Quality of Life of HIV+ and HIV- People Living in Elandsdoorn, South Africa

AND THE ROLE OF SOCIAL SUPPORT, COPING AND STIGMATIZATION

This study was part of the Ndlovu Research Consortium a collaboration of the Ndlovu Care Group (Elandsdoorn, South-Africa) , Utrecht University The Netherlands (the Julius Center for Health Sciences and Primary Care, the Department of Internal medicine & Infectious diseases, the Department of virology, the Department of immunology and the Faculty of Behavioral and Social Sciences) and the University of Witwatersrand Johannesburg South Africa (Reproductive Health and Research unit)

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Abstract

Objective: In cooperation with the Ndlovu Care Group, this master thesis has researched the effects of stigma, social support and coping strategies on the quality of life of HIV+ and HIV- people in a rural area in South Africa, Limpopo. The aim of the study was to find whether there exists a difference in quality of life between HIV+ and HIV- people and whether these difference could be explained by the mentioned social factors. Due to stigmatization, discrimination and a lack of social support, people living with HIV/AIDS are expected to have a lower quality of life than people not living with HIV/AIDS. It is of importance to create interventions which work to reduce stigmatizing behavior, encourage social support and help infected people to cope with the situation to better the quality of life.

Methods: The study was done among 198 black South Africans between the age of 19 and 65. Regression analyses have been conducted for all independent variables and for the independent variables combined to find if there were single and/or interaction effects with quality of life.

Results: Analyses showed that stigma was not significantly related to quality of life, that social support was significantly related to quality of life and coping strategies were partly related to quality of life. No significant difference in quality of life was found between HIV+ and HIV- people, only that the quality of life of both groups is influenced by another kind of social support in combination with avoidance coping. For the HIV+ population the combination of avoidance coping with family support is significantly related to a better quality of life and for the HIV- population avoidance coping in combination with household support is significantly related to a better quality of life.

Conclusion: The research has shown that there is little to no stigmatizing behavior in the research area and that social support and avoidance coping are found to be the most important predictors for a good quality of life. Another interesting finding is that there seems to be no difference in quality of life between the HIV+ and the HIV- population. A reason for these results could be that the Ndlovu Care Group has been working in this area for years already and has developed multiple plans to tackle the social problems related to HIV/AIDS.

Key words: quality of life, stigma, social support, coping strategies, HIV

Contents

List of abbreviations

AIDS	Acquired Immunodeficiency Syndrome
ART	Anti-Retroviral Treatment
ATC	Autonomous Treatment Centre
CD4	Cluster of Differentiation 4
CHAMP	Community Health Awareness & Prevention
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human Immunodeficiency Virus
NCG	Ndlovu Care Group
NRC	Ndlovu Research Consortium
NKPS	Netherlands Kinship Panel Study
NRC	Ndlovu Research Consortium
QOL	Quality of Life
RAP	Rural Advancement Plan
TB	Tuberculosis
WHO	World Health Organization

1. Introduction

Sub-Saharan Africa is severely impacted by HIV/AIDS. Estimates state that from all people in the world living with HIV/AIDS, five out of ten women, six out of ten men and nine out of ten children live in sub-Saharan Africa. From the sub-Saharan countries South Africa remains the country with the largest numbers of HIV infections (Shisana et al., 2005). In South Africa alone between 6 and 6,5 million people are infected, which makes up for 12% of the entire South African population (UNAIDS, 2013; Stats SA, 2014). Hundreds of thousands of children get orphaned by AIDS and hundreds of people are still getting infected on a daily basis (Kalichman and Simbayi, 2003).

A vast amount of research has already been done about the effects of HIV/AIDS in South Africa. Scholars have, among others, researched how HIV/AIDS patients who experience a lack of social support are likely to keep their situation a secret to their family (Ehiri, Anyanwu, Donath, Kanu and Jolly, 2005), how stigmatization can negatively affect the testing behavior of infected people (Corno and De Walque, 2013), and how stigma can negatively affect condom use, care seeking behavior (when being diagnosed with HIV/AIDS) and the actual care provision (Brown, Trujillo and Macintyre, 2001). This is just a small grasp out of the extensive research that has been done to HIV/AIDS and the effects of stigmatization and social support.

Ever since the HIV/AIDS epidemic began in the 1980s, infected people had to deal with stigmatization and insufficient social support (Mak et al., 2007). Not only does the disease have an impact on the physical health, but it also has a huge impact on the psychological well-being of the infected population (Mak et al., 2007). Due to stigmatization and a lack of social support from family and friends there are a lot of HIV infected people living with depression and a lot of them experience social rejection, loss of education, jobs and houses and acts of violence (Mak et al., 2007).

For this research the main collaboration will be with the Ndlovu Research Consortium (NRC) to research HIV/AIDS and its consequences for society and health. The consortium, which has been started in 2013, is a collaboration between the University of Witwatersrand (WRHI), University Utrecht (FSS) and UMC (NRC, 2015). The Ndlovu Care Group (NCG) is a non-profits, non-governmental organization, which operates in undeserved rural areas since 1994. The NCG organization aim is to develop a model for social mobilization with the use of integrated Community Care & Community Health Services by means of the NCG Rural Advancement Plan (RAP) in Elandsdoorn, Dennilton, and its goal is to address social problems as stigmatization and a lack of social support (Tempelman, Slabbert, Gosling and Vermeer, 2010).This study will be done by a survey among HIV infected and not HIV infected individuals. Understanding to what extent stigmatization, coping strategies and social support affect the quality of life (QOL) can help to understand what effects the social environment has on the QOL. It is assumed that lack of social support, stigmatization and lesser coping strategies affect the QOL negatively, which makes HIV very hard to tackle (Kalichman and Simbayi, 2005; Smith, 2008).

It is important to find out how social factors, as coping strategies, social support and stigmatization relate to QOL and how this differs between the HIV+ and HIV- population. When a difference can be found, and a reason for the difference in QOL is related to one or more of the social factors, there can be better understood how HIV affects someone's social life and thereby also someone's health. Intervention strategies to counter social problems which affect QOL could be designed to improve the QOL of both the HIV+ and HIV- population. In addition, what has also not been done yet, is comparing the QOL of the HIV+ and the HIV- population and linking this to social support, coping strategies and stigmatization. The above mentioned is what will be researched in this master thesis.

1.1 Contextual background of HIV in South Africa

HIV is a virus that attacks the immune system. CD4 cells usually fight infections and viruses in the body, but it is this important cell which is being invaded by the HIV virus. HIV uses the CD4 cells to make copies of themselves and the more CD4 cells get taken over, the sicker a person gets (AIDS.gov, n.d). The lower the healthy CD4 count gets, the further the stage of AIDS is reached (AIDS.gov, n.d). In South Africa the first HIV infection was reported in 1982 (Karim and Karim, 2002). In the beginning the HIV infections were mostly found in people who received blood transfusions or in homosexuals. Until 1987 the level of infections among heterosexuals remained relatively low (Karim and Karim, 2002). When the infections of heterosexuals began, however, the real 'explosive' epidemic began. Within five years more than 10% of the South African population got infected with HIV with most of the infections occurring in the black community. Two main reasons for this spread among especially the black community are the Apartheid regime and work migration (Hunter, 2007; Karim and Karim, 2002; Lurie et al., 2003;).

In the times of the Apartheid, South Africa was strongly divided and racialized. This social structure set the perfect conditions for a rapid HIV/AIDS epidemic (Hunter, 2007). During the Apartheid regime, HIV was mainly seen as a gay and black community problem, members of the community whom were already viewed as less worthy and whom were being stigmatized. Both these populations were not considered as to deserving serious (medical) attention (Karim and Karim, 2002).

During Apartheid, which took place in times of urbanization and industrialization, black men were forced to work in mines far away from their home villages and families to find a job (Hunter, 2007). It was mostly the black community that was being forced to move away, because the white community usurped all the proper jobs and the white community found the dangerous and physical exhausting work more suitable for the black people (Hunter, 2007). Sometimes men only had the chance to come back home once every three months (Lurie et al., 2003). Being away from home for a longer period of time caused men to engage with more sexual partners, making them more receptive for HIV (Hunter, 2007; Lurie et al., 2003). The instable living condition of the black community has shown to make them more vulnerable for HIV infections (Lurie et al., 2003).

The economic crisis of the 80's shook up South Africa even more. It were especially black men that became unemployed which caused them to look for jobs even further away from home. A lot of black women during the crisis survived through the sex industry (Hunter, 2007), a profession that was being frowned upon by both the black and the white community, and also by moving away from the home villages to do domestic work (Lurie et al., 2003). During the Apartheid it was thus the black community that was being forced to fulfill risky occupations and work far away from home for a longer period of time. For that reason the black community became more susceptible to the HIV virus. The Apartheid regime did not care about the health status of the black community, hence, they lacked proper sexual education or health care, and the virus gained free play to spread out (Kalichman and Simbayi, 2003).

