The relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt

Sumaia Jawad

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Supervisor: Professor N. Roman

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ABSTRACT

HIV patients face an array of social and psychological problems, such as depression, which can affect their quality of life. Moreover, HIV infection is also linked to psychological distress such as anxiety. In addition, avoidant emotion-focused strategies such as acceptance, wishful thinking and self-blame are associated with higher levels of psychological distress in persons with HIV. Current health services in the city of Cairo, Egypt, are not adapted to provide advice and psychological support to people living with HIV to aid in the development of problem-solving skills to cope with the stress of living with HIV. The purpose of this study was to examine the relationship between quality of life, psychological distress and the coping strategies of persons living with HIV/AIDS in Cairo, Egypt. A quantitative methodology with a cross-sectional correlational design was adopted in this study. Data collection entailed questionnaires that consisted of four sections: Demographics, Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q), Depression, Anxiety, Stress Scales (DASS) and the Cope Inventory. The sample consisted of 202 HIV/AIDS participants who access the National AIDS Program (NAP). The data were analysed using the Statistical Program for Social Science V23 (SPSS). The results are provided using descriptive and inferential statistics. The findings of the study show that in terms of the prevalence of psychological distress, the moderate scales were stress and depression, while the severe scale was anxiety. The most prevalent of coping styles was emotion-focused coping, specifically in terms of acceptance and religion. In terms of the prevalence of quality of life, the highest scores were for family and social relationships, while the lowest scores were for sexual drive and leisure time activities. The findings also show that psychological distress and certain coping styles such as substance use negatively predicted quality of life of patients with
HIV/AIDS. Positive predictors included coping styles such as venting, positive reframing, humour, acceptance and religion.
KEYWORDS

• Quality of life
• Psychological distress
• Coping
• Coping strategies
• Anxiety
• Depression
• Stress
• HIV/AIDS
• Antiretroviral therapy
• Family
DECLARATION

I declare that The relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt is my own work, that it has not been previously submitted for any degree or examination, and that all sources have been acknowledged.

Sumaia Jawad 2016

Signed: ........................
Date: ........................
DEDICATION

I would like to dedicate this dissertation to:

- the Almighty God, whose bountiful and unmerited favours saw me through this research project and the degree programme;

- all those who are affected by HIV/AIDS in any way; and

- all students studying in the Department of Public Health at the University of Tripoli.
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This thesis would not have been possible without the grace of God, who through his mercy has granted me the resilience to come this far in my academic achievement.

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To people living with HIV/AIDS in Cairo, for their generosity and trust to allow me to conduct this study.
# TABLE OF CONTENTS

Abstract ........................................................................................................................................................................... ii
Keywords ........................................................................................................................................................................ iv
Declaration ...................................................................................................................................................................... v
Dedication ......................................................................................................................................................................... vi
Acknowledgements .......................................................................................................................................................... vii
List of tables .................................................................................................................................................................... xii
Abbreviations .................................................................................................................................................................... xiii
Appendices ........................................................................................................................................................................ xiv

## Chapter 1 Introduction .................................................................................................................................................. 1

1.1 Background and rationale ........................................................................................................................................ 1
1.2 Theoretical framework ........................................................................................................................................... 4
1.3 Problem statement .................................................................................................................................................. 5
1.4 Research questions ................................................................................................................................................ 6
1.5 Aim and objectives ................................................................................................................................................ 6
  1.5.1 Aim .................................................................................................................................................................. 6
  1.5.2 Objectives ...................................................................................................................................................... 7
  1.5.3 Hypothesis ..................................................................................................................................................... 7
1.6 Research methodology ........................................................................................................................................... 7
  1.6.1 Methodology ................................................................................................................................................ 7
  1.6.2 Research design ............................................................................................................................................ 8
  1.6.3 Research setting ............................................................................................................................................ 8
1.7 Significance of the study ....................................................................................................................................... 9
1.8 Ethics statement .................................................................................................................................................... 9
1.9 Definitions and descriptions of key concepts and terms ....................................................................................... 10
1.10 Structure of thesis ............................................................................................................................................. 11

## Chapter 2 Theoretical framework ........................................................................................................................ 13

2.1 Introduction ............................................................................................................................................................. 13
2.2 Definition of coping ............................................................................................................................................... 13
Chapter 2 Coping with AIDS

2.3 Coping as a style .......................................................... 14
2.4 Coping as a process .......................................................... 15
2.5 General coping .............................................................. 17
2.6 Problem-focused and emotion-focused coping .......................... 19
2.7 Critique of problem-focused coping and emotion-focused coping .... 21
2.8 Methods of coping ............................................................ 23
2.9 AIDS and coping ............................................................. 25
2.10 Coping with AIDS – extended family .................................... 26
2.11 Conclusion .................................................................. 30

Chapter 3 Literature review .......................................................... 32

3.1 Introduction .................................................................. 32
3.2 Understanding HIV/AIDS .................................................... 32
3.3 Effects of HIV/AIDS ........................................................... 38
  3.3.1 Demographic and health effect ........................................ 38
  3.3.2 Effect on societies and economies .................................... 39
  3.3.3 Households ................................................................ 39
  3.3.4 Healthcare systems ....................................................... 40
  3.3.5 Business and agriculture ............................................... 40
  3.3.6 Economic stability ....................................................... 40
3.4 Prevalence of HIV/AIDS ....................................................... 41
3.5 HIV/AIDS in Egypt ............................................................ 44
3.6 Psychological distress and HIV/AIDS ....................................... 47
3.7 Quality of life and HIV/AIDS ............................................... 52
3.8 Coping strategies and HIV/AIDS ........................................... 57
3.9 Conclusion .................................................................. 59

Chapter 4 Research methodology .................................................... 61

4.1 Introduction .................................................................. 61
4.2 Objectives of the study ....................................................... 61
4.3 Research methodology ....................................................... 61
4.4 Research design ............................................................. 62
4.5 Population and sample ....................................................... 62
4.6 Instruments .................................................................. 63
6.3 The prevalence of psychological distress ................................................................. 86
6.4 The prevalence of coping styles ............................................................................. 89
6.5 The prevalence of quality of life ............................................................................ 90
6.6 The relationship between quality of life and psychological distress and coping ....
style............................................................................................................................. 92
6.7 Limitations .............................................................................................................. 96
6.8 Conclusion ............................................................................................................... 96
6.9 Recommendations .................................................................................................. 97

References ..................................................................................................................... 99

Appendices .................................................................................................................... 125
LIST OF TABLES

Table 4.1: Measure of DASS

Table 5.1: Personal demographics

Table 5.2: Family demographics

Table 5.3: Mean scores and standard deviation of the subscales of stress

Table 5.4: Mean scores and standard deviation of the subscales of anxiety

Table 5.5: Mean scores and standard deviation of the subscales of depression

Table 5.6: Subscales of psychological distress

Table 5.7: Mean scores and standard deviation of the items for the coping styles

Table 5.8: Prevalence of problem-focused and emotion-focused coping

Table 5.9: Mean scores of quality of life

Table 5.10: Correlations between the variables

Table 5.11: Regression analyses: Psychological distress predicts coping style

Table 5.12: Regression analysis: Predicting quality of life
# Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency syndrome</td>
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<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
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<tr>
<td>Bio-BSS</td>
<td>Bio-behavioral Surveillance Survey</td>
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<tr>
<td>CDS</td>
<td>Centre for development services</td>
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<td>DASS</td>
<td>Depression Anxiety Stress Scales</td>
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<tr>
<td>FHI</td>
<td>Family health international</td>
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<td>FSW</td>
<td>Female sex worker</td>
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<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<tr>
<td>IDU</td>
<td>Injection drug users</td>
</tr>
<tr>
<td>MOHP</td>
<td>Ministry of health and population</td>
</tr>
<tr>
<td>MENA</td>
<td>Middle East and North Africa</td>
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<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
</tr>
<tr>
<td>NAP</td>
<td>National AIDS Program</td>
</tr>
<tr>
<td>Q-LES-Q</td>
<td>Quality of Life Enjoyment and Satisfaction Questionnaire</td>
</tr>
<tr>
<td>QoL</td>
<td>Quality of life</td>
</tr>
<tr>
<td>SPSS</td>
<td>Statistical Package for the Social Sciences</td>
</tr>
<tr>
<td>UNAIDS</td>
<td>Joint United Nations Programme on HIV/AIDS</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
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</table>
APPENDICES

Appendix A: Information sheet (English and Arabic)

Appendix B: Consent form (English and Arabic)

Appendix C: Full questionnaire (English and Arabic)

Appendix D: Letter of approval to conduct research by Ethics Committee and Senate of University of the Western Cape

Appendix E: Permission to conduct the study at Abassia Hospital from National AIDS Program, Ministry of Health and Population, Egypt

Appendix F: Letter from the Director of the National AIDS Program, Egypt for completing the data collection

Appendix G: Proof of editing
CHAPTER 1
INTRODUCTION

1.1 Background and rationale

HIV is a virus that causes an infectious disease called the acquired immunodeficiency syndrome (AIDS) (Kallings, 2008; Paul & Beatrice, 2011). In 1981, AIDS was recognised for the first time by the US Centres for Disease Control and Prevention (Siegal et al., 1998; Gallo, 2006). Science returned to the challenge of AIDS by rapidly identifying causes and ways of transmission and describing pathogenesis, as well as expanding treatment and diagnostic tests. Nevertheless, this did not prevent the global prevalence of HIV with 25 million fatal cases, 33 million people have been infected in addition to the calamitous demographic and socio-economic consequences that it causes (Kallings, 2008). HIV and AIDS are found in all parts of the world, with some areas being more affected than others. Countries that are most affected by the AIDS epidemic are exposed to major losses, such as the unfortunate loss of productive citizens and institutions. Losses of life as a result of HIV has not only affected families, but are extended to places of work such as farms, health systems, schools and governments (Ashford, 2006). Consequently, close family members suffer the direct impact of HIV/AIDS, because they are the main caregivers for the sick. In addition to emotional trauma, families suffer AIDS-related financial burdens for extended periods as a result of illness caused by AIDS. Furthermore, the lack of income and cost of caring for a dying family member can financially ruin households. Hence, the epidemic is far-reaching and touches almost every facet of life (Ashford, 2006).

HIV statistics are alarming and have been recorded for the end of the year 2014 as 36.9 million people globally living with HIV. The rapid rate of infection of HIV is evident, and was documented in 2014, which saw 2 million people as newly infected with HIV around the
world (UNAIDS, 2015). In the same year, 1.2 million people died from AIDS-related causes worldwide compared to 2 million in 2005 (UNAIDS, 2015). Simultaneously, in sub-Saharan Africa, it was recorded that there were 25.8 million people living with HIV and that there were an estimated 1.4 million new HIV infections (UNAIDS, 2015). Sub-Saharan Africa accounts for 66% of the global total of new HIV infections (UNAIDS, 2015).

In 2014, there were 240,000 people living with HIV in the Middle East and North Africa (MENA) region, and it was estimated that there were 22,000 new HIV infections in the region (UNAIDS, 2015), with Egypt’s general population having a low HIV-prevalence rate of less than 0.02% (HIV/AIDS Situation, 2014). In 2014, people living with HIV in Cairo, Egypt, were estimated to be 4,631 (UNAIDS, 2015). During the mid-1980s the first case of AIDS was reported in the MENA region. By 1990, every country was home to people living with HIV, and the vast majority of infections through exposure to HIV abroad was caused by organ transplants or contaminated blood products. Nevertheless, new patterns of Contamination have emerged over the following years (Gatrad & Sheikh, 2004; Setayesh et al., 2014). The Arab world has the second highest infection rate in the world of the disease due to the population’s lack of knowledge about HIV/AIDS, cultural norms and laws, the bureaucratic health system, lack of development and implementation of effective surveillance systems as well as an increasing population, such as in Egypt (Gatrad & Sheikh, 2004; Boutros & Skordis, 2008). On the other hand, HIV patients experience many social problems, such as depression, substance abuse, poverty and strict cultural beliefs, which can affect their quality of life (QoL), not only from a physical health aspect, but also from a mental and social health point of view. This may cause numerous problems in terms of their interests and may hinder the everyday useful activities of the patients (Aranda, 2004). The impact of HIV on QoL falls under four major domains: physical, psychological, social and environmental (Basavaraj et al., 2010).
Likewise, HIV infection is related to psychological distress, which is further associated with symptoms such as anxiety and depression (Ciesal & Roberts, 2001; Camo et al., 2008). Consequently, there is a strong relationship between AIDS-related physical symptoms and psychological distress (Ostrow et al., 1998; Hays et al., 1999). In the United States and Canada, HIV stigma has been found to be associated with various psychological problems among persons living with HIV, and include depression, hopelessness, stress, anxiety and low self-esteem (Clark et al., 2003; Dowshen et al., 2009). HIV is particularly much more stressful to adapt to due to the stigmatising nature of the disease and the detrimental effect of HIV-related symptoms (Weitz, 2001) from which the patient suffers. It is therefore quite challenging for individuals to adopt adaptive capabilities in order to maintain psychological equilibrium while living with a severe chronic illness such as HIV (Kaplan & Toshima, 1999; Charmaz, 2000). Furthermore, depression may occur as a result of this psychological distress, and in turn, exacerbate the physical impact of the disease, thereby increasing the risk of subsequent physical morbidity and mortality. This is particularly evident when examining the effects that depression has on the immune system (O’Leary, 2000; Herbert & Cohen, 2003).

Although the relationship between stress and adaptation has been widely explored across a variety of illnesses (Lazarus & Folkman, 1998), limited studies have examined this relationship for individuals coping with HIV/AIDS (Fleishman & Fogel, 1998; McCain & Cella, 2002). This may in part be due to the fact that HIV is a fairly ‘new’ disease, where the first case of HIV/AIDS was diagnosed only in 1981 and subsequently included in the disease spectrum. However, one of the first HIV-specific studies that explored the impact of coping on levels of psychological distress (Namir et al., 1999) discovered that avoidance coping (a kind of emotion-focused coping strategy) was positively correlated with depression in HIV.

In Cairo, Egypt, current health services were not adapted to provide advice and psychological support to people living with HIV to aid them in the development of problem-solving skills to
cope with the stress of living with HIV (Kabbash et al., 2008). Moreover, the government of Cairo, Egypt does not have a specific mechanism in place that allows for the monitoring and evaluation of HIV infection, which challenges data. These challenges adversely affect monitoring and evaluation of data related to HIV, and hinders provision of high-quality reporting on its efforts in the area of combating HIV/AIDS (GARPR, 2014). In addition, the escalating population, spread of poverty, lack of culture and education in remote areas, as well as the lack of means of necessary preventive care for patients pose additional challenges, especially for people living with HIV/AIDS (Kabbash et al., 2008). Therefore, studies that explore the prevalence of psychological distress and QoL as well as the coping strategies used by persons living with HIV/AIDS in Cairo, Egypt, are necessary. The current study proposed to examine these aspects.

1.2 Theoretical framework

The theoretical framework for this study was guided by Lazarus’s (1993) coping theory. This theory entails two approaches to coping, namely coping in terms of style as a personality characteristic, and coping as a process, which examine the efforts made to manage stress that changes over time and is shaped by the context in which it is generated. Lazarus’s theory defines coping as an “ongoing cognitive and behavioural effort to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus, 1993: 237). The coping process is reliant on a number of factors, such as the type of person, the type of encounter and the outcome modality being studied, with reference here to the psychological stress and threats to the somatic health of an AIDS sufferer (Lazarus, 1993). Lazarus expounds on problem-focused strategies and emotion-focused strategies. Problem-focused coping means that the patient attempts to alter the person–environment relationship by directing his/her coping either towards the environment or towards him-/her self. In contrast, the emotion-focused strategy examines the manner in which the relationship
with such environment is being dealt with or efforts are made to alter the relational meaning of what is happening (Lazarus, 1993:244). External coping includes pessimistic strategies (negative expectations) and denial (avoidance of difficult situations). Internal coping includes positive coping strategies (positive and optimistic attitude and outcomes), self-expressive strategies (expression of emotions and feelings), vigilant strategies (patience, waiting and persistence) and time-out (escapist and self-preserving coping techniques). Furthermore, the reaction of the patient is variable and will alter according to the threat that he/she attempts to manage at that particular time and the progressive level of the disease. Consequently, this could have a negative effect on the psychological wellbeing of the patient. Hence, the process of coping with the physical and psychological threats of AIDS also leads to severe psychological stress (Folkman & Lazarus, 1985; Folkman et al., 1986). Unfortunately, the necessary advice and psychological support to cope with the stress of living with HIV/AIDS are not afforded to these patients in Cairo, Egypt. Therefore, identification of the threat is vital as well as how the individual will perform in the coping process, which will differ from person to person. Therefore, people living with HIV/AIDS need support systems that will enable them to maintain their psychological health and integrity. This can be manifested with the assistance of a supportive family structure, friends, financial support, ego strength, intelligence and skills. These are examined under the theoretical framework in Chapter 2.

1.3 Problem statement

Since the 2011 revolution, Egypt witnessed considerable political disturbance and deteriorating security. This unrest had caused a current change in senior government leadership. Accordingly, Egypt’s Ministry of Health and Population has had seven different ministers since 2011 (GARPR, 2014). This high rate of rotation in leadership had complicated and delayed progress in HIV programming in Cairo, Egypt. The declining and fluctuating security situation has also hindered the implementation of several outreach
activities and service prudence for key populations (GARPR, 2014). There are several factors encountered by HIV-infected individuals that may affect their QoL. These may include social issues such as, but not limited to, poverty and stigmatisation (Vosvick et al., 2002). The consequences may further be linked to psychological distress such as depression, anxiety and stress (Clucas et al., 2011). Pakenham and Rinaldis (2001) found that higher levels of psychological distress were associated with avoidant emotion-focused strategies. This has however not been studied in Egypt. Current services in Cairo, Egypt have not been adapted to provide advice and psychological support to people living with HIV to help them develop problem-solving skills to cope with the stress of living with HIV (Kabbash et al., 2008). Therefore, a potential gap in the literature is the unexplored question of the QoL of persons living with HIV, whether they experience psychological distress and which coping styles they use in their life and specifically in Egypt. Therefore, the aim of this study was to examine the relationship between these variables in the context of Cairo, Egypt.

1.4 Research questions

The following three research questions were formulated for this study:

1. What is the psychological distress and quality of life of persons living with HIV/AIDS in Cairo, Egypt?

2. What are the coping strategies used by persons living with HIV/AIDS in Cairo, Egypt?

3. What is the relationship between the quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt?

1.5 Aim and objectives

1.5.1 Aim

This study aimed to examine the relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt.
1.5.2 Objectives

The objectives of the study were to:

1. Establish the levels of psychological distress and quality of life of persons living with HIV/AIDS in Cairo, Egypt.
2. Determine the coping strategies used by persons living with HIV/AIDS in Cairo, Egypt.
3. Investigate the relationship between the quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt.

1.5.3 Hypothesis

There is a significant relationship between the quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt.

1.6 Research methodology

1.6.1 Methodology

This study used a quantitative approach, De Vos (2005) states that quantitative research entails the measurement and analysis of various cause-and-impact relationships between variables as well as a method where data are collected in the form of numbers and are analysed using statistical measures. According to Aliaga and Gunderson (2000), quantitative research entails “Explaining phenomena by collecting numerical data that analyses using mathematically based methods” (Muijs, 2011:1). In this study, questions were answered by using data gathered through self-administered questionnaires and the responses were assigned a number. The variables were then correlated to assess the relationship between the variables.
1.6.2 Research design
This study was conducted using a cross-sectional correlational design. Cross-sectional studies are used to study a fraction of a population at one single point in time (Trochim, 2001; Thisted, 2006). A correlation-relationship design was used to determine the relationship among the variables. The correlation design examines the strength of the relationship between variables (Asadoorian & Kantarelis, 2005).

1.6.3 Research setting
This study was conducted in Cairo. Cairo is the capital city of the Arab Republic of Egypt. It is regarded as the most important city of all with a population of 7 787 000 people. It is the largest and most populated city in Africa and the Middle East (GARPR, 2014). The official religion is Islam; however, it recognises Judaism and Christianity as well. The official language is Arabic and the system of government is Republican Democratic. Cairo boasts a large number of universities, schools and academic institutions. It is famous for Cairo University and Al-Azhar University, which is the oldest in the Middle East. Cairo and Giza are considered the main centres for medical treatment in Egypt. Among the many state hospitals and health facilities are the famous General Qasr al-Aini Hospital and the Cairo 57357 Hospital, which specialises in the treatment of childhood cancer. There are many private health centres to care for AIDS patients in Egypt, including the Central Laboratory and Abassia Hospital in Cairo as well as Kafr El Sheikh General Hospital in Alexandria.

The study was based at Abassia Hospital in Cairo. This is a hospital to which most patients from primary healthcare centres are referred for HIV/AIDS services and other health services. This site was chosen because it offers HIV care (Anti-retroviral drug, Voluntary Counselling and HIV testing, and other medical routine care). Each patient comes three times a week for treatment.

The research methodology is explained in Chapter 4.
1.7 Significance of the study

The results from this study will contribute to knowledge of the prevalence of psychological distress, quality of life and coping strategies among people living with HIV/AIDS. In addition, the outcome of this study may be useful to social service providers who lead and promote HIV/AIDS programmes and activities within their communities through offering counselling and psychological support to people living with HIV/AIDS and helping them develop problem-solving skills to deal with the stress of living with HIV. Healthcare workers may benefit from this study and use the opportunities they have with people living with HIV/AIDS attending screenings to discuss various concerns and make references where necessary. This study may help future researchers to relate other variables to the participants or different participants to the same variables used.

1.8 Ethics statement

After obtaining ethical clearance from the University of the Western Cape’s Senate Research Committee (Appendix D), permission was provided by the chief executive officer at the National AIDS Program (NAP) to conduct the study in Abassia Hospital in Cairo, Egypt. Researchers need to practise care that the rights of individuals and institutions are preserved when conducting research (Pilot & Hungler, 1999). For this research study, participants were recruited via the NAP. The aims and objectives of the study were explained in great detail to all participants who volunteered to participate in the study. They were given an information sheet (Appendix A). This was to ensure that they fully understand the purpose and agree to take part in the study. The participants were asked to sign a consent form (Appendix B) if they agreed to participate in the study. Anonymity was ensured, as no names were indicated on the questionnaires and only codes were used. Confidentiality was ensured, as the participants were anonymous and no one would know who the participants are based on accessing the researcher via the flyer, which invited people to voluntarily participate in the
study. The researcher was also not able to relate certain answers to a particular participant. Beneficence was ensured by informing the participants that they will not be harmed during the study. The participants were referred for the professional assistance of a counsellor should they need these services due to involvement in the study. They were further informed that all relevant research documents would be carefully stored for a period of five years and accessed by the researcher and supervisor only. The participants were also given full access to the reported findings of the research, should they want to know the outcomes. The ethical principle refers to the obligation on our part as researchers to respect each participant as a person capable of making an informed decision regarding participation and access to findings. The results of this study were not generalised to a larger population, as they are very specific to participants with HIV/AIDS in Cairo, Egypt.

