve my problems for me.	1	2	3	4	5	
60. If I have any problems I try to take it with a sense of humour.	1	2	3	4	5	

Section 2 f: Your locus of control(MHLC)

Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

	Strongly Disagree	Moderately Disagree	Disagree	Agree	Moderately Agree	Strongly Agree	Official Use
61. If my condition worsens, it is my own behaviour which determines how soon I will feel better again.	1	2	3	4	5	6	
62. As to my condition, what will be will be.	1	2	3	4	5	6	
63. If I see my doctor regularly, I am less likely to have problems with my condition.	1	2	3	4	5	6	

64. Most things that affect my condition happen to me by chance.	1	2	3	4	5	6	
65. Whenever my condition worsens, I should consult a medically trained professional.	1	2	3	4	5	6	
66. I am directly responsible for my condition getting better or worse.	1	2	3	4	5	6	
67. Other people play a big role in whether my condition improves, stays the same, or gets worse.	1	2	3	4	5	6	
68. Whatever goes wrong with my condition is my own fault.	1	2	3	4	5	6	
69. Luck plays a big part in determining how my condition improves.	1	2	3	4	5	6	
70. In order for my condition to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6	
71. Whatever improvement occurs with my condition is largely a matter of good fortune.	1	2	3	4	5	6	
72. The main thing which affects my condition is what I myself do.	1	2	3	4	5	6	
73. I deserve the credit when my condition improves and the blame when it gets worse.	1	2	3	4	5	6	
74. Following doctor's orders to the letter is the best way to keep my condition from getting any worse.	1	2	3	4	5	6	
75. If my condition worsens, it's a matter of fate.	1	2	3	4	5	6	
76. If I am lucky, my condition will get better.	1	2	3	4	5	6	
77. If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6	

78. The type of help I receive from other people determines how soon my condition improves.	1	2	3	4	5	6	

<u>Section 3: Your Life satisfaction</u>

In this section I will ask you a question regarding how satisfied you are with your life

79. Ladder scale; at the bottom of this ladder is the worst situation that you expected to have, at the top of the ladder is the best situation that you expected to have, where would you put your situation now?

Best life I could expect to have

10
9
8
7
6
5
4
3
2
1

Worst life I could expect to have

<u>Section 4: Your Health Care</u>

In this section I will ask you questions regarding your relationship with Health Care Providers

Below you will find some statements relating to how you take your medication. It is not a test, so there are no right or wrong answers. Answer each item as carefully and as accurately as you can by choosing the numbers from 1 to 7 (AAI)

1= None of the time
2= Very rarely
3= A little of the time
4= Some of the time
5= A good part of the time
6= Most of the time
7= All of the time

80. _____My medical provider makes sure that I have a plan for fitting the medication dosing schedule into my personal routine
81. _____My medical provider wants me to participate in making decisions about my medicine
82. _____My medical provider understands how difficult it is to follow my medication regimen
83. _____My medical provider wants to know what problems I have that make it hard to take my medications
84. _____My medical provider understands my personal life and why it is hard for me to take my medications
85. _____My medical provider makes time for me to ask all the questions I need about my medications
86. _____My medical provider asks me if I can handle any possible side-effects of my medication

Section 4b In this section I will ask you questions about your satisfaction with health care 9.5 SATISFACTION WITH HEALTH CARE

Please use the rating scale below to describe how accurately each statement describes your beliefs. beliefs Please tick the answer that applies to you the most						
	1: Strongly Disagree	2: Disagree	3: Neutral	4: Agree	5:Strongly Agree	Official Use
87. I am very satisfied with the medical care I Receive	O	O	O	O	O	
88. If I have a medical problem, I can reach someone for help without any problem	O	O	O	O	O	
89. There are things about the medical care I receive that could be better	O	O	O	O	O	

<u>Section 5: Your Social Support (ISEL-12)</u>

In this section, I will ask you questions about the social support that you have from your environment (Family, friends, colleagues)

This scale is made up of a list of statements each of which may or may not be true about you. For each statement circle "definitely true" if you are sure it is true about you and "probably true" if you think it is true but are not absolutely certain. Similarly, you should circle "definitely false" if you are sure the statement is false and "probably false" if you think it is false but are not absolutely certain.					
	O: Definitely false	1: Probably false	2: Probably true	3: Definitely true	Official Use
90. If I wanted to go on a trip for a day (for example, to the country or mountains), I would have a hard time finding someone to go with me.	O	O	O	O	
91. I feel that there is no one I can share my most private worries and fears with.	O	O	O	O	
92. If I were sick, I could easily find someone to help me with my daily chores.	O	O	O	O	
93. There is someone I can turn to for advice about handling problems with my family.	O	O	O	O	
94. If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me.	O	O	O	O	
95. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.	O	O	O	O	
96. I don't often get invited to do things with others.	O	O	O	O	
97. If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my house or apartment (the plants, pets, garden, etc.).	O	O	O	O	
98. If I wanted to have lunch with someone, I could easily find someone to join me.	O	O	O	O	

99. If I was stranded 10 miles from home, there is someone I could call who could come and get me.	O	O	O	O	
100. If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it.	O	O	O	O	
101. If I needed some help in moving to a new house or apartment, I would have a hard time finding someone to help me.	O	O	O	O	

Section 5b: Who provides your social support

Please indicate which of the following groups provide your social support. Please tick all that apply to you					
	Partner	**Family**	**Friends**	**Work Colleagues**	Official Use
102. Emotional support	O	O	O	O	
103. Practical support	O	O	O	O	
104. Financial support	O	O	O	O	
105. Social support	O	O	O	O	
106. Support for taking my medication	O	O	O	O	
107. Understanding	O	O	O	O	
108. Acceptance	O	O	O	O	

<u>Section 6: Being HIV positive</u>

In this section, I will ask you questions about your experiences as HIV positive individuals

6a: Your attitudes to HIV and sexuality

Please use the rating scale below to describe how accurately each statement describes your beliefs Please tick the answer that applies to you the most					
In most people’s opinions…	1: Strongly Disagree	2: Disagree	3: Agree	4: Strongly Agree	Official Use
109. To be an HIV positive individual is a bad thing	O	O	O	O	
110. Being homosexual is unacceptable in our society 111.	O	O	O	O	
112. Sexual identity is not important in nowadays	O	O	O	O	
113. Being promiscuous is acceptable by today’s standards	O	O	O	O	
114. HIV positive individuals will die younger	O	O	O	O	
115. HIV positive individuals are likely to have long term relationships	O	O	O	O	

Please use the rating scale below to describe how accurately each statement describes you. Please tick the answer that applies to you the most					
I believe that…	1: Strongly Disagree	2: Disagree	3: Agree	4: Strongly Agree	Official Use
116. HIV positive individuals are not a great danger for the spreading of HIV virus	○	○	○	○	
117. Being HIV positive motivates me to take care of myself more	○	○	○	○	
118. I don't take care of myself well	○	○	○	○	
119. HIV positive put other peoples' health in danger	○	○	○	○	

Section 6b: Your HIV severity

⇒ Please circle the number that applies to your beliefs

For me HIV/AIDS is …				
120.**Not serious**				**Serious**
1	**2**	**3**	**4**	**5**
121.**Mild**				**Severe**
1	**2**	**3**	**4**	**5**

Section 7: HIV Medication

In this section I will ask you questions about your experiences with HIV medication, your feelings when taking it, the side-effects and your compliance.

Section 7a: Experiences of taking HIV medication (medicalisation in everyday life)

⇒In this section, I will ask you questions about your experiences of taking HIV medication

122.**What medication are you taking at the moment?**

Name of HIV medication:	Dose:	When taken:

Has your medication ever been changed? YES ☐ NO ☐

123.**If yes, reasons for changing it, if no move on to section 7b**

Name of medication changed	How long were you taking it?	Why did you stop this medication?

Section 7 b: What you think about taking medication

Below you will find some statements relating to how you take your medication. It is not a test, so there are no right or wrong answers. Answer each item as carefully and as accurately as you can by choosing the numbers from 1 to 7 (AAI)

1= None of the time	5= A good part of the time
2= Very rarely	6= Most of the time
3= A little of the time	7= All of the time
4= Some of the time	

124._____In the afternoon, I have a hard time remembering if I took my early dose of medication.
125._____I have forgotten whether I have taken my medication, even while I am in the middle of doing it.
126._____I often have trouble remembering to get refills for my medication on time.
127._____I forget to talk to my medical provider about side-effects of my medication.
128._____Even though I want to take my medication, I just forget to take it.
129._____I lose track of time, and I have to take my medication late or not at all.
130._____I have a hard time remembering to take my medications with me when I leave home.
131._____I fear that I am not capable of taking my medication, as I should.
132._____I worry that I will not be able to keep making the effort to take this medicine for ever.
133._____No matter how hard I try, I don't think I'll be able to follow the medication plan.
134._____I find it nearly impossible to follow the food restrictions with my medications.
135._____I have trouble taking my medications on time.
136._____In the past, I have had trouble taking medication when I had no physical symptoms.
137._____Things get in the way of my taking my medication as prescribed
138._____When I take my HIV medication it reminds me that I HIV positive
139._____When I take my HIV medication I feel I am benefiting my quality of life

Section 7d: In this section I will ask you questions about your beliefs regarding the effectiveness of your medication

Please use the rating scale below to describe how accurately each statement describes your beliefs. Please tick the answer that applies to you the most						
If I stopped taking my antiretroviral medication I would…	1: Strongly Disagree	2: Disagree	3: Neutral	4: Agree	5:Strongly Agree	Official Use
140. Develop AIDS sooner	O	O	O	O		
141. Develop AIDS symptoms and associated diseases sooner	O	O	O	O		
142. Get sicker sooner	O	O	O	O		

Section 7e: In this section I will ask you questions regarding your beliefs about HIV medication

(direct attitude measure)

I find taking my HIV medication							
143.	**Dangerous**	**1**	**2**	**3**	**4**	**5**	**Safe**
144.	**Expensive**	**1**	**2**	**3**	**4**	**5**	**Inexpensive**
145.	**Inconvenient**	**1**	**2**	**3**	**4**	**5**	**Convenient**
146.	**Complicated**	**1**	**2**	**3**	**4**	**5**	**Simple**
147.	**Distressing**	**1**	**2**	**3**	**4**	**5**	**Comforting**
148.	**Harmful**	**1**	**2**	**3**	**4**	**5**	**Helpful**
149.	**Unimportant**	**1**	**2**	**3**	**4**	**5**	**Important**
150.	**Useless**	**1**	**2**	**3**	**4**	**5**	**Worthwhile**
151.	**Ineffective**	**1**	**2**	**3**	**4**	**5**	**Effective**

Section 7f: Your feelings about HIV medication

152. This scale consists of a number of words that describe different feelings and emotions. Read each item and then mark the appropriate answer. Indicate to what extent you feel this way **right now**. Use the following scale to record your answers.

