

# ***'Blood is definitely thicker than water!'***

but *'sshht...what will the neighbours say!?'*



Social support for black HIV-positive individuals in a resource limited setting in  
South-Africa

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Period: February - August 2009



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**Maaïke M. Hootsen, August, 2009**

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## Abstract

South-Africa is severely affected by the AIDS epidemic. Several Non Governmental Organizations (NGO's) try to suppress replication of the virus by offering programs which supply antiretroviral (ARV) therapy for HIV-positive individuals. A precondition of an effective use of this therapy is that patients stick to sustained medication adherence. Existing literature shows that an important factor associated with medication adherence is social support. This research focuses on social support for HIV-positive individuals within the South-African context.

Based on existing literature, social support is distinguished in five forms: emotional, instrumental, financial, informative/advisory and spiritual support. Furthermore, the following support providers are distinguished: kin relations, partners, friends, fellow patients and HIV/AIDS management programs. A qualitative approach is taken in this study in order to answer the following research question: *'What are the assumptions of (beneficial) social support for black HIV-positive individuals and why might support be lacking, according to patients and professionals of the Tapologo ARV-outreach program around Rustenburg, South-Africa?'* In order to answer this question, interviews and focus group discussions with 24 HIV/AIDS patients and 16 Tapologo professionals have been conducted.

The results show that patients have various support needs. They need emotional support by being accepted and discussing their situation with a confidant. Informative/advisory support needs include getting advice concerning infection, re-infection and living a healthy lifestyle. Instrumental assistance with heavy work and housekeeping activities is necessary during days patients don't feel well. Patients often struggle to survive due to a lack of financial resources. This increases the need of financial assistance for healthy food and transportation to the clinics in order to adhere to their treatment. Patients also benefit from spiritual support in the form of singing and discussing bible stories. It gives them hope and it lifts up their spirit.

In general, patients seem to be very happy about the support they get from their social environment. Some patients have a supportive network and feel loved and cared for by their social environment. They have a confidant to discuss their problems with and they expect that there will be people in their network (mainly relatives) who will take care of them in case they will get sick. However, both patients and Tapologo professionals notice a lack of (beneficial) social support. Friends of the patients are generally not supportive at all and even gossip about the patient. Partners sometimes leave when they find out about the HIV-status of their partner. When it comes to instrumental and financial needs, patients can often only receive support from family members. And even these family members, who are generally viewed as the main support providers, sometimes withhold support.

This absence of social support finds expression via four support lacking scenarios: (1) patients don't have anyone to rely on (lack of network ties), (2) potential support providers refuse to give support, (3) patients withhold themselves from asking support and (4) patients receive wrong or contradictory support. Within these scenarios, there are some general barriers notable. The (fear of) HIV/AIDS related stigma and discrimination forms an important barrier. People often don't want to be associated with an HIV/AIDS patient and therefore withhold support. Furthermore, the socio-economic context, including a lack of resources (finances and information) and, especially when it comes to immigrants, the absence of a social network forms a major barrier. People lack the information to give the right advice and when it comes to the money story, they are forced to set priorities with respect to who they will support. Finally, cultural norms and values function as a general barrier, including traditional gender roles and the prioritising of the family.

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## Preface

This master's thesis is written in order to graduate from the master's program 'Social Policy and Social Interventions' in which I have been enrolled at the department of Interdisciplinary Social Science, Faculty of Social and Behavioural Sciences at Utrecht University from September 2009 until August 2009.

After studying in Stellenbosch, South-Africa and travelling through Southern Africa in 2008, I totally fell in love with this fascinating continent and its intriguing people. South-Africa's complicated social-economic background, combined with the sensitive issue of the ongoing HIV/AIDS epidemic give rise to several interesting research opportunities. Therefore, the opportunity to conduct the research necessary for my master's thesis in South-Africa was something I aspired immediately. For me this was a chance to, after being a traveller in this country, finally gain more in depth information about South-Africa's complex social-economic situation. This time not as a traveller or student, but as a researcher 'on the spot'.

I would like to express my appreciation to several individuals, who have assisted me in facilitating my research. Most importantly, I wish to thank all the patients and Tapologo employees who were willing to share their personal stories and experiences with me during the face-to-face interviews. Furthermore, I want to thank Basetsana Rangoa and Stephen Blakeman, my supervisors from Tapologo, who have showed me the way to and opened the doors of the Tapologo clinics, which made it possible for me to get in touch with the patients. I also want to thank our enthusiastic and talented interpreters Mmalagae, Kele, Refilwe and Gloria, whose enthusiasm and excellent social skills helped to create a confidential atmosphere between myself and the patients during the interviews. Furthermore, I would like to thank my supervisor Trudie Knijn, who even travelled to South-Africa in order to support my fellow students and me and to provide feedback on our research designs. I am also grateful to my fellow students who accompanied me during my stay in Rustenburg, namely Linda van der Kevie and Mariëlle Lunenburg, who provided me with unconditional support and who stood by me during crucial moments. And last but not least, I would like to thank my friends and family: Jorrit Nicolai, Quirien Toppinga and Paul and Dorres Hootsen for their assistance with transcribing the interviews and their encouraging words.

Utrecht, August 10, 2009

Maaïke M. Hootsen



*Picture 1: Tapologo nurses and the 'terror three'*

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## Introduction

South-Africa has the highest number of HIV (Human Immunodeficiency Virus) infected people in the world. An estimated 28 percent of the 48 million inhabitants is HIV-positive (National Department of Health, 2008). AIDS is a social problem, as much as it is a medical one (Epstein 2007). The social economical context of South-Africa highly contributes to the transmission of the virus. "Systematic dispossession and dislocation, the fragmentation and polarization of society, and the recasting and, in some places, dismantling of social systems helped create a social and ideological terrain that would hugely favour the spread of the virus" (Marais 2004, p.8). The medical, economic and social consequences are striking, traditional family structures and extended families are breaking down under the strain of HIV, and population growth and death rates are increasingly affected (van der Lubbe & Schinnij 2004; Briët & van Pelt 2006).

A wide range of initiatives have been taken to tackle this complex problem in South-Africa. Many of these initiatives focus on suppressing expansion and on improving the health of HIV-positive individuals. Several Non Governmental Organizations (NGO's) offer programs which supply antiretroviral therapy (ART) for HIV-positive individuals. This therapy has proven to be highly successful in improving the health of many HIV-positive individuals in South-Africa. A precondition of an effective use of the therapy is that patients stick to sustained medication adherence. This, in turn, puts a great effort on the patients to adhere to their treatment and therefore constitutes a serious challenge (Mills et al. 2006). As the role of the patient is crucial in the final effect of the therapy, it is important to know more about the factors that influence medication and program adherence.

Previous studies focusing on these factors are often based on social-cognitive models by Fishbein and colleagues. These studies show that the use of these models in the South-African context turned out to have some practical problems. These included low response, language problems and low level of literacy as well as cultural bias which resulted in less satisfactory results. Furthermore, results from these studies show the lack of explanatory power and significant correlations (Briët et al. 2006; van Dijk et al. 2008; van der Lubbe et al. 2008). Therefore, this study steps aside from this individual cognitive perspective and start to look in an explorative way for cultural and contextual factors related to ARV medication adherence instead. Existing literature on the cultural and contextual factors demonstrates that an important factor associated with medication adherence is the social support offered to patients (Heyer & Ogunbanjo 2006; Moratiao 2007; Edwards 2006; Gonzalez, Penedo et al. 2004; Murphy, Marelich, et al. 2004). Therefore, this research will focus on the needed and actually provided social support for HIV-positive individuals within the South-African context.

This research investigates social support, via an explorative case study at HIV/AIDS clinics of the Tapologo ARV- outreach program that is financed by the SACBC (Southern African Catholic Bishops' Conference) AIDS office, with its main office situated in Pretoria. The SACBC is a faith based NGO that coordinates the Catholic Church's response to AIDS in South-Africa, Swaziland and Botswana (UNAIDS 2006). The SACBC AIDS office has established more than 100 service programs for people infected with HIV. These service programs consist of hospitals, clinics, hospices, home based care, prevention of mother to child transmission (PMTCT) and orphan care ([www.sacbc.org.za](http://www.sacbc.org.za), February 14, 2009).

The Tapologo centre, one of the HIV/AIDS sites of the SACBC AIDS office, started with ARV roll-out in 2004 and has 9 clinics which offer ARV-treatment for around 1800 HIV/AIDS patients. The Tapologo main centre is situated in Phokeng, a village close to Rustenburg in the North-West province. Supplementary on

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these medical services, counselling and emotional support, education, support groups and adherence programs are offered. The programs thus combine the provision of medication on the one hand with different forms of support for the patients and their families on the other. All clinics are situated around Rustenburg, South-Africa, which is a mining area that attracts migrant labour workers who leave their families to work in the mines (de Waal 2008). Statistics collected by the Tapologo centre show that on average, 18% of the patients who started the ARV-treatment at these clinics stop collecting their ARV's (Tapologo 2004 – 2009)<sup>1</sup>.

The aim of this research is gaining more insight in the provision of social support for the HIV/AIDS patients at the Tapologo clinics around Rustenburg, South-Africa. This insight can function as background information for future evaluation and interventions of these Tapologo clinics and possibly also other HIV-management programs in Southern Africa.

Chapter 1 and 2 both cover the theoretical examination of this study. Chapter 1 provides an overview of the South-African context related to social support. Subsequently, the theoretical framework of this research will be presented in chapter 2. In the following chapter the research design of this study will be revealed, including the central research question and sub questions. Chapter 4 includes the presentation of the results and analysis of this study. In this chapter the different sub-questions and the main research question will be answered. Finally, chapter 5 contains the conclusion and discussion of this research.

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<sup>1</sup> See Appendix 1: Statistics Tapologo 2004-2009



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## **Chapter 1 Social support in a (South) African context**

This chapter describes the South-African context related to social support: How do black inhabitants of South-African traditionally care for each other, what macro structural changes are notable and what influence did the apartheid era have?