1.9 Definitions and descriptions of key concepts and terms

**Quality of life:** The subjective and multidimensional are best measured from the patient’s perspective. As well, it is multidimensional, its measurement requires the investigator to inquire about a range of areas of the patient’s life, including social welfare, functional ability, emotional wellbeing and physical wellbeing (David, 2009).

**Psychological distress:** This refers to the general connotation of maladaptive psychological functioning to face stressful life events. Psychological distress is an integral part of the within the context of distress, strain and stress (Abeloff et al., 2000).

**Coping strategies:** Coping is defined as the person’s constantly changing behavioural and cognitive efforts to manage specific internal or override the person’s resources and external demands that are assessed as taxing (Folkman et al., 1986).
Anxiety: Anxiety is a natural reaction to pressures. Sometimes, the anxiety human response can be disproportionate to the stressful condition or trigger, and this can produce psychological problems (Kessler & Wang, 2008).

Depression: Depression is defined in the literature as a mood state, a group of symptoms and a clinical syndrome. Depression has been tracked in relationship with many other severe or chronic illnesses (Weisse, 2008).

Stress: Stress is defined as restriction strength, effect of a force exerted when one part of the body propulsion against another concentration, intense effort, or the prominence of a sound in verse. As a transitive verb, stress means to subject to psychological or physical stress (Random House Webster’s Unabridged Dictionary, 1998; Merriam-Webster’s Collegiate Dictionary, 2000).

HIV/AIDS: The term demonstrates the complete range of disease caused by the human immunodeficiency virus from early infection to late-stage symptoms (Anthony, 2003).

Antiretroviral therapy (ART): These are drugs that treat HIV. The medication does not cure or kill the virus. However, when taken in structure it can hinder the growth of the virus when the virus is slowed down (Nela & Kageeb, 2011).

Family: This is an intergenerational social complex orderly and governed by social standards regarding affinity and descent, the nurturing socialisation of the young and generation (White, 2007).

1.10 Structure of thesis

Chapter One is an introduction to the study of the relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo and provides the context and background for the study. It also discusses the research questions,
aims, objectives, definitions, motivation, the significance of the study and ethical considerations.

**Chapter Two** provides a conceptual framework for the study. It provides an overview of the theoretical underpinning of the study.

**Chapter Three** presents a review of the literature concerning for quality of life, psychological distress and coping strategies of persons living with HIV/AIDS.

**Chapter Four** describes the research design and methodology. This chapter also explains and discusses sampling, procedures and data collection, data analysis, and the issues of reliability and validity.

**Chapter Five** provides an analysis of the findings as well as a presentation using tables. Descriptive quantitative results were analysed using the Statistical Package for the Social Sciences (SPSS) and these are presented. The statistical presentation reflects the descriptive, correlations and inferential data.

**Chapter Six** presents a discussion of the study results in detail. The results are interpreted in this chapter, and the limitations and recommendations of the study are discussed.
CHAPTER 2
THEORETICAL FRAMEWORK

2.1 Introduction

This chapter examines and explores the theoretical framework of this study. The purpose of this study was to examine the coping strategies of persons living with HIV/AIDS and adaptive coping styles that are related to AIDS, as well as correlations that exist between the different methods of coping. The first section of this chapter details an explanation of Lazarus’s theory of coping, which is the overarching of this study. Furthermore, it provides an explanation of coping, particularly the process and styles of coping. It also discusses studies on the importance of coping with AIDS and gives a detailed description of Lazarus’s coping styles typology, which emphasises internal and external means.

2.2 Definition of coping

According to Lazarus and Folkman (1998:141), coping is defined as “the person’s constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person’s resources”. Coping is primarily categorised into coping responses that are either problem-focused or emotion-focused. Problem-focused coping is also referred to as confronted coping, a strategy employed by the individual to identify the instrumental factors for an incidence. Once the identification of such factors is ensued, the individual will devise means and methods of dealing with these factors in an effective way (Lazarus & Folkman, 1998). Therefore, problem-focused coping is a process that entails the following steps: (a) identification and definition of the problem; (b) development of alternate resolutions; (c) evaluation of costs and benefits; (d) selection of a most effective solution and; (e) application of the solution to
the problem. Confronted coping include strategies such as bargaining, focusing on the positive angle of the problem, relying on social support and concentrating on the application of efforts (Lazarus & Folkman, 1998).

Coping is considered a means for an individual to effectively manage an occurrence that has exceeded his/her capabilities. The process of coping is dependent on a number of factors. These include the type of person, the type of encounter and the outcome that is desired. All of these factors are to be considered to ensure effective coping and will vary among individuals and the strategies they have adopted. As such, Skinner and Edge (2003:217) maintain that coping is not a one-dimensional behavioural pattern, but functions on numerous levels, due to the individualistic nature thereof. Individuals’ coping strategies are therefore attained through an adoption of a plethora of behavioural patterns, cognitions and perceptions. However, even though the method and techniques of coping vary greatly from one individual to another, the word ‘coping’ is still used and applied, regardless of the outcome process. Hence, a simplified definition of copings reads that “coping consists of cognitive and behavioural efforts to manage psychological stress” (Skinner & Edge, 2003).

2.3 Coping as a style

The approaches to coping are twofold, namely coping as a process and coping as a style (Haan, 2004) expound on and refer to the hierarchical approach to coping. This is derived from the developmental psychoanalytic formation. Based on their studies, this hierarchy is divided into coping, defence and ego failure, which form the basis of coping as a style. According to Haan (2004), coping is considered a healthy and developmentally advanced process, which the individual could adopt in order to adapt to the stressor. Self-failure was first considered the most regressed form of an adaptive process. The hierarchical developmental approaches are based on the trait measures of coping. These include
repression (such as avoidance or denial) and sensitisation (vigilance, isolation and intellectualisation). However, at a later stage, a new development in the coping theory and measure occurred and this view was abandoned. Lazarus expounded on his theory of coping as a process (Lazarus, 1993). From his viewpoint, coping is seen as a vigorous process that fluctuates over time and confers on the situational settings wherein it arises. This process could be adaptive or non-adaptive. The adaptive value of coping refers to the level of efficacy of the coping in improving the progression of adaptation to the stressor (Lazarus, 1993). This progression of adaptation to the stressor refers to the moral, physical and social functioning of the person. The quality of the process being successful or unsuccessful is based on the degree of the coping-related reappraisal as believed by the person.

Lazarus further expounds on problem-focused strategies and emotion-focused strategies. Problem-focused strategies refer to the person’s attempt to alter the person–environment relationship by way of directing the coping strategy either towards the environment or towards him-/herself, as opposed to the emotion-focused strategy that is directed at generating a change within the relational meaning of what is happening (Lazarus, 1993).

2.4 Coping as a process

The principles of the ‘coping as a process’ approach as expounded on by Lazarus are based on six fundamental characteristics. This approach measures coping thoughts and actions under stress as separate from their outcomes, as a means to determine the adaptive or maladaptive nature of such outcomes. Lazarus maintains the viewpoint that the coping process cannot be labelled as good or bad in terms of its efficacy and adaptability, but that some have been proven better or worse than others based on research conducted. The process adopted is entirely reliant on the particular individual, the type of encounter and the time period in which the encounter occurred as well as the outcome modality being studied, such
as moral, social functioning or somatic health under examination. Denial is clearly a process strategy of coping and is resorted to when the person faces certain excessive physical and psychological burdens, and it may even be useful in certain circumstances (Lazarus, 1993). However, a distinction must be made between denial, avoidance and illusion, which might be detrimental to the person’s mental and somatic health. Interestingly, previous studies have also proposed that denial can have positive significances and an effect on many factors, such as the rate of restorative health, the presence of minor medical complications and the period of hospitalisation (Lazarus, 1993).

The ability of the person to cope with the illness, in this case AIDS is dependent on the particular time and whether he/she is encountering one or many of the threats. As a result, the manner of coping that the individual adopts is reliant on the context or environment in which the disease occurs. This environment is variable, as the threats are constantly changing (Lazarus, 1993). Therefore, it is imperative to examine how individuals cope with AIDS and essential to understand that certain threats are of immediate concern to such individuals. Therefore, such threats should be allocated separately and not be assembled into a singular one. Therefore, the focus should not be directed at the complete illness, on a continual basis, but at the separate individual threats.

Coping measurement should be based on the thoughts and actions of the patient, and how these measures aid the individual in the process of coping with the threat. Therefore, the observation is made by the professional observer and not by the patient him-/herself (Lazarus, 1993). Coping categories include physical and psychological coping. Psychological coping strategies are as follows: (a) confronted coping, (b) distancing, (c) self-controlling, (d) seeking social support,(e) accepting responsibility, (f) escape-avoidance, (g) painful problem solving and (h) positive reappraisal (Lazarus, 1993).
The term ‘coping’ is employed irrespective of the outcome, which range from adaptive to non-adaptive. Adaptive coping outcomes refer to the efficacy of the coping process in order to improve the outcome, such as the moral, somatic and social functioning of the person. These outcomes may be determined as either successful or unsuccessful. Successful and unsuccessful outcomes refer to the extent a coping-related reappraisal is believed to be by the individual. When the individual has identified the outcome, it will be succeeded by the consolidation, fluidity or instability of that outcome. Fluidity refers to the ability of the person to attain a degree of stability in the coping process, whereas instability refers to the defensive ability that the individual adopts in order to cope, and as a result the person struggles with the coping process but is still hopeful about the situation.

2.5 General coping

Few studies have been conducted that have examined the effects of coping strategies on the psychological functioning of persons living with HIV/AIDS. According to Brook et al. (1997), coping strategies are methods for approaching internal or external stressors, which the individual perceives to be beyond his/her competence. Coping strategies vary in their abilities to help the patient adjust successfully to the stressful encounter or situation. For instance, a coping strategy such as problem solving could prove to be more useful than drug abuse. However, coping strategies such as seeking social support may be more useful for certain individuals.

As previously mentioned, coping measures fall into three broad areas. These are general coping, adaptive coping and maladaptive coping strategies (Brook et al., 1997). Coping strategies are further classified into AIDS-related coping strategies that are adaptive and those that are maladaptive. Maladaptive coping strategies include substance abuse and aggression, whereas adaptive coping strategies include problem solving, seeking social support and self-
help. Adaptive coping strategies have been associated with certain psychological outcomes that include higher self-esteem, lowered degree of depression and a greater sense of emotional regulation (Brook et al., 1997).

Techniques of general coping and avoidance as one of the maladaptive techniques of coping are relatively linked and related. As a result, when the individual increases his/her adoption of general coping techniques, it could result in a decrease in the use of maladaptive coping techniques. In terms of stability, both adaptive and maladaptive coping strategies share this trait when adopted over a period of time (Brook et al., 1997). Interestingly, AIDS patients might even adopt both techniques simultaneously over a period of time and change between the two during different times. As a result, in order to cope with AIDS, patients would at a later stage decrease their adoption of maladaptive techniques in favour of general coping strategies. However, it should be noted that this adoption would not automatically lead to an increase in the adoption of an adaptive strategy (Brook et al., 1997).

According to Hansen et al (2012), a link exists between earlier general coping and maladaptive coping and better intrapersonal functioning. Therefore, the patient, when diagnosed with AIDS and adopting general coping techniques such as a fighting spirit, would as a result enjoy better intrapersonal functioning. This would eventually result in a higher self-esteem and an increased ability to cope better with the situation. Leserman (2008) states that threats become decreased when maladaptive coping techniques are adopted and that it is associated with more “intrapsychic harmony”. This refers to the psychological harmony of the person and includes attributes of high self-esteem and a general decrease in the degrees of depression, resulting in fewer mental problems.

In a recent analysis of studies (Moskowitz et al., 2009) that focused on coping with HIV, in which the specific and general classifications of coping strategies were addressed, the
following discoveries were made. Active and positive coping solutions were associated with lower levels of distress, more health-protective behaviour and better physical health, while avoidant coping had the opposite effect. Spiritual coping and solution-focused coping were positively associated with self-efficacy and adversely related to depression and loneliness only, whereas distancing and self-destructive coping were associated with depression, loneliness and anxiety (Hansen et al., 2012). Therefore, the patient is able to cope with the threat of AIDS more effectually when using AIDS-related adaptive coping processes.

2.6 Problem-focused and emotion-focused coping

According to the theory of coping as a process, governs that there are two chief functions of coping. These are problem-focused and emotion-focused strategies. As previously mentioned, problem-focused coping refers to changing the person–environment relationship by changing and acting either on the person or the environment. However, emotion-focused coping is based on the method by which the stressful situation is managed by emotions or by altering the interpersonal meaning of what is occurring. This is employed in order to adopt a less aggressive and more passive manner of managing the threat and is often adopted when the individual prefers to change the interpersonal context of the situation. For instance, when faced with a threatening situation that usually causes anger and confrontation, the patient would resort to empathy and forbearance as a coping strategy (Lazarus, 1993). Lazarus holds the viewpoint that this method of coping is a “healthy form of repression and denial” (Lazarus, 1993: 238). He maintains that the reappraisal of the threat can be eliminated or reduced when an appraisal is made. This is because the threatening impulse is no longer existent and relevant, and as a result does not have to be removed from the consciousness or has to be acted upon. Therefore, this type of change is a healthy and powerful approach to coping. Research and studies conducted over the years have shown much favour to the problem-focused strategy of coping. This strategy should result in taking action in order to
deal effectively with the threat rather than to merely change the relational meaning of what is happening. However, there is also evidence to suggest that emotion-focused strategies have been proven to be more successful when the threat is eminent and there is nothing beneficial or useful that could be done in order to remedy the situation (Lazarus, 1993).

According to research conducted by Carver et al (1989) concerning the measurement of coping, the extent to which coping strategies are linked is quite challenging. These could include a number of facets, such as the threat contents, the goal that is at stake, prior beliefs and temporary factors. In addition, Carver et al (1989) established that the consistency or inconsistency of certain strategies of coping is evident across certain stressful situations. Inconsistent coping strategies include seeking social support, whereas positive reappraisal appeared to be more consistent. Hence, one coping strategy might be revisited more than another based on its ability to be fluid and consistent when applied to different threatening encounters. Scheier (1986) holds the viewpoint that the ability to be optimistic or pessimistic plays a major role in the person’s ability to effectually cope with the stressful situation. Also, the typology of coping changes from time to time when dealing with a stressful encounter. This may range from tension, confrontation and denial to seeking information and gaining social support. Lazarus also holds that when the stressful conditions are regarded by the person as “refractory to change” (Lazarus, 1993: 239), the emotion-focused coping strategy will be predominantly applied. However, when the situation is perceived as controllable by action, then the problem-focused coping will predominate. Hence, coping has the ability to change the emotional state of the patient. Lazarus and Folkman (1984) also maintain that certain coping strategies such as painful problem solving and positive reappraisal are associated with variations in the moods and emotional states of the patient. These range from negative to less negative and eventually positive. However, some strategies, such as confronting and distancing, lead to a more negative emotional state and eventually distress.
(Lazarus, 1993). It should be noted that one coping strategy could be applicable to some patients and prove to have a positive emotional outcome, whereas when adopted by a different group it might prove the opposite.

Therefore, the two approaches of coping as a style and as a process have different outcomes, but also have many limitations. Lazarus (1993) expounds on these limitations and states that coping as a style does not provide the specific description of the details and the specific strategies of coping that are used in certain stressful contexts. Approaches that are governed by process enable focus on particular coping thoughts and actions within the stressful contexts. However, there are limitations to this process. The most important limitations are that it is not associated with the person, is detached and is primarily directed towards goals and intentions that would offer a solution to the current stressful situation.

Anger, anxiety, guilt, shame, sadness, envy, jealousy and disgust are referred to as stress emotions. These emotions provide us with insight as to how well people are dealing with their stressful encounters. In conclusion, both coping as a style and coping as a process are useful and vital, as they report of diverse facets of the same problem.

### 2.7 Critique of problem-focused coping and emotion-focused coping

According to Skinner and Edge (2003), problem-focused coping and emotion-focused coping are not theoretically clear and are mutually limited and extensive. This is especially apparent with regard to emotion-focused coping. This is the case when the patient attempts to calm him-/her self down and resort to uncontrolled venting and panic (Skinner & Edge, 2003).

In addition, the categorisation of these two strategies is ambiguous and not as clear. Evidently, most methods of coping can serve both functions and therefore fit into both categories. This is illustrated when a person attempts to cope with the stress, such as making a plan, which is part of problem-focused coping, but simultaneously can also calm emotion,
which is included in emotion-focused coping (Skinner & Edge, 2003). Venting, on the other hand, negatively escalates the emotional status, but also impedes the implementation of effective and beneficial actions that would solve or enable the individual to cope with the problem.

Furthermore, the two categories are not extensive in terms of the lower sub-categories of coping. Some methods of coping fall outside the perimeter of these two categories. This is illustrated in the coping strategy of seeking social support. This method cannot be classified as either problem-focused or emotion-focused, but rather occurs on other people and accommodation, which in essence focuses on the self (Skinner & Edge, 2003).

Moos and Billings (1999) have divided coping into three categories. These are emotion-focused, problem-focused and appraisal-focused. Appraisal-focused refers to those methods or coping efforts that purport to reframe the situational meaning of the stressor. Hence, Moos and Billings (1999) state that these categories are not mutually exclusive and that appraisal-focused coping can be directed at either the contributory or the effective facets of a situation (or both). Furthermore, problem-focused coping aids the individual to deal with emotions provoked by the stressful situation. However, emotion-focused coping could inform of the necessary resources to lever the problem (Moos & Billings, 1999:214).

This theory is consistent with that of Lazarus (1996), who also recommends that researchers should no longer be reliant on the problem-focused versus emotion-focused distinction as a fundamental structure for the classification of coping methods. Furthermore, Lazarus maintains that this distinction between the two functions of coping and regarding them as distinct types of coping actions would lead to an over-simplification of the conception and the way coping works. Hence, the methods of coping are not functions, but rather action types that have functions.
2.8 Methods of coping

Individuals who employ maladaptive coping processes such as substance abuse or the expression of aggression in an inappropriate manner have been proven to be significantly more psychologically disturbed as a result of this method of coping. They suffer from low self-esteem and experience difficulty in expressing their emotions (Brook et al., 1997). The coping strategy for persons living with HIV/AIDS that includes greater adaptive coping measures was associated with elevated degrees of self-esteem and reduced levels of depression. Another major impact of coping is that the strategy employed by the patient is dependent on the duration of time of knowledge of HIV status (Brook et al., 1997). Therefore, the duration of knowledge of HIV/AIDS was adversely associated with general coping scores, but was positively associated with seeking social support. An implication of this is that the adoption of general coping techniques over time results in a simultaneous decrease in maladaptive coping techniques. This is dependent on the fact that general coping is not associated with AIDS-related adaptive coping (Brook et al., 1997) at an advanced stage.

There are several levels on which coping can be theorised. Instances of coping refer to the constant change of real-time responses that individuals employ in order to delay specific stressful transactions. In addition, there are basic adaptive processes that intercede between stress and its outcomes, be it the psychological, social or physiological facets. This process is referred to as coping as a “strategy of adaptation” (White, 2009). As previously mentioned, Haan (2004) has arranged the categories of coping hierarchically. In addition, Skinner and Edge (2003) divided this hierarchy into the following categories:

- Voluntary primary control engagement coping, which includes problem solving, emotional regulation and emotional response.
• Voluntary secondary control engagement coping, which includes positive thinking, cognitive restructuring and acceptance.

• Voluntary primary control disengagement coping, which includes avoidance and denial.

• Voluntary secondary control disengagement coping, which includes wishful thinking and distraction.

• Involuntary engagement, which includes rumination, intrusive thoughts, emotional arousal, physiological arousal and impulsive action.

• Involuntary disengagement, which includes emotional numbing, cognitive interference, involuntary flight and inaction.

According to a study conducted by Lewis and Brown (2002), findings from the Adolescent Coping Orientation for Problem Experiences Questionnaire showed that the most-used coping strategies that were identified by the adolescents were as follows: thinking about positive issues, engaging in entertainment such as watching television and listening to music, taking own decisions, close affiliation to a friend, eating, sleeping, personal attempts to deal with problematic issues, daydreaming and praying. Adolescents also reported reduced use of certain maladaptive coping strategies such as alcohol and illicit drug usage (Lewis & Brown, 2002). Chronic illnesses such as HIV are considered challenging for adolescents because of the unique developmental maturity required to understand the social and psychological impact that flows from this and many similar chronic illnesses. This research exemplifies the intricacies of stress and the effects of coping on the psychological and somatic wellbeing of the patient (Lewis & Brown, 2002).
2.9 AIDS and coping

Living with AIDS is accompanied by many stressors, and stressful life events could actually lead to the progression of AIDS and many other health problems, thereby affecting the psychological and somatic health of the person. Chronic stress has been proven to have an altering effect on the hypothalamic-pituitary-adrenal axis, which could result in the suppression of the immune system (Hansen et al., 2012). Therefore, the health outcomes are directly linked to the type of coping strategies that are engaged and are indicative of internal coping. Internal coping includes positive and optimistic attitudes, self-expressive strategies (expressions of feelings and emotions), vigilant strategies (patience, persistence and waiting) and time-out (escapist and self-preserving coping techniques). External coping includes pessimistic strategies (negative expectation) and denial (avoidance). Hence, pessimism and negative feelings and expectations were correlated with a decrease in the count of CD4 cells. In addition, avoidant coping was also associated with a decrease in the count of CD4 cells and men who showed greater denial in fact showed a faster progression to AIDS over a period of a few years as opposed to patients who had a positive enthusiastic approach. Also, patients who resorted to avoidant coping measures presented a noteworthy surge in depression and anxiety (Hansen et al., 2012). However, when the avoidant coping methods were followed up with interventions, it was succeeded by a substantial decrease in depression and grief.

Therefore, the range of coping is immense. Some patients in Africa reported fewer depressive symptoms due to better support from family and friends, greater self-efficacy and the use of more multiple coping strategies as opposed to Caucasian patients. Religion and spirituality are also employed as a coping strategy in order to deal with stressful events (Hansen et al., 2012).
The types of coping strategies vary greatly and aid the individual in adapting effectively to the stressor, in this case the disease AIDS. Coping with this disease leads to a lower level of depression and an increase of positivity and self-estate. As mentioned previously, coping strategies are classified into adaptive coping and maladaptive coping (Brook et al., 1997). Adaptive coping includes problem solving, seeking social support and self-help to cope with the disease of AIDS, while maladaptive strategies include strategies that will increase the negative mental state of the patient, methods of aggression and the use of drugs (Brook et al., 1997).

Adaptive coping was correlated with social support, which is considered imperative in the development and nurturing of the fighting spirit in order to cope with the stressor. Therefore, social support from family and social organisations can be related to better and healthier coping. Numerous studies expound on the psychological factors associated with HIV status. These studies aim to explore and discover the relationship that exists between coping strategies and the psychological functioning of people.