1= Very slightly, 2= A little, 3= Moderately, 4= Quite a lot, 5= Extremely

Taking HIV medication makes me feel….

___________Interested

___________Distressed

___________Excited

___________Upset

___________Strong

___________Guilty

__________Scared

___________Hostile

___________Enthusiastic

___________Proud

___________Irritable

___________Alert

___________Ashamed

___________Inspired

___________Nervous

___________Determined

___________Attentive

___________Jittery

___________Active

___________Afraid

Section 7h: Your Symptoms (SSC-HIV)

⇒In this section I will ask you questions about the symptoms you are experiencing.

Below is a list of potential problems that **you may be experiencing today**. If you have the problem, rate the degree of **INTENSITY** which best describes the extent of the problem.
If you do not have the problem, do not check a box.

Mild	Moderate	Severe	Problem
MALAISE/WEAKNESS/FATIGUE			
☐	☐	☐	Muscle aches
☐	☐	☐	Weakness
☐	☐	☐	Painful joints
☐	☐	☐	Fatigue
☐	☐	☐	Dry mouth
☐	☐	☐	Thirsty
CONFUSION/DISTRESS			
☐	☐	☐	Difficulty concentrating
☐	☐	☐	Depression
☐	☐	☐	Memory loss
☐	☐	☐	Fear/Worries
☐	☐	☐	Anxiety
☐	☐	☐	Disorientation
FEVER/CHILS			
☐	☐	☐	Fever
☐	☐	☐	Chills
☐	☐	☐	Day sweats
☐	☐	☐	Night sweats
GASTROINTESTINAL DISCOMFORT			
☐	☐	☐	Loose stools
☐	☐	☐	Diarrhea
☐	☐	☐	Gas/bloating
☐	☐	☐	Abdominal pain
SHORTNESS OF BREATH			
☐	☐	☐	Shortness of breath at rest
☐	☐	☐	Wheezing
☐	☐	☐	Shortness of breath with activity
NAUSEA/VOMITING			
☐	☐	☐	Nausea
☐	☐	☐	Vomiting
☐	☐	☐	Lack of appetite

Section 7i: Compliance with HIV medication (AAI)

⇒ In this section, I will ask you questions about the frequency you take your medication.

Below you will find some statements relating to how you take your medication. It is not a test, so there are no right or wrong answers. Answer each item as carefully and as accurately as you can by choosing the numbers from 1 to 5.					
	1:Yes	2: No	3:Can't remember	4: To the best of my recollection	Official Use
153. I have you taken all of my Medication as prescribed so far today	O	O	O	O	
154. I took all of my medication as prescribed so far yesterday	O	O	O	O	
155. I took all my medication as prescribed in the past week	O	O	O	O	
156. I took all of my medication as prescribed in the past month	O	O	O	O	

Section 7j: Commitment to medication

Below you will find some statements relating to how you take your medication. It is not a test, so there are no right or wrong answers. Answer each item as carefully and as accurately as you can by choosing the numbers from 1 to 7 (AAI)

1= None of the time
2= Very rarely
3= A little of the time
4= Some of the time
5= A good part of the time
6= Most of the time
7= All of the time

157._____I am determined to do whatever it takes to take my medication in schedule.
158._____I follow all the food restrictions that come with my medication no matter how hard it is.
159._____I am determined to take my medications even if there is no way to have privacy (i.e. in front of friends, family, co-workers).
160._____I take my medication even if I don’t feel well.
161._____I am determined to stick with a plan to help me remember to take my medication as prescribed.
162._____I learn as much as I can about my medications so I can take them exactly as prescribed.
163._____I am committed to taking my medication even if it tastes bad or is hard to swallow.

YOUR COMMENTS

⇒ In this section, please answer the following questions and make your own comments regarding the questionnaire and some possible comments that you would like to make regarding HIV medication and compliance..

164.How do you feel after completing the present questionnaire?

165.Did you find the questionnaire helpful?
YES ☐ NO ☐
Please explain why:

166.Please make comments on the questionnaire

167.Please make comments about HIV medication

168.Please make comments on HIV and compliance to medication

BACKGROUND INFORMATION

Date:

INSTRUCTIONS: Below you will find some statements relating to your experiences of living with HIV, complying with antiretroviral therapy, your relationship with health care professionals and the psychosocial factors that influence your compliance. It is not a test; therefore, there are no right or wrong answers. Many of the items require you to circle a response to indicate the answer that applies to you the most. But first, please fill in some personal details below:

⇒The following questions ask you about yourself and your medical condition.

1. ***What is your age?*** ☐
2. ***Nationality:*** ☐
3. ***What medical condition do you have?*** ☐
4. ***When were you diagnosed?*** Date⇒ Month: ___Year:___
5. ***When did you start taking HIV medication?*** Date⇒ Month: ___Year:___
6. ***What is your sex:*** Male ☐ Female ☐
7. ***How would you rate your sexual identity: Please put a cross on the line.***

Have sex with people of the same sex		Have sex with people of the opposite sex
100%	0	100%

|---|---|

8. Do you drink alcohol? YES ☐ NO ☐
9. How much do you drink approximately? Please specify in glasses

Per day ☐

Per week ☐

10. Do you smoke? YES ☐ NO ☐
11. How many cigarettes do you smoke on average per day? ☐
12. Do you work? Full-time ☐ Part-time ☐ Unemployed ☐
13. What is your occupation? ☐ (Optional)
14. What is your income? ☐

Thank you

Appendix 7: Interviews for qualitative survey

HIV positive people's perspectives on living with HIV and medication

Research aims and questions:

2) To explore the ways in which issues of identity and gender may influence compliance to medication/treatment regimes

What role do (sexual) identity and gender play, in dealing with the virus and associated medical treatment?

3) To explore the medicalisation of everyday life for HIV/AIDS individuals

How does taking medications fit into everyday life and impact on social relationships?

4) To explore how the relationship between health care professionals and people living with HIV impacts on compliance

How does the doctor-patient relationship influence HIV medication compliance?

What are patients' expectations of their doctor and of medication?

5) To understand the socio-cultural positioning of HIV/AIDS sufferers, and how such positioning influences compliance to medication.

What are the patients' perceptions of the position of HIV positive people within society?

How might such perceptions underpin compliance to medication?

TOPICS

1. **Experiencing symptoms**
    - The symptoms you were experiencing
    - What impact did they have on the quality of your life
    - Did you have any suspicions?
    - How did you feel when experiencing the symptoms?
    - Did you reveal your worries to anybody?
    - How did they react?
2. **Being diagnosed**
    - How did they make the decision to have an HIV test?
    - Where did they go
    - Which were their worries?
    - How did they feel when they were diagnosed as HIV positive?
    - Who told them?
    - What affect did it have on their life?
    - How do they feel now?
    - What happened in between and their feelings changed? If they have changed.
    - Describe how did you feel waiting for your blood test results
    - Describe how did reacted/felt at the moment you were diagnosed

3. **Medication and Compliance**
    - Since when being under HIV medication
    - Expectations from HIV medication
    - Satisfied or not
    - Does it fit in everyday life? Why?
    - Are you experiencing any side-effects?
    - Worries about any possible future side-effects
    - Have you ever stopped taking your medication? Why?
    - What medication are you taking?
    - How many times per day?
    - Are there any food or alcohol restrictions?
    - What are your expectations regarding medication for the time being?
    - What are your expectations regarding medication for the future?

4. **Revealing my HIV**
    - General acquaintances (friends, family, sexual partners)
    - Work environment
    - How did you decide to reveal it?
    - To whom?
    - How did they react?
    - Why did you reveal it?
    - Which were your expectations?
    - How necessary do you find the revealing of your health condition to other people?
    - Which reactions do you experience more, positive or negative?
    - Why do you think this happens?
    -

5. **Impact of your social network**
    - Have you told them?
    - Their reactions
    - Impact of their reactions
    - Are they supportive or not?
    - Does support play any role on your compliance?
    - What was the impact of your health condition on your social network when you were first diagnosed?
    - What is the impact of your health condition now?

6. **Relationship between Doctors/Health care professionals and you**
    - Beliefs and expectations about Doctors and Health care professionals
    - Satisfied or not
    - Do you want to be treated as special patients (within the health care profession) or not?