Nowadays the virus is still prevalent among many black South Africans. And on top of the lack of education and health care, the virus causes people to feel rejected, shunned and dirty (Kalichman and Simbayi, 2003). In this master thesis the QOL of HIV+ and HIV- will be compared, and by studying the association with social problems like stigmatization, coping strategies and social support a reason for the difference in QOL will be explored.

2. Theoretical framework

The AIDS epidemic can according to UNAIDS (2002) be characterized by three phases. The first stage is the epidemic of HIV infections. A community gets infected without noticing and HIV spreads because of unawareness. The second phase is the AIDS epidemic. People start to show signs of the disease and life-threatening infections get triggered by the HIV virus. The third phase is the epidemic of stigmatization, discrimination and collective denial. Because of the third phase, the first two phases are extremely difficult to counter, which makes a good QOL more difficult to attain (UNAIDS, 2002). In the last few years a new fourth stage has emerged due to Highly Active Anti-Retroviral Therapy (HAART) (Tempelman et al., 2010). Due to HAART, HIV can be seen as a chronical disease, which makes it that more important to counter the stage of stigmatization and collective denial to attain a good QOL. This stage can be seen as the stage where HIV+ people have to learn how to live with the disease.

2.1 Quality of Life

What is taken into account when talking about QOL varies between studies, for this research mainly the health care related aspects of QOL will be taken into account. The World Health Organization (WHO) defines QOL as the "individuals' perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (The WHOQOL Group, 1997: 263). Elements such as social relationships, physical health, psychological state and salient environmental features are included in this concept of QOL. The subjective nature of QOL has to be emphasized. People use a personal yardstick to judge how good or bad their QOL is. QOL is a multidimensional concept, including a number of domains to get a comprehensive view of someone's QOL (The WHOQOL Group, 1997). The WHOQOL-HIV Group (2003) explains that social relationships and social interaction are important variables of the experienced QOL of people living with HIV/AIDS.

Research of Holzemer et al. (2009) and Greeff, et al. (2010) show that there is a strong link between stigmatization and the experienced QOL of the HIV infected population. They explain that the more stigma a person experiences, the lower the QOL of this person will be. Greeff et al. (2010) explain in their study that certain factors which positively influence the QOL are negatively influenced by stigma and a lack of social support. Disclosing your health status to a friend or a family member, taking ARV's and positive HIV media reports all positively influence the QOL satisfaction of HIV+ people. But when there are no interventions to address and reduce stigmatization, individuals continue to report a loss of control in life, more depression, decrease in social interaction and a decrease in social support, which all negatively influences the QOL (Greeff et al., 2010).

Holzemer et al. (2009) and Greeff et al. (2010) explain that due to stigma, people are likely to get depressed, feel insecure and socially isolated. This affects the help seeking behavior negatively which, together with depression, causes a reduction in the QOL (Holzemer et al. 2009; Greeff et al., 2010). The

QOL of HIV+ people reduces because, due to the lack of help seeking behavior, the medical attention which is needed for HIV+ people to manage the disease is not occurring.

The amount of social support a person receives, has in multiple studies also shown to form a link with QOL (Friedland, Renwick and McColl, 1996; Helgeson, 2003; Kristofferzon, Löfmark and Carlsson, 2005; Tang, Brown, Funnel and Anderson, 2008). The more a person feels supported, the better the QOL will be rated. Also explained is that the more social support a person receives, the more the infected person is able to cope with the situation, which reduces stressful situations and helps to improve adherence. This all would lead to a better QOL (Helgeson, 2003; Kristofferzon et al., 2005).

2.2 Stigmatization

Goffman (1963) explains stigma as a phenomenon whereby an individual is being rejected and or excluded on the basis of an attribute which is discredited by his or her society. The person with the attribute (in this case being infected with HIV/AIDS) gets classified by the society as undesirable and this person gets shunned. By societal labeling, the infected person gets labeled as deviant or different. Four types of stigma have been identified: enacted, internalized, felt normative and vicarious stigma (Steward et al., 2008).

For this research the focus will be on enacted stigma, because enacted stigma measures the attitude of people towards people living with HIV/AIDS. It measures to what extent acts of stereotyping, discrimination, intolerance and rejection are present in a community (Steward et al., 2008). Enacted stigma can be understood as the actual perceived discriminative behavior, but it also includes a broader understanding of stigmatization than is captured in the term discrimination (Brown, Trujillo and Macintyre, 2001). Discrimination is usually understood as unlawful acts of exclusion (USAID, 2006). Enacted stigma refers to this type of discrimination, but also includes acts of gossip, social isolation and loss of work, for instance due to the HIV status (USAID, 2006). Understanding to what extent a community deals with stigma and how this might affect the QOL, is what is important to know for this research.

Research has shown that the population that never has been tested for HIV is more likely to find HIV/AIDS dirty and shameful, also because a common thought is that being infected with HIV is caused by your own wrongdoing. The HIV+ population is found to be less likely to stigmatize but are also found to experience more stigmatizing behavior from their surroundings (Kalichman and Simbayi, 2003). Ehiri et al. (2005) explain that stigma is shaped by social, political, economic and cultural factors and the effects stigmatization has on the attitude of infected people highly depends on the structure of the community and society the infected person lives in.

Scholars (Ehiri et al., 2005; Kalichman and Simbayi, 2009; Zukoski and Thorburn, 2009) state that stigmatized persons mostly feel shame, anger and social isolation. In addition, infected people rather keep their health situation at secret, so they are not likely to look for help (Simbayi, Kalichman, Strebel,

Cloete, Henda and Mqeketo, 2007). HIV+ people are a lot of times perceived as dirty, shameful and cursed by the HIV- population, and even though scholars state that AIDS related stigma is slowly declining, it is still prevalent. In 2005, for example, 41% of the South African population stated that the HIV+ population should get restrictions on their freedom (Kalichman et al., 2005), 29% said not to buy food from a HIV+ vendor, and 20% believed HIV+ children should be held separate from other children (Shisana et al., 2005). People infected with HIV/AIDS seem to experience acts of discrimination due to the disease and therefore they feel socially isolated and ashamed. There also still exists a pervasive negative social response to the disease, even in highly affected communities (Parker and Aggleton, 2003).

If stigma gets addressed and preventive counselling will be given to HIV+ people before they experience stigma, it could help them prepare for stigmatizing behavior which could help them manage the stigma. Holzemer et al. (2009) explain that addressing stigma could help declining depression, help infected people to search for treatment and better the adherence, all leading to a better QOL. A link between stigmatization and social support can be made here. Scholars point out that stigma can be intensified when there is little tolerance for different lifestyles, where the fear of HIV is greater and where the anonymity is less, which most intensively occurs in rural areas.

2.3 Social support

Rural areas mostly experience a lack of social support programs, less comprehensive HIV/AIDS related health services and have less medical experts than their urban counterparts. Studies have shown that the social context, such as whether one lives in an urban or a rural community, and especially the amount of social support an HIV+ person receives from the community matters for stigmatizing effects (Ehiri et al., 2005., Greeff et al., 2010., Holzemer et al., 2009., Zukoski and Thorburn, 2009). The QOL of HIV+ people in rural settings is much lower than for HIV+ people in urban setting (Heckman, Catz, Heckman, Miller and Kalichman, 2004).

So, besides stigmatization, also the lack of social support can have a negative effect on the QOL (Smith, Rosetto and Peterson, 2008). Since the age of Durkheim and his suicide theory, where he explains that suicides occur because of the lack of social cohesion and regulation (Durkheim as written in Vaux, 1988) and thereby points out the importance of the presence of social relationships and social support, theories about social support have been further developed. Vaux (1988) explains that social support is best to be understood as the support from a persons' closest networks (as in family and friends) and the way this network shows specific supportive behavior. Leung and Lee (2005) also explain social support as the social capital and the community involvement a person experiences and receives. Social support is a term which includes the supportive ways that people give and receive in different settings in different ways (Helgeson, 2003). Social support can thus be seen as a dynamic process between the actions of the

network and how these actions from the network are being valued and perceived by the person being questioned (Helgeson, 2003; Leung and Lee, 2005).

Research has shown there are three ways of social support; emotional support, instrumental support and informational support (Helgeson, 2003). Emotional support means having people around you who listen, care, who provide reassurance, who make you feel loved, care for you and value you and who are able to sympathize. Instrumental support refers to tangible assistance. So, assistance with the household, running errands or lending money. Informational support refers to the provision of guidance and information (Helgeson, 2003). It is mostly thought that emotional support is the best predictor for a better QOL, but it depends on the situation of the patient (Helgeson, 2003). In most medical cases the informational support was found to be the most important predictor for a higher QOL, but in the case of HIV, especially emotional support is found to be an important predictor for a better QOL (Helgeson, 2003).