2.10 Coping with AIDS – extended family

Consequently, AIDS impacts on the psychological wellbeing of the patient and his/her coping, but this impact is also extended to those close to the individual. Family members and friends may be directly affected by the death of their family member as a result of AIDS and may experience bereavement. Subsequently, bereavement as a coping strategy may be even more prominent for persons who are themselves infected with HIV (Rodkjaera et al., 2014). In terms of its association with coping strategies, AIDS-related grief was closely related to emotional suppression, avoidance and depression. Mediation for AIDS-related bereavement is required to lessen distress and, more specifically, maladaptive methods of coping, in order to treat the secondary prevention needs of bereaved persons living with HIV/AIDS (Rodkjaera et al., 2014).
A study was piloted to ascertain the prevalence, nature and severity of AIDS-related bereavement among persons who are themselves infected with HIV (Sikkema, Koob & Heckman, 1998). HIV-infected participants who were receiving healthcare from HIV medical clinics were enlisted to complete a mental health needs assessment. The study established that HIV bereavement experiences among these HIV participants were predominant and severe. Thus, 80% of the participants reported loss due to AIDS of a partner or spouse, a family member or a close friend. Furthermore, 80% of those participants who described any bereavement reported that they experienced several and repetitive episodes of grief because of the loss of partners, family members or friends to AIDS.

The study also reported that depression, traumatic stress and levels of grief were very high among the participants who reported AIDS bereavement (Sikkema, Koob & Heckman, 1998) and established the following findings. Firstly, patients who experience AIDS-related bereavement reported that problems with coping with the loss of their loved ones to AIDS are among their most severe problems. Secondly, these individuals exhibited elevated scores on general psychiatric symptomatology and measures of depression and grief. Thirdly, avoidant coping methods were reported and associated with higher levels of reaction to grief. Lastly, the participants expressed a desire to obtain support in coping with AIDS-related bereavement (Sikkema, Koob & Heckman, 1998).

In general, correlations of depression and various coping styles vary slightly among male and female patients. Accordingly, female patients have been noted to have elevated levels of depression in comparison to their male counterparts. In a sample population, strategies of escaping or avoidance, confrontation, seeking of social support and distancing themselves were employed as coping styles. In the sample population, male patients adopted escaping and avoidance, confrontation coping and distancing as coping strategies, whereas female
patients adopted strategies that involved seeking social support, escaping, avoidance and distancing only (Shanthi et al., 2007).

In addition to the psychological impact that bereavement and coping with the loss of a loved one due to AIDS imposes on the individual are the physical and medical issues related to HIV disease as well as the social and emotional consequences of living with HIV infection. Apart from the loss of loved ones to AIDS and facing their own HIV-related health problems, participants often also experience other losses. These losses affect socio-economic conditions such as unemployment, diminished status in society, loss of housing and economic instability (Shanthi et al., 2007). Treatment is therefore necessary and imperative to curb such losses. Furthermore, treatment issues such as substance abuse and premorbid psychopathology must also be considered and combined in intervention procedures. Specific strategies that have been noted for dealing with issues of loss and grief include the following: a) establishment of a sense of control and predictability, b) management and emotional expression, c) resolution of guilt and d) promotion of self-mastery through adaptive coping and empowerment (Shanthi et al., 2007).

Certainly, social support is a constant theme and appears to be dominant as a coping strategy. Interventions to cope with AIDS include emotional expression, personal disclosure, identifying feelings and developing effective ways for expression. In addition, adaptive coping strategies have been associated with reduction in psychological distress and the identification of coping difficulties has been specifically related to living with HIV and AIDS-related losses.

The intervention coping model (Folkman et al., 1991) includes the distinction between problem-focused and emotion-focused coping and is often presented by group therapists. As a result, HIV-infected individuals identify their current coping strategies and first set short-term goals. As the patients progress with their coping strategies, they are able to establish
mid-range goals for coping with AIDS-related losses. The final intervention module involves the implementation of adaptive and suitable methods of coping. Consequently, this will result in a decline in psychological distress, where the individual will utilise the support of group members and obtain feedback from them (Folkman et al., 1991).

The AIDS epidemic has impacted enormously on individuals that are infected with HIV and, by extension, their caregivers and close friends and family. Previous studies describe the psychosocial effects of AIDS and the uniqueness of the symptoms that are associated with AIDS-related bereavement. These studies strongly recommend the need for the improvement and appraisal of psychological bereavement treatment that is specifically designed for this population (Sikkema et al., 2002). Considerable evidence now exists that problems in coping with AIDS-related bereavement are quite common and severe. In addition, the significant impact that it has on the psychological health of those left behind when a person with AIDS dies is also severe. Therefore, specialised mental health services are necessary for persons with HIV who have difficulty coping with HIV infection and AIDS-related bereavement. Moreover, amplified clinical studies are required in order to recognise and assess which types of services are most effective for secondary prevention among persons with HIV infection (Sikkema et al., 2002).

HIV/AIDS is therefore a major concern and has only recently attracted the attention of psychosocial research, especially regarding individuals that are at higher risk. Numerous studies have been conducted where a number of clinical psychiatric syndromes have been identified in relation with HIV infections. HIV patients must learn to adapt to a set of disease-specific factors, which include the medical, psychological and social effects of the disease. In addition, the disease poses a general threat of death for the patient (Namir et al., 1999). These factors may often lead to several psychiatric conditions such as anxiety and depression. As a result, individuals adapt to maladaptive coping styles. Even though such patients may not
report or even identify depressive symptoms, they may present behavioural changes, which may suggest the presence of underlying depression. This study indicated that depressive disorders are more prevalent among female patients (Namir et al., 1999).

As previously mentioned, studies have also established a link between passive coping strategies (e.g. denial) and the progression of the AIDS disease. In terms of correlation with coping, denial as a coping strategy was associated with a lowered CD4 count. This implies that denial negatively impacts on the physical health of the patient. In addition, depression was associated with a faster progression to AIDS. This further implies that elevated levels of depression lead to a speedier progression of the disease and may even increase the risk of mortality (Namir et al., 1999). In addition, studies reported one of the first prospective findings that stressful events and social support were related to HIV progression to AIDS. Conscientiousness and adherence to medical regimes were positively associated with active coping and negatively correlated with depression, avoidant coping and perceived stress. Moreover, greater health worries discomfort at the thought of how one contracted HIV and less social support and spiritual wellbeing were also associated with substantial depressive symptoms. Male patients were more likely to resort to substance abuse such as alcohol abuse or dependence and engagement in certain risky sexual behaviour (Namir et al., 1999).

2.11 Conclusion

The theoretical perspective and understanding of coping and its processes and strategies with respect to HIV is a fundamental study in that it illustrates the manner in which patients deal with stressful situations. Coping takes two forms, namely style and process, depending on whether it is defensive and/or ego failure for the former, or adaptive or non-adaptive for the latter. The strategies include problem-focused (controllable by action on environment or patient), emotion-focused (refractory to change, i.e. relational meaning of what is happening) and the newly researched appraisal-focused strategies. While the ability to cope is dependent
on the timeframe as well as the amount of threats involved, it is important to examine how a patient copes as well as to understand the severity of threats. Hence various kinds of psychological coping methods were discussed and it was found that there exists a link between passive coping strategies and HIV disease progression. Patients suffering from HIV/AIDS encounter stressful life conditions, which could lead to the progression of the disease. This in turn affects their psychological and somatic health. Strategies discussed in this chapter include adaptive coping strategies such as problem solving, seeking social support, self-help, etc. Maladaptive coping strategies impede the general skills of the patient as well as general coping. The next chapter provides a detailed explanation of the literature review.
CHAPTER 3

LITERATURE REVIEW

3.1 Introduction

This chapter focuses on the literature review and general information concerning the disease of HIV/AIDS and covers the following issues: the definition, transmission, symptoms, diagnosis, prevention and treatment as well as the effects and prevalence of HIV/AIDS in Egypt. The key concepts that are discussed are HIV/AIDS in Egypt and the Key words that have been focused on in this review were: Quality of life, psychological distress which includes anxiety, depression and stress and how they relate to HIV/AIDS.

3.2 Understanding HIV/AIDS

According to Evian (2000), the nature of the HIV/AIDS disease can only be understood by differentiating between two key concepts that is HIV and AIDS.

HIV (human immunodeficiency virus): This is the virus that causes AIDS. HIV attacks the immune system by destroying CD4 positive (CD4+) T-cells, which is a type of white blood cell that is crucial for combating infection. The destruction of these cells causes individuals who are infected with HIV to become susceptible and vulnerable to other infections, diseases and complications (Kalichman, 2003). Unlike some other viruses, which may be reversed or treated, HIV cannot be disposed of by the human body. Therefore, HIV is a chronic disease and is life long.

AIDS (acquired immunodeficiency syndrome): This is the concluding phase of HIV infection. When an individual is infected with HIV, he/she will be diagnosed with AIDS when he/she has one or more opportunistic infections. These are infections such as
pneumonia or tuberculosis. In addition, the person will have a dangerously low number of CD4+ T-cells – less than 200 cells per cubic millimetre of blood (Kallings, 2008).

According to Van Dyk (1999), the HIV virus invades the body’s white blood cells, the CD4+ cells, and attaches itself to the genetic material (DNA) of the cells and starts to replicate. CD4+ cells are also known as T-lymphocytes, T-cells or T-helper cells. Even though the body continues to produce CD4+ cells, the HIV virus will gradually destroy CD4+ cells, thereby reducing the efficacy of the body’s immune system (Rowet, 2004). As the number of CD4+ cells in the blood are reduced, the immune system loses its capability to suppress and arrest infections (Van Dyk, 1999). Accordingly, the body’s debilitated immune system is left endangered and susceptible to AIDS-related opportunistic diseases such as cancer, tuberculosis, hepatitis, pneumonia and diarrhoea. Hence, from this perspective, AIDS is considered as the final stage of HIV infection (O’diaji, 2005).

Parker and Aggleton (2002) state that there are three phases that dominate the AIDS illness. During the first phase, the HIV infection is often unobserved, undetected and silent. The second phase is characterised by a more visible and evident presence in terms of the variety of communicable diseases. The third phase is considered potentially the most detrimental and destructive of all. This is because AIDS is an illness that involves social, cultural and political dimensions. Social dimensions include stigma, discrimination and denial.

Although only discovered in the early 1980s, AIDS has recently become the world’s greatest threat to health and communities. It has contributed to the deaths of millions of people of all ages and ethnicities (Lachman, Lachman & Butterfield, 1998; Duh, 1999; Kalichman, 2003). Several researchers have maintained that due to the rampant and aggressive spread of AIDS, it will result in devastating problems in society for years to come (Doka, 2000; Jacoby, 2002). The disease is not selective, as it threatens the lives of people all over the world.
Even though a large portion of society still views HIV/AIDS as ‘someone else’s disease’, studies have demonstrated that any individual is susceptible to contract HIV and as a result, die from AIDS (Duh, 1999). Subsequently, Duh argues that the end result of this viewpoint is that persons with AIDS have and still are suffering and are faced with a lack of sympathy from others, a lack of support and, in many cases, discrimination, due to the negative connotation attached to the disease. Therefore, the stigmatisation of HIV/AIDS still remains a major challenge and problem.

**Transmission:** HIV cannot survive for a very long period outside of the body. Transmission via daily activities such as the use of a toilet seat, sharing of food pots or drinking glasses, shaking hands or kissing is not possible. Furthermore, the virus can only be transferred from a human to a human and not via animals or insect bites (Quinn et al., 2000). Antiretroviral therapy does not impede sexual transmission of the virus. Therefore, people infected with HIV who are using antiretroviral therapy are still able to transmit the disease during unprotected sex and needle-sharing. Transmission only occurs via certain fluids, such as blood, semen, pre-semenal fluid, rectal fluids, vaginal fluids and breast milk from an HIV-infected mother. Transmission of the virus through these fluids is only successful by way of direct contact with a mucous membrane or damaged tissue or direct injection into the bloodstream (from a needle or syringe). These mucous membranes can be found inside the rectum, the vagina, the opening of the penis and the mouth (Quinn et al., 2000).

Transmission is successful through unprotected sexual intercourse with an infected partner. The exchange of needles, syringes, rinse water or other equipment that is used in the preparation of injection drugs from someone who has HIV will also ensure transmission of the disease. HIV may be transmitted from a pregnant mother to her unborn baby via birth or breastfeeding. Also, direct exposure to an HIV-contaminated needle or other sharp object is
considered a risk mainly for healthcare workers. In addition, the receiving of blood transfusions, blood products or organ/tissue transplants that are contaminated with HIV also represent a minor risk due to rigorous testing of the blood supply as well as donated organs and tissues (Attia et al., 2009). Interestingly, the consumption of food that has been pre-chewed by an HIV-infected person could lead to contamination when infected blood from the chewer’s mouth mixes with food while chewing. Although this is rare, it is quite possible. Being bitten by a person with HIV, involving severe trauma with extensive tissue damage and the presence of blood, has also been documented as a possible means of transmission, although a very small number of cases have been documented. However, there is no risk of transmission if the skin is not broken. Oral sex, which is the use of the mouth to stimulate the penis, vagina or anus, is also risky. Mouth-to-penis oral sex followed by ejaculation in the mouth is particularly riskier than other types of oral sex. Direct contact between broken skin, wounds or mucous membranes and HIV-infected blood or blood-polluted body fluids may also result in transmission. Nonetheless, confirmation of these reports has also been extremely rare. Although HIV is not spread through saliva, deep, open-mouth kissing may cause transmission if the person with HIV has sores or bleeding gums and blood is exchanged. However, transmission through kissing alone is extremely rare (Attia et al., 2009).

**Symptoms:** In the first phases of HIV infection, most people will experience few obvious symptoms succeeding infection. Patients may experience a flu-like illness, which includes headache, fever, enlarged lymph nodes in the neck and groin area and exhaustion (Kalichman, David & Marjorie, 2000). Usually, these symptoms disappear within a week to a month and are often erroneously diagnosed as another viral infection, such as the common flu. However, it should be noted that during this period, people are highly infectious because the HIV virus is present in large measures within the genital fluids and bloodstream. For
some individuals, the visible and noticeable presence of the symptoms of HIV may range from slight to severe symptoms and may last a long time, as opposed to other individuals, who may not experience any symptoms for 12 years or more (Kalichman, David & Marjorie, 2000).

During the advanced phases of HIV infection, the virus relentlessly incapacitates the immune system, and causes the persons infected to have the following symptoms: extreme and unexplained tiredness; pneumonia; memory loss; depression and other neurologic disorders; recurring fever or profuse night sweats; rapid weight loss; lengthy swelling of the lymph glands in the armpits, groin or neck; blotches on or under the skin or inside the mouth, nose or eyelids; diarrhoea that lasts for more than a week; and sores found in the mouth, anus or genitals (Sharp & Hahn, 2011). Even though each of these symptoms can be associated with other illnesses, HIV-positive infection will only be established through testing.

**Diagnosis:** Healthcare providers and doctors can test a sample of blood in order to detect the presence of human antibodies (disease-fighting proteins) that are specific to HIV. The two key types of HIV antibody tests are the enzyme-linked immune sorbent assay (ELISA) and the Western blot (Peeters et al., 2003). However, these antibody tests may not detect HIV antibodies in an individual who has been recently infected with HIV within the first three months after infection. In this period, healthcare providers can test the blood for the existence of HIV genetic material, which will inform of positive infection. This test is regarded as extremely critical for the identification of recently infected persons who are at risk of unknowingly and unintentionally infecting others with HIV (Peeters et al., 2003).

**Prevention:** Currently, there is neither a vaccine that inhibits and prevents HIV infection, nor is there a cure for HIV/AIDS. In order to reduce the risk of infection with HIV or transmission of the virus to others, it is imperative to follow these guidelines: getting tested
on a regular basis for HIV, avoiding needle-sharing, practising abstinence, consistently using male latex or female polyurethane condoms and finally, maintaining fidelity to one’s spouse or sexual partner (Merson et al., 2008).

According to Mirzoyan et al. (2013), less risky sexual behaviours may reduce the possibility of contraction. Therefore, oral sex is less risky in terms of transmission than anal or vaginal sex. The consistent and correct use of condoms is vital and also leads to a lower risk of infection in addition to the reduction of sexual partners, which will ultimately affect the risk of contracting HIV. In addition, individual consultation with a general practitioner about pre-exposure prophylaxis and taking HIV medicine daily may also lead to the prevention of HIV infection. It is also vital to get tested and treated for other sexually transmitted diseases (STDs) and encouraging partners to do the same. STDs can have long-term health consequences; therefore, testing at least once a year is vital. Subsequently, HIV-infected partners are urged to attain and maintain treatment (Mirzoyan et al., 2013).

ART reduces the amount of HIV virus (viral load) in blood and body fluids, and is an effective treatment that may keep an HIV-infected individual healthy for many years. Also, the consistent and correct use of ART drugs greatly reduces the chance of transmitting HIV to sexual partners (Mirzoyan et al., 2013).

**Treatment:** In the early 1980s when the AIDS epidemic began, it was unlikely for people with AIDS to live longer than a few years. Today, over 31 ARVs have been ratified by the Food and Drug Administration for the management of HIV infection. ARV treatment aids in the management of HIV infection, and is, in no uncertain terms a cure for it. Rather, ARVs act as suppressants of the virus, even to levels that are untraceable, but they do not totally eradicate HIV from the body. Due to the suppression of the quantity of the virus within the body, people infected with HIV are now afforded the ability and opportunity to live longer
and healthier lives. However, transmission of the virus is still credible and the incessant and continual ingestion of ARVs is indispensable for the preservation of their health quality (Nela & Kageeb, 2011).

Currently, there is no safe and effective cure for HIV and AIDS. However, scientists are exerting every effort towards the discovery of one and are still hopeful. Meanwhile, with proper medical care, HIV can be controlled. Treatment for HIV is often called antiretroviral therapy or ART. ART can radically extend the lives of people infected with HIV and decrease the possibility of infecting others. Prior to the introduction of ART drugs in the mid-1990s, HIV-infected persons could rapidly progress to AIDS in a span of a just a few years. Today, due to the availability of such treatment, HIV-infected patients may be medically treated before the disease reaches the advanced stages and can, as a result, lead a fairly normal life and enjoy a certain life expectancy (Nela & Kageeb, 2011).

3.3 Effects of HIV/AIDS

The AIDS epidemic is one of the most devastating health crises of modern times, ravaging families and communities throughout the world (Ashford, 2006). It also has shocking political, social and economic consequences (Arndt & Lewis, 2000).

3.3.1 Demographic and health effect

Recently, in the last decade, the AIDS epidemic has caused a surge in the mortality rate and a decline in life expectancy, specifically in countries that were hardest hit by it. However, due to the high fertility rate (average births per woman) in the severely affected countries such as in sub-Saharan Africa, the AIDS epidemic has not resulted in a decline of the population within the region. Countries such as Botswana, Lesotho and South Africa have confirmed a decrease in population growth, which has become either dramatically slowed or retarded due to the epidemic. However, overall growth in the Africa region has surpassed that of other
world regions. Furthermore, when considering AIDS-related deaths, it has been predicted that sub-Saharan Africa’s population will grow from 767 million in 2006 to 1.7 billion in 2050 (Carl Haub, 2006).

Evidently, the epidemic of AIDS has devastating consequences for society as a whole, and has been ranked fourth among the main causes of death worldwide and first in sub-Saharan Africa. According to a report by the Joint United Nations Programme on AIDS (UNAIDS), it is estimated that 3.1 million adults and children had died of AIDS, of whom 2.4 million were located in sub-Saharan Africa (Carl Haub, 2006).

3.3.2 Effect on societies and economies

The epidemic of AIDS is not limited to its symptoms and healthcare treatments and implications, but also affects all facets of life, be it on a social or an economic level. Countries that are more severely impacted by the epidemic of AIDS have been exposed to considerable losses. These losses include the tragic death of productive citizens and members of society, which ultimately leads to the deterioration of workplaces and farms. Schools, health systems and governments are adversely affected as well. Therefore, the epidemic has impeded almost every aspect of people’s lives (Ashford, 2006).

3.3.3 Households

Households are directly impacted by the consequences of HIV/AIDS due to the taxing financial burden that the disease enforces on the caregivers of AIDS patients. Due to the long period of the illness, loss of income and cost of caring for a dying family member, financial burdens may cripple families. This is especially evident in the situation where a parent dies of AIDS resulting in the closure of the household and the displacement of children who may be sent to live with relatives or left to fend for themselves (Ashford, 2006).
3.3.4 Healthcare systems

Healthcare systems are also under increasing strain and experience enormous demands as a result of the rapid transmission of HIV/AIDS. Poor healthcare systems in Africa have been crippled by HIV/AIDS, in comparison to the rest of the world that enjoys better healthcare systems. Subsequently, this resulted in the increase of expenses in order to facilitate the treatment and management of AIDS and AIDS-related opportunistic infections. Moreover, the allocation of scarce resources for HIV/AIDS has diverted attention from other health concerns and caused decreased public funds for healthcare. However, such costs are increasingly borne by the private sector and by families and individuals (Ashford, 2006).

3.3.5 Business and agriculture

Agriculture and business have also been extremely negatively affected by HIV/AIDS. Issues such as loss of employees, absenteeism and the rising costs of providing healthcare benefits (including expensive AIDS drugs) as well as the payment of death benefits have become quite prominent in the workplace. The economic viability of small farms and commercial agriculture is also compromised by a loss of farm workers (UN, 2004). A study by the Food and Agriculture Organization found that in the 10 African countries most severely affected by HIV/AIDS, the agricultural workforce will decline between 10% and 26% by 2020. In another study it was established that in countries such as Kenya, Malawi, Tanzania and Zambia, slow growth in agricultural produce could result in growing food insecurity by 2010 (UN, 2004).

3.3.6 Economic stability

Economic stability has been compromised as businesses and agriculture suffer. Some studies have established that in countries where the infection rate of AIDS is high, 1 to 2 percentage points of the annual gross domestic product compare with a hypothetical “no-AIDS” situation
(UN, 2005). Subsequently, the long-term impact may be more solemn than what these analyses suggest. Human capital such as children’s education, nutrition and health suffer directly and indirectly due to AIDS and these losses cannot be calculated. The effects of lower investments in the younger generation could affect economic performance for decades (UN, 2005).

3.4 Prevalence of HIV/AIDS

AIDS is spreading at an alarming rate. According to Perkel (1997), when AIDS was first documented as a separate condition, it became gradually apparent that it was spreading at a disturbing rate. Similarly, Duh (1999) states that AIDS is an old disease, but it has become part of our lives. It is not restricted in terms of infection, and may extend to the immediate family, friends and people within communities and society as a whole, who are being positively diagnosed on a daily basis. The first case was identified in 1981 in the USA and within eight years, 167,373 cases have been identified around the world, followed by Africa, which reported cases of AIDS in 1982 (Duh, 1999). Doka (2000) states that the HIV virus has likely existed for a period prior to the 1970s and it probably did so by only infecting and being transmitted among isolated groups of people. In addition, researchers argue that significant social changes in the 1970s caused changes in patterns of mobility. Also, risky sexual behaviours, drug use and blood use and collection also created a perfect context in which a viral disease such as HIV/AIDS could spread exponentially. As specified by Doka (2000), the emergence of AIDS in the 1970s in Western Europe, North America, Australia, New Zealand and urban areas of Latin America was primarily characterised by its infection of gay men, drug users and persons infected with blood products. He also indicates that heterosexual and prenatal transmission represented a small but increasing proportion of those infected. In sub-Saharan Africa, parts of Latin America and the Caribbean, HIV was recognised at about the same time, but it primarily spread through heterosexual intercourse and the use of blood and
unsterile needles (Doka, 2000). In Eastern Europe, the MENA region, Asia and the Pacific, the disease is beginning to emerge among those engaged in high-risk behaviours (Doka, 2000). Based on studies conducted in Zambia (Bond, Chase & Aggleton, 2002), it was estimated that 30 to 40% of infants who are born to women infected with HIV become infected, constituting around 21 000 infant infections each year.