### **1.1 Kin and community support systems in Africa**

The way in which communities and households are affected and able to respond to the AIDS epidemic will determine the outcome of societies' encounters with AIDS (Marais 2005). According to Sagner and Mtati (1999), the nature of kinship with regard to social support in African societies is associated with morality and reciprocity. Morality implies the recognition of social obligations towards kin, which acknowledges mutual responsibility between kin, also in situations in which these responsibilities are actually a burden for one of the persons involved. The principle of reciprocity involves more than exchange of goods, 'it is embedded in a cultural matrix that both defines givers' obligations to give and constructs the deservingness of receivers to be supported' (Sagner & Mtati 1999, p. 405).

In times of struggling to overcome hardship, kin and community support systems traditionally attribute to overcome adversity by lending money, assisting with labour, providing food and fostering children among others. Although these provisions seem to be purely altruistic at first sight, a closer look shows us that the support is extended within reciprocal networks indicating mutual entitlement and responsibility; 'the support implies a new obligation or the settling of a previous one' (Marais 2005, p 50). The ability of an individual in South-Africa to be and remain included in the social circuitry of reciprocity, depends on the individuals' ability to spend the time, energy and resources which are required to fulfil social obligations. This ability will therefore ultimately express differences in the network of relations (Marais 2005), which explains why especially poorer households find themselves pushed back in their right to claim support. These households are not entirely ignored, but they do not receive the amount of support they actually need from their social environment. 'Even in generally poor communities, the unequal distribution of resources and opportunities alters the ways in which households-and their various members- experience and are able to respond to the epidemic' (Marais 2005, p.50). Following the findings of research conducted in Tanzania by Lundberg et al. (2000), poor households have to rely more on loans than less poor households, whereas the latter have greater options to require for reciprocal provisions.

Even if the networks of reciprocity are functioning relatively well, these networks can not address all acquired needs in cases of troubled households: 'The cumulative stress of economic hardship, environmental degradation and disease has been taking its toll on these networks, with households reporting greater difficulties in drawing on assistance from families and friends' (Marais 2005, p.50). This implies that community support networks cannot function adequately without supplementary support from external institutional sources of support, for example from NGO's (Marais 2005).

### **1.2 Macro-economic perspectives on socio-structural change**

Traditional kinship relations in African societies are currently under constrain. Social support received from kin relations, especially social support for the elderly seems to be declining (Aboderin 2004a; Barnett 2006; van der Geest 2002; Burman 1996). There are two main theories mentioned in the literature that explain this decline: the modernisation theory and the political economy theory. The main cause of decline in family

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support is according to the modernisation theory 'the weakening of traditional extended family and filial obligation values' (Aboderin 2004a, p.129), which is, among other reasons, caused by the rising influence of western values of individualism among others. This breakdown of the extended family and its replacement with the more isolated nuclear family is, according to this theory, the result of the growing urbanisation, industrialisation and secularisation (Aboderin 2004b).

Especially for the elderly, this has far reaching consequences in gaining social support, since their children or relatives, now focusing on their own nuclear family, are no longer prepared to give them a lot of support and attention: 'Migration, urbanisation, the shift from extended to smaller, mobile families...and other socio-economic changes can marginalize older persons... taking away their purposeful economic and social roles and weakening their traditional sources of support' (UN 2002, p.9).

Aboderin (2004a) found evidence in shifts in status criteria, with Western material goods, technology and lifestyle prioritised above the well-being of relatives. Elements of unwillingness of the young to take care of their elders are also mentioned. Filial support has become dependent on the way the younger individuals judge their parents on their past behaviour and support for their children. An increased emphasis on reciprocity is the key here: parents who fulfilled their parental duties are rewarded by receiving care of their children, where parents who didn't, are now punished by getting less support (Aboderin 2004a). Van der Geest (2002) also emphasizes this reciprocity in his empirical findings. According to him, the help elderly receive depends very much on the way they are regarded by others: '...it is only money that begets money. The guarantee of care at old age is first and foremost a matter of reciprocity' (p. 28). In the developing world, 'this theory became the most dominant framework for explaining the diminished adequacy of material family support' (Aboderin 2004a, p. 34). The roots of these ideas about the weakening bonds of the extended family can be found in the work of early sociological analyses of family structure by Durkheim, Weber and Tönnies, who developed this modernisation theory for the Western world a century ago. Aboderin suggests that these features of modernisation in the past decades have also inflicted African family life (Aboderin 2004b).

The political economy theory, by contrast, stresses the importance of growing material constraints for the increasing lack of material family support in developing countries (Aboderin 2004a). This theory, 'seeks to highlight what the reality of economic development has been for many poor countries' (Aboderin 2004a, p. 129). Due to insufficient resources, the young have to set priorities whether they support their extended family or their own nuclear family, which most often turns to be in favour of the latter (Aboderin 2004a). According to this perspective, relatives are not less willing to give support to their (extended) relatives these days, but they are, due to the lack of (material) resources, not capable of taking care of people in their social environment: 'The issue is not whether the family will abandon its role as a care provider. Instead it concerns the difficulties and hardships that families encounter in trying to care for them... impoverished families do not even have a minimum income with which to meet their basic needs' (Aboderin 2004b, p. 34).

### **1.3 Impact of the apartheid era**

In 1948 the Nationalist Party won the elections and the apartheid state erected causing systematically discrimination against the black majority of South-Africans. Apartheid has caused so much strain that it has weakened the basic bonds of society. The social division apartheid has created, for example by separate development and migrant labour policies, has long term effects (Albertyn 2003). Low skilled labour was reserved for the black population and 3.5 million people were forcefully relocated by the state between 1960

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and 1982 (Helman, 2000). Thereby, families on the micro level and original social structures on the meso level, were forcefully disrupted. These policies during the apartheid era therefore directly attacked the family cohesion of the black South-African family and therefore the ability to provide support for its members (Albertyn 2003). According to Burman (1996), the former apartheid legislation in South-Africa has long-term implications for mutual family support in black South-African households. Apartheid thereby reinforced the already destructive influences on the African family deriving from the aforementioned changes regarding urbanisation and industrialisation among others. According to Burman (1996), 'the South-African family suffered considerably more disintegration than seen in most of the continent' (p. 587). The still ongoing high rate of unemployment as well as the limitations of South-Africa's economy imply that the role of the black family in providing support for its members falls short. The growing amount of AIDS orphans will put even more pressure on these families (Albertyn 2003). Furthermore, the history of discrimination as experienced by the black South-African population during the apartheid era leads, not surprisingly, to avoiding voluntary HIV-testing. This can be explained by the idea that testing (or a HIV-positive status) adds another source of stigma and discrimination on this already underprivileged and discriminated population group (Briët & van Pelt 2006).

#### **1.4 Mining influences**

The area around Rustenburg, where this research is conducted, is characterized by a population consisting of high numbers of black immigrant workers who work in the platinum mines around this area. These mineworkers come from different regions both within and outside of South-Africa and now live in single-sex hostels close to the mineshafts. The original people of this area, the Royal Bafokeng Nation, do not want the immigrants on their Bafokeng tribal land, which sometimes causes tensions (Blakeman, personal communication, February 9<sup>th</sup> 2009). The area is characterized by a high infection rate: approximately 15.8% - 19.2% of its inhabitants are infected (World Health Organization, 2005). This high infection rate exists due to the 'extreme poverty of its inhabitants, a lack of extended families and a lack of personal and community resources' (de Waal 2006, p. 418). The mineworkers living around the Rustenburg mining areas lack extended families due to the fact that most of their (extended) family members are still living in their home countries. Women have set up informal settlements close to the gates of the hostels where they work as prostitutes, in order to generate an income (de Waal 2006).

In addition, millions of migrant workers have been sent from rural provinces of Mozambique, Botswana, Lesotho and Swaziland, as well as from other parts of South-Africa itself to the South-African mining industry. These mine workers travel back and forth between their home countries and provinces (mostly rural areas). The migrants usually migrated to the mining areas without bringing their women and children with them (Van Groenweghe 1997). According to Epstein (2007), 'the migrant labour system in southern Africa has been blamed for many of the region's ills, including the disruption of family life and rural underdevelopment' (p 90). The migrant labour systems also had a negative impact on the stability of marriages and the regulation of sexual partners (Van Groenweghe 1997). The mining influences in the Rustenburg area can be seen as a specific example of the influences of modernisation (industrialisation, migration) under apartheid conditions on family structures at a micro perspective level.

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## Chapter 2 Theoretical Framework

This chapter contains the theoretical framework of this research: Why is social support important for HIV-positive individuals, what sorts of social support can be distinguished, who is expected to provide this support? This chapter will be completed by presenting the research model of this study.

### 2.1 The importance of social support for HIV-positive individuals

Receiving social support directly affects individuals' health status. Socially isolated individuals who suffer from lack of support within their social environment are more vulnerable to all kinds of illnesses as well as to premature death (Berkman et al. 2000). Living with a life threatening disease like HIV/AIDS is very stressful and people living with HIV/AIDS also face extra challenges based on other peoples' and society's reaction, which is often negative. This negative association can be defined as stigma; the negative behaviour related to stigma is a form of discrimination (Department of Health 2003). HIV-positive people often carry a huge emotional burden. Many individuals are therefore seeking counselling and other forms of emotional support in order to deal with these emotions (Department of Health 2003). Research conducted by Ncama et al. (2008), in KwaZulu-Natal, states that a supportive social network is important for HIV-positive individuals in South-Africa. Besides the positive influence of social support on the general well-being of HIV/AIDS patients, social support seems to be an important factor in the behaviour of HIV/AIDS patients according to voluntary testing and medication adherence. A supporting and stimulating social environment is essential for South-African HIV-positive individuals in order to adhere to ARV-therapy (Heyer & Ogunbanjo 2006). Several other authors found an association between social support and HIV-medication adherence as well (Edwards 2006; Gonzalez, Penedo et al. 2004; Murphy, Marelich, et al. 2004). A qualitative study among Afro-American women conducted by Edwards (2006) shows that 'HIV/AIDS related stigma and feeling unloved and uncared for' are social barriers to medication adherence (p. 683). This study also concludes that 'having a supportive family' functions as a facilitator in order to adhere to the ARV-programs (p. 686).