When social support is lacking, the infected person experiences more stress and Helgeson (2003) explains it is the level of stress which influences which kind of social support is needed. The more stress a person experiences, the more emotional support is needed and people who deal with HIV/AIDS experience a fair amount of stress (Helgeson, 2003). Another finding is that when a person feels like they will not get social support, they are likely to keep their health status secret (Du Preez, 2011; Smith et al., 2008). Du Preez (2011) explains that the fear of rejection from the family members and friends keeps an HIV infected person from disclosing their health status. Even when friends and family suspect a friend or family member of having HIV/AIDS, the situation will frequently not be discussed. Scholars state that HIV+ people have to face the dilemma whether to disclose or not to disclose their status. Telling you are infected means not having to conceal a secret anymore, but facing the possibility of being stigmatized and not getting the social support hoped for. In both situations the infected person has to struggle with a high amount of stress which is not beneficial for their health and QOL (Du Preez, 2011; Hegelson, 2003; Smith et al., 2008). This high amount of stress asks for the emotional support of family and friends, but even though the majority of the South African population indicates they would be willing to take care of a family member with HIV/AIDS, most of them also display negative attitudes and negative perceptions towards HIV/AIDS (Shisana et al., 2005). A gap might exist between the willingness to take care of an infected family member, and absent actual social support. Du Preez (2012) explains this phenomenon as instrumental care. Care will be given, but the emotional connection is lacking (Du Preez, 2011). So, it is especially emotional support which seems to be missing when dealing with HIV/AIDS (Frieland et al., 1996). Greeff et al. (2010) have shown in their study that a lack in social support makes individuals lose the ability to take control of their life, which reduces the QOL satisfaction.

2.4 Coping strategies

A lot of the reduction in QOL has to do with the effect social support has on the coping strategies of the infected person (Douaihy and Singh, 2001; Frieland et al., 1996). Coping can be explained as the response to reduce stress whereby stress can be best described as the psychological, environmental, emotional or physical factors that cause distress to a group, organization or individual (Gore-Felton, Koopman, Spiegel, Vosvick and Brondino et al., 2006). To comprehend all these stress situations, there are three coping strategies that can be identified. The first is problem oriented coping. This type of coping can be identified as the deliberate attempts to find a solution for the problem or trying to change the stressful situation, the problem in this case being infected with HIV. The second type of coping is avoidance coping. This type of coping strategy explains the activities which are undertaken by the infected person to avoid the stressful situation by, for example, searching for distraction or company and denial and delaying testing. The third coping strategy is emotional coping. Emotional coping strategies can be explained as the emotional reactions a person has to a certain problem to reduce stress, ranging from getting angry to fantasizing about the problem (Frieland et al., 1996; Norman, Endler, James and Parker, n.d).

Frieland et al. (1996) found a close link between coping strategies and the amount of social support a person receives. They explain that the combination of a lack of social support and a lack of emotional coping is negatively related to QOL. When there is a presence of social support and problem oriented coping, there is a positive relation with QOL. Avoidance coping in combination with a lack of social support was found to be unrelated or negatively related to QOL (Frieand et al., 1996). It thus depends on the amount of social support a person receives and what kind of coping strategies this person uses, how satisfied this person will be with the QOL. Gore-Felton et al. (2006) also emphasize the importance of proper coping strategies for reducing the amount of stress a person experiences. They state a proper guidance is needed to help people cope with stressful and difficult situations to improve their QOL.

3. Research question

Based on the theories, the dependent variable in the research will be the 'Quality of Life' of HIV+ and HIV- people. The independent variables are stigmatization, social support and coping strategies. Demographic variables will be taken into account as control variables. The aim is to provide a quantitative analysis to determine the effects of social support and stigmatization on the QOL of both HIV+ and HIV- people.

The main research question will therefore be:

To what extent do stigmatization, social support and coping affect the Quality of Life of HIV positive people in comparison to HIV negative people in Elandsdoorn, South Africa?

This question is subdivided in two sub-questions:

1. Does the quality of life rate differs between the HIV+ and HIV- population?
2. Can this difference be explained by social support, coping strategies and/or stigmatization?

3.1 Hypotheses

Based on the theories and the research question, there are four main hypotheses to be analyzed in this master thesis. The first hypothesis is that there will be a difference in QOL between HIV+ and HIV- people, and this difference is influenced by the lack of social support HIV+ people receive from their surroundings. The second hypotheses is that there is expected to be a positive relationship between coping strategies and QOL. The third hypothesis is that the reason that QOL of HIV+ people will be lower than QOL of HIV- people is due to the stigma HIV+ population experience enacted stigma. This hypothesis will be tested by comparing the HIV+ population, expected to be exposed to a lot of stigmatization, with the HIV- population, expected to be exposed to a little or no stigmatization. Finally, it is expected that there is an interrelationship between stigmatization, social support and coping. When there is stigma present, the social support and therefore the coping strategies are expected to be lower and when social support is low, stigmatizing behavior and lower coping strategies are expected. Figure 1 schematically shows the hypotheses described above.

The blue circle is the dependent variable and the white circles are the independent variables. The plusses and minuses indicate the hypothesized presence of the independent variables in relation to the dependent variable. So, stigma is expected to be present (+) with the HIV+ population and is expected to be absent (-) with the HIV- population. Social support is expected to be absent or less with the HIV+ population and more important with the HIV- population and finally, coping strategies are expected to be present in both populations, but they are expected to be different with the HIV+ population than with the HIV- population. The expectation is that the HIV+ population will have more difficulty with coping and the

HIV- population less difficulty. The arrows between the independent variable indicate in which direction the relationship is expected to be present, which ultimately will lead to a higher or lower QOL.

Figure 1. Research scheme and hypotheses.
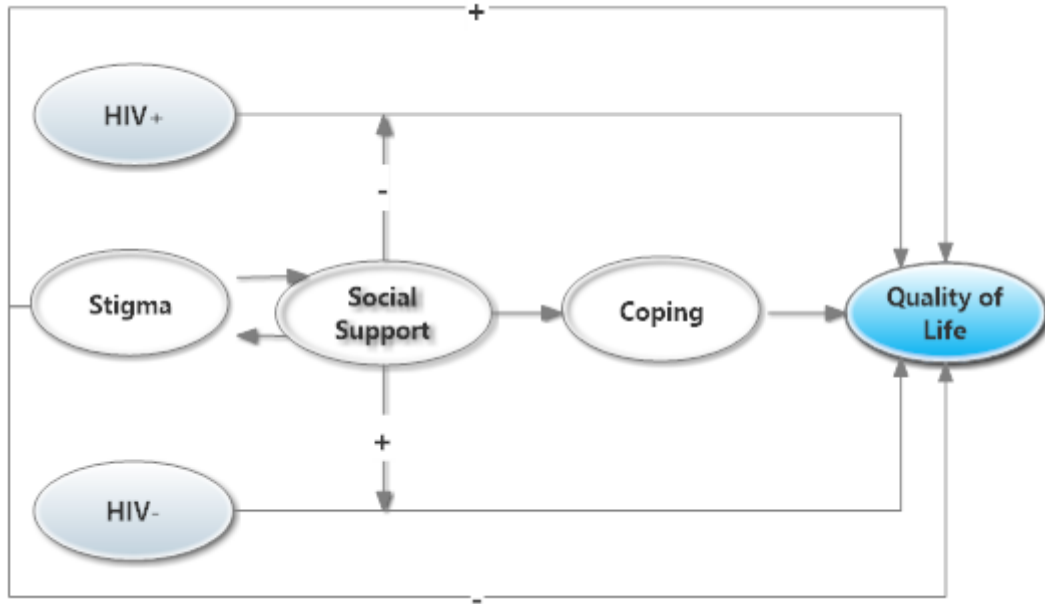
3.2 Interdisciplinarity

This master thesis is an interdisciplinary study. Sociological aspects as well as psychological aspects are taken into account. The way the community interacts and handles HIV/AIDS can be analyzed from a sociological point of view. The questions about how the respondents feel about the disease are psychological and the contextual circumstances that will be taken into account can be contributed to social demographics. The use of more disciplines makes sure more points of view are taken into account when analyzing stigma, social support and QOL. It will give a broader understanding of the social problem and thus also a better solution for the problem.

4. Method

The research is of a quantitative approach. The study is intended to give an insight in how the NCG RAP can be improved. The RAP can be divided into two main activities: first, the Autonomous Treatment Centre (ATC) which is a clinical service which provides comprehensive community health services. These include chronic disease management, quality primary health care, laboratory services, radiology and HIV/AIDS care (Tempelman et al., 2010). Second, there is the Community Health Awareness & Prevention (CHAMP) programs. CHAMP provides the community with future orientation. They provide HIV/AIDS prevention programs, community liaison, sports, arts and culture programs and community development programs (Tempelman et al., 2010). This study could contribute to both RAP activities by trying to improve the community services and by providing information to improve the chronical disease management.

The population for the research are HIV+ and HIV- people. This study is part of a larger research program, the NCG cohort study. The cohort study recruits people from the rural area Elandsdoorn and communities surrounding Elandsdoorn to understand their medical and social conditions comparatively. The respondents participating in the cohort study are asked to also participate in the Social Science study, and to fill in the social science questionnaire (SSQ). Some respondents are HIV- some are HIV+ at enrollment and some new HIV+ people have known their health status only since the pre-screening results. The HIV+ and HIV- population are asked to fill in the same questionnaires. The baseline questionnaire contains questions on demographic characteristics, mental health, HIV testing behavior and stigma. The SSQ questions the family support, coping strategies, sexual behavior and Quality of Life. The aim of the questionnaires is to find out which factors influence the attitude towards HIV/AIDS, how certain factors can be of influence to the testing behavior and how certain factors are of influence to the QOL (NRC, 2015). The last purpose of the questionnaire is of interest for this study. The intention of the study is a longitudinal but for this study only one wave is available. Therefore only current QOL, experienced acts of stigmatization and social support connecting to someone's health status are measured.