**Spread of HIV in Middle East and North Africa (MENA):** Rates of HIV infection in the MENA region are among the lowest in the world, yet the MENA region is one of only two world regions where HIV rates are constantly on the rise. Even though the major methods of transmission may, HIV infections are rapidly spreading in every country. MENA countries cannot exclusively depend on their cultural and religious values to protect their populations against HIV infection (Setayesh et al., 2014).

According to UNAIDS, it has been reported that approximately 270 000 people were living with HIV in the MENA region by the end of 2012 (UNAIDS, 2013b). This concludes to an overall HIV prevalence of 0.1% among adults of ages ranging from 15 to 49, which is regarded as one of the lowest rates in the world. Yet, other statistics tend to differ significantly. Between 2001 and 2012, the number of new infections in the MENA region grew by 52%, regenerating it the most expeditious increase in HIV among world regions (UNAIDS, 2013b).

AIDS-related deaths are also on the rise, more than magnified in the MENA region between 2001 and 2012, while declining by 16% worldwide (UNAIDS, 2013b). The increase in the rapid infection of the disease could be due to the unavailability of ART. On average, across the MENA region, only one in five people who require ART have access to it, and as such illustrates the lowest coverage rate among world regions (UNAIDS, 2013b). Inadequate coverage for women and children with respect to ART is particularly stark, where less than
10% of pregnant women living with HIV have access to ARVs to prevent HIV transmission to their newborns.

The first AIDS cases in the MENA region were reported in the mid-1980s. By 1990, every country was home to people living with HIV; the vast majority were those infected through exposure to HIV abroad, HIV-contaminated blood products or organ transplants (Setayesh et al., 2014). However, within a few years, new patterns of transmission emerged. With the exception of South Sudan, parts of Somalia and Djibouti, where the virus is spreading in the general population, HIV in the MENA region is concentrated in certain groups whose practices put them at a higher risk of infection, namely men who have sex with men (MSM), female sex workers (FSWs) and injection drug users (IDUs) (Setayesh et al., 2014).

In Iran and Libya, for example, the majority of infections occur among IDUs and their networks of sexual and injecting partners. Injecting drug use is a primary contributing factor to HIV transmission in several other countries as well (Setayesh et al., 2014).

In Djibouti, South Sudan and parts of Somalia, HIV is primarily spreading through commercial sex networks. Concentrated epidemics (that is, an HIV prevalence of more than 5%) exist among subgroups of FSWs in a number of countries. Concentrated HIV epidemics are emerging among MSM in parts of the region (Setayesh et al., 2014).

Global experience has shown that HIV can spread from these key groups to the general population, especially when the former lacks access to prevention and treatment services (UNAIDS, 2011). In Morocco, for example, the vast majority (89%) of HIV infections among men are due to high-risk behaviours such as having unprotected sex with other men or with FSWs, or sharing contaminated needles (Mumtazet et al., 2013). About half of Morocco’s new HIV infections are among women, nearly three-quarters of whom acquired the infection through sexual relations with their husbands. Also in Iran home has the second largest
number of people living with HIV in the MENA region (Mumtaz et al., 2013), where three-quarters of women living with HIV acquired the virus from their husbands, who were mainly injecting drugs (Nasirian et al., 2012). As the number of women living with HIV grows in the region, so does mother-to-child transmission, in the absence of adequate preventive measures (Setayesh et al., 2014).

Research on key populations in the MENA region is limited and scattered, making it difficult to form a complete picture of the spread of HIV in the region. Published studies have increased progressively over time, with much progress in recent years, although most focus on issues related to HIV surveillance rather than on high-risk behaviours or HIV programmes (Abu-raddad et al., 2013). Iran and Morocco are among the few countries that have conducted wide-ranging research on HIV, reflected in the greater use of their data in this and other reports (Setayesh et al., 2014).

3.5 HIV/AIDS in Egypt
The first case of HIV in Egypt was detected in 1986. The data show that the number of detected cases of the virus has increased gradually since then. From 2001 to 2005, 1,040 HIV cases were detected, between 2006 and 2009 (HIV/AIDS Situation, 2010). While Egypt’s general population has a low HIV-prevalence rate of less than 0.02% (HIV/AIDS Situation, 2010), there are demographic groups with markedly higher prevalence rates. The prevalence of HIV among these groups represents a main development concern for Egypt. The number of people living with HIV in Egypt was estimated to be 6,500 in 2013 (UNAIDS, 2013a).

In 2010, the Ministry of Health and Population, Family Health International and the Center for Development Services conducted the most recent round of the Bio-Behavioral Surveillance Survey (Bio-BSS). The Bio-BSS 2010 suggested that there was a concentrated epidemic among MSM and male IDUs. The HIV prevalence was 5.4% among MSM in Cairo.
and 6.9% among MSM in Alexandria. Among male people who inject drugs (PWID) the prevalence was 7.7% in Cairo and 6.7% in Alexandria (HIV/AIDS Situation, 2010). This Bio-BSS 2010 data confirmed the high concentration of HIV infection in these populations that was detected in the first round of the Bio-BSS in 2006 (Bio-BSS, 2006). The 2010 data also identified HIV-positive cases among street children (Bio-BSS, 2010).

The populations associated with HIV globally are known in Egypt to be female sex workers (FSWs), men who have sex with men (MSM) and injection drug users (IDUs) and links from these high-risk groups to the general population have been documented (UNAIDS, 2008).

**Female sex workers** worldwide, commercial sex workers are considered one of the most at-risk groups for contracting HIV infection (Sarkar et al., 2005). Sex workers frequently have insufficient access to adequate health services, male and female condoms and other preventive services (UNAIDS, 2009). The extent of HIV infection among FSWs in Cairo, Egypt is not exactly known due to the reality that few field studies have been undertaken and there is therefore a scarcity of data. Conducting studies among FSWs can be difficult because of the stigma related to sex work. That said, the prevalence of HIV infection in Cairo still appears to be lower than that in other industrialised cities (UNAIDS, 2009). Worldwide studies estimate that nearly 5 million people are being infected with HIV every year (WHO, 2005; Abu-raddad et al., 2010) and about half of those currently infected with HIV are women (WHO, 2005). Rates of HIV infection are higher among those involved with sex work than in most other populations (UNAIDS, 2009). The number of FSWs has been increasing over the past two decades, mainly due to economic reasons (WHO, 2000; WHO, 2005). Many studies indicate that the risk of getting infected with HIV is high among FSWs and their clients (Wolffers, 2001). Paid sex remains an important factor in many of the HIV epidemics in West, Central and East Africa. In Egypt, commercial sex is illegal, but it does exist (Kabbash et al., 2012).
Men who have sex with men are considered one of the modes of HIV transmission. This type of transmission is often difficult to address and the estimation of the rate of transmission is just as difficult due to the stigma attached to homosexuality. Men who engage in sexual intercourse with other men will often not view themselves as non-heterosexual due to such stigmatisation and may wish to not be identified as such (UNAIDS, 2004). According to a study conducted in the Middle East, it has been estimated that 89% of all cases of HIV infection are transmitted via sexual relations, and that a mere 2% of that figure is due to sexual intercourse between men (UNAIDS, 2004; WHO, 2006).

It has been estimated that there are over 100 million homeless children and youths in the streets of large cities, especially in developing countries. These children are often forced to fend for themselves and prostitution is one way for them to earn money for such survival. In addition, liberal sexual relations among one another is rapidly posing as a major cause of transmission among these groups. According to a study by UNAIDS, such groups are considered to be one of the high-risk groups for HIV/AIDS transmission in the community (UNAIDS, 2004). In the city of Cairo, there are many such street children groups. They often gather in the main squares of Cairo and offer their services for any available employment such as washing cars in the street or domestic work in the homes. It is hypothesised that this group of homeless boys may be willing to offer sex for money, shelter or food (El-sayyed et al., 2008).

Injection drug users the actual sizes of groups of IDUs who are at highest risk of HIV exposure and transmission in Egypt have not yet been accurately estimated. Studies that have been conducted around other parts of the world, such as the Middle East, established that IDUs could be the reason for the large proportion of HIV transmission (UNAIDS, 2004; UNAIDS, WHO, 2010). However, a previous study suggested that the number of IDUs in Egypt may not be as high (Soliman et al., 2010), as of the cumulative 2 483 HIV cases
reported to the Egyptian Ministry of Health from 1986 to 2006, IDUs only accounted for 1.6% of the modes of transmission (UNAIDS, 2006).

**Political Challenges** Due to the 2011 revolution, Egypt was faced with significant political unrest and a sense of declining security. As a consequence, it has resulted in a numerous changes in senior government leadership. An example of this constant change is that Egypt’s Ministry of Health and Population has had seven different ministers since 2011. This high turnover rate in terms of leadership has complicated the progression of HIV treatment programmes within Egypt. Therefore, the hindrance of administrative and executive outreach activities as well as service provision for key populations has also contributed to the instability of the security situation (GRPR, 2014).

3.6 Psychological distress and HIV/AIDS

Psychological distress is defined as “the unique discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary or permanent to the person” (Ridner, 2004:653). Furthermore, psychological distress is an emotional condition and entails negative opinions of the self, others and the environment. Some of the characteristics of psychological distress include feeling tense, worried, worthless and irritable, and it is used as an indicator of general health (Pandey & Shukla, 2014). The psychological scenario surrounding HIV/AIDS is much more severe than that of other chronic illnesses such as cancer. This is owed to the stigma, discrimination, allegations of promiscuity, gossip and character assassination for persons infected and affected by HIV/AIDS.

Psychological stress among men and women vary greatly. It impacts negatively on all facets of the individual’s life, be it physical or psychological. In addition, financial dependence is amplified by the disease (Esplen, 2007). Psychological stress is much more magnified when
the infected person is female. Furthermore, the poor socio-economic status of women, especially, results in deprived access to health services. Men also experience psychological distress via an expression of their inability to handle the problem, whereas psychological distress experienced by women largely stems from the constant state of worry concerning the state of their lives. Interestingly, recorded levels of high stress do not necessarily correlate with HIV/AIDS infection and may serve as a joint function of various social, attitudinal and financial factors (Esplen, 2007).

Psychological distress is often confused with strain, stress and distress. These terms are often used interchangeably and erroneously. Psychological distress could be associated with symptoms of acute and chronic illness, which compromise both comfort and discomfort of the psychological state of the patient, resulting in mental anguish (Mc Clement et al., 1997).

Lazarus (1998) identified stress caused by illness as one of the affecting problems faced by individuals. Therefore, the term ‘psychological distress’ may more accurately describe the unique responses of the individual to the illness.

According to Selye (2003), the word ‘stress’ has positive and negative meanings. Selye (2003) holds the viewpoint that stress is always present and that good stress is referred to as eustress and bad stress is referred to as distress. This view corresponds with the opinion of Murray and Huelskoetter (2006:374), who defined stress as a “physical an emotional state always present in the person as a result of living, it is intensified in a non-specific response to an internal or external change or threat”.

A lack of clarity in terms of the definition of psychological distress has resulted in the erroneous application of the terms ‘stress’, ‘distress’ and ‘psychological distress’. Another term that is often used interchangeably is ‘strain’. Strain is used to describe the impact of stressors, such as caring for a child with a behavioural disorder (Bussing et al., 2003). On the
other hand, distress is used by health professionals in reference to physical, emotional and spiritual conditions. Psychological distress in people living with HIV/AIDS is caused by dysfunction of these conditions. These include feelings of worthlessness, unhappiness, depression and lack of enjoyment and, by extension, a general lack of participation in daily activities. It is therefore of vital importance that studies are conducted that explore treatment for psychological distress among HIV patients.

Psychological distress is construed as the general concept of maladaptive psychological functioning in the face of stressful life events (Abeloff et al., 2000: 556). In addition to this definition, one might add that psychological distress has five discerning qualities. These are (1) the apparent incapability to cope efficiently, (2) an alteration in emotional status, (3) a sense of uneasiness and discomfort, (4) inability to communicate the discomfort, and (5) harm. These qualities of psychological distress are discussed in the following sections.

The perceived incapability to cope efficiently originates from the preconception that there is in fact no means to remove the stressor such as HIV/AIDS. As a result, the patient realises an inability to resort to problem solving because there is no means to solve that particular problem. This is all dependent on the individual’s perception of coping. Furthermore, an unawareness of the stressor is regarded as a form of ineffective coping, whereas conviction that the ability to cope is possible would result in problem solving as a coping strategy. This would result in the elimination of the perception that there an inability to cope effectively with the stressor, in this case HIV.

A change takes place in the emotional state of the patient, which is often the case with HIV-infected individuals. Such an alteration may be transferred from a stable emotional baseline and reach emotions such as anxiety, demotivation, irritability, aggression and self-depreciation (Massee, 2000).
Uneasiness and discomfort experienced by the individual are prominent features of psychological distress and refer to anything that ‘disturbs comfort’. Discomfort is related to the change in the patient’s emotional state that occurs as a result of being infected with or affected by HIV/AIDS.

Patients often experience an inability to effectively communicate and convey such discomfort due to psychological distress. Communication might occur via facial expressions, be it overt or subtle (Ridner, 2004). Seyle (1976) maintains that distress is harmful to patients and that they may suffer from it as a direct result of symptoms of chronic illnesses.

One of the antecedents of psychological stress is the existence of a stressor, which may assume multiple forms. These forms may be manifested as a symptom, such as fatigue, nausea or weight loss. In addition to this stressor is the realisation on behalf of the individual that the stressor is an actual personal threat. This is then followed by the loss of control, be it perceived or actual in nature. According to a study conducted by Kuehn and Winters (2001), individuals who have an internal nature of control have better coping skills than those patients who have an overt quality of control. Ineffective coping is another antecedent of distress and ineffective coping will result in psychological distress.

The consequences of psychological distress may permanently affect the mental interest of the patient (Murray & Hoelskutter, 2006). This damage may be manifested in suicide, hypertension, a heart attack or other forms of physical damage. However, if the stressor is removed, the individual may return to normal baseline functioning.

Individuals differ with regard to the rate of progression during the successive phases of HIV infection. Some remain asymptomatic for extended periods and respond well to medical treatment and therefore are not overtly faced with the illness on a daily basis. However, other patients may progress rapidly since the onset of AIDS and rapidly develop numerous
difficulties and opportunistic contagions. Studies have supported that stress may account for some of this variability within HIV progression (Ridner, 2004).

Many studies that have explored the relationship between stress and HIV progression have been published. However, evidence published before the year 2000 concerning the influence of stress on HIV progression has been largely inconsistent. However, later publications have generally supported a link that exists between stress and HIV progression (Cohen et al., 2007). Furthermore, some findings indicate that an accumulation of negative life events over several years of follow-up predicts worse AIDS-related outcomes.

Associations between psychological stress and disease have been established, particularly for depression, cardiovascular disease and HIV/AIDS. Other areas in which evidence for the role of stress is beginning to emerge include upper respiratory tract infections, asthma, herpes viral infections, autoimmune diseases and wound healing (Vedhara & Irwin, 2005).

Stress-management interventions have been designed and evaluated and are a necessary measure to promote psychological wellbeing and adaptive coping among people living with HIV/AIDS (Leserman et al., 2002). As for recent stress-management interventions for people living with HIV/AIDS, four categories have been stipulated. These are (a) interventions that are aimed at the improvement of coping and modification of health behaviours such as adherence to ART medication and an alteration in sexual behaviour, (b) relaxation and meditation-based stress-management approaches, (c) computer-delivered intervention, and (d) specific interventions that are aimed at specific populations, including older individuals, individuals with childhood sexual abuse histories and women (Brown & Vanable, 2011).

It is of relevance to note here that psychological distress could also be correlated with depression. Depression is defined as a mood state, a set of symptoms and a clinical syndrome (Weisse, 2008). Subsequently, it is highly possible that HIV-positive individuals may be
diagnosed with a major depressive disorder. The HIV infection can also aggravate and promote the depressive symptoms and therefore, depression could be considered a side effect of the disease.

According to Leserman (2003) and Whetten et al. (2006), a study has established that depression is associated with HIV infection. The medical procedures that are associated with the disease are often harrowing and may trigger a range of mental crises. In addition, poor mental health and a heavy mental health burden are as a result correlated with reduced adherence to medical treatment, thereby resulting in poorer outcomes.

3.7 Quality of life and HIV/AIDS

Many individuals infected with HIV/AIDS are faced with the crucial decision of with whom they would like to share the information. This could often have a negative or positive effect on the mental stability of the person, and as a result it affects their quality of life. A poor quality of life could lead to a range of problems. Quality of life is a term that is popularly used to convey the general feeling of wellbeing and includes aspects such as happiness and satisfaction with life as a whole. The World Health Organization (WHO) has defined QoL as individuals’ perceptions of their position in life in the framework of the culture and value systems in which they live and in relation to their goals, standards, expectations and concerns (WHO, 2008). Recently, there have been numerous medical advances within clinical tests and treatments concerning patients who are diagnosed with HIV/AIDS. As a result, the survival of these patients has been increased and their QoL has become an important focus for researchers and healthcare providers (Clayson et al., 2006).

The AIDS epidemic is considered a chronic disease and is considered as one of the greatest health problems in the world (Fauci, 1999). HIV/AIDS enforces an increasing burden on the health of the population. Furthermore, it causes further socio-economic issues, such as
problems relating to individuals, communities, families and governments in many countries (Walker et al., 2004). In addition, a person living with HIV/AIDS has to cope with a range of HIV-related symptoms for long periods. These symptoms may be related to the infection itself or may be comorbid illnesses or iatrogenic effects from HIV-related medication (Beck et al., 2001).

Moreover, many HIV patients struggle with numerous social problems attached to the disease, such as stigma, poverty, depression, substance abuse and cultural belief. This has an adverse effect on their QoL. This could not only impact from the physical health aspect, but also from mental and social health points of view and may be the reason for numerous problems in terms of useful activities and interests of the patients (Aranda, 2004). It is noteworthy to mention that the assessment of health-related quality of life might be considered a helpful measure for documenting patients’ perceived burden of chronic disease. Furthermore, such an assessment could track variations in health over time, evaluate the effects of treatment and quantify the return on healthcare investment (Hays et al., 2000).

Attending to daily tasks such as working and cleaning is often challenging to HIV patients. Their participation in these tasks might range from moderate to strong physical activities. They might not have the sufficient energy or vitality to engage in an active social life while managing HIV/AIDS. Therefore, tiredness as a result of HIV has been negatively associated with both the physical and the psychological health of the patient. Hence, morbidity and poor QoL in persons with HIV/AIDS as a result of this psychological strain have become evident (Perez et al., 2005).

As mentioned previously, AIDS patients adopt various methods of coping with their illness. Coping by disengagement or avoidance is one these methods that have been connected with greater health-related stress (Swindells et al., 1999). Furthermore, poor social functioning,
such as conflictual and poor social relations, has been shown to increase the levels of stress. Therefore, it may be connected with better usage of avoidance coping strategies such as withdrawal, which has been shown to increase stress and lead to poorer overall social functioning. Increased use of avoidance strategies has been adopted by patients living with HIV/AIDS, such as behavioural disengagement and self-distraction. Increased usage of alcohol and drugs as a coping strategy has also lead to poorer physical and social functioning.

Therefore, it has been reported that patients with HIV who have previously engaged in injected drug use, especially on a serious basis, reported poor health-related QoL. Hence, compound role workings such as career, housework and educational pursuits have been shown to be even more limited than the physical functioning in persons with HIV/AIDS. This suggests that coping by avoidance may directly reduce an individual’s productivity and as a result lead to a poorer QoL (Ruiz- Pérez et al., 2005).

There are three major components of social support, namely emotional, tangible and informational support. Social support plays a vital role in the patient’s ability and scope to deal effectively with this harrowing and socially stigmatising disease. Therefore, it is important to establish social support for patients with HIV/AIDS as carrying a strong potential to impact on the health-related quality of life of patients. Social support provides the patients and every individual that belongs to a society with a sense of nurturance, belonging and alliance. Therefore, it is emotionally sustaining and functions as means to ease stress in non-HIV settings. Two studies have specifically reported that emotionally sustaining support was considered more desirable and was more often adopted as opposed to other forms of support coping and would considerably influence QoL.

As for coping by denial (avoidance), it has been associated with a significantly lower QoL in a previous study. Even though denial as a coping strategy has been established as an effective
coping method in non-HIV settings, its application within HIV settings has suggested otherwise (Schmitz & Crystal, 2000). Within HIV settings, denial has been shown to correlate with low self-esteem and depression in HIV patients. Such patients who resort to denial as a coping strategy may do so as an expression of helplessness, anger or depression. These patients may as a result psychological intervention (Fleishman et al., 2000).

Spirituality has always been known to be a setter of emotional equilibrium and is considered an important contributor to feelings of wellbeing. Spirituality for HIV-infected individuals could be considered as a means to gain a sense of meaningfulness in their lives. This could be perceived as a useful countermeasure against hopelessness, which may lead to depression, and as such negatively impact on QoL (Holmes et al., 1999).

Depression is common among HIV-infected patients. However, predictors of depression in HIV-infected individuals are not limited to psychological areas, but are extended to comorbid psychiatric illnesses as well. Furthermore, in one study, external contributing factors such as younger age, unemployment, lack of health insurance, low CD4+ cell counts, HIV-related symptoms, lack of a partner, poor degree of social support and use of injection drugs were established as significant predictors of depression (Kelly et al., 1999). Interestingly, it has been discovered that HIV-infected patients who are older than 35 years are more likely to suffer from depression, anxiety, confusion and tiredness. Furthermore, insomnia, pain and emotional control were also correlated with depression (Wagener et al., 2000).

Hence, it may be concluded that although HIV-infected patients face an array of psychologically taxing problems and comorbid illnesses, such as depression, it should be noted that the treatment of depression in patients with HIV may not prolong their life, but can lower the risk of suicide. This could and will ultimately improve QoL, which is achieved
through the direct and increased adherence to strict medical regimens (Wagener et al., 2000).

HIV affects individuals in different ways, but it is evident that it impacts on the economic and social arenas of the patient’s life, which significantly affects QoL. Unlike other illnesses, individuals with HIV/AIDS struggle with an illness that is unpredictable and unstable. Furthermore, persons with HIV/AIDS may by extension receive further financial and social support, which will be reached through employment. Therefore, employment affords not only financial benefits, but may also be exporter of structure, social support, role identity and meaning (Murdaugh et al., 2006). Even if the physical health of the patient is stable, the illness itself may limit the occupational functioning of the patient. These limitations include HIV-specific factors such as episodic illness, fatigue, physical and cognitive limitations, medication schedules and frequent medical appointments (Semba et al., 2005). Other acute medical conditions allow patients to return to pre-disease levels of functioning after therapy, but patients with HIV infection are not afforded that and must recurrently acclimatise to an erratic illness course.

Accordingly, some leave the workforce and receive disability benefits, while others remain employed to different degrees. In terms of depression, previous research has confirmed that unemployed individuals normally report more depression, anxiety and social isolation in addition to low self-esteem as opposed to employed individuals. Hence and Aroet et al (1998) established that employment was one of several factors associated with improved QoL.