7. **The role of the general public on their experiences as HIV positive individuals**
    - Is general public's opinion positive or negative?
    - What do HIV positive individuals think about people's opinion? Agree/disagree and which is the impact of it?
    - Does general public's opinion play any role on your compliance?
8. **Knowledge of HIV**
    - Where did you find information on HIV
    - Did somebody else inform you?
    - Legitimacy of information, accurate or not? (From friends etc or Doctors)
    - Do you update your knowledge? If yes, how? If no, why?
    - Did you take information from the media?
    - What is their opinion on the way that media inform people regarding HIV?
    - Were you informed about HIV at all when you were first experiencing the symptoms?
    - Where did you first look for information on HIV? Before/ after diagnosis?
    - What did you understand from the information that you found?

9. **Social support (Family, friends, colleagues)**
    - How does it feel to talk about your health condition with someone who experiences the same situation?
    - Which are the reasons that would possibly lead you to talk about it with someone who knows?
    - How would you characterise this type of conversation?
    - How do you feel about people who have the same health condition like you?

Background information

15. What is your age? ☐

16. Nationality: ☐

17. Gender:

Male ☐ Female ☐

4. Sexual identity:

Men who have sex with men ☐

Men who have sex with women ☐

Women who have sex with men ☐

Bisexual ☐

5. Date diagnosed as HIV positive:

Month: ____ Year: ____

6. How many years have you been taking medication for HIV?

☐

Today’s Date: ________

Informed consent

The aims to be explored through the interview process are issues of identity, gender, the relationship between doctors and patients and social understandings of HIV positive individuals of HIV within society. Through interviews, the present issues, along with issues that might arise during the process of the questionnaires and diaries will be given the chance for a more in depth exploration, which will be understandable from your point of view. The interviews will be recorded and access to the information you will give will be given to the researcher only.

- I have fully understand the subject and the aims of the research

Yes **No**

- I understand that my name and any other personal details will be dealt with the outmost respect and confidentiality. Anonymity will be maintained at any time of the process. At no time will my details be passed at another hospital/organization without my permission.

Yes **No**

- I understand that I have the right to withdraw from the process at any time.

Yes **No**

- I understand that I have the right to avoid disclosing any information that I do not want.

Yes **No**

Signature:

Date:

Researcher's personal details: Margarita Gavriilidou, tel: (GR) 6946755895, (GB) 00447817769907, e-mail: mgavriilidou@hotmail.com

Medication they are taking

Frequency

Food restrictions

Alcohol restrictions

Appendix 8: Diary for qualitative survey

My
Everyday life
Diary

Contact details:

Margarita Gavriilidou,

Tel: 6946755895/00447817769907

e-mail: mgavriilidou@hotmail.com

My Diary

This diary has been designed as part of a research project on how HIV medication makes you feel and how it fits into your everyday life. Only the researcher will see what you have written. Please complete the diary for one week only. The blue diaries are for men and the pink diaries are for women. There is no need to put your name on the diary.

Aim of the diary

- To help the researcher understand what you do during your day, who was with you when it happened and how you felt about it.
- I also need to know how taking medication for HIV fits into your everyday life.

Instructions

- Each page will have a different colour, and it will be divided into the two different parts.
- Please complete the diary every day. Give as many details as you can
- Please write the date that you complete the diary each day.
- At the end of the diary, you will find a box where you will be asked to give more detailed information about your feelings when you took HIV medication during the week
- At the end of the week, please answer the questions on the last pages of the diary

What to write about

- Write about what you did, who with and how you felt.
- Please remember to indicate when you took your HIV medication or if not, why not, every day.
- At the end of the diary, please complete the questions concerning the completion of the diary and some background information.

MONDAY

⇒ In the next two pages, you will be given a brief example of what you have to do

DATE:10/02/2005

Time……	What I did today	Who with	Where	My feelings
07.00-09.00	Today I woke up at 7.30am got ready and went to work. At 9am I had a break from work in order to take my medication.	With one of my colleagues	At work	I was anxious because I was afraid that my colleague might have seen me
09.00-11.00	Still at work, writing at my computer, I was very busy today	Alone in my office	At work	No special feelings, I was concentrating on my work
11.00-13.00				
13.00-15.00				
15.00-17.00				
17.00-19.00				

MONDAY Continued

Time ……	What I did today	Who with	Where	My feelings
19.00-21.00				
21.00-23.00	Chatted on the phone for an hour with one of my friends and then my partner came to visit me.	With my partner	At home	I felt relaxed and happy as my day was quiet.
23.00-01.00				
01.00-0300	Sleeping	With my partner	At home	No feelings
03.00-05.00				
05.00-07.00				

⇒In the box bellow, record the impact of the feelings you experienced every time that your were taking your HIV medication. Such as, what you did after experiencing those feelings.

Example

When I was about to take my medication this morning, I realised that one of my colleagues was standing beside me. I felt very anxious because I didn’t want her to see me taking my medication. The result of it was that I finally took my medication half an hour later than I was supposed to take it while waiting for her to leave the room. Later on the same evening, I felt very relaxed as I was chatting on the phone with my friend and then my partner visited me.

MONDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.

DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00				
09.00-11.00				
11.00-13.00				
13.00-15.00				
15.00-17.00				
17.00-19.00				

MONDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00				
21.00-23.00				
23.00-01.00				
01.00-0300				
03.00-05.00				
05.00-07.00				

TUESDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.

DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00				
09.00-11.00				
11.00-13.00				
13.00-15.00				
15.00-17.00				
17.00-19.00				

TUESDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00				
21.00-23.00				
23.00-01.00				
01.00-0300				
03.00-05.00				
05.00-07.00				

WEDNESDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.

DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00				
09.00-11.00				
11.00-13.00				
13.00-15.00				
15.00-17.00				
17.00-19.00				

WEDNESDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00				
21.00-23.00				
23.00-01.00				
01.00-0300				
03.00-05.00				
05.00-07.00				

THURSDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.

DATE:10/02/2005

Time……	What I did today	Who with	Where	My feelings
07.00-09.00				
09.00-11.00				
11.00-13.00				
13.00-15.00				
15.00-17.00				
17.00-19.00				

THURSDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00				
21.00-23.00				
23.00-01.00				
01.00-0300				
03.00-05.00				
05.00-07.00				

FRIDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.

DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00				
09.00-11.00				
11.00-13.00				
13.00-15.00				
15.00-17.00				
17.00-19.00				

FRIDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00				
21.00-23.00				
23.00-01.00				
01.00-0300				
03.00-05.00				
05.00-07.00				

SATURDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.

DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00				
09.00-11.00				
11.00-13.00				
13.00-15.00				
15.00-17.00				
17.00-19.00				

SATURDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00				
21.00-23.00				
23.00-01.00				
01.00-0300				
03.00-05.00				
05.00-07.00				

SUNDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.
DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00				
09.00-11.00				
11.00-13.00				
13.00-15.00				
15.00-17.00				
17.00-19.00				

SUNDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00				
21.00-23.00				
23.00-01.00				
01.00-0300				
03.00-05.00				
05.00-07.00				

BACKGROUND INFORMATION

⇒The following questions ask you about yourself, your medical condition and your medication.

1. What is your age?
2. Nationality:
3. What medical condition do you have?
4. Date diagnosed ⇒ Month:_ _Year:_ _
5. What medication are you taking at the moment?
   __Idon'tremember____
   ____
6. How many times per day do you have to take your HIV medication?
7. How many pills do you have to take every day?
8. Are you supposed to have a meal before or after your HIV medication?(Tick the appropriate box)

   Before medication ☐

   After medication ☐
9. Do you experience any side-effects? If yes, please write them, If not move on to the next question
   ____
   ____
10. Gender:

    Male ☒ Female ☐
11. Sexual identity:

    Men who have sex with men ☐

    Men who have sex with women ☐

    Women who have sex with men ☐

    Bisexual ☐

⇒ Complete the following questions at the end of the week

15. Was the diary helpful? Explain why.

16. What was difficult about writing the diary?

17. How did the completion of the diary made you feel?

18. Any comments you might want to make.

⇒In the box bellow, record the impact of the feelings you experienced every time that your were taking your HIV medication. Such as, what you did after experiencing those feelings.

Boulton, M. (1994) *Challenge and Innovation: Methodological advances in social research on HIV.* L

Appendix 9: Transcribed Translated Interview

(Dialogs in Italics are the ones been used in chapters four and five)

R: So…here we go, at first I’d like you to tell me eeeh…what happened when you first realized that you might were HIV positive, anything….before you have any check up, something like a story, tell me how it started

P. Yes, basically I did the check up because I had a relationship then and I wanted to do it (the check up), so as to move on…sexually eeeh…the man, he (the participant’s boyfriend)… had a relationship with, eeeh …had already passed away, from AIDS, he had died before a year or so eeeh… he (the participant’s boyfriend)had stood by his side for seven years, he was telling me and I believe it (now), and then … he told me that “my boyfriend has...the others were not coming close to him, I did not have a problem with that, and we started a relationship together and…at some point ….but he was not infected...”

R. Yes….

P. Eeeh…and they were treating him in England because he lived there….a Greek in England and they were treating him because ….experimentally, to see what was happening and he wasn’t infected, although he wanted (to get infected) because as he said he loved him and made love to him without using a condom because he wanted to become infected..eeeeh…to stay together to go through the… so the time we met each other there were many people that didn’t come close to him since his friend had died (from AIDS) so he was supposed to have AIDS, and…eeeh…he knew from him that he had done a check up and he wasn’t (HIV positive) eeeh….so after a while that we decided….that I decided to (bad sound) , I thought I should have a check up to see, I couldn’t believe that I could have…!!.probably I was think about it at some point …that I could be (HIV positive), even though I didn’t have a certain life (meaning engaging in risk behaviours)

R. Why was it possible then?

P. *Eehh.. because as a homosexual, I believe that everybody is prepared that something like that might happen to them, this is possibly how I was thinking about it, and there was a time that I even wanted to have it (HIV)…*

R. For what reason?

P. I don’t know, it is something that sometimes is happening to us, to do bad things to ourselves, let’s say that I went through a crisis eeeh… although I thought I was careful in general and I was careful because I didn’t….go to parks, bars, dark rooms and all of these, because I thought they were very dangerous and I wasn’t doing them (he means I wasn’t going), I was meting people. Anyway I did the check up so as to be together and I found that (bad sound)…that I am HIV positive.