### 2.2 Social support in a wider framework

Social support derives from interaction between (groups of) individuals and their social environment. Following the definition of Caplan and Killilea as cited in Moratioa (2007), social support can be defined as 'the attachment among individuals or between individuals and groups which improves adaptive competence in dealing with short-term crises and life transitions as well as long-term challenges, provisions and stresses' (p. 22). Following the definition of House, Umberson et al. (1988) social support is a multidimensional construct, consisting of belonging to a social network, perceived satisfaction with support, emotional support and instrumental support.

According to the theory of Bandura (2001), actions of individuals are partially determined by their social environment. This social environment includes the social networks individuals belong to as well as social structural systems. Following this theory, individuals are both producers and products of these social systems. However, social networks have to be considered in an even broader context. According to Berkman et al. (2000), in order to have a comprehensive framework of the way in which phenomena of health outcomes (like medication adherence) of individuals can be explained by micro-social mechanism like social support 'we must move 'upstream' and return to a more Durkheimian orientation to network structure and social context'. This orientation means that is it critical to 'maintain a view of social networks as lodged

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within those larger social and cultural contexts which shape the structure of networks' (Berkman et al. 2000, p 847).

According to their framework<sup>2</sup>, macro socio-structural conditions, like social change and culture, determine the extent and shape of social network structures within communities. These generated social networks can be characterized by different features, like the number of network members involved, the density of the connection between members, the extent to which traditional group structures determine structures and the homogeneity of the members in these networks. Characteristics of individual ties within these networks are the frequency of contact, the forms of support generated by these ties and the extent of reciprocity (Berkman et al. 2000). The way social networks are constructed, provide opportunities for psychosocial mechanisms, like social support. Together with other mechanisms, like social influences (norms towards help seeking/adherence, peer pressure) and access to resources and material goods (job opportunities, access to health care), social support impacts health through different pathways like health behaviour (medication adherence, help seeking behaviour). The authors emphasise that 'by embedding social networks in this larger chain of causation, we can integrate 'upstream' macro-social forces related to the political economy with social networks as mediating structures between the largest and smallest scale social forms' (Berkman et al. 2000, p. 846). By integrating these forces, it is possible to look how macro-social forces influence the structure of the social networks. Thereby we can identify the role, for example culture and rapid social change on the structure of social networks (Berkman et al. 2000).

### **2.3 Forms of social support**

The structure of network ties influences health behaviour via the provision of many kinds of support. The ties within the social network of an individual might not all be supportive and there is variation in type, frequency, intensity and the extent of the support offered (Berkman et al. 2000). Following the work of several social support theorists, different types of social support can be distinguished, categorized by their specific function. This functional approach to social support often differentiates social support in the following types: instrumental, informative/advisory and emotional support (Cohen 2004). Some theorists also mention spiritual support (Simoni, Frick et al. 2006).

#### *Emotional support*

According to Cohen (2004) emotional support 'involves the expression of empathy, appreciation, caring, reassurance, and trust and provides opportunities for emotional expression and venting' (p.677). Listening to the patients' needs and emphatic companionship can also be categorized as emotional support (Simoni, Frick et al. 2006). Social support in the form of companionship for HIV-positive individuals include spending time with the patient in leisure and entertaining activities (Moratioa 2007). This can be beneficial for the patient since it 'may reduce stressful life experiences by fulfilling a need for affiliation and contact with others, by helping to distract people from worrying about problems, and by facilitating positive affective moods' (Moratioa 2007, p. 24). When specifically focusing on HIV/AIDS patients on ARV-treatment, keeping them company during clinic visits might also be relevant.

According to Thoits (1995), 'perceived emotional support both decreases psychological symptoms directly and buffers the physical and psychological impact of negative events and chronic strains' (p. 70). Emotional support might encourage adaptive coping and can increase the self-esteem of HIV-positive

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<sup>2</sup> See Appendix 3: Conceptual model of how social networks impact health

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individuals (Simoni, Frick et al. 2006). Berkman et al. (2000) argue that emotional support 'is most often provided by a confident or intimate other, although less intimate ties can provide such support under circumscribed conditions' (p. 848).

#### *Informative/advisory social support*

According to Berkman et al. (2000), informative social support includes the provision of advice or information in the service of particular needs. Informative support thus refers to the provision of relevant information, typically in the form of advice or guidance, intending to help the patients coping with their current difficulties (Cohen 2004). Kahn (1985) defines informative support as giving advice, suggestions, directives or relevant data.

Within existing literature, appraisal support is also defined as the third type of support and includes support in the form of advice in decision making, providing suitable feedback and offering help in deciding which track of action to take (Berkman et al. 2000). Appraisal could be considered a subcategory of informative support; its primary content is feedback or assessment of a person's behaviour and its effects. Not all such assessments are supportive, which is visible in the many unsuccessful programs of supervisory appraisal, but appraisal and affirmation can be supportive (Kahn 1985). Since it is hard to distinguish appraisal support from informative support and they can be easily mixed up (Berkman et al. 2000), the term informative/advisory support will be used in order to cover both of these support forms.

Social networks can spread the right information about health behaviour or encourage positive lifestyles, but they can also have negative influences. This can happen when incorrect or incomplete information is spread, for example when the lifelong nature of ARV's is ignored or when the patient is told that traditional healing should be prioritised above ARV-treatment (Moratioa 2007).

#### *Instrumental social support*

Following the definition of Cohen (2004), instrumental support involves the provision of material aid for HIV-positive individuals like financial assistance or helping with daily tasks. This type of social support includes the actual daily care for the patient. It refers to help, aid or assistance with the daily needs of a person like doing groceries, cleaning and cooking (Berkman et al. 2000). Examples of instrumental support that might be specifically beneficial in order to adhere to ARV-treatment are the provision of healthy, variety nutrition (Feitsma, Koen et al. 2007), providing transport to the HIV-clinics and making sure that the patients take their ARV's and other prescribed medication on the right times. Another important form of instrumental support is help with the patients' responsibilities at home like taking care of (sick) family members (Nachegea et al. 2004). The latter makes it easier for the patient to find time and energy to attend the HIV-programs at the clinics. A lack of help in their daily care responsibilities implicitly illustrates the difficulties in balancing daily care responsibilities regarding family and work with their own medical health issues (Nachegea et al. 2004). Although financial support is defined here as part of instrumental support, financial support can also be considered separately (Berkman 2000).

#### *Spiritual social support*

Besides the aforementioned main types of support, some theorists also acknowledge spiritual support (Simoni, Frick et al. 2006). Spiritual support includes 'encouraging spiritual coping, praying with an individual, suggesting there is a sacred purpose or larger meaning in life' (Simoni, Frick et al. 2006, p.75). According to

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Moratioa (2007), spiritual support can be beneficial for HIV/AIDS patients, because religion plays an important role for some patients. It gives them hope and helps them to accept their HIV-status. Hope can be described as giving inspiration and vitality to people. 'Faith in a higher power may help patients to make sense of their world and acts as a foundation for daily decision making' (Moratio 2007, p. 17). Research conducted by Lichtenstein et al. (2002) shows that for some patients, religious faith even functions as a substitute for family and friends.

Besides these positive aspects of spiritual support, there are also some possible negative aspects of this type of support. Strong religious beliefs regarding sin and morality may have a negative effect by 'playing into the stigma attached to HIV' (Moratio 2007, p. 17), as will be described later in more detail. Strong religious beliefs also may indicate that a disease is the inevitable outcome of sin and therefore have to be suffered in humility, constraining patients' efforts to take medication. Furthermore, in case the spiritual support offered is not in line or even contradictive to the religious beliefs of the patient, this type of support might not be beneficial (Lichtenstein et al. 2002).

The lack of one form of social support can increase the need for other forms of support. For example in case a person diagnosed with HIV/AIDS is not aware of the possibility to, with the right medical treatment, enjoy quite a long and physically acceptable life. This lack of knowledge (informative support) might contribute to the emotional distress of a person and thereby increases the need for emotional support (Department of Health 2003). Of note: this lack of knowledge might also result in decision making and behaviour that places the person at even more risk, such as not seeking medical help for treatable medical conditions (Department of Health 2003). It is also possible that community responses positively influence one form of support which interferes with other forms of support. For example, 'the perception of HIV/AIDS as a death sentence' (Kelly, Parker et al. 2001, p.17), creates a positive context for sympathetic reactions (emotional support), but a poor context for response in an affirming way (appraisal support).

## **2.4 Possible support providers**

Research indicates that the social support patients receive, depends on the type of close relationship the HIV/AIDS patient has with potential support providers (Derlega et al. 2003). Some ties within the network provide just one type of support, while other types might provide different forms of support (Berkman et al. 2000). The ties within the social network of HIV-positive individuals in South-Africa that might provide social support can contain kin relatives, friends, colleagues and partners (Heyer & Ogunbanjo, 2006). Also fellow patients (similar others dealing with the same circumstances), are mentioned in the literature as possible support providers for HIV-individuals (Thoits 1995).

Since patients might not be able to sufficiently generate all their support needs from their informal support systems, supplementary support from external institutional sources, for example from NGO's, is provided (Marais 2005). Besides the own social network of the patient, which can be considered the non-institutional, informal part of support sources, the patient might also rely on social support offered by (employees of) these institutions. In this context these are most noticeable the HIV-management programs in which the patients are enrolled for ARV-treatment and other forms of care. Counsellors within HIV-management programmes (like the support group leaders and spiritual counsellors at the Tapologo clinics) are explicitly mentioned in the literature as potential support providers for HIV/AIDS patients. A supportive patient- healthcare provider relationship is crucial as well (Heyer & Ogunbanjo 2006).

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## ***Informal social support providers***

### *Kin relatives*

According to the barrier theory of Smith and Rapkin (1996), there are several barriers which HIV-positive individuals have to pass through when seeking access to social support from their families (Serovich 2000). These obstacles include: 'lack of access to family members, lack of acceptance, lack of intimacy, negative interactions, feeling smothered, and wanting to protect family members' (Serovich et al. 2000, p. 652). Although their theory is focused on the support from kin relatives in particular, they conclude that the barrier theory might be applicable to the provision of support by friends and possibly also to the support from other providers.