Subsequently, it is of vital importance to note that many clinical issues flow from life-threatening illnesses such as HIV. These issues are complex and include thoughts of suicide and even attempted suicide. It has been reported that suicide in persons with HIV/AIDS was associated with a linked psychiatric disorder (Dickey et al., 1999). This may arise as a result
of the fear of contracting HIV infection and by extension, infecting the family and partners of those infected. Furthermore, certain negative patterns of behaviour that have been associated with the risk of acquiring HIV infection (e.g. injection drug use) have also been adversely correlated with higher degrees of suicidal ideation and psychiatric disorders (Dickey et al., 1999).

3.8 Coping strategies and HIV/AIDS

The relationship between stress and adaptation has been widely explored across a variety of illnesses. However, the exploration of these studies has been very limited concerning this relationship in individuals coping with HIV/AIDS.

Individuals employ various coping methods to combat different stressors in a unique manner. These stressors include the physical, mental and psychological demands of life (Lazarus & Folkman, 1984). The aim of these coping strategies is the establishment and maintenance of psychological homeostasis and mental equilibrium. In addition, previous studies conducted have indicated a clear association between reliance on problem-focused coping and, as a result, better adjustment to HIV/AIDS.

There are two distinct and discrete approaches to understanding coping. These are transactional and ego psychology. Lazarus and Folkman (1984) are the proponents of the transactional viewpoint, which states that the coping mechanism is dependent on factors that are external to the individual and include external support networks. Coping in this viewpoint is a cognisant process concerned with what a person truly thinks or does in a specific context (Lazarus & Folkman, 1984). However, the ego psychology perspective concentrates on the regulation of the individual’s internal factors such as the psychological processes that are employed in an attempt to effectively cope with the stressor. An example of such a psychological mechanism used in this perspective is the use of the defence mechanism. This
perspective is of a developmental nature and focuses on how the individual will mature developmentally, spanning from a state of distress to a more integrated and mature state of being. This approach is very distinct from the transactional approach because it regards factors external to the individual as of symbolic value.

Two alternative models have been proposed to explain the relationship between stress appraisal, coping resources and coping strategies that have direct effects on adjustment. According to some researchers, coping is better regarded as a response to stress rather than being moderated by a high stress level (Reeves et al., 1999). HIV-infected persons attempt to maintain ego integrity and mental stability under stressful situations. Some individuals employ more mature defence mechanisms to cope, such as humour, altruism, suppression, anticipation and sublimation, which will result in a healthier adaptation to the disease. Furthermore, neurotic mechanisms such as repression, immature mechanisms such as acting out and psychotic mechanisms (Reeves et al., 1999) will result in a less healthy adaptation to the diseases of HIV/AIDS.

Denial is one the most common methods of coping with a stressful event or occurrence in life. Denial is defined as “a refusal to acknowledge an event or feeling … denial allows one to literally forget that has happened” (Reeves et al., 1999: 345). In this instance, denial may be utilised to maintain emotional and mental equilibrium for a short period of time. However, according to Aldwin (1994), coping with the stressors of being diagnosed with HIV/AIDS can initiate change or transformation within that person and may not necessarily bring about homeostasis, be it in a psychological or a physical manner.

The status of HIV/AIDS is severely stigmatised in society and often denotes connotations of promiscuity and infidelity. In a study conducted in Liuzhou, China, which explored the feelings, experiences and coping strategies of persons living with HIV/AIDS, many
participants confirmed this finding and felt severely stigmatised. In addition to this negative stigmatisation, low self-esteem and feelings of despair were also reported (Zhang et al., 2014).

In previous study was classified according to the intrapersonal and interpersonal coping styles and established four types of coping that participants employed to deal with HIV-associated stigma. These are as follows: (1) compassion (passive/avoidant-interpersonal), (2) hiding HIV status (passive/avoidant-intrapersonal), (3) social support (active/problem-focused-intrapersonal, and (4) self-care (active/problem-focused-intrapersonal) (Zhang et al., 2014).

It is vital that educational and stigma-reduction interventions be considered as latent social support networks to aid persons living with HIV/AIDS, such as family, close friends and peers. These networks could reinforce active interpersonal persons living with HIV/AIDS coping strategies. Consequently, further interventions coaching self-care to people living with HIV would encourage active intrapersonal coping. These may both improve the QoL of people living with HIV (Zhang et al., 2014).

In terms of emotional support as a method of coping with AIDS, Pakenham and Rinaldis (2001) propose that it is the most frequently identified and most helpful type of support for managing AIDS. Emotional support is traversed from acceptance, understanding, nurturing, self-disclosure, intimacy, listening, physical affection and even humour. However, it should be noted that individuals infected with HIV/AIDS are able to exhaust their social support resources.

3.9 Conclusion

This chapter has described the general overview of HIV/AIDS worldwide, including in Egypt. Relevant literature on psychological distress, quality of life and coping strategies of people living with HIV/AIDS has been reviewed. The HIV disease is a chronic health
problem that cannot be cured. It places considerable physical and psychological stress on the patient and his/her family. However, both the patient and the physician have to deal with this stress and control it. In summary, there are many coping styles that are employed by people and some may prove more effective than others. This is dependent on the nature of the stressful situation and the individual. Coping strategies are governed by a range of techniques and are completely individualistic, and depend entirely on the person, type of stressor and context within which the stressor occurs. Coping strategies are internal and external, ranging from the interpersonal to the intrapersonal, passive to active, and are physical, psychological as well as social. The next chapter provides a detailed explanation of the methodology used to collect and analyse the data.
CHAPTER 4
RESEARCH METHODOLOGY

4.1 Introduction

This chapter outlines the methodology used to conduct the present study to accomplish the specific aims and objectives as described in Chapter 1. A detailed explanation is provided for the research design. It also provides an explanation of how the sample was recruited and presents a full description of the sample. Further, this chapter presents the instruments used to collect the data for analysis. It also presents the pilot study conducted before undertaking the main study, while the data-collection procedure and analysis procedures are also discussed. Lastly, the ethical considerations are discussed.

4.2 Objectives of the study

The objectives of this study were to:

1. Establish the levels of psychological distress and quality of life of persons living with HIV/AIDS in Cairo, Egypt;

2. Determine the coping strategies used by persons living with HIV/AIDS in Cairo, Egypt; and

3. Investigate the relationship between the quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt.

4.3 Research methodology

This study used a quantitative approach. De Vos (2005) states that quantitative research entails the measurement and analysis of various cause-and-impact relationships between variables as well as a method where data are collected in the form of numbers and are
analysed using statistical measures. According to Aliaga and Gunderson (2000), quantitative research entails “Explaining phenomena by collecting numerical data that analyses using mathematically based methods” (Muijs, 2011:1). In this study, questions were answered by using data gathered through self-administered questionnaires and the responses were assigned a number. The variables were then correlated to assess the relationship between the variables.

4.4 Research design

This study was conducted using a cross-sectional correlational design. Cross-sectional studies are used to study a fraction of a population at one single point in time (Trochim, 2001; Thisted, 2006). A correlation-relationship design was used to determine the relationships among the variables. The correlation design examines the strength of the relationship between variables (Asadoorian & Kantarelis, 2005).

4.5 Population and sample

According to De Vos et al. (2005), a population is defined as a set of entities in which all the measurements of interest to the practitioner or researcher are presented. In this study the population was 202 people living with HIV/AIDS. A sample is defined as “a subset of the population”. An important fact is that the sample must be representative of the population being studied in terms of size and bias (Goddard & Melville, 2001:34). The sample of this study was accessed via the NAP in Cairo, Egypt. The NAP identifies new work models and innovative activities so that it can work effectively to respond to the effects of extensive and long-term HIV/AIDS, especially as the epidemic is threatening to wipe out development gains and undermine the productive capacity of Egypt. The activities carried out by the organisation include an extensive range of initiatives, ranging from prevention of infection with HIV to the end of the reduction of the effects of the AIDS epidemic. Currently, there are five organisations working towards preventing the spread of HIV in Cairo, Egypt. In addition
to providing healthcare services to people living with HIV/AIDS and combating the stigma surrounding HIV-infected people, testing, counselling and clinical care, the NAP includes approximately 2000 people living and infected with HIV/AIDS (GARPR, 2014). Therefore, this study was focused on the NAP accessed by people with HIV/AIDS. The participants were conveniently accessed through meetings with the respective authorities and leadership (director) at Abassia Hospital regarding the research purpose, aims and objectives of the study. At this meeting a flyer was presented, which invited people to voluntarily participate in the study. Recruitment for the study entailed participants referred by community officers of the NAP. A sample of 10% (202) was recruited to participate. The participants’ ages varied between of 18 and 66 years.

4.6 Instruments

The instruments that were used were (i) Demographics, (ii) the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q), (iii) Depression Anxiety Stress Scales (DASS), and (iv) The Cope Inventory. The questionnaire was translated into Arabic, back-translated and adapted to the specific socio-cultural context of Egypt (Appendix C).

4.6.1 Demographics

The participants were asked to record their age, sex, marital status, race, language and educational grade. They were also asked to indicate their source of income and living arrangements.

4.6.2 Quality of Life Enjoyment and Satisfaction Questionnaire

The Q-LES-Q is a self-reported questionnaire, with 16 items derived from the general activities scale of the original 93-item form (Endicott et al., 1993). It evaluates overall enjoyment and satisfaction with physical health, mood, work, household and leisure activities, social and family relationships, daily functioning, sexual life, economic status,
overall wellbeing and medication. Responses are scored on a five-point scale (very poor, poor, fair, good and very good), where higher scores indicate better enjoyment and satisfaction with life (possible range 14–70). Fourteen summated items create the total Q-LES-Q score. The Cronbach’s alpha is 0.7.

4.6.3 Depression Anxiety Stress Scales

The DASS is a quantitative measure of distress along the three axes of depression, anxiety and stress. In addition, the dependability of DASS either full version (42 items) or short version (21 items) was well established in samples of healthy general population (Lovibond, 1995; Crawford & Henry, 2003; Henry & Crawford, 2005; Musa et al, 2007). However, DASS contains 21 items. The rating scale is as follows: did not apply to me at all (never), applied to me to some degree, or some of the time (sometimes), applied to me to a considerable degree or a good part of the time (often) and applied to me very much or most of the time (always). The Cronbach’s alpha is between 0.63 and 0.67. Table 4.1 below presents the DASS subscales used to measure the dimensions of depression, anxiety and stress.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Stress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal</td>
<td>0–4</td>
<td>0–3</td>
<td>0–7</td>
</tr>
<tr>
<td>Mild</td>
<td>5–6</td>
<td>4–5</td>
<td>8–9</td>
</tr>
<tr>
<td>Moderate</td>
<td>5–10</td>
<td>6–7</td>
<td>10–12</td>
</tr>
<tr>
<td>Severe</td>
<td>11–13</td>
<td>8–9</td>
<td>13–16</td>
</tr>
<tr>
<td>Extremely severe</td>
<td>14 +</td>
<td>10 +</td>
<td>17 +</td>
</tr>
</tbody>
</table>
4.6.4 Cope Inventory

The brief cope scale is intended to evaluate a broad range of coping responses among adults for all diseases (Carver et al, 1989; Carver, 1997). It comprises of 28 items and is rated by means of a four-point Likert scale, ranging from I haven’t been doing this at all (score 1) to I have been doing this a lot (score 4). In total, 14 dimensions are covered by this scale, namely self-distraction ($\alpha=0.71$), active coping ($\alpha=0.68$), denial ($\alpha=0.54$), use of emotional support ($\alpha=0.71$), substance use ($\alpha=0.90$), use of instrumental support ($\alpha=0.64$), venting ($\alpha=0.50$), behavioural disengagement ($\alpha=0.65$), positive reframing ($\alpha=0.64$), humour ($\alpha=0.73$), planning ($\alpha=0.73$), acceptance ($\alpha=0.57$), religion ($\alpha=0.82$) and self-blame ($\alpha=0.69$). There are two items for each dimension (Yusoff et al., 2010).

4.7 Pilot study

A pilot study is used to aid in the additional development of a larger study. It may be utilised in order to test study measures, the validity of tools and the evaluation of outcome variables (Arain et al. 2010). A pilot study was used in this study as a method of recognising faults in the data-collection plan, while also permitting enough time for correction prior to the commencement of the main research. A pilot study was carried out using a small sample of subjects, namely 10% of the main study. As part of the pilot study, the questionnaire was administered to a second group that was similar to the sample to allow for a test-retest method. The test-retest method also assists in gauging the internal consistency of the questionnaire. Twenty participants were chosen in the same manner as the participants for the main study. The pilot participants were briefed to make sure of challenges experienced with the questionnaire and during data collection. The structure and content of the questionnaire were then amended accordingly. The researcher used the data collected in the pilot study to generate dummy data for participants in order to run a trial test on the selected method of data analysis, as recommended by Robson (2007). A pilot study further serves to measure the
reliability of the tool, explore language options or obstacles within the questionnaire and consider the data-collection process. The research questionnaire and process will subsequently either be changed or remain the same based on the outcome of the selected data. After the pilot study, the research participants for the main study were selected. The questionnaires took approximately 30 minutes to self-administer, and the contact persons were asked to participate in the study and attend an interview, which took place at Abassia Hospital in Cairo, Egypt.

4.8 Data collection of the main study

Once the pilot study had been completed, including both data collection and analysis of the research process and questionnaire, the results of this process informed the process for the main study. The planning phase of the main study included meetings with the NAP. Accordingly, as was conducted with the pilot study, the process of requesting permission from the NAP was followed, where participants were informed about the study and asked to voluntarily participate in the study. Participants were asked to attend an interview at Abassia Hospital in Cairo, Egypt.

4.9 Data analysis

Data were analysed by means of descriptive and inferential statistical tests. The data analysis was done with the Statistical Program for Social Science (SPSS). Descriptive statistics were used to present the results of the demographic information of the participants. This included percentages, means and standard deviations. Mean scores were generated for the variables of the study, which were quality of life, psychological distress and coping styles of participants. In order to determine the relationships and predictions, inferential statistics such as correlations and regression analysis were used.
4.10  Reliability and validity

The data-collection tools, namely Q-LES-Q, DASS and the Cope Inventory, were selected for their reliability scores. The internal consistency of the Q-LES-Q was 0.90, while the test-retest reliability was 0.93 (Stevanovic, 2011). The internal consistency reliability was assessed by the Cronbach’s alpha and should exceed 0.7. Test-retest reliability was analysed using the interclass correlation coefficient to derive the reliability coefficient (Streiner & Norman, 2008). All the items were significantly correlated to the total score and ranged between 0.41 and 0.81 (Stevanovic, 2011). A study done by Yusoff (2013) to test the reliability of DASS found the internal consistency coefficient value, according to the Cronbach’s alpha of each subscale, to range between 0.81 and 0.97 (Brown et al., 1997). The Cronbach’s alpha values of the DASS-21 subscales ranged between 0.63 and 0.67 with the overall value of 0.82. The Cronbach’s alpha values for each subscale of the new models ranged between 0.52 and 0.59 with overall values between 0.72 and 0.76 (Brown et al., 1997). The internal consistency of the Brief Cope scale was assessed by calculating the Cronbach’s alpha coefficient (Cohen, 1977). However, the test-retest reliability was assessed using the intraclass correlation coefficient, which ranges from one to zero (Deyo et al., 1991). The internal consistency indicated by the Cronbach’s alpha values ranged from 0.25 to 1.00, whereas the test-retest intraclass correlation coefficient ranged from 0.05 to 1.00 (Yusoff et al., 2010). The validity of the instruments is well established in previous research (Deyo et al., 1991; Stevanovic, 2011).

4.11  Ethics statement

After obtaining ethical clearance from the University of the Western Cape’s Senate Research Committee (Appendix D), permission was provided by the chief executive officer at the National AIDS Program (NAP) to conduct the study in Abassia Hospital in Cairo, Egypt. Researchers need to practise care that the rights of individuals and institutions are preserved
when conducting research (Pilot & Hungler, 1999). For this research study, participants were recruited via the NAP. The aims and objectives of the study were explained in great detail to all participants who volunteered to participate in the study. They were given an information sheet ( Appendix A). This was to ensure that they fully understand the purpose and agree to take part in the study. The participants were asked to sign a consent form ( Appendix B) if they agreed to participate in the study. Anonymity was ensured, as no names were indicated on the questionnaires and only codes were used. Confidentiality was ensured, as the participants were anonymous and no one would know who the participants are based on accessing the researcher via the flyer, which invited people to voluntarily participate in the study. The researcher was also not able to relate certain answers to a particular participant. Beneficence was ensured by informing the participants that they will not be harmed during the study. The participants were referred for the professional assistance of a counsellor should they need these services due to involvement in the study. They were further informed that all relevant research documents would be carefully stored for a period of five years and accessed by the researcher and supervisor only. The participants were also given full access to the reported findings of the research, should they want to know the outcomes. The ethical principle refers to the obligation on our part as researchers to respect each participant as a person capable of making an informed decision regarding participation and access to findings. The results of this study were not generalised to a larger population, as they are very specific to participants with HIV/AIDS in Cairo, Egypt.

4.12 Conclusion

This chapter explained the research design, sampling method, data-capturing procedure and the statistical methods and process that were used to analyse the data. The analysed data obtained from the above methods are supplied in the following chapter.
CHAPTER 5

RESULTS

5.1 Introduction

Chapter 5 presents the results of the analysis of this study. The Statistical Package for the Social Sciences (SPSS V23) was used to analyse the data that were gathered. The results of this research are provided by means of descriptive and inferential statistics.

5.2 Overview of the analysis

The overview of the analysis lies within the aim and objectives as well as the hypothesis are provided as follows:

5.2.1 Aim of the study

This study aimed to examine the relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt.

5.2.2 Objectives of the study

The objectives of the study were to:

1. Establish the levels of psychological distress and quality of life of persons living with HIV/AIDS in Cairo, Egypt;

2. Determine the coping strategies used by persons living with HIV/AIDS in Cairo, Egypt; and

3. Investigate the relationship between the quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt.
5.2.3 Hypothesis

There is a significant relationship between the quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt.

5.3 Demographic profile

Tables 5.1 and 5.2 below presents an overview of the demographic profile of the 202 participants in this study in terms of personal demographics and family demographics, respectively.

Table 5.1: Personal demographics

<table>
<thead>
<tr>
<th>Variables</th>
<th></th>
<th>N = 202</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td>142</td>
<td>70.3</td>
</tr>
<tr>
<td>Female</td>
<td></td>
<td>60</td>
<td>29.7</td>
</tr>
<tr>
<td>Educational level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td></td>
<td>28</td>
<td>13.9</td>
</tr>
<tr>
<td>Primary</td>
<td></td>
<td>42</td>
<td>20.8</td>
</tr>
<tr>
<td>Secondary</td>
<td></td>
<td>86</td>
<td>42.6</td>
</tr>
<tr>
<td>University</td>
<td></td>
<td>46</td>
<td>22.8</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wheatish</td>
<td></td>
<td>113</td>
<td>55.9</td>
</tr>
<tr>
<td>White</td>
<td></td>
<td>68</td>
<td>33.7</td>
</tr>
<tr>
<td>Mixed race</td>
<td></td>
<td>21</td>
<td>10.4</td>
</tr>
<tr>
<td>Home language</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arabic</td>
<td></td>
<td>188</td>
<td>93.1</td>
</tr>
<tr>
<td>English</td>
<td></td>
<td>14</td>
<td>6.9</td>
</tr>
<tr>
<td>Age</td>
<td>Minimum</td>
<td>Maximum</td>
<td>M</td>
</tr>
<tr>
<td>18</td>
<td>66</td>
<td>35.66</td>
<td>10.16</td>
</tr>
</tbody>
</table>
The personal demographics in Table 5.1 indicate that there were more male (n=142, 70.3%) than female participants (n=60, 29.7%). The highest level of education indicated was secondary education (n=86, 42.6%). Of the 202 participants, 113 (55.9%) identified themselves as “wheatish”. The majority of the participants were Arabic-speaking (n=188, 93.1%). The average age of the participants was 35.66 ($SD = 10.16$) years, of which the minimum age was 18 and the maximum 66 years of age.

Table 5.2: Family demographics

<table>
<thead>
<tr>
<th>Variables</th>
<th>$N = 202$</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who is the head of your home?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>69</td>
<td>58.5</td>
</tr>
<tr>
<td>Mother</td>
<td>25</td>
<td>21.2</td>
</tr>
<tr>
<td>Sibling</td>
<td>14</td>
<td>11.9</td>
</tr>
<tr>
<td>Grandparent</td>
<td>2</td>
<td>1.7</td>
</tr>
<tr>
<td>Stepfather</td>
<td>8</td>
<td>6.8</td>
</tr>
<tr>
<td>What is the structure of your family?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single (never married)</td>
<td>76</td>
<td>37.6</td>
</tr>
<tr>
<td>Married</td>
<td>70</td>
<td>34.7</td>
</tr>
<tr>
<td>Divorced</td>
<td>24</td>
<td>11.9</td>
</tr>
<tr>
<td>Widowed</td>
<td>32</td>
<td>15.8</td>
</tr>
<tr>
<td>Is there a biological father present in your home?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>80</td>
<td>39.6</td>
</tr>
<tr>
<td>No</td>
<td>122</td>
<td>60.4</td>
</tr>
<tr>
<td>Is there a stepfather present in your home?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14</td>
<td>6.9</td>
</tr>
<tr>
<td>No</td>
<td>188</td>
<td>93.1</td>
</tr>
<tr>
<td>Is there a grandfather present in your home?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>26</td>
<td>12.9</td>
</tr>
<tr>
<td>No</td>
<td>176</td>
<td>87.1</td>
</tr>
</tbody>
</table>
As shown in Table 5.2, the majority of the participants indicated that the father was the head of the family (n=69, 58.5%). When asked about biological fathers being present or absent in the family, the majority indicated that biological fathers were absent (n=122, 60.4%). If a father was present, the majority of the participants highlighted that there was a father present who interacts with the children (n=85, 73.3%). Furthermore, in these families, the majority had no stepfathers (n=188, 93.1%) or grandfathers (n=176, 87.1%) in the home. In terms of the structure of the family, the majority of the participants stated that the family was a single (never married) family structure (n=76, 37.6%). The majority of the participants also indicated that there were children under 18 (n=151, 74.8%) in their households.

### 5.4 Psychological distress

This section presents the mean ($M$) and standard deviation ($SD$) scores of psychological distress. The scores for stress, anxiety and depression of the participants are displayed from Table 5.3 to Table 5.5.
Table 5.3: Mean scores and standard deviation of the subscales of stress

<table>
<thead>
<tr>
<th>No</th>
<th>Items</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I found it hard to wind down.</td>
<td>1.25</td>
<td>0.83</td>
</tr>
<tr>
<td>6</td>
<td>I tended to over-react to situations.</td>
<td>1.52</td>
<td>0.99</td>
</tr>
<tr>
<td>8</td>
<td>I felt that I was using a lot of nervous energy.</td>
<td>1.59</td>
<td>0.94</td>
</tr>
<tr>
<td>11</td>
<td>I found myself getting agitated.</td>
<td>1.70</td>
<td>0.93</td>
</tr>
<tr>
<td>12</td>
<td>I found it difficult to relax.</td>
<td>1.74</td>
<td>0.98</td>
</tr>
<tr>
<td>14</td>
<td>I was intolerant of anything that kept me from getting on with what I was doing.</td>
<td>1.10</td>
<td>0.95</td>
</tr>
<tr>
<td>18</td>
<td>I felt that I was rather touchy.</td>
<td>1.84</td>
<td>0.75</td>
</tr>
</tbody>
</table>

Responses were on a scale of: 0 = never to 3 = always.