R. Did you expected that then or not? Or that stage that you say had passed?

P. I didn’t want it and I wanted it, sometimes I believe that everything that comes is because that we want it. That time I didn’t want it (HIV) but…finally…I had read somewhere that if you wanted it (HIV) so much it will get in your body let’s say, is…it mostly happens to people that they want to get it, now…what I say is bullshit but ok…

R. Especially for this virus?

P. Yes, yes, maybe and for other things too, things that you are afraid a lot, happen to you or things that you want so much eee…I think that….I don’t know if the…deep inside me as far as I’ve considered it when I was younger, several years passed now, eee…(bad sound)…I wanted it…to get into this situation, but that time… I didn’t want it…that time as I was with that relationship. I don’t know what happened…(he laughs) I guess reality (he laughs) some things of the ((bad sound)…and I took (got infected with…)the virus without intending to…not because I wasn’t careful, I had some relationships with people that had told me that they had the virus, without being afraid, with protection of course, this thing had happened, it’s not from that relationship, I know even from which case it is, ok and…these years were bad for sure, I don’t know…

R. How were you feeling?

P. Eee….I remember the moment that…that they told me, I was doing ok, there was another guy inside(the hospital), and he was younger than me and he was saying eee…I know, it’s negative, I said my name, aaah he was full of joy…me and him…and then he told me (the doctor) we want to see me at the office, I immediately understood, there was no chance not to understand, because in England there was …the…(bad sound)…and he kept saying, saying things that I had already knew but when I got out of the hospital and took the bus to go back to work eee…*I felt like I loosing the earth under my feet, I was in a bus looking at people and it seemed that they were moving very fast, and I didn’t know where they were going, generally I felt panicked those first days, in fact when I came back here* (in Greece, he was in England) *it was October, it was my birthday, a good weather in Greece* (October is considered as a high temperature month) *and I covered myself with five blankets in order to avoid getting cold*

R. Were you afraid?

P. I thought I was…basically…I was thinking about my family, my relationship…mostly these, and it went through my mind…and I said ok, yes, I won’t manage to go (to England) because they had booked me a ticket for next week to go to England, I won’t manage to go to England, so …(he is laughing) silly but it went through my mind…

R. Were you afraid that something bad could happen?

P. Yes…and I went on a bad process which no matter how much I wanted it, subconsciously I mean, I didn’t consciously want it eee…I felt bad, I mean no matter how enthusiastic I was, even if it was not something to be enthusiastic, I felt very bad and all the knowledge I had about this, back then, didn’t exist.

R. Just like you forgot it.

P. Yes, I thought that someone dies right away(from HIV), back then people died, it was a vicious disease, this story was before 1996, on 1996 new medication came out and AIDS changed as a disease, there was no medication until then, they gave you an azete(type of HIV medication) and it was very bad…even though I knew some things, I knew that you wouldn’t die, that time eee…at that stage, I felt I hadn’t any time left…

R. Despite of all these, this contradicts to all the things you are telling me, that you wanted subconsciously to have something like this (HIV), but when it happened …well it seemed right that you felt panicked, because this…I’m telling you so because it impresses me…

P. I believe I would have been more panicked if I had never thought about it and didn’t want it, I mean if I lived a normal life and I wasn’t thinking of it at all, if I was away from these things…then out of the blue I would be shocked, because I solved this fairly quickly…because it is something, it was a situation I wanted to live. I knew it was bad, it wasn’t a nice thing, I knew that it was … a horrible disease, I saw people, and you know people who were dying…and in London… with all these symptoms at their faces …to see people melting eee…it wasn’t at all pleasant, because it was very bad, this was the message of the disease back then, that someday you will die and die very bad…by losing mostly(your mind), I remember I didn’t want to loose my mind (he is laughing).

R. And how did you manage to recover fast after the….?

P. I left…eee…I was thinking to go to England, because the guy I had a relationship with was living in England, finally I went to England, I told them there(that I was HIV positive), I didn’t deal with the attitude that I wanted, that’s for sure…

R. (attitude)From….your relationship?

P. Yes, yes…the relationship ended of course, I was very annoyed, so much at that point eee…
R. Why was that annoying?
P. Because I …when he was telling me (the boyfriend)that people didn’t come close to him and I told him that I would stay with him, that I didn’t mind, and…you’re telling me this instead of…(that I should)feel good that a person is honest with me when is telling me that his friend died from…and (bad sound)… corresponding and is telling me excuses “I don’t want to go through the same things with my friend and live that again”, so he was giving me the sign that I would go away very soon and he told me to live the most intense I could…
R. How did that make you feel?
P. I knew, I knew it that there was no future at this story, at least at that time, and it was not that I knew it, that I was optimistic that things would become better, however I subconsciously remember that I had told him that I would not die from AIDS, I had told him in one of the many conversations that we had at that time, that many years would pass by and I wouldn’t …eee…sometimes I was thinking that I can even beat this disease (he is laughing) but ok, I think this is something that everybody thinks at the beginning, we want to beat it, you are so optimistic that you can fight it and all of these things. Finally I got used to it (bad sound)…in England …eee…the doctor at the hospital (bad sound)… I requested for a verification.
R. By yourself or somebody suggested it to you?
P. I wanted it and a girl-friend of mine suggested it.
R. For what reason?
P. Not my boyfriend and that bothered me…because…She came and hug me, I felt that I could trust her, that she felt sympathy for me, and se said maybe they were wrong, with the mentality…(bad sound)… and I did it at three different hospitals and every time that they told me the result I felt like the first time, every time was as much painful as the first one…
R. But why at three hospitals? You could end it the second time.
P. We went at the first, then at the second, we went at the third because we would do it… it would be very fast, I think in an hour, so as to verify it…
R. Did you believe that there was some kind of mistake?
P. but that’s why I was going, eeeh.. I don’t know, at that point I wasn’t …following my friends in England…and I thought maybe it wasn’t, I wasn’t doing something that…(bad sound)…consciously eeeh…and there were times that the answer was the same, the third time was even better because the doctor gave me his hand and told me that I was ok and I felt …I stopped being ashamed, because I was a little ashamed until then.
R. Why ashamed?
P. Eh, generaly speaking… how he will say it, how we were going to understand each other (bad sound)…how was I infected and all these things…
R. There were also the mass media that had a negative attitude back then…right?
P. Even now they talk badly, but back then much more…even worst…
R. Were you feeling ashamed for your health condition or because you had to justify for your life?
P. Mostly this…because eeeh…”look what happened to him”…something happened….I mean you did something and you paid the price (bad sound)…what you did (bad sound)…and did (bad sound)… to people…I mean those who were not careful and it could be anyone…from that time I changed myself, I saw it differently, I saw it differently, from my perspective, I gathered my family and I told them, to my whole family.
R. How did they react?

P. *During that time my boyfriend came back to Greece with me, ehhh…I went ….with…my sister and I, were already talking about issues like that, so maybe she knew a few things, so she was the one that would announce it to the family, it was like a frozen picture, now I can explain it, after so many years, I mean I would prefer my frriends' reaction in England, (I wanted them) to come and hug me, only if someone from the family would do it, and they didn't…because we are not the type of family that hug or kiss each other and stuff*

R. They keep their distance…

P. Yesthey keep their distance, it is a typical family, like most (of the families), but…they didn't show me something negative, then I left…of course I told them…I presented it positively of course…I told them this is it, blah blah, this is what the check up showed, I have nothing for now, years will pass by, I am not in danger, I was telling them in advance, my knowledge…I was giving them the answers before they even asked and when I left I knew that my sister would take over to unite the family and tell them…how to support me. At the beginning I was supported from my brother, alot, but it bothered me because he was telling me not to get a cold, if I ate and all of these…eeeh…since then they clearly saw that (bad sound)…*I went at the centre of inspirational living(Non governmental organization for HIV positive people) and I became a volunteer, I was visiting hospitals and all that stuff in order to learn everything around this subject, what will happen and when…you know I was feeling much stronger…I was feeling…*

R: When you are saying what will happen? In regards to health?

P: Health yes

R. To see what was going on in general (regarding HIV)?

P. Regarding health, that interested me the most…

R. How? (To learn) From doctors or by meeting people that might had…(HIV)

P. Mostly from patients at the hospital, and these were bad experiences…and after all these years I think that if I had so many experiences then…I was dealing with that and I did not know what it left inside me, I've seen a lot of deaths, many people that I was losing after a while and some of them had become my friends, and until recently I was losing friends and some of them left very bad..

R. You put yourself in a very weird situation.

P. Yes but that's the way I wanted to learn (about HIV), I wanted to know what would happen to me, I didn't want not to know things eeeh…and maybe I became stronger, I don't know, my family was telling me that I was ditacched, they had never seen me…at the hospital, only once at the beginning at the hospital, since then…(bad sound)…only my brother went to the hospital once at the beginning, and he was asking how everything was but…nothing else.