### *Friends and partners*

Research conducted by Derlega et al. (2003) in Virginia, USA, indicates that persons with HIV/AIDS have more difficulties in seeking and receiving social support from their parents than from their friends or intimate partners. In line with several other studies, they argue that this is due to the more voluntary character of the relationship between friends and intimate partners compared to the more involuntary character of relationships with parents. Where the former relies on free choices on the basis of mutual attraction, trust and common interests, the latter is based "on a sense of duty and mutual obligations" (p 121). Furthermore, Derlega et al. 2003 found that support from friends and intimate partners is likely to be perceived as more helpful than support from relatives. According to Derlega et al. (2003), HIV-positive individuals cite the argument "to protect someone from being upset emotionally" (p.121) more often as a reason for not disclosing to a family member than to disclosing to a friend (or intimate partner). Also a lack of understanding was used more often as an argument for not disclosing to and seeking support from parents than from friends and intimate partners.

### *Fellow patients*

It is argued that the most effective support-givers may be similar others who have dealt with the same circumstances the patient is dealing with. These similar others are expected to be better able to offer the support in line with the actual emotional and practical support needs of the patient (Thoits 1995). The support from fellow patients can be considered as part of the support from HIV-management programs, since fellow patients probably meet each other during their visits at the clinics and will attend the same support groups. However, since they are not formally hired to support the patients in one way or another, they will be viewed as informal support providers.

## ***Professionals from HIV-management programs***

HIV-management programs can provide various forms of social support, via different types of employees and care provisions. In addition to the medical services provided by the Tapologo centre, counselling, education, support groups and adherence programmes (via home-based care) are offered. The programs thus combine the provision of medication with different forms of support for the patients and their families (www.tapologo.org, February 28, 2009).



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### *Counselling and education*

HIV-management programs can offer assistance through (spiritual) counselling and education which can generate different forms of social support (Moratioa 2007). Examples are: praying for the patient during consults, the provision of HIV/AIDS related information by a professional nurse and encouragement by a care worker to disclose to a family member. Counselling is normally provided in order to benefit the emotional needs of a person, but it can also function as a space in which information and education regarding HIV/AIDS is shared. Sometimes individuals will first seek individual counselling in one way or another and will later be transferred to a support group (Department of Health 2003).

### *Support groups*

'A support group is a structure/meeting wherein people with common challenges, concerns and needs come together to support one another in various aspects of daily living and functioning- emotional, spiritual, physical and psychological' (Department of Health 2003, p.21). In these groups information, knowledge, ideas and experiences can be shared. Support groups can have value in providing emotional relief and support to individuals. Possible benefits of support groups include social contact with similar others, obtaining valid information and the development of different ways of dealing with the challenges related to living with HIV/AIDS (Department of Health 2003).

### *Home based care (adherence programs)*

Another way to provide support to the patients is through the provision of home based care, which might entail all the different forms of social support. Care workers of HIV/AIDS management programs, who often live in the same community as the patients themselves, visit patients at their houses to provide one or more forms of social support (Moratioa 2007). This can vary from assisting with the daily practical tasks, like cleaning activities (instrumental support), to the encouragement to stick to the ARV-treatment (including pill counting), to providing information about the treatment and general emotional support by keeping them company and discussing their situation and feelings (Wagemakers 2006).

Whether the social support offered by the different healthcare providers turns out to be beneficial for the HIV-patients in South-Africa largely depends on the patients' perceptions of competence of the healthcare provider and the communication skills of the provider. These include clarity, compassion and the willingness to include the patient in the process of treatment decision-making (Moratioa 2007). According to Heyer & Ogunbanjo (2006), the treatment plan for South-African HIV/AIDS patients should be negotiated and a supportive relationship or partnership between patient and healthcare provider should be fostered. Distrust and dislike of medical professionals can also create a barrier in receiving beneficial social support from healthcare providers (Moratioa 2007).

## **2.5 Different pathways of barriers**

Altogether, there are three different pathways which might create a barrier in order to generate social support: (1) refusing to seek and ask for social support, (2) refusing of the potential support provider to give social support and (3) the provision of 'wrong' forms of social support. First of all, patients might refuse to seek and ask for support from their social network and therefore not receive it. For example because they are self-stigmatising and afraid to be rejected by their families and partners when they disclose their status

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and ask for support (Derlage et al., 2003). Secondly, the potential support provider might refuse to give social support. This might be caused by not being able to give support (due to a lack of resources), or because a lack of will to help the support seeker (because they do not have a close relationship, because the patient is stigmatised by the potential support givers or, in line with the reciprocity claim, because they assume that the involved person doesn't have payback possibilities). A third pathway is the provision of the 'wrong' sort of social support, for example by providing wrong information and giving advises which are not beneficial for the patient.

#### *General barriers*

Some general contextual factors might function as a barrier in order to generate social support. These include a lack of resources to be able to provide support (time, knowledge, money). Households affected by HIV/AIDS have to deal with financial burdens related to (the treatment of) the infected in situations where families are often already struggling to survive and where a lack of earning capacity of the patients themselves is experienced (Department of Health 2003). Another general barrier is the lack of close-knit ties in ones social network (Marais 2005). Although this does not necessarily have to be related to being HIV-positive, Ncama et al. (2008), suggests that HIV-individuals with co-morbid illnesses receive significantly lower levels of social support. This might indicate 'the difficulties of maintaining supportive relationships with poorer functioning' (p.1761).

#### *HIV/AIDS related barriers: social stigma*

Besides these general barriers, another important aspect related to the (lack of) social support is social stigma (Simbayi et al. 2007; Heyer & Ogunbanjo 2006; Nachega et al. 2004). Stigma is a powerful social label that discredits and taints a person's image, changes his or her self-identity, and can often lead to self-hatred and shame (Alonzo & Reynolds 1995). Adversarial views of people living with HIV/AIDS seem to be common according to research conducted across the world. Stigmatising derives from different social influences including "attributions of responsibility for HIV infection and beliefs that individuals with HIV/AIDS are contaminated and tainted" (Simbayi et al. 2007, p. 1823). Research by Nachega et al. (2004), conducted in Soweto, South-Africa, shows that fear of being stigmatised by sexual partners was associated with lower medication adherence. According to their findings, fear of stigmatisation may cause patients to hide their antiretroviral drugs or skip drug doses when being in the presence of others.

Negative public opinions and beliefs which are associated with HIV-positive people may result in friends and family not wanting to be too much involved with the patient and therefore withhold support (Heyer & Ogunbanjo 2006). Besides self-stigmatising and being stigmatised by informal support providers, HIV/AIDS management programs might also (indirectly) contribute to stigmatisation. Stigmatisation might even be enhanced by the behavioural change message about HIV/AIDS, as propagated by institutions dealing with HIV/AIDS. This is an unintended consequence of the change message according to a 'sinful' sexual behaviour and lifestyle in African countries, where children stigmatise this generation by "having acted sinfully and having breached taboos" (Barnett 2006, p. 299).

## 2.6 Research model

Keeping in mind the specific South-African context related to social support as described in chapter 1 and focusing on the provision of the different types of support by the possible support providers as described in chapter 2, the question is to what extent HIV/AIDS positive individuals can rely on their social environment in order to receive beneficial social support in this resource limited setting in South-Africa. This is the focus on this research and can be schematically summarized in the following simplified model which functions as a basic framework of the research.

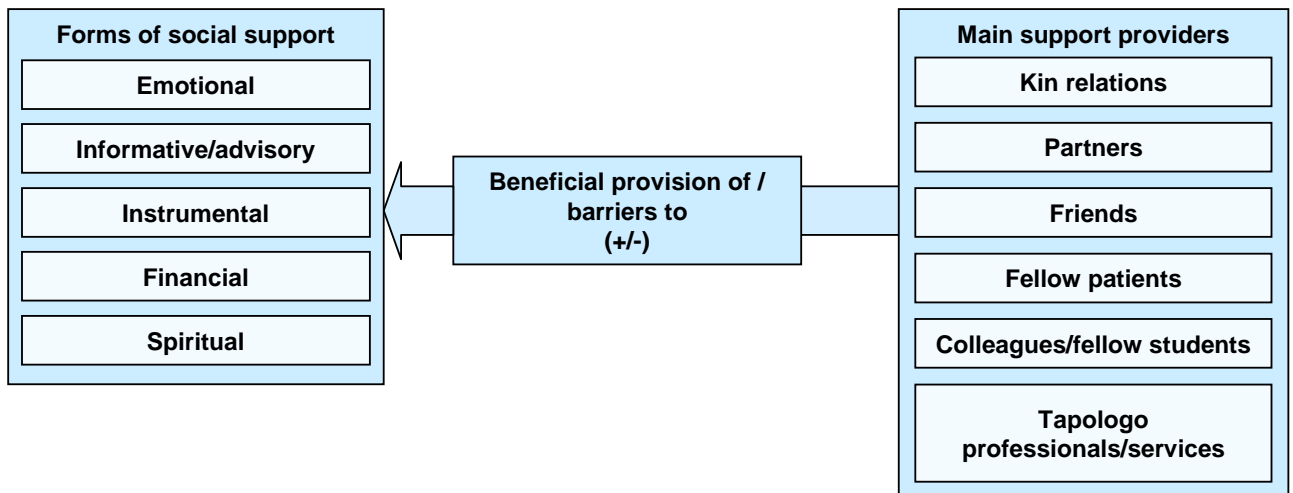


Figure 1: Support provision model

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## Chapter 3 Research Design

### 3.1 Research question

The research model as presented in figure 1 shows that the different support providers can beneficially provide or negatively restrain the provision of the different forms of social support. How do patients experience the amount and sorts of social support they receive from support providers in their social network (who is doing what) and which factors might constrain the provision of sufficient social support? How is this perceived by HIV/AIDS patients and employees of the Tapologo ARV-outreach program? The aforementioned gives rise to the following overall research question:

*What are the assumptions on (beneficial) social support for black HIV-positive individuals and why might support be lacking, according to patients and professionals of the Tapologo ARV-outreach programs around Rustenburg, South-Africa?*

In order to be able to answer this research question, the following sub-questions are formulated:

1. What are the support needs of the patients concerning the different forms of support?
2. Who are the main support providers of the different forms of support? (who is doing what)?
3. Do patients experience and Tapologo professionals notice a lack of support in order to sufficiently fulfil their support needs?
4. What might be barriers in asking and receiving (beneficial) social support?