Table 5.3 illustrates the mean scores of stress. The highest mean scores were from participants who indicated *I felt that I was rather touchy* ($M=1.84$, $SD=0.75$). The lowest scores were from participants who indicated *I was intolerant of anything that kept me from getting on with what I was doing* ($M=1.10$, $SD=0.95$).

Table 5.4: Mean scores and standard deviation of the subscales of anxiety

<table>
<thead>
<tr>
<th>No</th>
<th>Items</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>I was aware of dryness of my mouth.</td>
<td>0.79</td>
<td>0.84</td>
</tr>
<tr>
<td>4</td>
<td>I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion).</td>
<td>0.97</td>
<td>0.85</td>
</tr>
<tr>
<td>7</td>
<td>I experienced trembling (e.g. in the hands).</td>
<td>0.98</td>
<td>0.79</td>
</tr>
<tr>
<td>9</td>
<td>I was worried about situations in which I might panic and make a fool of myself.</td>
<td>1.20</td>
<td>0.89</td>
</tr>
<tr>
<td>15</td>
<td>I felt I was close to panic.</td>
<td>1.66</td>
<td>0.87</td>
</tr>
<tr>
<td>19</td>
<td>I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat).</td>
<td>0.70</td>
<td>0.79</td>
</tr>
<tr>
<td>20</td>
<td>I felt scared without any good reason.</td>
<td>1.74</td>
<td>0.79</td>
</tr>
</tbody>
</table>

Responses were on a scale of: 0 = never to 3 = always.
Table 5.4 illustrates the mean scores of anxiety. The highest mean scores were from participants who indicated *I felt scared without any good reason* ($M = 1.74, SD = 0.79$). The lowest scores were from participants who indicated *I was aware of the action of my heart in the absence of physical exertion* (*e.g.* sense of heart rate increase, heart missing a beat) ($M = 0.70, SD = 0.79$).

**Table 5.5: Mean scores and standard deviation of the subscales of depression**

<table>
<thead>
<tr>
<th>No</th>
<th>Items</th>
<th>$M$</th>
<th>$SD$</th>
</tr>
</thead>
<tbody>
<tr>
<td>3</td>
<td>I couldn’t seem to experience any positive feeling at all.</td>
<td>1.13</td>
<td>0.92</td>
</tr>
<tr>
<td>5</td>
<td>I found it difficult to work up the initiative to do things.</td>
<td>1.17</td>
<td>0.90</td>
</tr>
<tr>
<td>10</td>
<td>I felt that I had nothing to look forward to.</td>
<td>1.02</td>
<td>0.88</td>
</tr>
<tr>
<td>13</td>
<td>I felt down-hearted and blue.</td>
<td>1.73</td>
<td>0.91</td>
</tr>
<tr>
<td>16</td>
<td>I was unable to become enthusiastic about anything.</td>
<td>1.38</td>
<td>0.92</td>
</tr>
<tr>
<td>17</td>
<td>I felt I wasn’t worth much as a person.</td>
<td>1.41</td>
<td>1.01</td>
</tr>
<tr>
<td>21</td>
<td>I felt that life was meaningless.</td>
<td>1.64</td>
<td>0.98</td>
</tr>
</tbody>
</table>

Responses were on a scale of: 0 = never to 3 = always.

Table 5.5 illustrates the mean scores of depression. The highest mean scores were from participants who indicated *I felt down-hearted and blue* ($M = 1.73, SD = 0.91$). The lowest scores were from participants who indicated *I felt that I had nothing to look forward to* ($M = 1.02, SD = 0.88$).

Table 5.6 below presents the subscales of psychological distress
Table 5.6: Subscales of psychological distress

<table>
<thead>
<tr>
<th>Subscale</th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress</td>
<td>202</td>
<td>2.00</td>
<td>21.00</td>
<td>10.73</td>
<td>4.57</td>
</tr>
<tr>
<td>Anxiety</td>
<td>202</td>
<td>0.00</td>
<td>18.00</td>
<td>8.04</td>
<td>3.80</td>
</tr>
<tr>
<td>Depression</td>
<td>202</td>
<td>0.00</td>
<td>21.00</td>
<td>9.49</td>
<td>4.80</td>
</tr>
</tbody>
</table>

Responses were on a scale from normal to extremely severe.

The moderate scales were stress ($M =10.73$, $SD = 4.57$) as well as depression ($M = 9.49$, $SD = 4.80$), while the severe scale was anxiety ($M = 8.04$, $SD = 3.80$). Consequently, the prevalence of anxiety was higher than stress and depression.

5.5 Coping styles

This section presents the means ($M$) and standard deviation ($SD$) scores of the coping styles (Table 5.7) and the prevalence of problem-focused and emotion-focused coping (Table 5.8).

Table 5.7: Mean scores and standard deviation of the items for the coping styles

<table>
<thead>
<tr>
<th>No</th>
<th>Items</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I’ve been turning to work or other activities to take my mind off things.</td>
<td>2.00</td>
<td>1.09</td>
</tr>
<tr>
<td>2</td>
<td>I’ve been concentrating my efforts on doing something about the situation I’m in.</td>
<td>2.59</td>
<td>0.92</td>
</tr>
<tr>
<td>3</td>
<td>I’ve been saying to myself “This isn’t real”.</td>
<td>2.49</td>
<td>0.84</td>
</tr>
<tr>
<td>4</td>
<td>I’ve been using alcohol or other drugs to make myself feel better.</td>
<td>1.77</td>
<td>0.99</td>
</tr>
<tr>
<td>5</td>
<td>I’ve been getting emotional support from others.</td>
<td>2.62</td>
<td>0.95</td>
</tr>
<tr>
<td>6</td>
<td>I’ve been giving up trying to deal with it.</td>
<td>1.80</td>
<td>0.79</td>
</tr>
<tr>
<td>7</td>
<td>I’ve been taking action to try to make the situation better.</td>
<td>2.65</td>
<td>0.86</td>
</tr>
<tr>
<td>8</td>
<td>I’ve been refusing to believe that it has happened.</td>
<td>2.39</td>
<td>0.85</td>
</tr>
<tr>
<td>9</td>
<td>I’ve been saying things to let my unpleasant feelings escape.</td>
<td>2.49</td>
<td>0.96</td>
</tr>
</tbody>
</table>
I've been getting help and advice from other people. 2.76 0.99
I've been using alcohol or other drugs to help me get through it. 1.75 1.00
I've been trying to see it in a different light, to make it seem more positive. 2.59 0.87
I've been criticising myself. 2.70 1.02
I've been trying to come up with a strategy about what to do. 2.59 0.95
I've been getting comfort and understanding from someone. 2.89 0.92
I've been giving up the attempt to cope. 1.81 0.87
I've been looking for something good in what is happening. 2.18 0.86
I've been making jokes about it. 1.72 0.86
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping. 2.63 1.02
I've been accepting the reality of the fact that it has happened. 3.07 0.76
I've been expressing my negative feelings. 2.55 1.04
I've been trying to find comfort in my religion or spiritual beliefs. 3.00 0.94
I've been trying to get advice or help with what to do. 2.78 0.92
I've been learning to live with it. 3.13 0.80
I've been thinking hard about what steps to take. 2.74 0.86
I've been blaming myself for things that happened. 2.79 1.00
I've been praying or meditating. 3.07 0.91
I've been making fun of the situation. 2.08 1.02

Responses were on a scale of 1 = I haven’t been doing this at all to 4 = I have been doing this a lot.

Table 5.7 presents the mean scores for the coping styles. The highest mean scores were indicated as I’ve been learning to live with it ($M = 3.13, SD = 0.80$) and I’ve been accepting the reality of the fact that it has happened ($M = 3.07, SD = 0.76$) as well as I’ve been praying or meditating ($M = 3.07, SD = 0.91$). The lowest scores were from participants who indicated
I’ve been making jokes about it \((M = 1.72, \ SD = 0.86)\) and I’ve been using alcohol or other drugs to help me get through it \((M = 1.75, \ SD = 1.00)\). 

Table 5.8: Prevalence of problem-focused and emotion-focused coping 

<table>
<thead>
<tr>
<th>Subscale</th>
<th>(M)</th>
<th>(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Problem-focused</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active coping</td>
<td>5.24</td>
<td>1.55</td>
</tr>
<tr>
<td>Substance use</td>
<td>3.52</td>
<td>1.96</td>
</tr>
<tr>
<td>Instrumental support</td>
<td>5.54</td>
<td>1.79</td>
</tr>
<tr>
<td>Behavioural disengagement</td>
<td>3.61</td>
<td>1.42</td>
</tr>
<tr>
<td>Planning</td>
<td>3.89</td>
<td>1.17</td>
</tr>
<tr>
<td>Humour</td>
<td>3.81</td>
<td>1.70</td>
</tr>
<tr>
<td><strong>Emotion-focused</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-distraction</td>
<td>4.64</td>
<td>1.63</td>
</tr>
<tr>
<td>Denial</td>
<td>4.88</td>
<td>1.47</td>
</tr>
<tr>
<td>Emotional support</td>
<td>5.51</td>
<td>1.68</td>
</tr>
<tr>
<td>Venting</td>
<td>5.04</td>
<td>1.73</td>
</tr>
<tr>
<td>Positive reframing</td>
<td>4.77</td>
<td>1.40</td>
</tr>
<tr>
<td>Acceptance</td>
<td>6.20</td>
<td>1.38</td>
</tr>
<tr>
<td>Religion</td>
<td>6.07</td>
<td>1.77</td>
</tr>
<tr>
<td>Self-blame</td>
<td>5.49</td>
<td>1.82</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subscale</th>
<th>(N)</th>
<th>Minimum</th>
<th>Maximum</th>
<th>(M)</th>
<th>(SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Problem-focused</td>
<td>202</td>
<td>2.50</td>
<td>6.33</td>
<td>4.27</td>
<td>0.80</td>
</tr>
<tr>
<td>Emotion-focused</td>
<td>202</td>
<td>3.50</td>
<td>7.00</td>
<td>5.32</td>
<td>0.76</td>
</tr>
</tbody>
</table>

Responses were on a scale of \(1=\) I haven’t been doing this at all to \(4=\) I have been doing this alot.

Table 5.8 presents the most prevalent coping style as emotion-focused coping \((M = 5.32, \ SD = 0.76)\), specifically in terms of acceptance \((M = 6.20, \ SD= 1.38)\) and religion \((M = 6.07, \ SD = 1.77)\).
5.6 Quality of life

This section presents the means (\( M \)) and standard deviation (\( SD \)) scores of quality of life.

Table 5.9: Mean scores of quality of life

<table>
<thead>
<tr>
<th>No</th>
<th>Items</th>
<th>( M )</th>
<th>( SD )</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Physical health?</td>
<td>3.25</td>
<td>0.82</td>
</tr>
<tr>
<td>2</td>
<td>Mood?</td>
<td>2.86</td>
<td>0.92</td>
</tr>
<tr>
<td>3</td>
<td>Work?</td>
<td>3.15</td>
<td>1.02</td>
</tr>
<tr>
<td>4</td>
<td>Household activities?</td>
<td>3.10</td>
<td>1.07</td>
</tr>
<tr>
<td>5</td>
<td>Social relationships?</td>
<td>3.69</td>
<td>0.85</td>
</tr>
<tr>
<td>6</td>
<td>Family relationships?</td>
<td>3.81</td>
<td>0.97</td>
</tr>
<tr>
<td>7</td>
<td>Leisure time activities?</td>
<td>2.81</td>
<td>0.82</td>
</tr>
<tr>
<td>8</td>
<td>Ability to function in daily life?</td>
<td>3.41</td>
<td>0.92</td>
</tr>
<tr>
<td>9</td>
<td>Sexual drive, interest and/or performance?</td>
<td>2.63</td>
<td>1.06</td>
</tr>
<tr>
<td>10</td>
<td>Economic status?</td>
<td>2.94</td>
<td>0.82</td>
</tr>
<tr>
<td>11</td>
<td>Living/hosing status?</td>
<td>3.17</td>
<td>0.87</td>
</tr>
<tr>
<td>12</td>
<td>Ability to get around physically without feeling dizzy or unsteady or falling?</td>
<td>3.47</td>
<td>1.06</td>
</tr>
<tr>
<td>13</td>
<td>Vision to work on hobbies?</td>
<td>3.26</td>
<td>0.90</td>
</tr>
<tr>
<td>14</td>
<td>Overall sense of wellbeing?</td>
<td>2.90</td>
<td>0.80</td>
</tr>
<tr>
<td></td>
<td><strong>Total quality of life score</strong></td>
<td><strong>44.44</strong></td>
<td><strong>8.84</strong></td>
</tr>
<tr>
<td>15</td>
<td>Medication?</td>
<td>3.45</td>
<td>1.02</td>
</tr>
<tr>
<td>16</td>
<td>Life satisfaction and contentment?</td>
<td>3.16</td>
<td>0.89</td>
</tr>
</tbody>
</table>

Responses were on a scale of 1 = very poor to 5 = very good.

Table 5.9 indicates that the mean scores of quality of life were the highest for family relationships (\( M = 3.81, SD = 0.97 \)) and social relationships (\( M = 3.69, SD = 0.85 \)), and the lowest for sexual drive (\( M = 2.63, SD = 1.06 \)) and leisure time activities (\( M = 2.81, SD = 0.82 \)). The majority of the participants used medication (\( M = 3.45, SD = 1.02 \)) and experienced life satisfaction and contentment (\( M = 3.16, SD = 1.02 \)).
5.7 Relationships between the variables

This section provides the results of the relationships between quality of life and psychological distress and coping style as well as the relationships between psychological distress and coping style.
| No | Variables          | 1     | 2     | 3     | 4     | 5     | 6     | 7     | 8     | 9     | 10    | 11    | 12    | 13    | 14    | 15    | 16    | 17    | 18    | 19    |
|----|-------------------|-------|-------|-------|-------|-------|-------|-------|-------|-------|--------|--------|--------|--------|--------|--------|--------|--------|--------|
| 1  | Stress            |       |       |       |       |       |       |       |       |       |        |        |        |        |        |        |        |        |        |        |
| 2  | Anxiety           | 0.30**|       |       |       |       |       |       |       |       |        |        |        |        |        |        |        |        |        |        |
| 3  | Depress           | 0.26**| 0.70**|       |       |       |       |       |       |       |        |        |        |        |        |        |        |        |        |        |
| 4  | Self-distraction  | 0.23**| 0.03  | 0.01  |       |       |       |       |       |       |        |        |        |        |        |        |        |        |        |        |
| 5  | Active coping     | -0.01 | -0.11 | -0.24*| 0.48* |       |       |       |       |       |        |        |        |        |        |        |        |        |        |        |
| 6  | Denial            | 0.32**| 0.25**| 0.26**| 0.09  | 0.12  |       |       |       |       |        |        |        |        |        |        |        |        |        |        |
| 7  | Substance use     | 0.28**| 0.26**| 0.37**| 0.18  | -0.06 | 0.14* |       |       |       |        |        |        |        |        |        |        |        |        |        |
| 8  | Emotional support | 0.09  | -0.05 | -0.06 | 0.06  | -0.01 | 0.04  | 0.06  |       |       |        |        |        |        |        |        |        |        |        |        |
| 9  | Instrumental supp.| 0.11  | -0.03 | -0.04 | 0.08  | -0.04 | 0.01  | 0.09  | 0.86**|       |        |        |        |        |        |        |        |        |        |        |
| 10 | Behdisengage      | 0.39**| 0.36**| 0.41**| 0.18  | -0.09 | 0.24**| -0.23**| -0.06 | -0.02 |        |        |        |        |        |        |        |        |        |        |
| 11 | Venting           | 0.20**| 0.03  | -0.11 | 0.31**| 0.33**| 0.24**| -0.04 | 0.08  | 0.12  | 0.03  |        |        |        |        |        |        |        |        |        |
| 12 | Positive reframing| -0.15 | -0.31**| -0.44**| 0.40**| 0.37**| -0.04 | -0.21**| 0.03  | 0.07  | -0.09 | 0.26**|        |        |        |        |        |        |        |        |
| 13 | Humour            | 0.21**| -0.18 | -0.18 | 0.02  | 0.13  | -0.07 | 0.13  | 0.10  | 0.06  | -0.21**| 0.05  | 0.11  |        |        |        |        |        |        |        |
| 14 | Acceptance        | -0.36**| -0.45**| -0.00 | 0.27**| -0.15 | -0.30**| 0.07  | 0.05  | -0.15 | 0.17  | 0.36**| 0.28**|         |        |        |        |        |        |        |
| 15 | Religion          | 0.26**| -0.16 | -0.35**| 0.07  | 0.13  | -0.02 | -0.63**| 0.03  | 0.03  | 0.12  | 0.20**| 0.25**| -0.14**| 0.37**|         |        |        |        |        |
| 16 | Self-blame        | 0.51**| 0.31**| 0.44**| 0.33  | 0.24**| 0.21**| 0.28**| -0.07 | 0.00  | 0.26**| 0.34**| 0.06  | -0.01  | -0.12 | -0.10  |        |        |        |        |
| 17 | Planning          | 0.10  | 0.09  | 0.13  | 0.10  | 0.01  | 0.03  | 0.24**| 0.05  | 0.06  | 0.45**| 0.02  | 0.04  | 0.64**| 0.00  | 0.15  | 0.12  |        |        |        |
| 18 | Problem-focused   | 0.22**| 0.12  | 0.15**| 0.35**| 0.31**| 0.16  | 0.60**| 0.37**| 0.43**| 0.38**| 0.16 **| 0.08  | 0.56**| 0.03  | 0.31**| 0.28**| 0.73**|        |        |
| 19 | Emotion-focused   | 0.16  | -0.04 | -0.01 | 0.36**| 0.30**| 0.36**| -0.12 | 0.12**| 0.34**| 0.04  | 0.70**| 0.56**| 0.05  | 0.39**| 0.41**| 0.47**| 0.06  | 0.29**|        |
| 20 | Total for Qol     | -0.54**| -0.69**| -0.28**| -0.11 | -0.34**| 0.09  | 0.11  | -0.21**| 0.28**| 0.42**| 0.15**| 0.38**| 0.30**| 0.10  | -0.04 | -0.01 | 0.36**|        |        |

* Correlation is significant at the 0.05 level (2-tailed)
**Correlation is significant at the 0.01 level (2-tailed)
5.7.1 The relationships between quality of life and psychological distress and coping style

The results in Table 5.10 show that there were no significant positive relationships between quality of life and psychological distress. There were significant negative relationships to be found between quality of life and stress \((r = -0.46^{**})\), anxiety \((r = -0.54^{**})\) and depression \((r = -0.60^{**})\). The relationships between quality of life and coping style indicate that there were eight significant positive relationships to be found between quality of life and self-distraction \((r = 0.24^{**})\), active coping \((r = 0.28^{**})\), venting \((r = 0.20^{**})\), positive reframing \((r = 0.42^{**})\), humour \((r = 0.15^*)\), acceptance \((r = 0.38^{**})\), self-blame \((r = 0.30^{**})\) and emotion-focused \((r = 0.36^{**})\), as well as significant negative relationships between quality of life and substance use \((r =-0.31^{**})\) as well as behavioural disengagement \((r = -0.21^{**})\).

5.7.2 The relationships between psychological distress and coping style

The relationships between stress and coping style indicate that there were four significant negative relationships to be found between stress and positive reframing \((r = -0.15^*)\), humour \((r = -0.21^{**})\), acceptance \((r = -0.44^{**})\) and religion \((r = -0.26^{**})\). In addition, seven significant positive relationships were found between stress and denial \((r = 0.32^{**})\), substance use \((r = 0.28^{**})\), behavioural disengagement \((r = 0.39^{**})\), venting \((r = 0.20^{**})\), self-blame \((r = 0.51^{**})\), problem-focused \((r = 0.22^{**})\) and emotion-focused \((r = 0.16^*)\). The relationships between anxiety and coping style indicate that there were four significant negative relationships to be found between anxiety and positive reframing \((r =-0.31^{**})\), humour \((r = -0.18^*)\), acceptance \((r = -0.36^{**})\) and religion \((r =-0.16^*)\). In addition, four significant positive relationships were found between anxiety and denial \((r = 0.25^{**})\), substance use \((r = 0.26^{**})\), behavioural disengagement \((r = 0.36^{**})\) and self-blame \((r = 0.31^{**})\). The relationships between depression and coping style indicate that there were six significant negative relationships between
depression and active coping ($r = -0.24^{**}$), positive reframing ($r = -0.44^{**}$), humour ($r = -0.18^*$), acceptance ($r = -0.49^{**}$), religion ($r = -0.35^{**}$) and emotion-focused ($r = -0.17^{*}$). In addition, five significant positive relationships were found between depression and denial ($r = 0.26^{**}$), substance use ($r = 0.37^{**}$), behavioural disengagement ($r = 0.41^{**}$), self-blame ($r = 0.44^{**}$) and problem-focused ($r = 0.15^{*}$).

### 5.8 Regression analysis

This section provides the regression analyses for the prediction of quality of life and coping styles. Table 5.11 below shows the regression analysis regarding prediction of coping style by psychological distress.

**Table 5.11: Regression analyses: Psychological distress predicts coping style**

<table>
<thead>
<tr>
<th>Variables</th>
<th>b</th>
<th>SE b</th>
<th>$\beta$</th>
<th>t</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Coping style: Planning</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>0.00</td>
<td>0.03</td>
<td>0.00</td>
<td>0.02</td>
<td>0.99</td>
</tr>
<tr>
<td>Anxiety</td>
<td>-0.00</td>
<td>0.03</td>
<td>-0.00</td>
<td>-0.04</td>
<td>0.97</td>
</tr>
<tr>
<td>Depression</td>
<td>0.03</td>
<td>0.03</td>
<td>0.13</td>
<td>1.11</td>
<td>0.27</td>
</tr>
<tr>
<td><strong>Coping style: Problem-focused</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>0.05</td>
<td>0.02</td>
<td>0.27</td>
<td><strong>2.31^{*}</strong></td>
<td>0.02</td>
</tr>
<tr>
<td>Anxiety</td>
<td>-0.01</td>
<td>0.02</td>
<td>-0.05</td>
<td>-0.48</td>
<td>0.63</td>
</tr>
<tr>
<td>Depression</td>
<td>-0.00</td>
<td>0.02</td>
<td>-0.02</td>
<td>-0.15</td>
<td>0.88</td>
</tr>
<tr>
<td><strong>Coping style: Emotion-focused</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>0.12</td>
<td>0.02</td>
<td>0.71</td>
<td><strong>6.85^{*}</strong></td>
<td>0.00</td>
</tr>
<tr>
<td>Anxiety</td>
<td>-0.02</td>
<td>0.02</td>
<td>-0.09</td>
<td>-0.99</td>
<td>0.33</td>
</tr>
<tr>
<td>Depression</td>
<td>-0.10</td>
<td>0.02</td>
<td>-0.64</td>
<td><strong>-6.19^{*}</strong></td>
<td>0.00</td>
</tr>
</tbody>
</table>

Note: Planning: $\Delta R^2 = < 1$

Note: Problem-focused: $\Delta R^2 = 3$

Note: Emotion-focused: $\Delta R^2 = 21$
In Table 5.11 the results of the regression analyses suggest that psychological distress has an effect on the problem-focused and emotion-focused coping styles. For problem-focused coping styles, stress was a significantly positive predictor ($\beta = 2.31, p = 0.02$). For emotion-focused coping styles, stress was a significant positive predictor ($\beta = 6.85, p = 0.00$) and depression was a significant negative predictor ($\beta = -6.19, p = 0.00$). Each model accounted for different variances. For planning the final model accounted for 1%, 3% for problem-focused coping styles and 21% for emotion-focused coping styles.