R. As far as your family, from what you have told me, you thought for them in advance…

P. Yes, yes…

R. …you should be strong already, so as to be able to (bad sound)…give them that…

P. Yes, I would never go, I don't even like it, I don't like to seem wick, that's my style as a person, at every phase of my life…I don't want to be inferior…not inferior, wicker than the others…

R. Wicker…

P. And (bad sound)…at all, to live it in my life and in my relationship and in everything… I did the same with my family, I tried to have the strength, to fight it before something happens to me, at least for now…

R. This…

P. What? Basically what I give is what I take back, if I was miserable and I know…that if was very bad and sad and all these, the others would see it bad, and they would give

me…you know panic and all these things, I wasn't panicked so that they would panick, I was optimistic, even if it was pretending it that time because deep inside me I wasn't ready, it was too early for me…that's why I came here right away (in Greece)…
R. Right away?
P. It was less than a month since I found out…eeeh and the delayed it because I had to think about it, because my father died that period and I didn't want to be at that process…I couldn't..
R. Despite of all these you seem to got over this very fast, is that right or you dealt with this at the beginning and then you were working this step by step? You are giving me the impression that you had questions, or let's say fears…
P. Yes, yes, yes…
R. You dealt the most of it in the beginning….
P. Yes, I wanted to learn those issues, it is just that when I don't know something in the beginning and I don't know how to deal with it, I pretend that I don't understand anything at first, I mean I don't want to deal with it so much until I will calm down and then I can think things over. I saw it like something distant from me, out of me…
R. Was it how you were feeling regarding this (issue)?
P. Yes and I started exploring it, visiting the hospital, anywhere, observing things(situations), to explore it good and then, to get it out of me, what is happening to me? what is happening? and all these things.. I am not so self-centred, (that I want) everybody has to run around me, and I didn't want them to show me neither mercy nor anything else and…when I was in a stable condition (psychologically) and I saw everything I wanted to see and I knew how strong I was…First of all I stopped being ashamed about it, and I wanted to say it but in the beginning my family wasn't letting me to, it is them that created …(bad sound)… and stopped me…why? I don't even want to say it out loud because it is my issue and nobody needs to know about it but…even my mother sometimes doesn't let me to do so, ok if somebody asks and all these…alright excuses but (excuses) that are logical, anyway, it bothers me, it brings up an issue that I didn't want to have in my life, I believe that is very important not to feel…not to have guilt….
R. was this happening anyway? (I mean) not feeling guilty or did it happen later on, after the diagnosis, because you told me that you were ashamed at that moment….
P. Yes, yes after, after (the diagnosis)…the doctor that announced me the results helped me a lot, I was announced the results in London because when I came back to Greece, the way they told me was very annoying…very…big problem and so on, I didn't like it. Eeeeh…I then came back to Greece and I did more check ups at the hospital, my health was fine, I could see that I still had time, I was looking at others and they were in a bad condition, Therefore, I had time and I was feeling stronger, I was observing that some people had it more years (than me) and their health was really bad, with zero "T", back then how many "Ts" you had was a serious matter, because they (levels) fell and couldn't come up without medication eeeh…so I was feeling that I was at arm's length from unpleasant issues, it wasn't bothering me reading things, I have read anything about AIDS and …(he is laughing) maybe literature and medical books, anything…and lately very bad things, things that, now that I'm thinking about it it's impossible not to be helped from all of those eeeh….and even if they don't come true, mostly things that I've dealt with and all these descriptions…the pictures I've seen. I will give you an example so that you can understand, although at that time I was travelling a lot, I was running, I was working, I couldn't sit, I am a person that can't relax easily, the fact that the stairs were tiring me up really impressed me, I couldn't walk on stairs. And I said what the hell, I am dancing…I remember we had parties and I was dancing from 10 o'clock (at night)until 6 in the morning, I couldn't stop(dancing), and now I was tired with few stairs? The bus's steps? The bus 's steps were the main trouble, the bus step,

and then I tried to think what was that…what was that…and I realised that at the first book I've read there was a French guy (bad sound)…who was saying about the disease…he finally died, and all these that he was saying…he begins when he was 60 years old, with anything that he couldn't do…and all these…and that was the first image that came in my mind so…and…I have it so deep inside, this influenced me a lot at…(he is laughing)…a step and I can't…(he is laughing)
R. Were you actually able to walk on the stairs?
P. Yes, but of course…(he is laughing) even at Nafplio's stairs (a Greek castle with 1000 stairs) and I walk a lot, lots of kilometres (he is laughing)
R. So you are giving me the impression that….
P. And finally all these that influenced me…these that I had struggled with… I hadn't realised them at all and…I was thinking that I had a difficulty with stairs, I imagine that there are many things that I may have solved and I haven't realised it yet, sometimes I feel that it is a heavy load…what I feel about AIDS, and all these people I've met and I was thinking to stand by them, because you know I;ve worked as a volunteer at the centre (centre of inspirational living), I've supported a lot of people and I've received a very…big load, sharing their load and I kept it, a self supporting group has come to an end already here and there was a guy that had a crisis…something…from somewhere …and I realised that this feeling was tiring me, so many new people, what is happening to me….?
R. You're giving me the impression that you are a guy …as far as I know, who is fighting, fighting from the first moment and you were seeing that you were coming close to all these people that were ill and hadn't any relationship with you, to see everything (beforehand) so when the time comes, if it does sometime, you will be able to know what will happen, what you will have to deal with…
P. Hmm…I believe that, look…
R. To be prepared for everything and even for the load that you were taking from the others…
P. I had to find strength…
R. Yes, from the others, from the groups, at some point though, it passes my mind maybe …you didn't have the courage as a human being but in order to see everything and show strength, this whole thing was coming back to you.
P. Look, we are doing what we are doing for a reason, and I believe that one of the reasons that I'm volunteering and I'm talking so much with…all these guys at the centre, all these years, is giving me strength and at the beginning I was giving more than taking, but I see their weaknesses, I see that they feel bad, that the worst things passed and I feel that I'm better (now)….
R. Yes…
P. Or at least that I am dealing with their issues instead of mine…
R. How could you put, could you talk about the reasons that make you help? because we both know that you are helping a lot of people that are HIV positive.
P. I'm doing it because I always did…even before…I was taking care of friends, patients and all that, I offer a lot, even at school I was sitting next to the dumpiest of the class every day, despite the fact that I was an idol at school, because I was in a music band and they thought of me as a very important person and later with other people who had problems, so that's my character and since then I realised that I'm taking strength from this.
R. So the difference from then…in relation with today is that now there is one more motivation, you are taking strength from this…
P. Yes, but don't forget that this is something that has to do with me
R. Its human of course…
P. It is something that concerns me, why bother with something else and not with this…

R. Yes but it is…(we are speaking at the same time and the sound is bad)…everybody does it….

P. I mean I was like that, it didn’t happen out of blue…this offer, I was like that from the beginning….

R. I understand, it is totally normal, besides that many…most (of the people)…even the volunteers at the centre are taking a lot of things (from volunteerism….

P. I’ve done relationships with HIV positives who are (bad sound) it is a possibility…(bad sound)….because relationships don’t work…

R. Why…(bad sound)?

P. Eeeh…because they know they won’t get infected, and they are sure, in words at least, …and because I think that we have to take risks at our life…

R. Taking risks? For what reason?

P. *Look in the...I was always interested in appearance, I always wanted somebody to appear good, sometimes though I wanted...to look who is beside me...besides appearance though I believe that I could reborn through a situation like this, I mean that...I want regeneration in my life...*I mean I had such…in my life to be regenerated, to get me out of my lassitude. My life was good, financially I was very good, the same at work, I didn’t have much problems, but my life was a little boring and I felt that this could lead me out of…life is not just traveling and stuff….

R. to shake up things a little…

P. yes, I feel better with myself, ok much better, I mean I sense my feelings better.

R. Did it happen?

P. It happened, I believe the best years were those after AIDS. All my life was empty…my previous life, at my youth I was living very intense but without understanding, but every year…every year that…it was fine, I don’t have anything to say, the most intense, the most emotional was the life after AIDS…

R. So it had…things were more essential…

P. Yes, yes…

R. …After this….

P. For many things…

R. …Because what you are saying is something… I’ve heard many times and impresses me…

P. *If you don’t take it...eeehhh...and if you don’t take it, and if it doesn’t take you with it and you won’t be...what happened to me and what a bad thing this is and be able to see the positive point of view, it has a positive point of view...you discover friends, you discover yourself better, you discover better relationships...you see life differently. For example I...what I will say might seem stupid or romantic but I remember we had gone for sailing with people from the centre of inspirational living....we were giving information to people (about HIV), it was sunset and I was on the boat, at the front, at the back...anyway I don’t remember...*

R: Anyway and?

P: I was looking at the sun disappearing into the sea, I was alone and I had sat there to read emm... I was thinking that, it was the first time that I realized that I might die and won’t be able to see this thing again tomorrow, this was the first...of death. And I was thinking what a wonderful thing was that...something that all my life...I had traveled so much, I had seen so many things, but I had never felt something so deep inside me as that moment. Since then I am looking at everything, the leaves from the trees, the winter, the yellow leaves that fall of the trees on fall, May...the summer sunset in Santorini all that, they are very interesting, I am looking at everything in a different way.