4.1 Instruments

In order to answer the formulated research questions, several existing questionnaires were used. The four main instruments that were used for this research are operationalized as follows:

Quality of Life. Questions from the World Health Organization Quality of Life questionnaire (WHOQOL) was used to measure QOL. The WHO made an adapted version of the questionnaire especially for people dealing with HIV. Instruments have been added to question about typically cultural aspects, such as spirituality, personal beliefs and religion (The WHOQOL-HIV Group, 2003). The questions that will be asked about the QOL are all derived from a validated questionnaire from the WHO (2002). The WHO designed a QOL questionnaire especially targeted for people dealing with HIV.

Thirteen questions have been incorporated into the social science questionnaire. Eleven of these questions are divided into a five point Lickert scale, scaling from 'very dissatisfied', 'dissatisfied', 'neither satisfied nor dissatisfied' to 'satisfied' and 'very satisfied'. The questions about QOL thus have to be rated in how satisfied you are about certain aspects of your life. Examples of the questions are: 'with your health', 'with your access to health services' and 'With yourself'. The last two questions are also scaled into a five point Lickers scale, but then scaling from 'very poor' to 'very good'. These two questions ask directly to the quality of life: 'how would you rate your quality of life' and their mobility: 'how well are you able to get around'.

All the questions can be divided into six domains which influence the QOL; 1) physical health, 2) psychological health, 3) level of independence, 4) social relationships, 5) environmental and 6) the general domain. For the total QOL score, all the domains have to be taken together and divided by the number of items per domain. For physical health the questionnaire contains one question, for psychological health also one, for domain three there are two questions, for domain four there are three questions, for domain five also three questions and for the general domain there are two. The Cronbach's alpha for the computed QOL scale, which includes the total list of QOL items (QOLTOT) counted .75.

Stigmatization. The questions about stigma have been derived from a validated questionnaire of Kalichman and Simbayi (2003). The validated questionnaire had a dichotomous scale. For this study the original questionnaire has been adapted into a four point scale, with the answer possibilities of 'never', 'sometimes', 'often' and 'always'. Before using the newly designed four point scale, there had to be validated whether the scale was reliable. The validated questionnaire of Kalichman and Simbayi (2003) counted a Cronbach's alpha of .69, which is just barely meeting the reliability criteria, which should ideally be above .70 if a scale can be found reliable (Field, 2009). For this study, the Cronbach's alpha counted .37, indicating a not reliable scale.

In order to explore whether there could be found coherence between the items in the stigma scale, which could enhance the Cronbach's alpha, a factor analysis was used. A factor analysis showed that the stigma questions contained six dimensions, dividing the twelve questions in sets of two. None of the dimensions, however, reached a Cronbach's alpha higher than .70. Because the questions in the stigma scale do not seem to cohere, the questions will separately be taken into account in the further analysis.

Social support. The questions about social support have been derived from the Netherlands Kinship Panel Study (NKPS) (Dykstra, Kalmijn, Knijn, Komter, Liefboer et al., 2005). Three subjects from the complete validated NKPS questionnaire have been selected for the SSQ. The three subjects are 1) the support one receives from persons living in the same household, which will be called the household support scale, 2) the support one receives from family members who do not live in the same house, which will be referred to as the family support scale and 3) values and norms about family life and family support, which will be referred to as family norms scale. The first two subjects consist of

five questions each and both ask the same questions. The answers can be given in a four point Lickert scale, ranging from 'No support' and 'A little support' to 'A fair amount of support' and 'A lot of support'. Examples of the subjects that are being questioned are: 'To what extent do persons […] support you', 'When you have worries or health problems' and 'In personal matters that are on your mind'. The five questions for the household support scale have been found to be highly reliable with a Cronbach's alpha of .96 and the family support scale was also found to be highly reliable with an alpha of .99.

The third subject consist of 15 statements. All the statements ask about how one feels the family is supposed to support each other and the answers can be given according to a five point Lickert scale ranging from 'Strongly disagree' to 'Strongly agree'. The 15 statements can be divided into four categories; 1) family norms with for example the statement 'One should always be able to count on family', 2) the support that should be given to parents with for example the statement 'Children should look after their sick parents', 3) support that should be given to children, for example 'Parents should support their adult children if they need it', and 4) the opinion about children with statements, like 'One's life is not complete if one has not had children'. The family norms scale can also be said to be reliable with an alpha of .77.

Coping strategies. Questions about coping strategies have been derived from a validated questionnaire, called the Coping Inventory for Stressful Situations (CISS). The list of questions that have been used in the SSQ consist of 21 questions the three types of coping strategies explained in the theoretical framework can be identified. All questions start with the sentences 'The following are ways people react to various difficult, stressful or upsetting situations. Please indicate how much you engage in these type of activities during this specific situation'. For all types of coping strategies there are seven questions taken into account. For the problem oriented coping a few examples are: 'Focus on the problem and see how I can solve it' and 'Determine a course of action and follow it'. For the avoidance coping strategy the questions ask for example: 'Treat myself to a favorite food or snack' and 'Visit a friend', and for the emotional coping strategy questions are for example: 'Blame myself for having gotten into this situation' and Become very upset'. The questions can be answered with a five point Lickert scale. The answers range from 'Not at all' to 'Very much'.

The coping strategies questionnaire has been designed to test the three coping strategies separately, so also for this study the three different strategies will be taken into account. For all three strategies there was done a reliability analysis. For avoidance coping the alpha is .71. This is already meeting the criteria for a scale to be found reliable, but because the higher the alpha is, the more reliable the measurements will be, one question has been removed from the avoidance coping scale. This question was 'Take some time off and get away from the situation'. By removing this question the alpha became .76.

For the emotional coping the alpha is .79 and for the problem solving coping strategy the alpha is .70. For these two scales no questions needed to be removed in order to increase the reliability.

4.2 Control variables

Besides the above mentioned instruments, other factors might also be of influence to the QOL, stigma, social support and coping strategies. To be fully able to compare the HIV+ and HIV- populations, control factors have also been taken into account in the analysis. To measure the control factors, the operationalization was as follows:

Age. In order to compare weather both groups had the same distribution in age, the date of birth of the participants were asked. For the analysis the date of birth was computed into the age in years.

Gender. In order to explore the gender of the participants, the participants were asked if they are a women (score = 1) or a man (score = 2).

Employment status. As explained in the theoretical framework, the HIV status can be of a negative influence to someone's abilities to enter the labor market, which could negatively influence the QOL. Therefore, the participants were asked to fill in weather they were employed or not. The question 'Are you currently employed?' could be answered in nine different ways, with two options of being employed: 'Yes, employed' and 'Yes, self-employed', and five options of being unemployed: 'No, unemployed', 'No, student', 'No, retired', 'No, disabled' and 'No, other'. The last two options were given if the participant or did not want to answer the question or the participant did not know the answer. In the results the last two answers have never been given. For the analysis the seven remaining answers have been recoded into two options; 'Yes, employed' (score = 1) and 'No, unemployed' (score = 2).

4.3 Population

The study has been done and will continue in the Moutse area in the Limpopo province, South Africa. The Ndlovu Care Center is located in this rural area: Elandsdoorn, Dennilton. People living in the area are known with the care center and participation is done on a voluntary basis. The final goal for the social science study is to reach a number of 1000 participants with 500 being HIV+ and 500 HIV-. The intention is to follow these participants for at least four years .

For this research 202 adults between the age of 19 and 65 (M=39,9) participated in the study. 198 of these participants have filled in both the questionnaires, and 4 participants have only filled in the baseline questionnaire. The analysis for this study will be done with the 198 participants that filled in everything.

Among the participants there is an unequal distribution between women and men and there is also an unequal distribution between HIV+ and HIV-. 79,2% of the participants is female and 20,8% of the participants is male. 27,6% of the participants is HIV+ and of these participants 73,6% is female, which means that 39 of the 53 HIV+ participants is female. The mean age of the HIV+ participants is 39,08 with a standard deviation of 10, 23. The HIV- population has an age of 40,30 with a standard deviation of 14,06. In educational level no big difference can be found. In the HIV+ population 20,8% says to be employed and for the HIV- population this is 15,9%.

5. Results

To explore whether there exists a difference between the HIV+ and HIV- population in respect to QOL, and before including the independent variables in the analysis, several assumptions for performing a regression analysis had to be evaluated.