**Table 5.12: Regression analysis: Predicting quality of life**

<table>
<thead>
<tr>
<th>Variables</th>
<th>$b$</th>
<th>$SE\ b$</th>
<th>$\beta$</th>
<th>$t$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life</td>
<td>41.27</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>-0.28</td>
<td>0.21</td>
<td>-0.14</td>
<td>-1.33</td>
<td>0.18</td>
</tr>
<tr>
<td>Anxiety</td>
<td>-0.49</td>
<td>0.19</td>
<td>-0.21</td>
<td>-2.57*</td>
<td>0.01</td>
</tr>
<tr>
<td>Depression</td>
<td>-0.57</td>
<td>0.21</td>
<td>-0.31</td>
<td>-2.75*</td>
<td>0.01</td>
</tr>
<tr>
<td>Self-distraction</td>
<td>1.31</td>
<td>0.37</td>
<td>0.24</td>
<td>3.50*</td>
<td>0.00</td>
</tr>
<tr>
<td>Active coping</td>
<td>-0.12</td>
<td>0.38</td>
<td>-0.02</td>
<td>-0.30</td>
<td>0.77</td>
</tr>
<tr>
<td>Denial</td>
<td>0.21</td>
<td>0.35</td>
<td>0.03</td>
<td>0.59</td>
<td>0.56</td>
</tr>
<tr>
<td>Substance use</td>
<td>-0.76</td>
<td>0.34</td>
<td>-0.17</td>
<td>-2.27*</td>
<td>0.02</td>
</tr>
<tr>
<td>Emotional support</td>
<td>-0.38</td>
<td>0.57</td>
<td>-0.07</td>
<td>-0.67</td>
<td>0.50</td>
</tr>
<tr>
<td>Instrumental support</td>
<td>0.77</td>
<td>0.53</td>
<td>0.16</td>
<td>1.45</td>
<td>0.15</td>
</tr>
<tr>
<td>Behavioural disengagement</td>
<td>0.49</td>
<td>0.60</td>
<td>0.08</td>
<td>0.83</td>
<td>0.41</td>
</tr>
<tr>
<td>Venting</td>
<td>0.23</td>
<td>0.33</td>
<td>0.04</td>
<td>0.68</td>
<td>0.50</td>
</tr>
<tr>
<td>Positive reframing</td>
<td>0.16</td>
<td>0.43</td>
<td>0.03</td>
<td>0.37</td>
<td>0.71</td>
</tr>
<tr>
<td>Humour</td>
<td>0.43</td>
<td>0.57</td>
<td>0.08</td>
<td>0.75</td>
<td>0.45</td>
</tr>
<tr>
<td>Acceptance</td>
<td>0.39</td>
<td>0.43</td>
<td>0.06</td>
<td>0.92</td>
<td>0.36</td>
</tr>
<tr>
<td>Religion</td>
<td>0.09</td>
<td>0.38</td>
<td>0.02</td>
<td>0.23</td>
<td>0.82</td>
</tr>
<tr>
<td>Self-blame</td>
<td>0.56</td>
<td>0.35</td>
<td>0.12</td>
<td>1.62</td>
<td>0.11</td>
</tr>
<tr>
<td>Planning</td>
<td>-0.46</td>
<td>0.88</td>
<td>-0.06</td>
<td>-0.52</td>
<td>0.60</td>
</tr>
</tbody>
</table>

Note: Quality of life: $\Delta R^2 = 47\%$
In predicting quality of life, the results in Table 5.12 indicate that psychological distress predicts quality of life. Specifically, anxiety ($\beta = -2.57$, $p = 0.01$) and depression ($\beta = -2.75$, $p = 0.01$) were both significant negative predictors of quality of life. In terms of coping styles as a predictor of quality of life, substance use ($\beta = -2.27$, $p = 0.02$) was a significant negative predictor, while self-distraction ($\beta = 3.50$, $p = 0.00$) was a significant positive predictor of quality of life. The final model accounted for 47% of the variance of quality of life.
CHAPTER 6
DISCUSSION, CONCLUSION AND RECOMMENDATIONS

6.1 Introduction

The aim of the study was to examine the relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt. In this chapter, the significant findings of the study are discussed.

6.2 Demographic characteristics of the sample

6.2.1 Personal demographics

According to an UNAIDS (2012) report on the AIDS epidemic, South Africa was the country with the highest number of women infected in the world. In South Africa, 58% of those with HIV were women (UNAIDS, 2012). The results of this study indicated that the sample consisted of 30% women, with 70% of the sample being men. Clearly, the number of female participants in this study is much lower than that of men. The high prevalence of male participation in the current study could be explained by the fact that at the time of data collection most participants attending Abassia Hospital were men. The largest number of people with HIV/AIDS was within the age group 25 to 49 years. This correlates with past studies that signify that AIDS-related mortality is the most common among individuals that are of reproductive age, which fall within this age group (Myer et al., 2009). Inconsistent with the findings of this study, a large proportion of the sample was in the age group 18 to 66 years. However, this is not the case, if people are beginning to live longer or if they are getting infected later in life. The majority of the sample classified themselves as “wheatish”, therefore these findings cannot be generalised across other racial groups. A large proportion (93%) of the participants were predominantly Arabic-speaking people over any other
language, some of which had some basic knowledge of the English language. This is owing to the fact that the area in which the study was undertaken comprises of a majority of Arabic-speaking people as well as the predominance of the Arabic culture in Cairo (Kabbash et al., 2008). The majority of the participants were schooled at secondary level. Another study conducted among Egyptian secondary school students indicated that the majority of people held the belief that people living with HIV should not be allowed to continue studying as usual (Kabbash et al., 2008).

6.2.2 Family demographics

Family is a social network of biologically related members and social relationships (Bonuck, 1993). The father is the head of the family among the majority of the participants (56%), with the majority of biological fathers not present at 60%. The majority of the participants had a father present who interacts with the children (73%). The issue of marital status as a possibility risk factor to the acquisition of the HIV/AIDS pandemic has been noted since the early 1990s. This study indicated that being single (never married) may contribute to a higher risk of infection (Buvé et al., 2001). Therefore, the higher number of single (never married) people within the sample may be a result of the use of a convenience sample, which is not representative of the population. This finding therefore may have occurred by chance. For the majority of the participants, a stepfather is not present (93%), neither is a grandfather (87%). The children under 18 in the house were at 75%.

6.3 The prevalence of psychological distress

HIV/AIDS enforces a considerable psychological burden. Depression is the most common psychiatric disorder among HIV patients (Asch et al., 2003). In addition, anxiety is frequently seen as comorbidity in people with HIV/AIDS (Charles et al., 2012).
Psychological distress among HIV patients has been associated with depression and also indicates that distress levels vary significantly across studies in comparison to population norms. Psychological distress in those with HIV/AIDS should be studied with a view to understanding the diversity of factors that can contribute to distress. In addition, the differential availability of resources to cope with stressors among those infected should also be examined (Asch et al., 2003). This study has been conducted in Egypt, which has shown the highest prevalence of common mental disorders, including anxiety and depression.

The prevalence of psychological distress in this study is relatively high, with all the participants in the moderate psychological distress category. Psychological distress among HIV patients has been reported to be associated with augmented HIV progression to AIDS (Leserman et al., 1999). Studies have also revealed that HIV infection prompts a number of biophysical fluctuations in the life of the infected person, such as diarrhoea, which was considered a source of discomfort for some. These biophysical fluctuations cause considerable difficulties in the management of the disease by healthcare practitioners.

The results of this study support previous findings. A study from Uganda comparing the prevalence of depression symptoms among HIV-positive and HIV-negative subjects indicates the likelihood of developing depression symptoms to be twice as high for HIV-positive individuals than for HIV-negative individuals (Nakasujja et al., 2010). Also, a study conducted by Herman, Stein, Seedat, Heerinag, Moomal and Williams (2009) found that the Western Cape region in South Africa has the highest prevalence of common mental disorders, including anxiety and depression (Herman et al., 2009). This study was conducted in Egypt and proved the following subscales of psychological distress and had the highest prevalence of common mental disorders, which includes stress, anxiety and depression. The severe scale was anxiety ($M = 8.04, SD = 3.80$), whereas depression ($M = 9.49, SD = 4.80$) and stress ($M$
were correlated on the moderate scale. Therefore, the prevalence of anxiety was recorded as higher than stress and depression.

In another study on needs assessment and coping strategies of persons infected with HIV in Egypt, Kabbash et al. (2008) found that the majority of the participants in the study of people living with HIV/AIDS suffered from anxiety and feelings of helplessness. This corresponds with the current study, which established the severe scale of anxiety. Myer et al (2008) report that individuals with low socio-economic levels are more at risk of depression compared to those from a higher socio-economic level.

Numerous studies have been conducted with widely varying samples and measures to determine the prevalence of depression and anxiety. For example, the prevalence of depression among HIV/AIDS patients ranges from 12% in south India (Charles et al., 2012) to 54.4% in Italy (Liuzzim et al., 2008). In Brazil, it is 29.4% (Castrighini et al., 2010) and in the USA it is 37% (Asch et al., 2003). In African countries, it is also high; for example, in South Africa it is 25.4% (Pappin et al., 2012), in Uganda it is 8.1% (Kinyanda et al., 2011) and in Botswana it is 28% (Gupta et al., 2010).

These findings all support previous research that have identified psychological distress symptoms as a key factor affecting the quality of life of persons affected with HIV/AIDS (Jia et al., 2004). However, in a study conducted by Molassiotism et al (2001), was associated with low QoL in men and women living with HIV. In this study, moderate stress events were independent risk factors for psychological distress. This is similar to other studies that revealed that high stress and a current stressful event were found to be associated with depression, and in HIV-positive women from South Africa the degree of stressful events was significantly associated with psychological distress (Olley et al., 2006).
Common psychological distress such as anxiety and depression can cause stress, which, in turn, can elicit psychological distress. In fact, further research is suggested to explore the cause-and-effect association of stress and psychological distress. Several studies (Chipimo et al., 2009; Patel et al., 2012; Charles et al., 2012) have found perceived stigma to be a risk factor for psychological distress, which is contrary to the findings of this study. It is well known that people with perceived stigma may have a low self-image and be socially isolated and predisposed to developing psychological distress (Horberg et al., 2008).

6.4 The prevalence of coping styles

Folkman and Lazarus (1980) have identified two general types of coping strategies: emotion-focused coping and problem-focused coping. Emotion-focused coping is the reduction or management of the emotional distress associated with the situation. Problem-focused coping is doing something or actively solving the problem to alter the source of stress.

The findings of this study indicated a high level of psychological distress among people living with HIV/AIDS and included feelings of loneliness, depression and despair. Consequently, these feelings may incapacitate people living with HIV/AIDS in terms of the ability to engage in problem-focused coping, such as gathering information and resources, planning, making decisions and taking action to solve or manage the source of stress (Kabbash et al., 2008).

The results of this study illustrate that the most prevalent of coping styles is emotion-focused coping, specifically acceptance succeeded by religion. Acceptance coping consists of removing oneself psychologically from the situation, cognitively redefining the situation or event, and accepting the situation or event as it is (Lohman & Jarvis, 1999). Religion plays a critical role within the coping process and serves as a foundation for the global beliefs and goals of many individuals (Pargament, 2000). This includes the types of initial appraised
meaning that people give to events, the extent to which this appraised meaning is different from their global meaning, and the types of resources and coping strategies that they have available to reduce their distress. The extent to which religion is participatory in a given individual’s coping with a particular event is largely predicated on the extent to which religion is part of his/her orientation system: Religion is much more likely to be used in the coping of those for whom religion is a highly prominent aspect of their understanding of self and world than in the coping of those who are less devout (Pargament, 2000).

The participants tended to emphasise religious aspects in this study. This correlates with previous studies. The participants try to cope with their spiritual beliefs; this could be owing to the fact that this illness is not curable, and therefore, they believe that nothing can be improved by changing themselves and they therefore resign their situation to religion (Charles et al., 2012).

In another study conducted in Egypt by Kabbash et al (2008), participants have also proved to engage in emotion-focused coping. These methods include avoidance, escaping, distancing, blaming one self and others and experiencing feelings of anger, sadness, hopelessness and helplessness.

6.5 The prevalence of quality of life

Assessment of quality of life in persons living with HIV/AIDS is becoming crucial to research and evidence-based practice in this area. According to the WHO, the quality of life of individuals is essentially defined as the subjective evaluation by such individuals of their own personal life embedded within the context of their culture and values (WHO, 2008). A good quality of life is of absolute importance and should be achieved through the employment of strategies of social support, coping and the alleviation of depressive symptoms (Jia et al., 2004). ART can in effect directly impact on quality of life in many
ways. If ART is taken too early, it will deteriorate the patient’s health-related quality of life. However, if started late and is administered when the disease has progressed to a level where the immune system has already been weakened, it is unable to resist the toxicities and inconveniences of the regimen (Nela & Kageeb, 2011).

QoL and satisfaction experienced within various domains or areas of life by the individuals are depicted within the Q-LES-Q. The results of the current study indicated that among the individuals living with HIV/AIDS, the highest QoL and satisfaction were experienced by the individuals within the family relations domain and the social relations of their lives. In another study on depression and QoL in adults diagnosed with HIV or AIDS, Loonat (2009) found the highest QoL and satisfaction experienced by the individuals within the social relations domain and the school and course work domain of their lives. The individuals who participated in the study were generally from collectivist society and therefore social relations had a major impact on QoL. In this study, the lowest average level of enjoyment and satisfaction reported by the sample indicates that sexual drive and leisure time activities. This study was conducted in Egypt, where culture is deeply rooted in religious morality that shuns all immoral behaviour, with special reference here to illegal sexual contact. O’Brien (1998) reports that some individuals experience a loss of sexual drive and behaviour, especially in the early course of HIV. As for the lower leisure time activity could be a result of the progression of HIV/AIDS or a result of the sense of hopelessness or lack of energy as a result of the depressed state of these individuals. Loonat (2009) found the lowest average level of leisure time activities.
6.6 The relationship between quality of life and psychological distress and coping style

A person living with HIV/AIDS has to cope with a range of HIV-related symptoms for extended periods. These symptoms are related to the infection itself and to comorbid illnesses. In addition, many HIV patients struggle with numerous social problems attached to the disease, such as stigma, poverty, depression, substance abuse and cultural beliefs, which can affect their quality of life in the mental and the physical domain (Charkhian et al., 2014). Patients experience negative opinions of the self, others and the environment, and the symptoms and psychological impact of the disease on the physical, mental and social wellbeing of the individual are psychologically taxing. Therefore, the psychological scenario surrounding HIV/AIDS is much more severe than in other chronic illness such as cancer. In addition, the negative stigma attached to the disease, such as discrimination, allegations of promiscuity, gossip and character assassination for persons affected by HIV/AIDS, considerably contributes to psychological distress. Moreover, patients confront a range of psychological challenges, including the prospect of real and anticipated losses, worsening quality of life, the fear of physical decline and death, and coping with uncertainty. HIV infection and/or AIDS bring additional challenges due to the rapidly changing treatment developments and outlook.

Recent research has shown that experiences of stigmatisation have an adverse impact on the psychological wellbeing of people living with HIV/AIDS. The psychological implications of HIV-related stigma in specific settings may be psychologically more detrimental than others. Studies conducted by Leserman (2003) and Whetten et al (2006) established that depression is associated with HIV infection. It is important to note that psychological distress is also correlated with depression. Interestingly, it is highly probable that HIV-positive individuals may be diagnosed with a major depressive disorder. Hence, HIV infection can also aggravate
and promote depressive symptoms, and therefore depression is a side effect of the disease. Coping strategies refer to the specific efforts, both behavioural and psychological, that people employ to master, tolerate, reduce or minimise stressful events. Two general coping strategies have been distinguished: problem-focused strategies and emotion-focused coping strategies. Research indicates that people use both types of strategies to combat most stressful events (Folkman & Lazarus, 1988). The predominance of one type of strategy over another is determined, in part, by personal style (e.g. some people cope more actively than others) and also by the type of stressful event; for example, people typically employ problem-focused coping to deal with potential controllable problems such as work-related and family-related problems, whereas stressors perceived as less controllable, such as certain kinds of physical health problems, prompt more emotion-focused coping. This study sought to examine and establish the relationship between quality of life, psychological distress and coping style.

The results of this current study show that there are no significant positive relationships between quality of life and psychological distress. No negative relationships were found between quality of life and psychological distress, and the correlations were significant for stress, anxiety and depression. This implies that patients who suffer from psychological distress experienced a negative impact on their quality of life. Participants who showed significant readings of stress, anxiety and depression had a significant decrease in their quality of life due to this negative relationship. On the other hand, there were positive relationships between quality of life and coping style, and the correlations were significant. In particular, self-distraction, active coping, venting, positive reframing, humour, acceptance, self-blame and emotion-focused. This implies that individuals who adopted coping styles showed an increase in quality of life and that positive reframing such as pointing out the humorous side of the disease was significant in increasing the quality of life of the
participant. Moreover, active coping strategies involve an awareness of the stress or resorting to finding a solution to reduce the negative outcomes of the disease. It was found that individuals who accepted their HIV/AIDS status and its consequences generally enjoyed better quality of life in terms of emotional stability, as opposed to participants who engaged in maladaptive coping strategies, such as substance abuse and behavioural disengagement.

In another study conducted in Toronto, where the participants had good levels of social support and used a variety of coping strategies, it was established that problem-oriented and perception-oriented coping were positively related to quality of life. However, tangible social support and emotion-oriented coping were negatively related. Although the participants indicated high levels of satisfaction with support in general, they expressed a need for more emotional support (Friedland et al., 2010). In addition, there were negative relationships between quality of life and the type of coping style that was employed by the participants. More specifically, the correlations were significant for substance abuse and behavioural disengagement. Therefore, there was a direct impact on quality of life for the participants who engaged in coping strategies such as behavioural disengagement and substance abuse.

The regression analysis of the current study suggests that psychological distress is a predictor of coping style and that it bears an effect on both problem-focused and emotion-focused coping styles. More specifically, stress significantly and positively predicted both problem-focused styles. This implies that participants who engaged in problem-focused coping styles experienced a positive impact on their stress. In addition, depression was a significantly negative predictor of emotion-focused coping. On the other hand, emotion-focused styles as predicting coping are more likely to prone to depression, as a result of the coping strategy. This has been confirmed by a study that examined emotion-focused strategies, such as denial, which was associated with increased distress (Revenson & Felton, 1998). Depression is therefore a negative predictor of emotion-focused coping. This implies that participants who
adopted emotion-focused strategies experienced a negative impact on their levels of psychological distress, which decreased their level of depression, whereas participants who adopted problem-focused strategies had shown a considerable and significant increase in stress levels. In previous findings, social isolation has also proven to increase stress. This has been supported by a study of emotion-focused strategies such as self-blame having been proven to be correlated with a higher level of distress for patients with HIV/AIDS (Pakenham & Rinaldis, 2001).

The regression analysis also suggests that psychological distress predicts quality of life, and that it was a negative prediction. Therefore, a negative relationship exists between quality of life and psychological distress. Hence, participants who suffer from psychological distress as a result of the psychologically taxing nature of the disease will, as a result, have a decreased quality of life. The quality of life, psychological distress and coping methods adopted are all interrelated with relationships of varying degrees. Psychological distress negatively predicts quality of life. Specifically, anxiety and depression were significant negative predictors of quality of life. This means that participants who showed higher readings of anxiety and depression had a decrease in quality of life. In addition, substance abuse was a negative predictor of quality of life. This implies that substance abuse is more likely to decrease quality of life; however, self-distraction was considered a positive predictor. This has also been supported that psychological distress considerably the quality of life of HIV-infected persons. In addition to poor quality of life, psychologically distress is particularly affected by the coping strategy that is adopted. The considerable impact that HIV/AIDS has on quality of life indicates the hindering and psychologically taxing nature of the disease.
6.7 Limitations

The limitations of this study were the following:

- One important limitation of the study is that the findings are not to be generally applies across all settings.

- There was an over-representation of men, which could be because they were much more at liberty to participate in the research, as opposed to women, who were perhaps culturally prejudiced not to participate.

- The higher number of single people within the sample may be a result of the use of a convenience sample, which is not representative of the population. Therefore, this may have occurred by chance.

- The majority of the sample classified themselves as “wheatish”, therefore, these findings cannot be generalised across other racial groups.

6.8 Conclusion

People with HIV experience adverse social and physical consequences when their status is revealed to family, friends or society as a whole. Consequences of HIV infection have been proven to negatively influence social support, which in turn leads to psychological distress, which negatively impacts QoL and life satisfaction. In conclusion, one can infer that social support positively impacts the ability of patients to cope easier with the psychological distress that follows the diagnosis of HIV infection. This effectively causes the patients, in turn, to enjoy better mental health and improves their QoL. In addition, better compatibility with the disease causes patients to manage it much more optimistically and consequently encourages regular visits to the doctor. In addition, this optimism to manage their HIV infection makes them more affable to be exposed to medical experiments. Therefore, consistent adherence to
anti-AIDS drugs is achieved and, in general, will lead to the promotion of better physical health. All these factors suggest that HIV patients with social support have a decent QoL (Charkhian et al., 2014). Furthermore, ART, psychological wellbeing, coping strategies, spiritual wellbeing and psychiatric comorbidity are considered as key predictors of QoL in this population. This study has shown significant relationships between psychological distress, coping style and QoL. More importantly, a relationship has been established between psychological distress and QoL. Therefore, the coping style directly impacts on the QoL of the patient, and as a result impacts on the psychological equilibrium.

Research has suggested relationships among various psychosocial and spiritual factors, symptomatology and general physical health. Documentation of the impacts of such relationships on the immune functionality and health status, disease progression and QoL among persons with HIV disease is still necessary. The role of psychiatry in the diagnosis and management of HIV and AIDS should be considered as a possible intervention module, with specific reference to liaison consultations. Furthermore, stress-management interventions for HIV-infected persons could be presented to facilitate positive regulation of the disease and maintain psychological equilibrium. Hence, additional research is mandatory to further evaluate the scope of psychological distress and coping styles in the assessment of QoL in patients who have HIV/AIDS. This will, hopefully, result in the positive adaptation to the psychological effects of the disease, and lead to a better QoL.