Although the presented model determines the framework of this study, the different support *providers* mentioned in this model only function as a broad guideline. This has to do with the fact that hypothetically everyone in the social network of an individual can provide social support combined with the explorative character of this research. When other support providers are mentioned, these are included in the analyses of the results. The different *forms* of social support as presented in the model, by contrast, do guide this research more strictly. This can be argued by the need to have some form of structure, together with the fact that every form of social support a patient or Tapologo employee might mention can be categorized into at least one of the five mentioned forms of social support.

### 3.2 Methodology

This research can be categorized as a qualitative case study. HIV/AIDS is a sensitive theme, as is the social support HIV-positive individuals receive. A qualitative approach makes it easier to describe behaviour, experiences and views of the participants (Boeije 2005). This study has an explorative character, though the research relies on existing literature with respect to the different types of social support and thereby also offers more in-depth analyses.

#### *Population (participants)*

The main participants within this study are the HIV/AIDS patients and employees of the Tapologo ARV-outreach programs. The following three Tapologo clinics are included in this research: Kanana, Tlaseng and Freedom Park. Two of these clinics are situated in more original formalised settlements. These clinics are

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less influenced by the mining industry and contain a higher amount of Original Royal Bafokeng tribe members. The third clinic is situated in a more recently established squatter camp characterized by a lot of mining influences like extreme poverty, lack of extended families and migrant labour among others (de Waal 2008). Both men and women of different age groups and with different (cultural) backgrounds are included in this study. In total 24 patients are interviewed, 10 patients in Tlaseng, another 10 in Freedom Park and 4 patients in Kanana<sup>3</sup>. Only 4 of the 24 patients are male (17%). This low number of male participants can be explained by the fact that there are on average only 30% male patients in the three clinics (Tapologo 2004 – 2009)<sup>4</sup>, combined with the experience that men are less willing to participate in an interview.

Furthermore, 16 employees (professionals)<sup>5</sup> of the Tapologo ARV programs participated in this study of whom 2 Tapologo head nurses, 4 professional nurses and 10 care workers. The head (professional) nurses function as managers; they point the direction of the different clinics and guide the professional nurses of the different clinics. These head nurses are staff members of Tapologo as well. Each clinic has one professional nurse who is in charge of the daily activities of this clinic and who give directions to the care workers, auxiliary nurses (who work alongside the professional nurses) and other employees at 'their' clinic. Of specific interest for this study are the views of the care workers. Their function includes going into the communities of the patients and visit their houses as well as their family members in order to give instrumental, emotional, informative/advisory and possibly also spiritual support. All participants of this study (both patients and Tapologo professionals) are black Southern-Africans, who live in or around the communities of the investigated Tapologo clinics.

#### *Research methods and data-collection*

In order to be able to answer the sub-questions and thereby ultimately the main research question, several qualitative research methods have been used. The research method which is used most often is face-to-face interviewing. Twenty patients at the three different Tapologo clinics as well as 5 Tapologo professionals have been questioned by using open ended, in-depth face-to-face interviews to explore and identify the features and assumptions of the social support the patients receive. The interviews are semi-structured by using questions which are based on the presented model and the formulated sub-questions. These questions only functioned as a guideline, and, depending on the generated answers there was room left for reaction and interaction to gain more in-depth information. The order in which the questions were asked varied, depending on the answers of the interviewees.

Furthermore, focus group discussions with Tapologo professionals have been used as a research method. Contrary to highlighting the views and attitudes of individuals which is characteristic of using in-depth interviews, focus groups "reveal the way in which particular individual's opinions are accommodated or assimilated within an evolving group process" (MacPhail & Campbell 2001, p.1617). In total there were five focus groups discussions, three with care workers, one with professional nurses and another one with female patients<sup>6</sup>. These research methods are supplemented with observations at the clinics, which made it possible to observe the behaviour of care providers and care receivers in their natural environment. However, generated data from these observations only function as an orientation on the research field.

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<sup>3</sup> See for a more detailed overview of the participants Appendix 2: Statistics participants and research methods

<sup>4</sup> See Appendix 1: Statistics Tapologo 2004-2009

<sup>5</sup> Although not all Tapologo employees can be considered as 'professional', the term 'professionals' will be used to cover all the different Tapologo employees.

<sup>6</sup> See for a more detailed overview of the research methods used Appendix 2: Statistics participants and research methods

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Since most patients do not speak English fluently, local translators have assisted the interviewer during the interviews. These translators are trained and instructed in order to objectively and literally translate both questions and answers. They followed a one-day training course in which they practiced with translating both the English interview questions into Tswana or Zulu and the generated answers from the (fictive) patients into English. By role-playing with one fictive interviewer, one translator and one patient they could both practice themselves and provide feedback to the other interpreters.

Both the atmosphere at the clinics and the promoting role of the professional nurse in charge of the concerning clinic seemed to influence the preparedness of patients to be interviewed. Altogether, the patients seemed to be a bit suspicious in the beginning of the data collection period, but once they observed other patients coming and going for an interview, they easily followed. However, in Kanana it occurred several times that there were no patients who wanted to participate in an interview. Therefore we had to go to Tlaseng instead, where patients regularly wanted to participate voluntarily. In Kanana, patients seemed to be less enthusiastic compared to the other two clinics. The patients were more quiet and not interacting as much as in Tlaseng and Freedom Park. Especially in Tlaseng, patients seemed to be more alive and enthusiastic. The interpreters noticed that the professional nurse in charge in Kanana didn't really promote participation to the patients and just easily accepted it if no one voluntarily wanted to participate. This non-response in Kanana also resulted in an unequal division of interviewed patients between the different clinics. In Freedom Park, as well as in Tlaseng, there were no problems with the recruitment of patients. However, in contrast to the situation in Kanana, some of the interpreters reported being concerned that the patients in Freedom Park felt obliged to participate by the professional nurse in charge.

### *Analyses*

All interviews are recorded on tape by the use of a voice recorder, which made it possible to punctually reconstruct the interview afterwards. The interviews are transcribed in Microsoft Word and labelled in MAXQDA. The forms of support and different support providers function as a basis in order to categorize the data in MAXQDA. Besides this main categorisation, the community situation, reasons and scenarios of lack of support, expressions of good support, changing relationships, HIV-related discrimination and examples of HIV-related exclusion among others are also part of the code tree.

Both during data collecting and afterwards, the data have been analysed. According to 't Hart et al. (2005), checking analyses while still collecting data contributes to the reliability and validity of the research. The aforementioned coding created the opportunity to both describe features of social support and analyse different scenarios of (the lack of) receiving social support.

## **3.2 Theoretical and societal relevance**

The Southern African countries experience the fastest growing AIDS epidemic in the world. 'South-Africa is experiencing one of the most intense, and probably the largest HIV/AIDS epidemic in the world' (Marais 2005, p.7). The frequency of adult HIV prevalence in Southern Africa has not been seen anywhere else in the world and above all, there is no evidence to suggest that a nationwide decline is or will occur in these epidemics soon. The effect of the pandemic is enormous since this involves several medical, economic and social aspects of life (Briët & van Pelt 2006). Traditional family structures and extended families are breaking down under the strain of HIV and population growth and death rates are increasingly affected by the epidemic (van der Lubbe & Schinnij, 2004). AIDS is a social problem, as much as it is a medical one

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(Epstein 2007). Successful antiretroviral therapy demands nearly-perfect medication adherence which remains an important challenge in the control of the HIV-virus.

The aforementioned gives rise to an important challenge for social and behavioural scientist to explain and increase medication adherence in order to control the virus and to improve the health and thereby the quality of life of people living with HIV/AIDS (Gonzalez et al. 2004). The crucial importance of the social context and its influence on individual health and well-being is increasingly recognized (Moratioa 2007). 'The daily experience of patients in their communities influences how they understand their illness, the importance they attach to their medication, and how they solve or fail to solve challenges associated with managing their illness' (Williams et al, 2005, in Moratioa 2007, p. 23).

Although a lot of information about HIV/AIDS and medication adherence is already available through previously conducted research, there are still blind spots in the literature, especially concerning the contextual and cultural factors related to this topic in this resource limited setting. Social support is a factor known to influence medication adherence. However, at the moment it is unclear to what extent people in this resource limited setting can indeed rely on their social environment in order to receive social support. More information about the factors that form a barrier in providing social support, can theoretically help to address a lack of support and therefore ultimately also a lack of medication adherence. In gaining more information about cultural and contextual factors related to social support, some of these gaps in the literature might be covered. Therefore, this research is also theoretically relevant for social and behavioural sciences in general and for scientific research of social support and HIV-positive individuals in Southern Africa in particular.

### **3.3 Interdisciplinary social science accountability**

Social support has much common ground with several social sciences. In line with the interdisciplinary character of Interdisciplinary Social Science as well as the presence of the African context and culture in this research, the author will use sociological, cultural and medical anthropological disciplines in an effort to understand and explain the phenomena of social support. Furthermore, the author will focus on the aspect of HIV/AIDS as an *illness*; considering the illness in its social context, the way infected individuals deal with the disease and the way being HIV-positive is perceived by others. This view differs from the focus on HIV/AIDS as a *disease*, which focuses solely on the biological disfunctioning of the infected person (Boomsma 2007). A social approach to HIV/AIDS and medication adherence asserts that the experience of living with HIV/AIDS is also a product of social influences. The social science approach recognises that the level of (non)adherence to ARV-treatment is not only the outcome of psychological processes, but also a result of interaction with family, friends and healthcare providers (Moratioa 2007). In this approach, social support links the social and individual context, 'a socially driven intervention prompts action on a social level to facilitate adherence behaviour on a personal level' (Moratioa 2007, p. 95).

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## Chapter 4 Research findings

In order to describe the support needs of the patients (sub-question 1) and in order to gather more insight in the support providers (sub-question 2), these questions are combined in paragraph one by distinguishing between the different types of social support as derived from the theoretical framework. Subsequently, the extent to which patients and Tapologo professionals experience a lack of (beneficial) social support (sub-question 3) and the barriers of seeking and receiving social support (sub-question 4) are combined in paragraph two. In this paragraph, a typology of social support scenarios will be revealed of how the (lack of) social support provision manifests itself. As a conclusion of this chapter, the central question will be answered via the presentation of the completed social support provision model.