R. You are living them more intense, living them, understanding them, feeling them…

P. Yes…

R. This is very important….

P. Ok…I believe that this is very important for certain people too, I mean how others see it…

R. One thing that I've understand is that…from the centre of inspirational living… the meaning of hugging a person…

P. It is…as a volunteer… I'm tired from all these, I feel very tired with the centre. At first I was so enthusiastic that I wonder how I did some things, I did things I couldn't imagine, at first I went sailing, who me, who hated sea and…(bad sound)...and imagine that we were arriving from Piraeus by boat by ourselves and then …I was going to the hospital and hugging people…people who were sceletors, I was a bit squeamish, imagine I was able to hug them, so much strength inside me by doing it. Now I'm not doing it so much, I keep my distance eeeeh…

R. What is the difference from back then?

P. To tell you the truth all this thing with AIDS is fading, I mean…the best years were those that AIDS was a deadly disease, they were very intense because it was something that you lived with and something that had rapidly… you could die from one time to the other, it was a direct threat, so direct were the feelings that were born(from this), how will you move on and so on. Now it is a chronic disease, ti is like freezer, that's what bothers me, it is that everything is outworn, it bothers me and all these things in general…

R. A routine came to your life again?

P. Life became a routine again and I want something eeeh…to break the silence…but on the other hand I don't feel the same about people that are coming…and they tell me things…maybe because I dried (inside) eeeh…what happened to me and stuff. Ok…there are worst things, there are cases that I've seen, with hands, feet being cut. I think other things…there are and…(bad sound)…that had, he couldn't dance, run and anything, I believe that psychologically I am fine…

R. So you could compare…

P. Yes, and on the other hand why hugging those people who are struggling…I talk to them, I understand them, I feel sympathy for them but I don't feel as I was feeling before about the people that I was meeting (HIV positive people)…maybe the next day I wouldn't see them, and they knew it too, I mean no matter what you would say to them they would give positive energy to each …

R. Were you taking strength from them?

P. Yes, yes…

R. From them?

P. Yes, yes, yes, I knew that at some point I would be in their place but I was saying ok…I might…make it?…at least I will know what my place will be and try not to fall down (metaphorically) as a person, not to show it, because these people were very pathetic during their last moments, I wasn't seeing it like that but for others…they saw it that way…not wanting to come close to them, hug them, touch them…

R. You are talking about people…I see that you are…that you have looked inside yourself, you have philosophized the situation, you have accepted it…you don't have problems with that situation… (bad sound)...for others…one…ok…(bad sound) totally, like they are out of you (your way of thinking) , not that it is not, but like they are in another dimension and that they understand completely different things (comparing to you)…

P. Eeeh…yes…look, that's it …(bad sound), they don't come close…

R. Regarding AIDS, their opinion and what they believe…

P. Yes, but even… (bad sound) and even if it doesn't pass now and will be let's say that some years ago AIDS was for… (bad sound) it was like that some years ago, now they say it's nothing, it is chronic disease, a lot of years will pass, those things that doctors say, but you feel the same thing, that you don’t have enough knowledge, I feel confident and I don’t feel…I can’t understand the panic, this issue….

R. And what do you believe…that people think…the average Greek people?

P. *They are not informed, no they are not informed eehh…they find something hideous and of course the strange thing is not only like…just because is a sexual transmitted disease and lately it is exclusively a sexual transmitted disease, they have to justify their lives, anything that they do secretly, they have to show that there are some people where…they belong to specific groups, wrong in every aspect, I am not in that mood…and I have passed the stage of this shame or this stress, however there are a few that still have it, I have seen it at the group therapy, a lot of people feel it*

R. is it a taboo?

P. *yes, yes pretty much…in my opinion some people have more difficulties on how they got infected from HIV than the HIV itself. I happened to be in front of an incident where a son revealed his positive status and his personal preferences (sexual) to his mother and she got fixated about her son’s choice of being homosexual than to his HIV positive status, which is (HIV/AIDS) more…straight… your life is in danger, she could lose her child, and she cared about what they were going to say to the people in the village (where they lived), and what will happen, and nobody should find out (about his being gay), this was her most important problem* (he is laughing)

R. Which do you think is the reason for that? What should be done about that?

P. It is… (bad sound) but you have to gain the knowledge by yourself so as to avoid all this, let’s say...and me...if I go into drugs and be around all these people I don’t know how will I be able to deal with them but probably I will see them as sad figures, but at least, speaking for myself, I don’t have an opinion, I see them (these people) from a different perspective, I have come to a point that my ideas regarding those issues are very far from theirs. Of course others don’t have any...they think that this matter is far away from us “it’s not my problem” and so on, and if they suddenly find out such an issue they will see it as tragic and very sad and I don’ know what else...

R. Yes, but it’s difficult for everybody to think about all these and find out about AIDS like other things…

P. But I don’t believe that people care about their lives, the leave it on others’ hands, so they move on depending from what they have learned (from others)...eeeh...I could say that I have different perception of things...eeeh..I think that if someone wants, can learn thinds and then the experiences are relevant to the knowledge (that s/he) has, which menas that my knowledge along with my experiences, and it’s not only my experiences, I myself as a person have been prepared for this issue...

R. Did you know from before…?

P. yes…but generally as a person and as...my way of thinking, for example I’d see that…(bad sound), with black guys, with Albanians…(bad sound) I would have a different reaction than my mother had…

R. Have you dealt with persons, as persons, in general?

P. That’s exactly because I’ve dealed with human beings, basically not with people, maybe more with myself and now you will say …(bad sound- he says that he was trying to look inside himself)…with myself, and from these things I was learning and that’s why my reactions were different, because is was not tragic for me, and as I’m growing and learning I become wiser, it’s not tragic. For everybody else that have…their initial habit seeing things as tragic, a disease,…a marriage with a foreigner, anything…(he is laughing) they do…they are turn insignificant problems to huge issues, they make them huge and then they...(he is laughing)

R. Have you ever faced something/someone that reacted…like that and turned simple facts to tragic issues? ... as far as it concerns the HIV positive situation?

P. You mean as an HIV positive person…me or someone else? Because I've seen a lot of people reacting paranoid…breaking up families, so as not to find out, these kinds of things…

R. When you revealed it and they reacted in a tragic way…

P. No, no, maybe they'll show me sometimes.... say aaah and all these but... I had informed a girl in the past at one school and she told me why don't you give more consideration (for an essay) on this issue since you have got HIV? And I replied that I don't have to deal with my issue, that I was just pointing out things that she should know and that I took the big decision and then... it is good to know certain things eeeh…I didn't eeeh…face rasism because I don't allow room to others, I'm not hiding, I am not miserable, not wanting the others to find out and then feel bad if they find out, to...put myself down, like let's say with…(bad sound), if somebody reacts with an aaah... like this... I don't feel like this, this thing will bother me …(bad sound) I can even leave and don't speak, I will laugh with this man's stupidity (he is laughing) who believes silly things that are not accurate, and has wrong perceptions about human nature.

R. Could you…Do you believe that people don't know how deal with HIV positive people just because of what the HIV positive persons show? That some of them(HIV positive people) are miserable as you are saying?

P. *Yes, yes, that is the image that people want to show, they want to feel good by seing others suffer eeehh….through t.v. and through all that stuff they read from the papers, they want to see it everywhere, that something bad is happening near them but they are having a good time so this means that they are ok,with this way they feel secure. If they want it like this, let it be like this so that they feel that security. Some others take advantage from it though, well with their own way, (they say e.g.) look what happened to me, I was in the train and I saw somebody begging, things that are not real…so they continue this situation. Basically AIDS has a big difference from other diseases, basically when somebody is getting sick (gets infected) now that we (people) know that it is something (HIV) that somebody will get over with, we run towards him and help him and we say oh.. the poor guy. In contrast to that, the first years of AIDS everybody wanted to run away from it, nobody wanted to be close to him (to an HIV positive person), even one mother, I remember I saw her on t.v., when they asked her if her son was HIV positive she asked them to forgive her and was saying to take him away, she excommnunicated him, with that kind of beliefs that… that mother had…anyway…. Since then, AIDS came to a new …to another stage of a chronic disease where is controlable, anyway it's how I say it, the keep it frozen. But people's mentality hasn't changed, I mean that all this panic, all this drama is also because it is something sexually transmitted, a disease that is trasmitted through sex and in a quite anorthodox way …as it is in many people's minds* (bad sound)

R. The way that mass media deal with it? The way that they are showing it?

P. They always want to find something bad, on a daily basis you see a meaningless story that ends up to court rooms, they go and find all these that are arguing, they are making a big deal out of this… so that people get scared and say Oh! What's happening…

R. Yes, I've read these that you're writing for this issue… about tv shows that…(he writes a column at a magazine)

P. *Hm…they have a subject when ever it suits them, if there is something new to say, lets say that they don't give an understandable information, it is not convenient, I don't think that…there isn't any information, especially in Greece. And this…Greece is very good at issues like dealing with HIV positive people regarding medication, retirement and so on, allowances I mean…but as it concerns information, I think that we are far behind*

R. Eeeemmm… what else… what else would you like to tell me about HIV positiveness, something I haven't thought of to ask you...

P. Look…

R. …Something that…

P. some years now, its been a decade since I found out, I have compromise with certain issues.What bothered me, was that before 97' we were given medication that we shouldn't receive, it was depending though, in the beginning they were saying that if you have less than 300 "T" (T cells) then you have to take medication. Then they were saying that the limit was 500 but at some point on 1997 they announced that you will take medication irrelevantly to the cell count, so that's why they (the doctors) gave me too. There was a great sensitivity for others…(bad sound) I tried to stop it (the medication) twice, with the interference of doctors, they suggested it to me, but it didn't work out for me, so I am in this category of people that have to do it (being medicated) for a life time, this conservation…it bothers me a bit. Now another issue that bothers me…

R. What you are saying about being in the freezer?

P. *Yes, yes this thing with medication, I remember when I was completing the questionnaire…I realised that taking medication is a routinized movement that makes me feel disgust, I just try not to think about it all the time*

R. Disguise concerning what?

P. *Why should I take medication, I don't want them, and what are they doing? Anyway I don't believe that...that they are doing something good to me, they probably harm me, and new health problems will appear in future…*

R: Like what?

P: I don't know, in my liver, kidneys, stuff like that

R. The future side-effects…

P. Stuff like that, cancer for example, I don't know…eeem…maybe I am chasing after these issues (laughing)…I don't know that's how I see it…

R. Is it self-destruction?

P. Yes, eeeh…yes I believe it's my character, is… but in general I'm not optimist with this entire medication story…eeeh….