6.9 Recommendations

The development of educational programmes that provide factual information about HIV/AIDS is recommended to address the negative stigmatisation of the disease and thereby increase general tolerance of people living with HIV/AIDS. A further recommendation is the development of social support programmes within communities for the provision of financial
support to families who are unable to meet the financial demands of the disease. Depression and anxiety are among the adverse effects of HIV/AIDS, which identifies a need for specialised psychiatric liaison programmes, which seem crucial for the alleviation of the comorbid illnesses associated with HIV/AIDS. The crucial need for coping skills among HIV/AIDS patients necessitates healthcare interventions where health workers will develop coping skills among patients.
REFERENCES


Appendix A

INFORMATION SHEET

Project Title: the relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt

What is this study about?
This is a research study being conducted by Sumaia Jawad at the University of the Western Cape. We are inviting you to voluntarily participate in this research study to understand the quality of life, psychological distress and coping skills of people living with HIV/AIDS in Cairo, Egypt.

What will I be asked to do if I agree to participate?
You will be asked to complete a questionnaire. This questionnaire will ask you questions about (i) Demographics, (ii) Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q), (iii) Depression, Anxiety and Stress Scale (DASS), (iv) Cope Inventory. Completion of the questionnaire will be 35 minutes.

Would my participation in this study be kept confidential?
Your personal information will be kept confidential. To help protect your confidentiality, the information you provide will be totally private; no names will be used so there is no way that you can be identified as a participant in this study. The information will be treated with anonymity and confidentiality. Your name will not be reflected on the questionnaire. The information obtained from the survey will not be collated with the information from completed surveys. Therefore there will be no way to connect you to the survey questionnaire.

What are the risks of this research?
Any research has risks but in this research study we will try to minimise the risk of being harmed in any way. If there are any painful memories of experiences or experiences which may evolve during the research process, we will refer you for the necessary support. If at any time there is disclosure of any incidents of risks or harm to participants, we are legally compelled to report the information.
What are the benefits of this research?

Information about this topic is limited. This outcome of this study may be useful to social service providers who lead and provide assistance for people living with HIV/AIDS such as programmes and activities within their communities through offering counselling and psychological support. This may help them develop problem solving skills to deal with the stress of living with HIV. Healthcare workers may benefit from this study and use the opportunities they have with people living with HIV/AIDS attending screenings to discuss various concerns and refer where necessary. This study may help future researchers to relate other variables to the respondents or different respondents to the same variables used.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part in the study. If you decide to participate in this research study, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalised or lose any benefits to which you otherwise qualify.

Is any assistance available if I am negatively affected by participating in this study?

Every effort has been taken to protect you from any harm in this study. If however, you may feel affected you can be referred to your nearest community resource for assistance.

What if I have questions?

This research is being conducted by Sumai Jawad a registered Master student in the Social Work Department at the University of the Western Cape. If you have any questions about the research study itself, please contact Sumai Jawad at: 061 754 1134 or email: sumaiagawad@gmail.com or contact the research study supervisor: Prof Roman at: 0219592277/2970 or email: nroman@uwc.ac.za.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Professor Jose Frantz – Dean of the Faculty of Community and Health Sciences

Tel No: 021 959 2631/2746

Email address: jfrantz@uwc.ac.za

This research has been approved by the University of the Western Cape’s Senate Research Committee and Ethics Committee.
جامعة الويسترن كيب
حقيقية بريد خاصة إكس 17 - بنيال 7535 - جنوب أفريقيا
تلفون : 7029 / 2277 / 959-27 ثان، + فاكس : 5482 959-27
البريد الإلكتروني : nroman@uwc.ac.za

Appendix A

ورقة المعلومات

ملحق أ

عنوان البحث: العلاقة بين نوعية الحياة والضغوط النفسية وإستراتيجيات المواجهة للاشخاص الذين يعيشون مع فيروس نقص المناعة البشرية / الإيدز في القاهرة / مصر.

حول ماذا هذه الدراسة?

هذا الدراسة البحثية التي تجريها الطالبة سمية جواد في جامعة الكيب الغربية حيث ندعوكم للمشاركة فيها طوعاً في بحث الدراسة هذا لفهم نوعية الحياة والضغوط النفسية ومهارات التأقلم للأشخاص الذين يعيشون فيروس نقص المناعة البشرية / الإيدز في القاهرة / مصر.

ما الذي يمكن أن يطلب مني للقيام به إذا وافقت على المشاركة؟

سوف يطلب منك إكمال الاستبيان وهذا الاستبيان يتكون من أسئلة حول (1) التركيبة السكانية (2) نوعية الحياة والتمتع بها (3) الأكتئاب والقلق ومقياس الإجهاد (DASS) (4) قدرة التحمل. فترة إنجاز الاستبيان ستكون 35 دقيقة.

هل سيتضح مشاركتي في الدراسة سرية؟

سيتم الاحتفاظ بالمعلومات الشخصية الخاصة بك سرية فإن المعلومات التي تقدمها تكون سرية تماماً وسيتم عدم استخدام أي أسماء حتى لا يكون هناك أي طريقة يمكن لها تعيين هوية أحد المشاركين في هذه الدراسة. سيتم التعامل مع المعلومات مع عدم الكشف عن الهوية والسرية لипعبرانك على الإستبان لن يتم مقارنة المعلومات التي تم الحصول عليها في الاستبان الخاص بكم مع المعلومات التي تم جمعها في الاستبانات الأخرى وبالتالي لن يكون هناك أي وصلة أربطكم في الإستبان.

ما هي مخاطر هذا البحث؟

إي بحث له مخاطرة ولكن في بحث الدراسة هذا سنحاول تقليل من خطر التعرض للأذى بالطريقة إذا كنا هناك أي ذكريات مؤلمة لتجربة أو التجارب التي قد تطور خلال عملية البحث سوف نحيلكم إلى العون اللازم.

127
ما هي فوائد هذا البحث؟

المعلومات حول هذا الموضوع محدودة قد يكون نتيجة هذه الدراسة مفيدة لمقدمي الخدمات الاجتماعية الذين يودون تقديم المساعدة للأشخاص الذين يعيشون مع فيروس نقص المناعة البشرية / الإيدز مثل البرامج والأنشطة داخل مجتمعاتهم المحلية من خلال تقديم المشورة والدعم النفسي هذا قد يساعدهم على تطوير مهارات حل المشكلات للتعامل مع الضغوط للذين يعيشون مع فيروس نقص المناعة البشرية / الإيدز قد يستفيد العاملين في الرعاية الصحية من هذه الدراسة وإستخدام الفرص مع الناس الذين يعيشون مع فيروس نقص المناعة البشرية / الإيدز.

هل يجب أن أكون في هذا البحث ويمكن أن أتوقف عن المشاركة في أي وقت؟

تعتبر مشاركتكم في هذا البحث طوعياً تماماً إذا قررت المشاركة وإذا قررت عدم المشاركة في هذه البحث يمكنك أن تختار أن تشارك في أي وقت وسوف لن تعاقب أو تفقد أي المزايا التي كنت مؤهلة لتخلاف ذلك.

هل هناك وجود مساعدة متوفرة إذا أنا تأثرت سلبًا من خلال المشاركة في هذه الدراسة؟

تم إتخاذ كل جهد ممكن لحمايتك من أي ضرر في هذه الدراسة ومع ذلك قد تشعر أنك تأثرت يمكنك أن تحاول أن تشاكل ذلك من خلال مصدر للمساعدة للحصول على المساعدة.

ماذا لو كان لديك أسئلة؟

يجري هذا البحث من سمية جواد طالبة ماجستير المسجلة في قسم العمل الاجتماعي في جامعة الكيب الغربية إذا كان لديك أي أسئلة حول بحث الدراسة نفسه يرجى الاتصال بسمية جواد على 0027 61 754 1134 أو البريد الإلكتروني sumaiagawad@gmail.com أو البريد الإلكتروني nroman@uwc.ac.za.

إذا كان لديك أي أسئلة بخصوص هذه الدراسة وحقوقك كمشارك في البحث أو إذا كنت ترغب في الإبلاغ عن أي مشكلة في هذا البحث أرجو أن تتم الاتصال بمشرف الدراسة الأستاذ نيكوليت رومان على الهاتف 0027 21 9592277 / 2970 أو البريد الإلكتروني nroman@uwc.ac.za.

أو إذا كنت ترغب في الإبلاغ عن أي مشكلة في هذه الدراسة في الرعاية الصحية والأمانيات أو الفيروسات يمكن أن تتم الاتصال بمشرف الدراسة الأستاذ نيكوليت رومان على الهاتف 0027 21 9592277 / 2970 أو البريد الإلكتروني nroman@uwc.ac.za.

وقد تم الموافقة على هذا البحث من قبل المجلس الأعلى للكتاب والإخلاق للبحوث في جامعة الكيب الغربية.
Appendix B

CONSENT FORM

Title of Research Project:
The relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant’s name ...........................................
Participant’s signature .................................
Date .............................................................

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator’s Name:  Prof N Roman
University of the Western Cape
Private Bag X17, Bellville 7535
Telephone: 021 959 2277/2970
Email: nroman@uwc.ac.za
Appendix B

Estimation of Agreement

The attachment with the following research:

Title: The relationship between quality of life and psychological stress and strategies of coping for people living with HIV/AIDS in Cairo, Egypt.

The study has been described in a language understandable to the participant and I agree on participating voluntarily and I understand that my identity will not be disclosed to anyone as I can withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Full name of the participant: ..........................................................

Signature of the participant: ..................................................

Date: ............. / .......... / ......

If you have any questions about this research or wish to report any problems related to the study, please contact the research coordinator:

Name of the coordinator: Professor Nicole Roman

University of the Western Cape

Postal bag 17 - Bepil 7535 - South Africa

Telephone: 27-9-7029/2277, 27-9-5482

E-mail: nroman@uwc.ac.za
Appendix C

QUESTIONNAIRE

Project Title: the relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt

Section A: DEMOGRAPHIC information

Please complete the following by marking the correct response.

Personal Demographics

<table>
<thead>
<tr>
<th>Gender</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Educational level</th>
<th>Illiterate</th>
<th>Primary</th>
<th>Secondary</th>
<th>University</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race</td>
<td>Wheatish</td>
<td>White</td>
<td>Mixed race</td>
<td></td>
</tr>
<tr>
<td>Home language</td>
<td>Arabic</td>
<td>English</td>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

Family Demographics

<table>
<thead>
<tr>
<th>Who is the head of your home?</th>
<th>Father</th>
<th>Mother</th>
<th>Sibling</th>
<th>Grandparent</th>
<th>Uncle/Aunt</th>
<th>Stepfather</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the structure of your family?</td>
<td>Single (Never married)</td>
<td>Married</td>
<td>Divorced</td>
<td>Widowed</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Is there a biological father | Yes | No |


<table>
<thead>
<tr>
<th>present in your home?</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is there a stepfather present in your home?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Is there a grandfather present in your home?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>If there is a father present, is he:</td>
<td>Present but does not interact with the children</td>
<td>Present and interacts with the children</td>
</tr>
<tr>
<td>How many children (under 18) are living in your home?</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

**Section B: COPING STYLE**

These items deal with ways you've been coping with the stress in your life since you found out you have HIV/AIDS. There are many ways to try to deal with problems. These questions ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each question says something about a particular way of coping. I want to know to what extent you've been doing what the question says. How much or how frequently? Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

<table>
<thead>
<tr>
<th>Items</th>
<th>1 = I haven't been doing this at all</th>
<th>2 = I've been doing this a little bit</th>
<th>3 = I've been doing this a medium amount</th>
<th>4 = I've been doing this a lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I've been turning to work or other activities to take my mind off things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>I've been concentrating my efforts on doing something about the situation I'm in.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>3</td>
<td>I've been saying to myself &quot;this isn't real&quot;.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>I've been using alcohol or other drugs to make myself feel better.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>I've been getting emotional support from others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>I've been giving up trying to deal with it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>I've been taking action to try to make the situation better.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8</td>
<td>I've been refusing to believe that it has happened.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>I've been saying things to let my unpleasant feelings escape.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10</td>
<td>I've been getting help and advice from other people.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11</td>
<td>I've been using alcohol or other drugs to help me get through it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12</td>
<td>I've been trying to see it in a different light, to make it seem more positive.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13</td>
<td>I've been criticizing myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14</td>
<td>I've been trying to come up with a strategy about what to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15</td>
<td>I've been getting comfort and understanding from someone.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16</td>
<td>I've been giving up the attempt to cope.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17</td>
<td>I've been looking for something good in what is happening.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18</td>
<td>I've been making jokes about it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19</td>
<td>I've been doing something to think about it less, such as going to movies, Watching TV, reading.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Daydreaming, sleeping, or shopping.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>----------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>20</td>
<td>I've been accepting the reality of the fact that it has happened.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21</td>
<td>I've been expressing my negative feelings.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22</td>
<td>I've been trying to find comfort in my religion or spiritual beliefs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23</td>
<td>I've been trying to get advice or help from other people about what to do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24</td>
<td>I've been learning to live with it.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25</td>
<td>I've been thinking hard about what steps to take.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26</td>
<td>I've been blaming myself for things that happened.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27</td>
<td>I've been praying or meditating.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28</td>
<td>I've been making fun of the situation.</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

**Section C: PSYCHOLOGICAL DISTRESS**

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The ANSWERS are as follows:

0 Did not apply to me at all - NEVER

1 Applied to me to some degree, or some of the time - SOMETIMES

2 Applied to me to a considerable degree, or a good part of time - OFTEN

3 Applied to me very much, or most of the time - ALWAYS

<table>
<thead>
<tr>
<th>Items</th>
<th>0 = Never</th>
<th>1 = Sometimes</th>
<th>2 = Often</th>
<th>3 = Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I found it hard to wind down.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>I was aware of dryness of my mouth.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>3</td>
<td>I couldn’t seem to experience any positive feeling at all.</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5</td>
<td>I found it difficult to work up the initiative to do things</td>
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<tr>
<td>6</td>
<td>I tended to over-react to situations</td>
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<tr>
<td>7</td>
<td>I experienced trembling (eg, in the hands)</td>
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<td>8</td>
<td>I felt that I was using a lot of nervous energy</td>
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<tr>
<td>9</td>
<td>I was worried about situations in which I might panic and make a fool of myself</td>
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<td>I felt that I had nothing to look forward to</td>
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<td>I found myself getting agitated</td>
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<td>I found it difficult to relax</td>
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<td>I felt down-hearted and blue</td>
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<td>14</td>
<td>I was intolerant of anything that kept me from getting on with what I was doing</td>
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<td>15</td>
<td>I felt I was close to panic</td>
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<tr>
<td>16</td>
<td>I was unable to become enthusiastic about anything</td>
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<tr>
<td>17</td>
<td>I felt I wasn’t worth much as a person</td>
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<tr>
<td>18</td>
<td>I felt that I was rather touchy</td>
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<tr>
<td>19</td>
<td>I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)</td>
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<td>20</td>
<td>I felt scared without any good reason</td>
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<tr>
<td>21</td>
<td>I felt that life was meaningless</td>
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**Section D: QUALITY OF LIFE**

Taking everything into consideration, during the *past week* how satisfied have you been with your

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<tr>
<th>Items</th>
<th>Very Poor</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very Good</th>
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<tr>
<td>1   physical health?</td>
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<td>2   mood?</td>
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<td>3   work?</td>
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<td>4   household activities?</td>
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<td>5   social relationships?</td>
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<td>6   family relationships?</td>
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<td>7   leisure time activities?</td>
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<tr>
<td>8   ability to function in daily life?</td>
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<td>2</td>
<td>3</td>
<td>4</td>
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</tr>
<tr>
<td>9   sexual drive, interest and/or performance?*</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>10  economic status?</td>
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<td>5</td>
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<tr>
<td>11  living/housing situation?*</td>
<td>1</td>
<td>2</td>
<td>3</td>
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</tr>
<tr>
<td>12  ability to get around physically without feeling dizzy or unsteady or falling?*</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13  your vision in terms of ability to do work or hobbies?*</td>
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<td>2</td>
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<td>14  overall sense of well being?</td>
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<td>15  medication? (If not taking any, check here _____ and leave item blank.)</td>
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<td>5</td>
</tr>
<tr>
<td>16  How would you rate your overall life satisfaction and contentment during the past week?</td>
<td>1</td>
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<td>3</td>
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</table>
Thank you for participating in this study

Appendix C

الملحق ج

عنوان البحث: العلاقة بين نوعية الحياتو الضغوطات النفسية واستراتيجيات المواجهة للأشخاص الذين يعيشون مع فيروس نقص المناعة / الإيدز في القاهرة، مصر.

معلومات ديموغرافية

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<tr>
<th>الجنس</th>
<th>ذكر</th>
<th>أنثى</th>
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<td>إمي</td>
<td>ضعيف</td>
</tr>
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<td>الإبتدائية</td>
<td>الثانوية</td>
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<td>الجامعة</td>
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العرق

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<th>أسمر</th>
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<td>اللغة العربية</td>
<td>اللغة الإنجليزية</td>
<td>أخرى</td>
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اللغة التي تتحدث بها

معلومات عائلية

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<tr>
<th>الأب</th>
<th>الأم</th>
<th>ชาย</th>
<th>جد/الجدة</th>
<th>الشقيق/الشقيقة</th>
<th>العمة/العم</th>
<th>زوج الأم</th>
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<tbody>
<tr>
<td>من هو رابطك</td>
<td>عزب</td>
<td>الحالة الاجتماعية</td>
<td>متزوج</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
هـذه العناصر تتعامل مع الطرق التي قد تتعامل مع الضغوطات في حياتك منذ أن أكتشفت أن لديك فيروس نقص المناعة/ الإيدز هناك الكثير من الطرق لمحاولة التعامل مع هذه المشاكل هذه الأسئلة تسأل عن ما فعلته للتعامل مع هذه المشاكل من الواضح الناس مختلفون يتعاملون مع الأشياء بطرق مختلفة ولكن أنا مهتم بكيفيتك للتعامل معها كل سؤال يقول شيء ما عن طريقة معيته للتعامل أريد أن أعرف إلى أي مدى قد فعلت ما يقوله السؤال كم أو كم مرة استخدم هذه الخيارات للرد حاول تقييم كل واحدة منهم منفصلة في ذهنك عن الأخرين إجعل إجاباتك صحيحة بالنسبة لك بقدر الإمكان.

<table>
<thead>
<tr>
<th>النمط</th>
<th>هل الأب موجود في بيتك؟</th>
<th>هل زوج الأم موجود في بيتك؟</th>
<th>هل الجد موجود في بيتك؟</th>
</tr>
</thead>
<tbody>
<tr>
<td>لا</td>
<td>لا</td>
<td>لا</td>
<td>لا</td>
</tr>
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</table>

هل يوجد أطفال (تحت سن 18) في بيتك؟

أساليب التعامل

الرجاء وضع دائرة على الرقم المناسب.

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<tr>
<th>البناد</th>
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<tr>
<td>4</td>
<td>لقد فعلت هذا كثيراً</td>
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<td>3</td>
<td>لقد فعلت هذا بقدر متوسط</td>
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<tr>
<td>2</td>
<td>لقد فعلت هذا قليلاً</td>
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</tr>
<tr>
<td>1</td>
<td>لم أفعل هذا على الإطلاق</td>
<td>4</td>
</tr>
</tbody>
</table>

إنتقلت للعمل أو أنشطة أخرى لكي أنسى

ركزت جهودي على عمل شيء يعن نفسي وضععي

قلت لنفسني "هذا غير حقيقي"

استخدمت الكحول أو المخدرات الأخرى لجعل نفسي أشعر بأنني أفضل

قد تم الحصول على الدعم العاطفي من الآخرين

تخيلت عن محاولة التعامل معه

إجحضت أجزاء في محاولة لجعل الوضع أفضل

رفضت أن أصدق بأنني مصاب

138
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</tbody>
</table>

**إضطرابات نفسيّة**

الرجاء قراءة كل عبارة ووضع دائرة على الرقم المناسب الذي تشير إلى مدى تطبيق العبارة بالنسبة لك خلال الأسبوع الماضي لا توجد إجابات صحيحة أو خاطئة لا تستغرق الكثير من الوقت على أي عبارة:

الإجابات كما يلي:

0 = غير مطبقة على الإطلاق بالنسبة لي – أبداً.
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</table>
شعرت بالخوف دون أي سبب وجيه

احست أن الحياة كانت بلا معنى

نوعية الحياة
أخذ كل شيء بعين الاعتبار خلال الأسبوع الماضي ما مدى رضاك عن:

<table>
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<tr>
<th>البند</th>
<th>الرغبة الجنسية؟</th>
<th>القدرة على الحركة الفجائية دون الشعور بالدوار أو التقلب أو الهبوط؟</th>
<th>مدى قدرتك على القيام بالعمل أو الهوايات؟</th>
<th>الإحساس العام بالرضا؟ (إذا لم تأخذ أي دواء ضع علامة هنا واترك البند فارغاً)</th>
<th>كيف تقيم رضاك للحياة بشكل عام والرضا خلال الأسبوع الماضي؟</th>
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شكرًا لكم حسن تعاونكم على المشاركة في هذه الدراسة.
Appendix D

OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH DEVELOPMENT

08 September 2015

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape approved the methodology and ethics of the following research project by:
Mrs S Jawad (Social Work)


Registration no: 15/6/21

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape
Appendix E

Ministry of Health and Population
Under Secretary for Preventive Affairs
Communicable Disease Control Department
National AIDS Control Program

To/ University of the Western Cape
Faculty of Community and Health Science
Department of Social Work

Permission to conduct the study from National AIDS Program -MOHP - Egypt

As we are the Executive Director at National AIDS Program -MOHP - Egypt Honored to give student Sumaia Jawad (student number: 3505645) permission to conduct her master project study (The relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt) and to collect her data from HIV respondent patients in Abassia hospital in compliance with the governmental and ethical regulation.

This to be conducted under the direct supervision of the National Aids Program -MOHP - Egypt in all data collection and implementation procedures, The National AIDS Program has the right to keep a copy of all data collected or used for the study.

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National AIDS Program Director
Dr. Walid Kamal
Date: 24/1/2015

Appendix F
To University of the Western Cape 
Faculty of Community and Health Science 
Department of Social Work 

This is to inform you that the student Sumaia Jawad student number: (3505645) has completed the data collection for her project study; "The relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt" for HIV/AIDS patients agreed to participate in the questionnaire in Abassia hospital in compliance with the governmental and ethical regulation. 

As to ensure the confidentiality of patients under the study, the National AIDS Program keep all consent forms by its own regulations.

National AIDS Program Director
Dr Walid Kamal
Date : 24/1/2015
Proof of editing
14 June 2016

This letter serves as proof that the thesis of Sumaia Jawad, titled “The relationship between quality of life, psychological distress and coping strategies of persons living with HIV/AIDS in Cairo, Egypt” was professionally copy (language) edited. As per request of the student, the in-text references, reference list and appendices were not edited. The finalisation of tracked changes and comments inserted remains the responsibility of the student.

Kind regards

[Signature]

UNIVERSITY of the WESTERN CAPE

LM Bedeker
BA, Postgraduate Diploma (Translation) cum laude, MPhil (Translation) cum laude
Accredited member of the South African Translators’ Institute [accreditation number 1001437]
Member of the Professional Editors’ Group