- Firstly, with stem-and-leaf plots, boxplots and an explorative analysis, there has been established that the dependent variable, QOL, is normally distributed.
- Second, the Normal Probability Plot of regression standardized residuals and the Scatterplot of standardized residuals, indicated that the residuals of the dependent variable were normally distributed which indicates the assumptions of normality, linearity and homoscedasticity of residuals have been met. For the independent variables the scales do not all meet the assumption of normality. The stigma questions and the household support scale are not normally distributed. The questions and scales, however, will be taken into account in the analysis, because the questions and scale do form a linear relationship, which can be seen in the Normal Probability Plot.
- Third, Mehalanobis distance did not exceed the critical Chi-Square for $df = 7$ (at $\alpha = .001$) of 24. 322 for any cases in the data file, indicating that multivariate outliers were not of concern.
- Next there had to be checked whether there were cases of multicollinearity. Multicollinearity explores if there is a high correlation between two or more variables. If the correlation exceeds the value of .8, the collinearity coefficient is found to be too high, indicating that two variables are measuring the same thing (Field, 2009). Combining all the variables in a Pearson Correlation martix, it can be seen that none of the variables correlate more than .8, indicating that the assumption of no multicollinearity has been met.
- Lastly, the assumption of sample size had to be met. According to Green's rule of thumb, a minimum sample size of 114 (50+8k, where k stands for the number of predictors) participants is needed to test the overall model (Field, 2009). The modal that is being used for this research is 198 participants, which meets the sample size criteria.

Now that the assumptions are clear, in order to explore whether social support, coping strategies and stigma are of influence on the QOL, first a univariate regression per independent variable will be conducted and next a multivariate regression analysis will be conducted. In both regression analyses there will be controlled for the control variables mentioned in the former chapter.

A first exploratory analysis shows that HIV status is not significantly related to QOL, indicating there is no difference in QOL between both HIV groups. HIV status on its own only accounts for 0.7% of the total variance of the model, $R^2 = 0.007$, adjusted $R^2 = 0.002$, $F (1,195) = 1.447$, $p = .230$. Adding all the control variables to the regression model, the model does become significant with $R^2 = 0.072$, adjusted $R^2 = 0.043$, $F (6,190) = 2.465$, $p = .026$. In the significant model only gender is found to be significantly

related to QOL with $p= < .05$. Even though age was not significant, it was taken into account to provide some more background information about the respondents in the study and to account for possible differences between both HIV groups or interactions with other variables in the model. Also, even though it turns out that there is no significant difference between HIV+ and HIV- people and their QOL, HIV status will be taken into account in the regression analysis as an ENTER statistic, so even though the relationship is not significant, the variable will be forced into the model. HIV status will be taken into account because the possible differences between the groups are of interest for this research.

For exploring how the independent variables relate to QOL, all variables have been entered into an ENTER regression model. For social support the computed variables household support, family support and family norms have been taken into account. For coping strategies the computed variables avoidance coping, emotional coping and problem solving coping have been taken into account. Because the stigma scale turned out to be unreliable, and the factor analysis did not give a reliable domain, all the separate stigma questions have been taken into account in the exploratory regression analysis.

The control variables age and gender show a significant relationship to QOL with $R^2= 0.039$, adjusted $R^2= 0.029$, $F (2,195) = 3.917$, $p = .020$. Adding HIV status to the model the adjusted explained variance of the model goes down and the model is no longer significant, $R^2= 0.042$, adjusted $R^2= 0.028$, $F (1,194) = 0.677$, $p = .412$. When all the variables for social support are added, the variables all showed a significant relation to QOL with $p= < .05$. Also the model became significant with $R^2= 0.172$, adjusted $R^2=0.146$, $F(6,191)= 6.59$, $p = .000$. With all the social support variables being significant, only the HIV status is not significant. Also age and gender are significant in this model, which indicates that there is a difference between men and women and a difference between age groups in how they experience and value social support, which influences their QOL. There can thus be said that the QOL, based on social support, differs between gender and age groups, but because HIV status is not significant, this relationship does not differ between HIV- and HIV+. The models explaining these values are reported in table 1.

The same regression analysis has been done to explore the variable of coping strategies (table 2). The first two models for this analysis are the same as with the social support model. A third model shows a significant relationship between avoidance coping and emotional coping and QOL, $p= < .05$, and a non-significant relationship between problem solving coping and QOL, $p= > .05$. Age, gender and HIV status all are not significant in this model. The model explains 15,2% of the total variance ($R^2=0.152$, adjusted $R^2=0.125$ $F(6,191) =5.68$, $p = .000$). The analysis has been repeated without the non-significant variable problem solving coping, to find out if age would become significant again, but the model stays the same. So, for coping there can be said that avoidance coping and emotional coping are significantly related to QOL, which indicates that the presence of these types of coping positively influence the QOL.

Table 1. Unstandardized (B) and Standardized (β) Regression Coefficients for each predictor on each step of the Multiple Regression Analysis are reported in Table 1.

Model		B	Std. Error	β	T	Sig.
1	(Constant)	3,902	,158		24,668	,000*
	Gender	,207	,090	,161	2,287	,023*
	AGE	-,005	,003	-,123	-1,748	,082
2	(Constant)	3,818	,189		20,231	,000*
	Gender	,201	,091	,156	2,213	,028*
	AGE	-,005	,003	-,120	-1,707	,089
	HIV status	,069	,084	,058	,823	,412
3	(Constant)	2,564	,392		6,536	,000*
	Gender	,178	,086	,138	2,065	,040*
	AGE	-,006	,003	-,149	-2,186	,030*
	HIV status	,073	,079	,062	,925	,356
	SOCIALSUPFAM	,089	,035	,197	2,508	,013*
	SOCIALSUPHH	,108	,049	,171	2,193	,030*
	FAMSUPNORM	,163	,082	,134	1,983	,049*

Dependent variable: QoLTOT I Adjusted R^2 for the third model = .146 I *= $p < .05$

Table 2. Unstandardized (B) and Standardized (β) Regression Coefficients for each predictor on each step of the Multiple Regression Analysis are reported in Table 2.

Model		B	Std, Error	β	T	Sig.
1	(Constant)	3,902	,158		24,668	,000*
	Gender	,207	,090	,161	2,287	,023*
	AGE	-,005	,003	-,123	-1,748	,082
2	(Constant)	3,818	,189		20,231	,000*
	Gender	,201	,091	,156	2,213	,028*
	AGE	-,005	,003	-,120	-1,707	,089
	HIV status	,069	,084	,058	,823	,412
3	(Constant)	3,483	,261		13,320	,000*
	Gender	,071	,090	,055	,791	,430
	AGE	-,002	,003	-,054	-,790	,430
	HIV status	,077	,080	,065	,967	,335
	COPINGAV	,158	,045	,267	3,486	,001*
	COPINGEM	-,134	,043	-,229	-3,103	,002*
	COPINGPR	,101	,062	,129	1,630	,105

Dependent variable: QoLTOT I Adjusted R^2 for the third model = .125 I *= $p < .05$

For the stigma variables, also the same procedure was followed. For these variables, no significant associations with QOL were found, but one. Only reversed question 8 showed a $p= < 0.05$. The questions asks: 'It is safe for people to work with children', which indicates that the only thing that can be said about stigmatizing behavior, is that both HIV+ and HIV- infected people of both genders and of all age groups, find that the QOL declines when an HIV+ person is to work with children. For this research, however, this finding is of non-significance, because in this research the goal is to find out whether HIV+ people experience more stigmatizing behavior which could negatively influence their QOL in comparison to HIV- people. With one question, which is answered identically by HIV+ and HIV- people, no proper conclusions can be drawn about the effect of stigma on the QOL. The stigma model with all items also showed not to be significant with the values of $R^2=0.112$, adjusted $R^2= 0.028$, $F(17,180)= 1.334$, $p= .176$.

So, for the separate effects of the independent variables on QOL, there can first be said there is no significant difference for HIV+ and HIV- people. Secondly there can be said that for social support an effect has been found for all three components of the social support variable, which means the amount of social support someone receives, positively influences his/her QOL (indicated by the positive β value). For the separate effect of the coping strategies variable on the QOL, there is also no significant difference between HIV+ and HIV- people. There is also no difference in problem solving coping found. The effects that do seem to occur are found in avoidance coping and emotional coping. The more avoidance coping is present, the better the QOL seem to be (indicated by the positive β) and the more emotional coping the lesser the QOL seems to be (indicated by the negative β).

Combining all the significant variables in the multiple regression model, which means taking into account social support and coping strategies and not taking into account stigma, it can be seen in table 3 that there are six models possible. This model has been built up using the STEPWISE option in the regression analysis for the independent variables. STEPWISE indicates that only significantly valuable variables, after combining the variables, will be taken into account in the model. The sixth model explains a total variance with R^2 of 0.226 (adjusted $R^2 = 0.197$, $F (7,190) = 7.914$, $p = .000$). In the multiple regression analysis there has been controlled for age and gender. As a separate controller, the HIV status, has also been taken into account. Without HIV status as a control variable, the model explained 19,6% of the total variance instead of 19,7% and for the significance levels of the remaining variables, the significance outcome did not differ too much. The same variables were found to be significant in the model including the HIV status as in the model excluding the HIV status, so for the completeness and the relevance of this research, the HIV status is taken into account.