R. So, although being HIV positive helped you... (we're talking at the same time)

P. I have to pay the price, I have to pay the price, but what is the price? Generally I'm ok with myself and this is where I take the, what helped me a lot back then, now it makes me feel tired eeeh…I am older of course that also has its part eeeh... *I don't have the same strength, the same courage, and I feel that my body became... all this toxicity and all the other things that (my body) could deal with…(bad sound), all these ugly situations, I don't feel I have the same strength to deal with them, that's the main issue that bothers me regarding medication and of course the problem is that ... I live with the virus and that... my contacts, my sexual contacts are very careful,* an issue that sometimes …(bad sound)

R. …(bad sound)

P. Yes, now that I live with my boyfriend, who's not HIV positive, there are many times it passes my mind, I say what will happen if something …won't go right…

R. How does his attitude make you feel? That he has accepted it and he doesn't have any problem.

P. I like it, I like it…(bad sound)… I can handle it, this is what I'm telling you, what you give and what you get, most people can't handle it because they go to someone (potential boyfriend/girlfriend) and they are crying and they remain like this even if the other doesn't want them, from what I've seen, a lot of HIV negative people wanted to have a relationship with me since I became HIV positive, but I didn't want them because they didn't fit me as personalities, I'm not lying to you about this eeeh…I like, I knew that it would happen me to be (in a relationship) with an HIV negative, but this you know. It scares me a bit, I am talking about me now…

R. You're dealing with a whole different situation than the others…

P. Because…because it is… I deal it in a different way, this… this is what I am saying to you that I believe, and you take back what you give…

R. it's the first time I hear that somebody had problems because only HIV negative people wanted him…

P. Ok, it's not a problem, I can't say it caused me troubles but I knew that I hadn't issues like others do, I remember I believed that there wasn't be a problem when I stopped working, eeeh if I would say at my work that I was HIV positive I would have more customers than somebody else who would have a store (a hair saloon), I would change it and they would come to me so as to what is happening, " What is this HIV positive thing that shakes us up?" And I would be busier (at work) I would change negative to positive, I can do it if I want it.

R. What do you believe that that the rest HIV positive people should do so as to overcome this one day?

P. To talk with their inner self, to talk with their inner self, yes, to be honest to talk with their inner self to see what's inside them, not what they want to see but what they really are…

R. Not all people have the same strength…

P. And they don't have the same abilities, as we grow up, people do not remain the same …(bad sound) that's how it is, it's easy for them to understand but they do not want to understand, I believe that it's easy to understand issues, but they have to learn … to get it, to understand it. But I cant't understand it when people in my age cannot understand things, lets's say they oversee them. They don't really want, they want to live in this fake world that they have created and that's why they are so scared with diseases…and they are easily scared and…with stuff that happen to their lives.

R. So they deal with them less…? (he interrupts me)

P. Look and imagine… you proving that I am HIV positive and I have this life instead of the one that I am presenting … I'm giving you an example… (bad sound)

R. Could you give them any excuse as far as it concerns medication?

P. To whom should I give excuses?

R. To the rest of HIV positive people, to those who are dealing with this situation in a completely different way than you do, the ones that are weaker…

P. I am giving excuses to everyone; first of all I can't blame anyone for this…

R. Ok, yes…

P. Yes, Ok, to all of those that understand, one reason that I became volunteer was to protect other people to deal with that…shock I've been through, some of them are still in this stage and constantly, even years after, eeeh... and they are older than me, but when I felt it deep inside me, even if it was for a short period of time, I didn't want that thing...if I could help... if they could not go through this, that was one reason that made wanting to become a volunteer at the centre and help. So I've given excuses to everybody, but I'm telling you how things are, what you'll give is what you'll receive.

R. One last thing that... we were talking about earlier and I didn't ask you, about this that you referred to for 4 times, the freezer, do you want to talk about it?

P. well*, the problem now, I am in a routine now, in a routine, this is not the issue, if I wanted to send a message it would probably be... to have a (bad sound) that I will have to take medication every day, and I am already taking them for several years, this thing is a bit tiring, I'll start my life every morning and I'll finish it every night depending to what time I will have to take my medication and eat food*, ehh… and this won't stop (bad sound), *It's not like antibiotics, two weeks, a month of patience and then it's over, I won't take them again. Now, I will take them, and take them, and take them and I will*

wait for the moment that something will happen to me, I mean honestly I don't believe that…this will give me something(meaning that medication will not help him)…and this happens because I want something to happen to me, this may sound weird (he is laughing)…
R. So as to get out of the freezer?
P. Not the medication...
R. Yes, you're saying... (he interrupts me)
P. I believe that...what ever that one believes eeeh... this will happen or anything that one is afraid of, this will happen, eeeh... I think that, I believe that medication will harm me, not with the invisible powers that we all have inside us, but sometimes I am thinking and I say to myself let them go, at least look at the positive site and keep going and it won't cost you anything, and if you really believe this it won't cost you anything. I am (bad sound) optimistic.
R. You don't believe that....
P. I'm bored; I'm tired of this situation...
R. Ok then... so it does this have to do with the freezer that you mentioned?
P. Yes, yes
R. What is the meaning of this freezer?
P. Eeeh... you are asking of what it is... it's when nothing is moving, it is frozen...
R. The routine...
P. Yes... exactly that, nothing is moving, life doesn't move on, I feel trapped, I want to free myself from this situation if it's possible, to end this story, and of course when I'm saying (end) ... I mean it metaphorically (bad sound), no matter how much I am saying that I am dealing with this situations, it bothers me inside, it annoys me I want to free myself from this…
R. Maybe eehhh...
P. Not to think about it at all...
R. Maybe eehhh...You gave me the impression that you put yourself in a tragic process, I mean, you said earlier "I felt strong, I could handle earthquakes, and every time (you are saying it) you are giving me the impression that you find strength through anything tragic that might happen...
P. *But yes, maybe inside you, the biggest cries, the strongest emotions originate through something very strong...*
R: something intense...?
P: I need something strong…in my case, medication made (my life) *look like a frozen thing, I have to throw it away from me because I can't…*
R: throw what?
P: eh...I don't know, to take it completely out of me, to stop thinking about it, even this small part of it that I have inside me now, this has to go as well, it bothers me
I have even thought of leaving from the centre (of inspirational living), I don't have anything else to give, I want to look at it as something temporary that it won't bother me a lot (bad sound), feeling that it doesn't exist. Well this is a type of freeing ness from AIDS, AIDS freed me from something else and I will have to be freed from this…and then….
R. You are in a constant race...
P. And then we'll see… (he is laughing)
R. Anyway, then we'll see. We have to finish now (the interviewer had to take his medication so the interview ended). Do you want to add something else?
P. No, I don't eeeh... what I said about... (bad sound) I think that most important of all is that they have to try and find something positive out of this, instead of what they are doing now. *The situation here in Greece is pleseant, in regards to the image that you present to the people, but still there are incidents where they (HIV positive individuals)*

complain..aahhh people don’t come near me, they don’t want me and all that stuff, well people do come close to us as long as we show them that we don’t have a problem with that, if we show them that we have a problem with this, then they never come close to us

Though, in reality... (bad sound) , usually girls and they shouldn’t, in my opinion, ... (bad sound) this mourning, from here and there, somehow they compromise, they get over it, you can see it... that’s all.

R.Thank you

Apendix 10: Translated Diary

Quality of Life Diary

A Study

By

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INSTRUCTIONS

- Please complete the diary every day.
- Please write the date that you complete the diary each day.
- At the end of the week, please answer the questions on the last pages of the diary

WHAT TO WRITE ABOUT

- Write about what you did, who with and how you felt.
- Please remember to indicate when you took your HIV medication or if not, why not, every day.
- Please complete the questions, concerning the medication you take, at the beginning of the diary
- At the end of the diary, please complete the questions concerning the completion of the diary and your background information.

1. How many times per day do you have to take your HIV medication?

2. How many pills do you have to take every day?

3. Are you supposed to have a meal before or after your HIV medication?

4. Do you experience any side-effects? If yes, please write them, If not move on to the next question

MONDAY

⇒ In the next two pages, you will be given a brief example of what you have to do

DATE:10/02/2005

Time……	What I did today	Who with	Where	My feelings
07.00-09.00	Today I woke up at 7.30am got ready and went to work. At 9am I had a break from work in order to take my medication.	With one of my colleagues	At work	I was anxious because I was afraid that my colleague might have seen me
09.00-11.00	Still at work, writing at my computer, I was very busy today	Alone in my office	At work	No special feelings, I was concentrating on my work
11.00-13.00				
13.00-15.00				
15.00-17.00				
17.00-19.00				

MONDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00				
21.00-23.00	Chatted on the phone for an hour with one of my friends and then my partner came to visit me.	With my partner	At home	I felt relaxed and happy as my day was quiet.
23.00-01.00				
01.00-0300	Sleeping	With my partner	At home	No feelings
03.00-05.00				
05.00-07.00				

In the box bellow, record the impact of the feelings you experienced every time that your were taking your HIV medication. Such as, what you did after experiencing those feelings.

Example

When I was about to take my medication this morning, I realised that one of my colleagues was standing beside me. I felt very anxious because I didn't want her to see me taking my medication. The result of it was that I finally took my medication half an hour later than I was supposed to take it while waiting for her to leave the room. Later on the same evening, I felt very relaxed as I was chatting on the phone with my friend and then my partner visited me.

MONDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.

DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00	I was sleeping			Normally
09.00-11.00	Today I woke up at 10.30, I don’t work today, I didn’t have breakfast, I took my morning antiretroviral medication and I went to the gym			Normally
11.00-13.00	I was working out, the issue of HIV doesn’t bother me, I don’t think about it			Normally
13.00-15.00	I came back home at 14.00, I had lunch and took my 2 antiretroviral medication			Normally
15.00-17.00	I went for a nap			Normally
17.00-19.00	I went to the centre of inspirational living			Normally

MONDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00	I came back home I had dinner and I watched tv	Alone		Normally
21.00-23.00	I lied down			Normally
23.00-01.00	I took one antiretroviral pill, I take four in total			Normally
01.00-0300	I slept			Normally
03.00-05.00	I slept			Normally
05.00-07.00	I slept			Normally

TUESDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.
DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00	I was sleeping			Normally
09.00-11.00	Today I woke up, had my breakfast and then took my medication			Normally
11.00-13.00	I went to the gym			Normally
13.00-15.00	I came back home for lunch and then took a nap			Normally
15.00-17.00	I went to a friend next door to play scrabble			Normally
17.00-19.00	I took my medication			Normally

TUESDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00	I cooked and then ate	With a friend	At home	Normally
21.00-23.00	I watched tv and then took my medication			
23.00-01.00	I slept			
01.00-0300	I slept			
03.00-05.00	I slept			
05.00-07.00	I slept			

WEDNESDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.

DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00	I was sleeping	Alone		Normally
09.00-11.00	I woke up, took my medication and had breakfast	Alone		Normally
11.00-13.00	I went to the gym	Alone		Normally
13.00-15.00	I came back home, I had lunch and then lied down for a nap	Alone		Normally
15.00-17.00	I woke up and I went to a friend next door	Alone		Normally
17.00-19.00	I came back home, had dinner and took my medication	Alone		Normally

WEDNESDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00	I lied down, watched tv and slept			Normally
21.00-23.00				
23.00-01.00				
01.00-0300				
03.00-05.00				
05.00-07.00				

THURSDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.

DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00	I hadn’t woken up yet			
09.00-11.00	I woke up, had breakfast and took my medication			Normally
11.00-13.00	I went to the gym			Normally
13.00-15.00	I came back home, cooked, ate and lied down for a nap			Normally
15.00-17.00	I woke up, I went to Pagrati *(location in Athens)* at a speech about yoga			Normally
17.00-19.00	I came back home, had dinner and took my medication			Normally

THURSDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00	I lied down to watch tv			Normally
21.00-23.00	I slept			
23.00-01.00				
01.00-0300				
03.00-05.00				
05.00-07.00				

FRIDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.
DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00				
09.00-11.00	I woke up, I had breakfast and took my medication			Normally
11.00-13.00	I went to the gym			Normally
13.00-15.00	I came back home, had lunch and took my medication			Normally
15.00-17.00	I lied down for a nap			Normally
17.00-19.00	I woke up and went at Menidi *(location in Athens)* to see my mother			Normally

FRIDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00	I came back home, had dinner, watched tv and took my medication			So and so
21.00-23.00	I lied down and listened to some music			
23.00-01.00	I slept			
01.00-0300				
03.00-05.00				
05.00-07.00				

SATURDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.

DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00				
09.00-11.00	I woke up, had breakfast. I took my medication and called a friend			ok
11.00-13.00	I went to the gym			ok
13.00-15.00	I came back home, had lunch and then I went to do some shopping at the super market			ok
15.00-17.00	I came back home, I cooked and then I lied down to watch tv			ok
17.00-19.00	I went for clubbing with friends			Nice

SATURDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00				
21.00-23.00				
23.00-01.00				
01.00-0300	I came back home for sleep, I took my medication			Ok
03.00-05.00				
05.00-07.00				

SUNDAY

⇒ Please complete the following boxes of the diary. Please remember that you have to state when you took your medications.

DATE:

Time……	What I did today	Who with	Where	My feelings
07.00-09.00				
09.00-11.00				
11.00-13.00	I woke up, had breakfast and took my medication			Ok
13.00-15.00	I went for a daytrip at Salamina *(island near Athens)* with friends			Nice
15.00-17.00	Walking at Salamina			Nice
17.00-19.00	Walking at Salamina			Nice

SUNDAY Continued

Time……	What I did today	Who with	Where	My feelings
19.00-21.00	I took my medication at Salamina			Ok
21.00-23.00	I came back home and slept			Ok
23.00-01.00				
01.00-0300				
03.00-05.00				
05.00-07.00				

⇒In the box bellow, record the impact of the feelings you experienced every time that your were taking your HIV medication. Such as, what you did after experiencing those feelings.

==

⇒ Complete the following questions at the end of the week

19. What was difficult about writing the diary?

20. Was the diary helpful? Explain why.

21. In what ways was the completion of the diary made you feel?

22. Any comments you might want to make.

BACKGROUND INFORMATION

⇒The following questions ask you about yourself, your medical condition and your medication.

9. What is your age? 45

10. Nationality: Greek

11. What medical condition do you have? Good

12. Date diagnosed ⇒ Month:_10_Year:_1999_

13. What medication are you taking at the moment?
__Idon'tremember____

14. How many times per day do you have to take your HIV medication? 3

15. How many pills do you have to take every day? 4

16. Are you supposed to have a meal before or after your HIV medication?(Tick the appropriate box)

Before medication ☐

After medication ☒

17. Do you experience any side-effects? If yes, please write them, If not move on to the next question

18. Gender:

Male ☒ Female ☐

19. Sexual identity:

Men who have sex with men ☒

Men who have sex with women ☐

Women who have sex with men ☐

Bisexual ☐

Appendix 11: Pilot, elicitation questionnaire and participants' letter

Elicitation questionnaire

What role do psychosocial factors play in influencing HIV positive peoples' compliance with the medical treatment?

The aim of the present research is to find out about your experiences of living with HIV and taking HIV medication. Due to the sensitive area of the research your personal details will be treated with respect. Your anonymity will be kept and no one will have access to any information given. Your identity will remain anonymous during all writing and confidentiality will be kept throughout the process. I would appreciate if you would complete the following questionnaire.

Answer the following questions

1. What is your age?
2. nationality:
3. What medical condition do you have?
4. Date diagnosed ⇒ Month: Year:

Tick the boxes that apply to you

Gender:

5. Male ☐ Female ☐

Sexual orientation:

6. Men who have sex with men ☐
   Men who have sex with women ☐
   Heterosexual females ☐
   Bisexual ☐

Your experiences and knowledge of HIV

Answer the following questions

7. What do the general public think about HIV positive people?

8. What was your response (feelings) to finding out you have HIV?

9. How do you feel about yourself now?

10. How does HIV impact on your social relationships?

11. How does HIV impact on your work?

12. What is your knowledge of HIV?

Complete the following incomplete sentences.

13. Since I found out that I was HIV positive my life improved……………………….

14. The things that have made my life worse since finding out I was HIV positive……………………

Your experiences of doctors since being diagnosed as HIV positive

Please complete the following questions (Write as many different things as you can think of)

15. What is your opinion on the way doctors think about HIV virus?

16. What is your experience of the doctors who prescribe your HIV medication?
17. What is your experience of talking to your doctor about your medication?

Your experiences of taking HIV medication

Complete the following incomplete sentences.

18. When I think about medical treatment………………………………

19. Complying with medication…………………………………………..

Please complete the following questions (Write as many different things as you can think of)

20. When did you start taking medication?

21. What medication are you taking?

22. What are the side effects of this medication, if any?

23. What facilitates you taking your HIV medication?

24. What prevents you from taking your HIV medication?

25. What are the advantages of taking your HIV medication?

26. What are the disadvantages of taking your HIV medication?

27. Who would approve of you taking your HIV medication?

28. Who would disapprove of you taking your HIV medication?

Participants' letter

What role do psychosocial factors play in influencing HIV positive peoples' compliance with the medical treatment?

The undersigned Phd student Margarita Gavriilidou is given the official permission by the present hospital/organization to conduct a study with the title: "What role do psychosocial factors play in influencing HIV peoples' compliance with the medical treatment?".

The aim of the present research is to place more emphasis on the psychological, social, cultural context which makes compliance/ non- compliance more understandable from the HIV positive person's perspective. It will be a multi-method approach which will include anonymous questionnaires and with the possibility of a follow up interview and weekly diaries from the optional participants.

Due to the sensitive area of the research all personal details will be dealt with respect. The anonymity of the optional participants will be kept and there will be no access to any information given. The names of the optional participants will be replaced with numbers. Everything that is going to be revealed during and after the process of the research will remain confidential between the participants and the researcher.

Advising support will be given regarding any issues that may arise. If at any point you need to discuss anything concerning the research or any issues that may rise you can contact your doctor, the psychologist of the unit (name and telephone will be provided) and me (personal details are provided at the bottom of the page).

Through the present study it is aimed to explore psychosocial factors, issues of identity, quality of life, medication in everyday life, relationships between health care providers and service users, social understandings of HIV within the society and the impact on compliance with the medical treatment. What is hoped to be achieved is the exploration of the already referred issues with the help of the optional participants through their lived daily experience.

I would really appreciate participation at the present study. In this research more emphasis will be given at the participants' sayings for the reason that they are the ones who understand the issue of HIV better? What is aimed to be achieved with your participation is that we will both try together to find the best possible way to achieve the goal of a better quality of life whilst undertaking medication.

Researcher's personal details: Margarita Gavriilidou, tel: 6946755895/00447817769907, e-mail: mgavriilidou@hotmail.com

- I have fully understand the subject and the aims of the research

Yes **No**

- I understand that my name and any other personal details will be dealt with the outmost respect and confidentiality. Anonymity will be maintained at any time of the process. At no time will my details be passed at another hospital/organization without my permission.

Yes **No**

- I understand that I have the right to withdraw from the process at any time.

Yes **No**

- I understand that I have the right to avoid disclosing any information that I do not want.

Yes **No**

Signature:

Date:

Researcher's personal details: Margarita Gavriilidou, tel: 6946755895/00447817769907, e-mail: mgavriilidou@hotmail.com