### 4.1 Support needs and current providers

#### 4.1.1 Emotional support: 'I want to be treated as a normal person'

##### *Emotional support needs*

Although different aspects of emotional support needs for HIV/AIDS patients are mentioned by both patients and professionals, acceptance seems to be the main key in order to feel emotionally supported. Being accepted by their social environment seems to be extremely important for patients. They just want to be treated as any other person. The feeling to be part of the community, a sense of belonging, has great value for them. Although acceptance can be considered as the first phase, as a precondition for receiving emotional support, patients mainly state that acceptance was the main thing for them: *'I want support by people showing that they are not afraid of eating with me, or sitting with me or talking to me and by sharing information'* (Male patient, age 40). Being accepted by others is also a way for patients to explain how people in their environment show them that they care about them: *'People, they can share everything with me, even a dish that I used just now. Somebody can just take it, or I can leave like food in a dish, and someone can be later and come and eat the food without they say 'no, I can't eat this food, because you are HIV-positive'* (Female patient, age 32). When others show that they accept the HIV-status of the patient, this also can enhance the own acceptance process of the patient in order to deal with their status: *At first I didn't want to believe it and I just didn't accept it, but then my family said that it is not the end of the world and they tried to consult me with those words. And then I started to realise: I might be sick, I might be positive, but I am still alive and my life is not over, I have to live my life'* (Female patient, age 33).

Besides feeling accepted by others, patients explain that they want to have the feeling that they are being loved and cared for by others, which helps them to feel emotionally well. Patients feel loved and cared for by getting a little attention from others, for example by the encouragement to continue their ARV-treatment: *'They give me support and they even remind me 'This is the time to take your pills, this is the time to go to the clinic, you have to eat this'* (Female patient, age 29). And a 26-year-old female patient explains: *'My mother is very strict, if I eat something I am not supposed to eat, or do something else, my mum says 'you don't have to do this, because your situation might be at risk', so they are always supporting me'*. Attention from others can also include having 'small talk' with people: *'People encourage me and especially in the morning they come and ask me 'how are you this morning', 'how did you sleep' and that stuff (...) even while I am on the street people come to me and ask 'how do you feel' and 'how are you coping', they are concerned about me which gives me the strength not to give up in life'* (Male patient, age 40). These forms of attention seem to give patients the feeling that others care about them: *'They just need somebody to be*



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there for them, just be there, sitting down with them, talking with them, would make them feel that they are considered as normal human beings' (Female head nurse).

Especially talking about their situation with others and expressing their thoughts and feelings benefits the well-being of patients: *'It makes it easier for me to speak with people for that I don't have too much stress about me being HIV-positive, it makes me more relieved when I speak to other people about my situation'* (Female patient, age 32). And: *'I'm not keeping it inside, I'm open to other people about it and that feels very good, because now I can live freely and don't have the stress'* (Female patient, age 34). Patients often feel that they benefit most from the interaction with other HIV-positive people. They usually feel most comfortable to talk about their disease in the presence of other patients and they strongly feel that other patients can understand them very well: *'When you are talking with others who are in the same situation, you feel you are not alone and you can share all the things with them, they understand you'* (Female patient, age 37). Talking with other patients also creates the opportunity for patients to put their problems into perspective, which makes it easier for them to cope with their disease: *'I discuss a lot of things with other patients, it is very, very important. Because you can think your problems are bigger than others or that you have many problems, more than others. But after talking with other patients you can hear that your problems are not that big and you will see that other people have more serious problems, your problems are then not that big anymore'* (Female patient, age 42).

Both patients and professionals assume that it is very important for patients that people listen to their stories and that they have to be patient with them during these conversations: *'The only person who can support you is a person who can listen to you, who can just listen to your problems and try to solve it with you'* (Female patient, age 48). Ana a female care worker states: *'A person with HIV/AIDS, you should show them that you love him or her. Like when you are going to their place, just smile, you don't have to be angry (...) And then, a person with HIV/AIDS, when you arrive at their homes, you don't have to say 'why are the kids not bathing', or 'why is the house not clean' you just have to be patient with a person with HIV/AIDS, because they just need love. You have to show them that they are not alone, that you are with them'*. This statement again shows the importance of acceptance, not only accepting their HIV-status, but also the way they act, because of the limitations due to their illness.

#### *Main emotional support providers*

It seems that Tapologo, especially during support group sessions, often functions as an important and sometimes even as the main provider of emotional support for their patients. This support is not possible without the input of other patients. The patients themselves are often the ones who actually support each other emotionally, but Tapologo enables this support provision by offering support group sessions. As expressed in the aforementioned examples, fellow patients function as an important support provider. Several patients mention that listening and talking during the support group helps them to cope with their status: *'When we are in the support group together we encourage each other to take care of ourselves and that we don't have to stress about this HIV thing. It is just like any other disease like flu or high blood pressure and there is treatment for it. The support gave me the courage to take my medication properly and on time (...) At first I was scared that people will have things to say to me, like look at her, she is positive, she is taking ARV's. But at the end, after attending the support group I started to realize that I have to take the medication, no matter what'* (Female patient, age 32). Tapologo also shows the progress of other patients during the support groups, which gives them the strength and motivation to adhere to their treatment as well:

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*'When we came here at the clinic one thing that encouraged me was that some people, who really looked weak and very sick, are now strong and alive. Even though they looked like they would die tomorrow'* (Female patient, age 61).

Also close kin relations, of whom mostly mentioned mothers and siblings, often function as a confidant for the patients. *'We [my family and I] sit down and talk and they encourage me not to take anything any person says to me and stress about it, because that can make me more sick'* (Female patient, age 26). Friends or neighbours are sometimes mentioned as confidants as well: *'The person I trust mostly is my neighbour (...) She is the one I usually talk to. Every time I see a paper or a book explaining something on HIV I usually read it and go to her to share it with her'* (Female patient, age 48). However, this support from friends or neighbours seems to be less common than emotional support from family members.

Although it seems to be very important for patients that they talk about their situation with others, patients often do not feel to open up to others in order to talk to them, especially not to friends or other community people. A lot of patients explain that they prefer not to disclose their HIV-status to their friends and ask them for support, because they are afraid of, or even experienced that, other people gossip about them: *'I haven't told any of my friends, because they can't keep a secret'* (Female patient, age 26). This indicates that patients do not always totally trust their friends in order to talk openly about their situation. Male partners<sup>7</sup> are also hardly mentioned as a confidant by the patients, although some women express that their partners encourage them to be strong: *'Sometimes when I have stress about something of HIV/AIDS, my husband will tell me that it is not the end of the world when you are living with HIV/AIDS, you have to accept it, in that way he will consult me'* (Female patient, age 48).

#### **4.1.2 Informative/advisory support: HIV is not the end of the world**

Knowledge on HIV/AIDS appears to be crucial; this can include knowledge on the lifelong duration of the sickness, the character of the medication, healthy behaviour and the consequences of sexual behaviour. Not all patients are aware of, for instance, the consequences of 'unprotected sex'. Some patients ask questions about how to deal with situations concerning sexual behaviour: *'When I have sex with another boyfriend without using a condom, what will happen?'* (Female patient, age 26).

The information and advices that could benefit an HIV/AIDS patient entails several aspects according to both patients and professionals: *'We do everything, we counsel them on a healthy lifestyle, we counsel them on nutrition, we counsel them on alcohol abuse, condom use, counting medication, traditional medication, going to the traditional healers, going to church or attending the support group. We tell them to do something with their own hands, to occupy their mind, not to sit there the whole day. We counsel them in various subjects, like maybe projects to be done, to be followed so on'* (Female professional nurse).

When it comes to information about infection and re-infection, advice concerning appropriate condom use is very important. A female professional nurse explains: *'We advice them that the two of them, the boyfriend and the girlfriend or the wife and the husband, are both infected. They should continue using a condom. Because, the male can still infect the female, the female can also still infect the male'*. This is quite a remarkable finding in an organisation based on the Catholic faith. A female head nurse explains: *'It is really not an issue here because Bishop Kevin<sup>8</sup> does not have a problem with that [condom use]'*. Patients endorse the importance of condom use: *'Everyone should know that you have to condomize, especially someone*

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<sup>7</sup> Only 1 of the male patients had a partner at the moment, therefore female partners are not mentioned

<sup>8</sup> Bishop Kevin Dowling is the 'founding father' of the Tapologo centre

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*who is positive*' (Female patient, age 42). Patients should be informed about HIV/AIDS related misconceptions as well: *'You have to tell them that you can't get HIV by using the same plates, not by touching someone when there is no blood involved and so on'* (Female professional nurse).

For patients it is crucial to realise that HIV/AIDS should be viewed as a 'normal disease': *'The support to be given to them is entire counselling, entire counselling sessions. To prove to them that having HIV and AIDS is not the end of the world. It is never the end of the world (...) They are stressed up because they think that once you are diagnosed, that means death (...) Those things, you have to sit down and explain to them: 'No, HIV and AIDS is just like any other chronic illness', that most of the people, I can say 65% in the whole world are sick. And with chronic, different chronic cases, but they don't give up hope. They live, and they can still live longer than those who are healthy'* (Female professional nurse).

In addition to information about living a healthy lifestyle, about the way people can be infected and re-infected and about the treatment of HIV/AIDS also practical information about the 'ARV treatment rules' is of importance: *'You can't take ARV's on an empty stomach'* (Female professional nurse). And: *'You have to take treatment at exactly the same time; each and every day or they won't work'* (Male care worker).