Table 3. Unstandardized (B) and Standardized (β) Regression Coefficients for each predictor on each step of the Multiple Regression Analysis are reported in Table 3.

Model		B	Std, Error	β	T	Sig.
1	(Constant)	3,902	,158		24,668	,000*
	Gender	,207	,090	,161	2,287	,023*
	AGE	-,005	,003	-,123	-1,748	,082
2	(Constant)	3,818	,189		20,231	,000*
	Gender	,201	,091	,156	2,213	,028*
	AGE	-,005	,003	-,120	-1,707	,089
	HIV status	,069	,084	,058	,823	,412
3	(Constant)	3,491	,195		17,925	,000*
	Gender	,155	,087	,121	1,778	,077
	AGE	-,006	,003	-,145	-2,145	,033*
	HIV status	,088	,080	,074	1,101	,272
	SOCIALSUPFAM	,135	,031	,301	4,426	,000*
4	(Constant)	3,154	,214		14,758	,000*
	Gender	,088	,087	,068	1,004	,317
	AGE	-,004	,003	-,096	-1,427	,155
	HIV status	,100	,078	,084	1,281	,202
	SOCIALSUPFAM	,124	,030	,276	4,142	,000*
	COPINGAV	,140	,041	,236	3,422	,001*
5	(Constant)	2,363	,389		6,074	,000*
	Gender	,102	,086	,079	1,175	,242
	AGE	-,005	,003	-,122	-1,813	,071
	HIV status	,106	,077	,089	1,375	,171
	SOCIALSUPFAM	,117	,030	,259	3,929	,000*
	COPINGAV	,146	,040	,246	3,613	,000*
	FAMSUPNORM	,195	,080	,160	2,420	,016*
6	(Constant)	2,138	,398		5,376	,000*
	Gender	,109	,086	,084	1,271	,205
	AGE	-,004	,003	-,100	-1,495	,137
	HIV status	,086	,077	,073	1,121	,264
	SOCIALSUPFAM	,076	,034	,170	2,218	,028*
	COPINGAV	,146	,040	,246	3,647	,000*
	FAMSUPNORM	,182	,080	,150	2,276	,024*
	SOCIALSUPHH	,108	,048	,171	2,254	,025*

Dependent variable: QoLTOT   I   Adjusted R^2 for the sixth model = .197   I   * = $p < .05$

In table 3 there can be seen that all the social support variables are positively related to QOL and that only one coping strategy is taken into account, avoidance coping, which is also positively related to QOL. The four remaining variables were found to be significant with $p = < 0.05$. This model explains that, when age, gender and HIV status are taken into account, all the social support variables and only avoidance coping are positively related to QOL.

For the completeness of the study, the stigma questions also have been added to the multiple regression analysis, to check it the variables that were found to be significant would change. Even with the stigma topics is the analysis only the four variables mentioned above were found to be significantly related to QOL.

Even though table 3 shows there is no significant difference between the QOL of HIV+ and HIV- people, a final regression analysis with a split file has been done to find out if the HIV+ and the HIV- population experienced the same social support and used the same coping strategies. A split file in this case indicated that the database had been split into HIV+ and HIV- data. Next the multiple regression analysis has been conducted, keeping age and gender as control variables in the equation and adding the social support and coping strategies variables in a STEPWISE regression. The results for this analysis can be seen in table 4.

Table 4 shows that both groups do experience a different kind of social support. For HIV- people there is a significant relationship between social support from people living in the same household (household support) and for HIV+ people there is a significant relationship between the support they receive from family not living in the same household (family support). Both groups do have the same coping strategy. For the HIV- population the model, according to the adjusted R^2, explains 13,4% with $p = < 0.05$ of the total variance and for the HIV+ population the model explains 35,3% with $p = < 0.05$ of the total variance. There can be said that the model of the HIV+ population can be used as a stronger predictor for QOL.

Another striking difference between the groups, is the significance level for age in the second model. For HIV- there seems to be no difference in age groups and their QOL, but in the HIV+ group $p = 0.017$, which would indicate there is a difference in age groups and their QOL and this relationship to QOL is negative. This study does not focus on the differences in age groups, but for further research it would be of an added value, because there can be found out where the difficult age lies.

Table 4. Unstandardized (B) and Standardized (β) Regression Coefficients for each predictor on each step of the Multiple Regression Analysis are reported in Table 4.

HIV status	Model		B	Std, Error	β	T	Sig.
Negative	1	(Constant)	3,829	,191		19,998	,000*
		Gender	,205	,115	,147	1,779	,077
		AGE	-,004	,003	-,090	-1,085	,280
	2	(Constant)	3,121	,262		11,906	,000*
		Gender	,204	,110	,147	1,855	,066
		AGE	-,003	,003	-,075	-,950	,344
		SOCIALSUPHH	,196	,052	,299	3,776	,000*
	3	(Constant)	2,848	,278		10,260	,000*
		Gender	,118	,113	,085	1,048	,297
		AGE	-,001	,003	-,036	-,461	,646
		SOCIALSUPHH	,187	,051	,285	3,666	,000*
		COPINGAV	,134	,052	,214	2,592	,011*
Positive	1	(Constant)	4,224	,287		14,737	,000*
		Gender	,202	,138	,197	1,463	,150
		AGE	-,012	,006	-,263	-1,952	,056
	2	(Constant)	3,967	,262		15,129	,000*
		Gender	,075	,126	,074	,596	,554
		AGE	-,013	,005	-,295	-2,466	,017*
		SOCIALSUPFAM	,166	,043	,476	3,856	,000*
	3	(Constant)	3,489	,302		11,572	,000*
		Gender	,047	,119	,046	,396	,694
		AGE	-,009	,005	-,210	-1,810	,077
		COPINGAV	,158	,058	,320	2,744	,009*
		SOCIALSUPFAM	,154	,041	,440	3,774	,000*

Dependent variable: QoLTOT   I   Adjusted R^2 for HIV negative = .134   I   Adjusted R^2 for HIV positive = .353   I   * = $p < .05$

6. Discussion

Looking back at the theoretical framework and the hypotheses that have been derived from the theories, there can be concluded that not all the hypotheses have been met. To recapitulate, the hypotheses are:

1. There will be a difference in QOL between HIV+ and HIV- people, and this difference is influenced by the lack of social support HIV+ people receive from their surroundings.
2. A positive relationship between coping strategies and the QOL is expected.
3. The QOL of HIV+ people is expected to be lower because of the stigmatization HIV+ people experience.
4. There is expected to be an interrelationship between stigma, social support and coping strategies on QOL.

The results of the study show that some of the theories have been met and some of the theories have not. The first important finding is that the QOL between HIV+ and HIV- people do not seem to differ. Answers that have been given by both groups were similar and were normally distributed, indicating the QOL of both groups are the same. The expectation of difference in QOL between the groups is therefore not supported by the results and there can be said that the QOL between HIV+ and HIV- people in Elandsdoorn, South Africa, is the same.

Social support was according to the theories supposed to have a positive effect on QOL. The less social support, the more stress and the more uncertainty, which would negatively affect QOL (Du Preez, 2011; Helgeson, 2003). From the first analysis, with only the social support scales compared to the QOL, the theories have proven to be correct for this situation as well. Both the HIV+ and the HIV- experience a significant positive relationship between social support and their QOL. So there can be said that the more social support is present, the better the QOL is.

Coping strategies were according to the theories supposed to enhance the QOL. The more coping strategies were properly used, the lesser a person would experience stress, which would enhance their QOL (Frieland et al., 1996; Gore-Felton et al., 2006). The analysis where the three coping strategies were compared to QOL, the theories were not fully supported. Only avoidance coping and emotional coping showed to be significant with QOL and problem solving coping showed to be not significantly related to QOL. Especially interesting to see is that avoidance coping was found to be positively related to QOL. According to the theories, avoidance coping was the least strong predictor for a good QOL and if present, it was expected to be negatively related to QOL (Frieland et al., 1996). There can be discussed that in the situation of Elandsdoorn, South Africa, avoiding the problem could lead to a better QOL. It is possible that by avoiding the problem, or denying the problem, the HIV infected people themselves and also the people dealing with the HIV infected people, find it easier to handle the situation. Freud (1937) describes this kind of behavior as using a defense mechanism to block out external events or repress threatening thoughts which could lead to stress, dissatisfaction or rejection. Further research

could be done to point out if avoidance coping is related to feeling normal and accepted which could reduce stress and improve the QOL.

Stigmatizing behavior was according to the theory supposed to have a huge impact on QOL and especially on the QOL of HIV+ people (Kalichman and Simbayi, 2003; Simbayi et al., 2007; Shisana et al., 2005). In this study, the stigma questions were not significantly related to QOL, indicating there is no difference between HIV+ and HIV- people, which indicates the HIV+ do not experience more stigmatizing effects. Only one of the questions in the questionnaire was found to be significant, which does not give the opportunity to draw conclusions about the overall stigmatizing behavior. In combination with social support and coping strategies, stigma did not become significant as well, which indicates stigma does not affect or does not get affected by social support and coping. The hypotheses that stigma would have a negative effect on the QOL has for this particular study been rejected. In the case of Elandsdoorn and the social programs of the NCG that have been running for the past two decades, it might well be possible that there is little to no stigmatization present, which would explain why no differences were found between HIV+ and HIV- people and the effect stigma has on their QOL.