#### *Main informative/advisory support providers*

As some of the aforementioned quotes of patients and professionals already indicated, Tapologo functions as an important support provider when it comes to informative/advisory support. As was the case with emotional support, the support group at the clinic plays an important role in gathering information and advices. Most patients state that Tapologo functions as their main source in gathering HIV/AIDS related information and advice: *'This is the only place where I get information and knowledge and ideas and advices'* (Female patient, age 42). Some patients even solely listen to Tapologo care workers and nurses. It seems that both patients and professionals share the assumption that Tapologo is the only 'right' source of information for patients, especially when it comes to HIV/AIDS-specific information. Sometimes, patients even literally tell the same stories about 'good information for a HIV/AIDS patient' as professionals. The phrases *'it is not the end of the world'*, *'you can still live a longer life'*, *'HIV is just like any other chronic disease'* and *'you first have to accept yourself'*<sup>9</sup> are mentioned several times in different interviews with both professionals and patients. The information patients get from the nurses at the clinics is sometimes literally copied by the patients. Tapologo also advices about condom use: *'They tell us that we have to condomize, and have to be faithful to one partner, and abstain, things like that'* (Female patient, age 33).

Community people and friends are often avoided as a source of information, since patients assume that they are not able to give the right information and advice. Information from community people is often viewed as the contradictive or wrong information: *'I don't take those, I don't want them, because others won't like you, others will tell you something that is crazy'* (Female patient, age 69).

As was the case with emotional support, patients benefit most from the information and advice from fellow patients. Patients feel connected to each other because they are all HIV-positive. This creates a trustful environment to openly share information and ask for advices: *'The support group really feels like a family, you can ask everything there, also things about problems with the private parts. You can just say it out, no one is going to laugh about you. No one is discriminating and you are free to talk'* (Female patient, age 34). Also professionals stress the importance of sharing information among patients and hence they

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<sup>9</sup> These phrases can also be viewed as part of emotional support, since these words can (be meant to) function as a pep talk for the patients in order to emotionally cope with their disease.

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promote and enable this: *'We usually come up with a topic, give it to them and they would discuss it amongst themselves and share information. Whether the topic is HIV, hygiene or TB<sup>10</sup>, they would share it among themselves. Different views, different information, different knowledge. And this really helps them to know what they didn't know, or understand something that they didn't'* (Male professional nurse).

Some patients ask people their social network for advice as well, again especially from their family members. However, the interviewed patients assume that Tapologo will always know the answer to every HIV/AIDS related question and people in their social network do not: *'Mostly I go to my parents and my sister if I want to know something about HIV. Sometimes the pills don't make you feel well, maybe you become dizzy, than I have rush, information about these things. You have to ask them and they talk about it and help you. And if I ask my sister and she doesn't know about it (...) she says I have to go to the clinic'* (Female patient, age 26).

However, patients also often experience that they receive information and advice from people in their social network<sup>11</sup> that is contradictive to the information they get from Tapologo. In most cases, contradictive advice has to do with belief in traditional medicine: *'They say ARV's are not good for me'* (Female patient, age 37). And: *'They say I have to go to the bushes to find the traditional medicines'* (Male patient, age 65).<sup>12</sup>

#### **4.1.3 Instrumental support: Heavy work, giving treatment and condom provision**

Instrumental support, actual help and assistance with the daily needs of the patient, doesn't always seem to be necessary. Most patients state that they can do everything by themselves when it comes to the daily household chores and they don't need any help from others: *'I can manage the world on my own, since coming to Tapologo, I got strength'* (Female patient, age 65). Although most patients might not need instrumental support on a structural basis, a lot of them explain that there are some days that they do need help: *'On some of my appointments I wake up not feeling well and then I can't come to the clinic, so I just usually call someone to bring the treatment for me'* (Female patient, age 48). Especially the heavy work, like fetching water and doing the laundry, becomes a problem for weak patients and when they find themselves in such situations they normally ask assistance from others. During days the patient is indeed weak, patients may need housekeeping assistance, such as home-based care. A female care worker explains: *'If you see the condition of the house is not good, you just have to clean that house. And if there is no water in the house, you just can even get the water and bring it to their house'*. Some patients explicitly appreciate this kind of care work: *'They do visit, they are there to check on you, if you are ok. If you are weak, they do help with household work (...) so Tapologo does help'* (Female patient, age 61).

When it comes to ARV-treatment specific assistance, patients might need help in preparing healthy food, if they are not able to do so themselves. Also assistance in order to take treatment is helpful. Besides being reminded to take their medication on time, some patients even notice that they appreciate assistance in getting their medication: *'My mother is very strict about taking treatment, about taking it in time, exactly on time and not later or anything else. She wakes me up in the morning for treatment every day, same time. The alarm of her mobile phone wakes her up to be exactly on time. At 7 o'clock it is supper or breakfast and 8 o'clock is definitely time for treatment'* (Female patient, age 38).

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<sup>10</sup> Tuberculosis (TB) is an infectious disease, mostly pulmonary. TB is a common opportunistic infection that goes often together with HIV. Physical complaints are coughing and night sweats and this disease can be very contagious (Coelho, 2000).

<sup>11</sup> The term 'social network' is used to cover all the informal support providers in the informal social network of a patient. Tapologo, by contrast is a formal support provider. The term 'social environment' is used to cover both the informal and formal support providers.

<sup>12</sup> See paragraph 4.2.4: Scenario 4: Wrong or contradictive support

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In addition, the provision of condoms is necessary, which can indirectly be derived from statements concerning advices about condom use as mentioned in the previous paragraph. Patients and professionals explain that it is important to use a condom and therefore indirectly state that they need condoms. Or, as a female head nurse states: *'We cannot encourage them to use them, while we don't supply them, isn't it?'*

#### *Main instrumental support providers*

Although the aforementioned quotes show that Tapologo tries to support their patients instrumentally, the care workers are generally not recognised as the main providers of instrumental support. Only in some exceptional cases, if patients don't have anybody to rely on for instrumental support, Tapologo automatically functions as their main support provider. The low priority of Tapologo in the hierarchy of main support suppliers can be attributed to the fact that the care workers normally visit the patients only once a week.

The provision of instrumental support is, according to the patients, mainly performed by their family members. Sometimes the patients are even supported by their little children: This example concerns an 8-year old boy: *'Mother and father were like very, very sick and what this little boy used to do was waking up in the morning, wash and make porridge for his parents. They were three in the house, make porridge for them and quickly give them their treatment and run to school. Come back during lunch break, give them food and run away again'* (Female head nurse). Also the healthy patients, who don't need assistance at the moment, expect and would prefer to get help from their female family members in case they would be sick, especially when it comes to nursing activities. However, there are also patients who depend on the assistance of neighbours and friends. This is especially the case with patients who don't have their family living around and are therefore looking for people who can replace the absence of a (supportive) family<sup>13</sup>.

Male partners don't appear to have a great share in the provision of instrumental support to their partners. Only a few of the female patients point to their partners as being of assistance with respect to these needs: *'My boyfriend cooks and I do the washing and normally the rest of the cleaning. But if I'm not feeling well my boyfriend is also helping with the cleaning and other things'* (Female patient, age 37). However, most of the women state that they are responsible for almost all the work in the household. Especially tasks concerning nursing activities are commonly viewed as not being provided by a male partner: *I don't think my partner would really help, because I think there are so many things that he might find disgusting in a woman, like when let's say I am at my final stage, I have diarrhea I don't think he can help* (Female patient, age 26). By contrast, female partners often do provide support to their sick partners<sup>14</sup>: *'Women are the ones who will look after their partner when he is sick. Cook for him, bath him, do the cleaning and also the nursing, yes, but no, the man normally won't do that, no they won't and I think they even can't'* (Female care worker).

Although the advice of Tapologo concerning condom use implicates that they would also provide them, this is not always the case. Patients experience that condoms are not always available at the clinics and at some clinics, condoms seem to be not available at all:<sup>15</sup> *'No, I don't think I have ever seen condoms here at the clinic'* (Female patients, age 26). Governmental clinics and the mines around Rustenburg often function as the main source of condom provision, since they are available for everyone and free of charge.

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<sup>13</sup> See paragraph 4.2.1: Scenario 1: No one to rely on

<sup>14</sup> Only 1 of the 4 male patients has a partner, therefore the own experiences of males are not included in this view.

<sup>15</sup> See paragraph 4.2.4: Scenario 4: Wrong or contradictory support

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#### 4.1.4 Financial support: poverty and dependency

##### *Financial support needs*

The financial circumstances of the patients are often quite alarming. Especially the migrants from outside South-Africa experience extreme financial difficulties, since they don't have an identification document (ID), which is necessary in order to receive a working permit as well as a social grant from the government. Only a few patients have a job at the moment, and these are mainly temporary jobs, for example as a domestic worker (women) or gardener (men). Also professionals confirm that some patients really struggle to survive, let alone to properly follow their treatment: *'There is no food. Sometimes, when you do home visits, you only have 10 Rand to offer, maybe she will even buy a loaf of bread for that day. But what about the next day? So these people are really suffering and only die because of hunger. Even some people stop taking treatment, because of not having food. Say they can't take treatment if they don't have food. When they are here, you can see they are happy, they are talking to each other, they have something to eat. But the problem is, when they have to go back home, where there is no food. It really becomes difficult, that's another problem, it is a serious problem'* (Female care worker).

When it comes to specific needs with respect to ARV-treatment, the availability of money for healthy food and money for transport to be able to visit the clinics are often mentioned as extremely important and highly necessary: *'Even some people stop taking treatment, because of not having food. Say they can't take treatment if they don't have food, since you can't take ARV's on an empty stomach'* (Female care worker). And another female care worker: *'Here they use wheelbarrows, donkey carts or they just take them on their back to hold him or her and just bring them to this clinic'* (Female care worker).

These findings indicate that it can be extremely difficult for patients to adhere to their treatment, due to the lack of sufficient financial resources. Being able to purchase food is of great importance to everyone, but especially for HIV/AIDS patients because they need to take their medicines with food. If they do not have money to buy food, they may feel uncomfortable in borrowing money or food: *'I normally don't ask people, because of their negativity toward me. The only person I always go to is my care worker who lives close to me. Even yesterday I went to her to ask the maize meal, but she didn't have so I try again today'* (Female patient, age 47). Another option is a so called 'loan shack', where they borrow money and pay it back with interest afterwards. This is a worst case scenario because one is never sure of being able to bring the money back at the end of the month and therefore the interest keeps rising over and over. According to a female head nurse, patients feel that the people at the loan shacks make advantage of their situation to make money out of them. According to this professional, patients get into even more trouble when they are involved in borrowing from these loan shacks.