When combining all the significant variables (all the social support items and emotional and avoidance coping), the regression model shows that all the social support items and only avoidance coping are significantly related to QOL. The hypotheses that there is expected to be an interrelationship between the independent variables is thus partly supported. Stigma takes no part in the interrelationship, and of the coping strategies only avoidance coping remains. This suggests that avoidance coping, in combination with family support, household support and family norms, are positively related to QOL. Again, there was no significant difference in HIV status found.

The last regression analysis that was performed, consisted of splitting the file into HIV- and HIV+. Even though the former regression analysis did not suggest there was a difference between the two groups, the split file regression analysis showed that for the HIV- population especially household support in combination with avoidance coping is related to a better QOL, while for the HIV+ population especially family support in combination with avoidance coping is related to a better QOL. These results suggest that for HIV+ people it is of more importance to have the support from your family and not necessarily of the people living in the same household. The regression model for the HIV+ population explained also over 35% of the variance in QOL, which indicates that family support in combination with avoidance coping is a strong predictor for a good QOL for HIV+ people. For the HIV- population the model only explained 13,4% of the variance, which indicates that the model is not a strong predictor for QOL. Why this difference in social support is found between HIV+ and HIV- people is not clear, and for this thesis the household composition of HIV+ and HIV- people was not compared. For further research it would be interesting to take household composition into account to find out if an explanation for this difference lies there. In this last regression analysis there was also a difference in age groups.

As stated in the results chapter, this research did not focus on the difference in age groups, but because for the HIV+ population age seemed to be significantly related to QOL in the final model, for further research it could be of an added value to find out where this difference in age group lies. When this difference would be clear, Ndlovu Care Group could use this information to adapt their intervention programs to the particular age group.

6.1 Practical implications

During the first months of working on the master thesis in South Africa, mostly reading into theories was done. Due to reading the theories and also reading where the questionnaire schemes were based on, created a few difficulties. Some of the topics in the questionnaire were based on validated questions which were only valid in certain circumstances. For the Stigma questions for instance, the scheme showed to be unreliable in the context of Elandsdoorn. The Stigma questions were found valid and reliable in the situation of a township in Cape Town (Kalichman and Simbayi, 2003). For the situation in Elandsdoorn, where over the past two decades a lot of interventions concerning HIV/AIDS related stigma have been done, the measurement scale is found to have a Cronbach's alpha of 0.37, which is considerably below the acceptable number of 0.7 for a scale to be found reliable. What it means for the Cronbach's alpha to be such an amount lower, is that the internal consistency of the measurement items is low.

Another practical implication was that the start of conducting the questionnaires got delayed. Due to miscommunication with the ethical commission, the approval for the research came in six weeks after the planned start of conducting the questionnaires was scheduled. Due to this delay, there was doubt if the minimum amount of participants could be reached. Fortunately, due to hard work of the Ndlovu staff, the minimum was reached.

6.2 Limitations

A first limitation is that the questionnaires had to be conducted in Sutu, Ndebele of Zulu, because most of the inhabitants in Elandsdoorn do not read and speak proper English. Due to this language barrier, the questionnaire had to be translated by counselors. This leaves more room for different translation by the counselors and therefore also a more diverse answering of the participants. What has also been found to be difficult, are some words that are clear in English, do not directly translate to Sutu, Ndebele or Zulu. This could cause unclear interpretation of the question, which could lead to biased answering.

Another limitation of the study is the fact that the participants volunteer for the study. Because the people can voluntarily join the research program, there might exist a biased population. For the case of stigmatization and social support for instance, it could well be that the people who entered the research already receive more support which makes them more secure and more willing to enter an HIV research program. This could also be the case for stigma. It could well be possible that, for this research, the truly stigmatized people have not been reached, which could also explain why the stigma scale is not reliable.

Almost half of the HIV+ participants have only heard officially of their health status a month before participating in the social science study, which was during the pre-screening. Because these participants have only known their health status for such a short period of time, it is difficult to tell if they have already altered their behavior to the new situation and if they have already noticed different attitude from their surroundings. This short amount of time can cause bias, because it does not measure, for example, their long term coping strategies and the support they receive in the long run. Coping strategies, social support systems and stigmatizing behavior might well be different when someone has been known to be HIV+ for a longer period of time.

Another limitation is that the questionnaires are conducted during working hours and also there is a compensation for entering the research. Most participants are therefore unemployed, which also gives a biased overview of the population. The research population is also biased because of the unequal distribution of men and female and the unequal distribution of HIV+ and HIV- participants. To draw better conclusions, the population should be more evenly distributed.

6.3 Recommendations

With all the above mentioned practical implications and limitations, there are a few recommendations that can be made. First is would be of an added value to get deeper into the community. Reach the people who do not have the opportunity to come to the research site because they might be too weak. If the research would be extended to home based visits, especially more HIV+ people could be reached, which would reduce the population bias.

The next recommendation is to make use of the validated questionnaires the way they were designed in the first place. In this research the stigma questionnaire turned out to be unreliable and it did not give enough information to make a proper analysis. For further study, the recommendation would be to use the originally intended dichotomous scale instead of the currently used four point scale, so a better comparison can be made to research that has already been done with the same scale. Comparing the outcomes of the dichotomous scale could give insight in whether the scale does not work for this particular situation because Ndlovu has already been campaigning against stigma for years or that there might be another reason. Because the questionnaire has been adapted for this study, it is not clear what has caused the outcome.

6.4 Conclusion

This research has been of scientific relevance because the understanding of which social factors influence the QOL of HIV+ and HIV- people can helps to understand what is needed to improve the QOL of these populations and how this could be differently achieved. Intervention strategies can be designed to improve the QOL, which means improving someone's social life and someone's health. There has also not been a lot of research done before to compare the QOL of the HIV+ and HIV-

population, so this master thesis gives a first insight in what kind of differences were found in a specific context.

The research is socially relevant because HIV is a huge social problem in South-Africa. A lot of people have to deal with the disease, whether they are infected themselves, or friends or relatives are infected. In the case of Elandsdoorn, a difference in QOL between HIV+ and HIV- caused by stigma, coping strategies or social support has not been found. This could mean that NCG is doing a good job in detecting HIV in an early stage and treating people in an early stage and it could mean that NCG also does a good job with the communal projects with creating awareness about HIV/AIDS. What has been found, however, is that different kinds of social support in combination with avoidance coping play an important role in explaining QOL. For HIV+ people it is especially the combination of family support and avoidance coping which relates to a good QOL. For HIV- people it is especially the combination of household support and avoidance coping which relates to a good QOL. The difference between HIV+ and HIV- people was thus not found in their overall QOL, but a difference was found in what way the QOL is achieved. To know what kind of social support influences different populations is an important finding for intervention strategies and for instance community based work. The populations can be better understood, which makes it possible to adapt community based work for even better support.

This master thesis is a beginning in understanding how HIV+ and HIV- people can come to the same QOL. To fully understand how HIV+ and HIV- people rate their QOL and how they come to their QOL differently, more research with more variables is needed. Also with more participants, a more diverse population, more men and extending the questionnaires to a home based setting, a population bias can be reduced. This all could lead to a better insight in how social factors can differently influence the QOL of HIV+ and HIV- people.

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8. Annex

In this section only the questions from the questionnaire that have been used for this master thesis have been added. The first annex holds the questions from the baseline questionnaire and second annex holds the pages from the social science questionnaire. The original baseline questionnaire consists of 115 questions and the original SSQ consists of 110 questions. The original numbering has been used in the annex.

8.1 Annex 1. Questions from the baseline questionnaire

Demographics		
(Questions marked *are based on the NIDS Wave 3 2012 Adults Questionnaire)		
Q1	Gender	☐ Female ☐ Male
Q2	Date of Birth	DD/MM/YYYY: ☐☐ ☐☐ ☐☐☐☐
Q3	Education	☐ None ☐ Primary school completed ☐ Secondary school completed ☐ Matric ☐ Technicon/ College ☐ University
Q4	Partnership status (Current situation; Please only select one)	☐ Married (since:_____ year) ☐ Life partner (since: _____ year) ☐ Living together >50% of the time (since: _____ year) ☐ Single (since: _____ year) ☐ Divorced (since: _____ year) ☐ Widowed (since: _____ year) ☐ Multiple partners (since: _____ year) ☐ Other (specify: _____)
Employment (Questions are based on the NIDS Wave 3 2012 Adults Questionnaire)		
Q5	Are you currently employed?	☐ Yes, employed ☐ Yes, self employed ☐ No, unemployed →Go to Q9 ☐ No, student →Go to Q9 ☐ No, retired →Go to Q9 ☐ No, disabled →Go to Q9 ☐ No, other →Go to Q9 Specify: _____ ☐ Refused →Go to Q9 ☐ Don't know →Go to Q9
Q6	In which economic sector do you work?	☐ Agriculture, fishing, forestry ☐ Mining and quarrying ☐ Manufacturing (e.g. clothing, food) ☐ Electricity, gas, water ☐ Construction ☐ Wholesale/ retail ☐ Catering and accommodation ☐ Transport, storage and communication ☐ Finance, real estate and business services

		☐ Public administration (local, provincial) government ☐ Community, social and personal services ☐ Security, police ☐ Education ☐ Private household ☐ Other - Specify : _____ ☐ Don't know ☐ Refused
Q7	How many hours do you work at this job in a typical week?	_____ Hours ☐ Refused ☐ Don't know
Q8	Would you say last month's take home pay was:	☐ Less than or equal to R600 ☐ R600- R1300 ☐ R1300 – R3100 ☐ R3100 – R5900 ☐ R5900 – R11 000 ☐ R11 000 – R18 000 ☐ More than R18 000 ☐ Refused ☐ Don't know

STIGMA

(taken from: HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa by S C Kalichman, L C Simbayi

Are you ever confronted with the following opinions?		Never	Sometimes	Often	Always
Q38	People who have AIDS are dirty	☐	☐	☐	☐
Q39	People who have AIDS are cursed	☐	☐	☐	☐
Q40	People who have AIDS cannot be trusted	☐	☐	☐	☐
Q41	People who have AIDS are like everybody else	☐	☐	☐	☐
Q42	People who have AIDS should be ashamed	☐	☐	☐	☐
Q43	People who have AIDS have nothing to feel guilty about	☐	☐	☐	☐
Q44	Most people become HIV positive by being weak or foolish	☐	☐	☐	☐
Q45	It is safe for people who have AIDS to work with children	☐	☐	☐	☐
Q46	People who have AIDS must expect restrictions on their freedom	☐	☐	☐	☐
Q47	A person with AIDS must have done something wrong and deserves to be punished	☐	☐	☐	☐
Q48	People who have HIV should be isolated	☐	☐	☐	☐
Q49	People who have AIDS should not be allowed to work	☐	☐	☐	☐
Q50	Would you care for a family member with HIV/AIDS?	☐ Yes ☐ No			
Q51	Would you mind if people knew if your family member had HIV/AIDS	☐ Yes ☐ No			

8.2 Annex 2. Questions from the social science questionnaire

Employment (Questions are based on the NIDS Wave 3 2012 Adults Questionnaire)		
Q1	Are you currently being paid a wage or salary to work on a regular basis for an employer (that is not yourself) whether full time or part time. (if you work for yourself we will ask this later	☐ Yes → **Go to Q4** ☐ No, self employed → **Go to Q8** ☐ No, unemployed ☐ Refused ☐ Don't know
Q2	For unemployed people: Do you think it is a realistic possibility that you will get a job in the next year?	☐ Yes ☐ No ☐ Refused ☐ Don't know
Q3	What was the main reason you were not available to work in the last six months? (only mention one)	☐ I am too old ☐ I am a full-time student/learner ☐ I am sick/disabled ☐ I do not like the available jobs and would rather not work ☐ I do domestic duties and look after children and or elderly/disabled family members ☐ It costs too much to look for work ☐ The wages are too low, it is not worth my time working ☐ Pregnant ☐ Other (specify) ☐ Refused ☐ Don't know
Q4	When did you start this job?	☐ 0-6 months ☐ 6-12 months ☐ >12 months ☐ Refuse ☐ Don't know
Q5	Are you employed on the basis of a written contract or a verbal agreement?	☐ A written contract ☐ A verbal agreement ☐ Refused ☐ Don't know
Q6	Is the contract/agreement of a limited duration or unspecified duration or is it permanent?	☐ Limited duration ☐ Unspecified duration ☐ Permanent ☐ Refused ☐ Don't know
Q7	Do you belong to a trade union?	☐ Yes ☐ No ☐ Refused ☐ Don't know

Actual support from household members

		No support	A little support	A fair amount of support	A lot of support
To what extent do persons in your household support you? (adapted NKPS)					
Q8	In decisions about work or education	1	2	3	4
Q9	When you have worries or health problems	**1**	**2**	**3**	**4**
Q10	In your leisure time activities and social contacts	**1**	**2**	**3**	**4**
Q11	With all kinds of practical things you need to do	**1**	**2**	**3**	**4**
Q12	In personal matters that are on your mind	**1**	**2**	**3**	**4**

Actual family support

		No support	A little support	A fair amount of support	A lot of support
To what extent do family members who do not live in your household support you? (adapted NKPS)					
Q13	In decisions about work or education	1	2	3	4
Q14	When you have worries or health problems	**1**	**2**	**3**	**4**
Q15	In your leisure time activities and social contacts	**1**	**2**	**3**	**4**
Q16	With all kinds of practical things you need to do	**1**	**2**	**3**	**4**
Q17	In personal matters that are on your mind	**1**	**2**	**3**	**4**

Coping strategies

		Not at all				Very much
The following are ways people react to various difficult, stressful or upsetting situations. Please indicate how much you engaged in these type of activities during this specific situation. (CISS:SSC)						
Q18	Take some time off and get away from the situation	1	2	3	4	5
Q19	Focus on the problem and see how I can solve it	**1**	**2**	**3**	**4**	**5**
Q20	Blame myself for having gotten into this situation	**1**	**2**	**3**	**4**	**5**
Q21	Treat myself to a favourite food or snack	**1**	**2**	**3**	**4**	**5**
Q22	Feel anxious about not being able to cope	**1**	**2**	**3**	**4**	**5**
Q23	Think about how I solved similar problems	**1**	**2**	**3**	**4**	**5**
Q24	Visit a friend	**1**	**2**	**3**	**4**	**5**
Q25	Determine a course of action and follow it	**1**	**2**	**3**	**4**	**5**

Q26	Buy myself something	1	2	3	4	5
Q27	Blame myself for being too emotional on the situation	1	2	3	4	5
Q28	Work to understand the situation	1	2	3	4	5
Q29	Become very upset	1	2	3	4	5
Q30	Take corrective action immediately	1	2	3	4	5
Q31	Blame myself for not knowing what to do	1	2	3	4	5
Q32	Spend time with a special person	1	2	3	4	5
Q33	Think about the event and learn from my mistakes	1	2	3	4	5
Q34	Wish that I could change what had happened or how I felt	1	2	3	4	5
Q35	Go out for a snack or meal	1	2	3	4	5
Q36	Analyze the problem before reacting	1	2	3	4	5
Q37	Focus on my general inadequacies	1	2	3	4	5
Q38	Phone a friend	1	2	3	4	5

Family support attitudes

Opinions about family life and support. The statements below describe how you feel family members should treat each other. Please indicate the extent to which you agree with each statement.		Strongly disagree	disagree	Neither agree or disagree	agree	Strongly agree
Q57	One should always be able to count on family	1	2	3	4	5
Q58	Family members should be ready to support one another, even if they don't like each other	1	2	3	4	5
Q59	If one is troubled, family should be there to provide support	1	2	3	4	5
Q60	Family members must help each other, in good times and bad times	1	2	3	4	5
Q61	Children should look after their sick parents	1	2	3	4	5
Q62	In old age, parents must be able to live in with their children	1	2	3	4	5
Q63	Children who live close to their parents should visit them at least once a week	1	2	3	4	5
Q64	Children should take leave to look after their sick parents	1	2	3	4	5
Q65	Parents should support their adult children if they need it	1	2	3	4	5
Q66	Parents should help their adult children financially if they need it	1	2	3	4	5

Q67	Parents should provide lodging to their adult children if they need it	**1**	**2**	**3**	**4**	**5**
Q68	Grandparents should be prepared to look after their grandchildren regularly	**1**	**2**	**3**	**4**	**5**
Q69	One's life is not complete if one has not had children	**1**	**2**	**3**	**4**	**5**
Q70	I believe that in this world one can only feel totally at ease in one's own family with children	**1**	**2**	**3**	**4**	**5**
Q71	If one never has children, one can never be really happy	**1**	**2**	**3**	**4**	**5**

Quality of Life (WHO QOL, brief version)

Please indicate how satisfied you are with the following aspects of your life						
		Very dissatisfied	dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
Q98	With your health?	1	2	3	4	5
Q99	With your sleep?	1	2	3	4	5
Q100	With your ability to perform your daily living activities?	1	2	3	4	5
Q101	With your capacity for work?	1	2	3	4	5
Q102	With yourself?	1	2	3	4	5
Q103	With your personal relationships?	1	2	3	4	5
Q104	With the support you get from family members?	1	2	3	4	5
Q105	With the support you get from friends?	1	2	3	4	5
Q106	With the conditions of your living place?	1	2	3	4	5
Q107	With your access to health services?	1	2	3	4	5
Q108	With your transport?	1	2	3	4	5

Please indicate which number that gives the best answer for you						
		Very poor	Poor	Neither poor nor good	Good	Very good
Q109	How would you rate your quality of life?	1	2	3	4	5
Q110	How well are you able to get around?	1	2	3	4	5