The financial circumstances of patients are that poignant that they are capable of almost everything to generate an income in one form or another. Both patients and professionals explain that some patients are under the assumption that they only receive a disability grant when their CD4 count is below 200<sup>16</sup>. Although there seems to be some vagueness about whether this is indeed the case or not, patients who are in the presumption that this is indeed the case sometimes 'abuse' this knowledge in order to continue receiving their disability grant: *'Usually when you come here at the clinic and your CD4 count is low you would get the grant for a certain period until your CD4 count has increased or after a year then they would*

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<sup>16</sup> The HIV-virus attacks the CD4 cells. The lower the amount of cells in the blood, the weaker the immune system and the more risk to get all different kind of complaints.

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cut you off the grants. When people realize that their CD4 count is about a point where they will cut you off the grant, they would stop treatment so as to go back to a point where their CD4 count drops again and then they start another process of getting the grants again. But now it got a little bit better since the only people who are getting the grants are those who have TB and are also HIV-positive' (Female care worker).

Another example of patients who use their HIV-status as an excuse to ask for money is the story of a 33-year-old female patient: 'When I am in need for money, I just call my boyfriend, aunt or little sister, I call them right away. They help me with money for healthy food, I just say I need healthy food for my treatment, but I abuse the situation sometimes as well. I love money, hahahaha [laughs]'.

#### *Main financial support providers*

Patients who do get financial support normally ask and receive financial support from one of their closest relatives. There are often one or more family members who receive a social grant in one or another form and this person shares that social grant with the rest of the family. It also seems common to receive money from male partners or (temporary) boyfriends: 'My sister advises me not to see many men, but I date lots of men, because they give me money' (Female patient, age 26). And: 'I never asked my partner for money, but he is the one who always gives by himself' (Female patient, age 32). However, there are also patients who have difficulties in generating financial support: 'There are those who cannot get a cent from anybody, especially if you are not known. But we encourage them to help each other, yes!' (Female professional nurse). Furthermore, friends are never mentioned as a provider of financial support. Financial support from neighbours and other community members seems to be quite uncommon as well.

As already became evident in the aforementioned quotations, the government also tries to support the patients financially by providing disability grants for patients with a low CD4 count in combination with TB or being disabled due to their HIV-status. Nevertheless, these grants are often only temporary and it seems unclear to patients and professionals what actually makes an individual eligible to receive such a grant.

Tapologo is never explicitly mentioned by the patients as a provider of financial support and professionals state that Tapologo cannot do anything for their patients when it comes to finances, except helping patients with their application for social grants by completing the official forms for them. However, an interview with a 50-year-old female patient indicates that Tapologo does help the patients indirectly by showing them ways to be self-supplying: 'They teach us that we have to plant seeds to grow our own vegetables and fruits so that we can sell them on the market'. This form of informative/advisory support therefore ultimately can lead to the fulfilment of the financial support needs.

#### **4.1.5 Spiritual support: 'A healing tool'**

##### *Spiritual support needs*

Both patients and professionals state that spiritual support is important in order to cope with their HIV-status and almost all of them have a strong believe in God: 'If you believe and when you agree with the word of God you sometimes will going to be healed, if not, you are not going to be healed' (Female patient, age 42). And a 40-year-old male patient: 'People with HIV/AIDS should be loved and consulted by the word of God, each and every time, because it gives them hope'. Some patients even have more faith in support from God than support from other people: I<sup>17</sup>: 'And what can you say in general, how are people supporting each other in this community?' P: 'According to me I think that sharing your problems with God is a better one, because

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<sup>17</sup> I is used as abbreviation for the interviewer, P is used as abbreviation for the interviewed patient or professional

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*God never spreads rumours or lies about a person, so I think that being a friend with God is the only way that you can survive'* (Female patient, age 47).

Especially professionals assume that spiritual support is really useful for their patients and they even try to bring them back to church if they are not a church-goer (anymore): *'Spiritual support is really very much important for people, because somewhere it lifts someone's spirit, it helps, it's somehow part of healing. To me, I would say it's a healing tool, because sometimes, when you get to the patients, the patient will ask you 'if you can just sing one song to me, I think I will be ok', or 'sister please, if you can say a little prayer with me, because last night I didn't sleep (...)' And sometimes you get into the house and find somebody is so down and sick, and you start singing at him and he will start singing with you and you will see that she will be a little bit brighter. And sometimes you will see some people are lost, they are no longer attending church. With us being there, singing with them, praying with them, you might be able to bring them back, and they are able to get back to church and they would know that it is important to pray and that it is important to put your problems and whatever in front of God'* (Female head nurse).

Patients confirm the importance of spiritual support: *'The support group really helps, because it always lifts my spirit up when I am down, even when I get here and being hungry, but by the time I attend the support group and we pray together, my stomach becomes full'* (Female patient, age 47). And: *'I feel happy while we sing, praise God and are praying. After that, even when I came here being angry, after singing and praying I just feel happy, it relieves me'* (Female patient, age 35).

Most patients state that the religious ideas of Tapologo are in line with their own religious beliefs, which also becomes evident in the previous quotation, and some patients state that it is in addition to their own beliefs: *'It is in addition to my own religion. Because here you are in different religions, you see. The churches differ and the religions differ, but it's not a big difference'* (Female patient, age 26). It seems important that a not too narrow interpretation of religion is exposed, as a Tapologo professional underlines: *'No no no, we don't follow one religion, we give chance to whoever, as long as it is, somebody, it's a religion. We don't discriminate, irrespective of religion, culture of whatever. We deal with everybody, from any church, from any religion or whatever. That is even when we hold our support groups, we don't say, no no no, we want a priest from (...) a Catholic priest, we invite whoever priest, whoever who is willing to come and be with us during the pray'* (Female head nurse).

#### *Main spiritual support providers*

Patients mainly rely on the spiritual support provided by, not surprisingly, their church: *'Sometimes when I am at home and I'm not feeling well and having the pimples and by the time I feel like scratching and remember the church and then I go to the church and the priest prays for me and ask for help. And after the pray of the priest it feels better. It feels like being relieved in the soul and emotionally. So my church is very useful for me, by the way that sometimes I feel better like when I feel bad things inside I take these bad things out of me when I am at the church'* (Female patient, age 34). In some cases the church even provides specific spiritual support for HIV-positive people: *'On Thursday usually the women from church come to visit to those who disclosed their status and pray with them and help them spiritually'* (Female patient, age 48).

Although patients seem to be very enthusiastic about the spiritual support offered by Tapologo, patients hardly mentioned Tapologo as a provider of spiritual support by themselves. Some even (indirectly) expressed their wish to receive more spiritual support from Tapologo: *'At Tapologo, once there was this priest who came and prayed with us, he even read us a scripture from the bible. But he just came twice, that*



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were the only times I saw him' (Female patient, age 48). A 42-year-old female patient, by contrast, states that Tapologo provides a lot of spiritual support: *'The spiritual support I get here at Tapologo, I do believe in it, because we also get to have a different kind of preachers here, from different churches who come here to the clinic. So they are doing a wonderful job by healing our spirit'*. A female professional nurse describes the spiritual support they provide to their patients: *'We have got spiritual leaders, like assemblies of God, they always come here and then pray for them. And we also pray for them if a patient is spiritually down. There are those who will tell you that, look you know I am down today' and there are those whom you feel that this person is down. But if the patient needs to be more spiritually uplifted we sort of refer them to a spiritual leader'*. Again, strong believe in Tapologo was visible in the answers of patients. They just assume that Tapologo wouldn't give spiritual support when it would not help them: *'They really lift you up, so I guess the bible sessions really help a lot, because we are doing it every morning'* (Male patient, age 35).

Besides patients' churches and Tapologo, no other direct spiritual support providers in their are mentioned. However, they do often seem to talk about religion with others or are encouraged to visit the church: *'My husband tells me that I have to go to church if I have a problem, so that I maybe can feel relieved after going there'* (Female patient, age 37). This type of encouragement can also be considered as (indirect) provision of spiritual support.

#### **4.1.6 Conclusion: Answer sub-questions 1-2<sup>18</sup>**

Based on the aforementioned analysis in paragraph 4.1, sub-questions 1 and 2 can be answered.

##### **1: What are patients' support needs concerning the different forms of social support?**

When it comes to emotional support, patients most importantly feel the need to be accepted by others, they want to be treated as a normal person. Furthermore, they want to feel that they are being loved and cared for. This can be achieved by getting a little attention from others, for example by encouraging them to continue their treatment or having little chats with people. Expressing their thoughts and feelings with others also benefits the well-being of patients, especially with other patients, because they understand them better. During conversation it is very important for patients that people really listen to them and that they are patient with them during the conversations.

Informative/advisory support that benefits the patients includes information and advices about living a healthy lifestyle, infection and re-infection (including condom use) and about the lifelong duration of the illness. It is crucial that patients realise that HIV/AIDS should be viewed as a normal disease and that they still can grow old with it, since they sometimes think that their HIV-states automatically means one will die rather quickly. Also practical information concerning 'ARV-treatment-rules' is of importance. This includes information about taking medication on exactly the same times of the day and not taking medication on an empty stomach.

Although patients often don't need help and assistance in their daily household chores on a structural base, they do need help during days they feel weak. Especially assistance in heavy work, like fetching water, is important during these days. Also housekeeping assistance, such as home-based care, is appreciated. ARV-treatment specific instrumental needs include preparing healthy food and assistance in taking medication. Furthermore, the provision of condoms is of importance.

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<sup>18</sup> Sub-question 3 can also already partly be answered after this paragraph. However, this will be done after the following paragraph that goes more into detail about the lack of (beneficial) social support which complements the aforementioned information.

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The financial circumstances of patients are often really alarming, especially for immigrants. Only a few patients have a job and they are sometimes really struggling to survive. Some don't even have money to buy food. Being able to purchase food is of great importance to everyone, but in particular to HIV/AIDS patients, because they need to take their medication in combination with food. Also money for transport to visit the clinics is needed. Since patients often lack these finances it is extremely difficult for them to adhere to their treatment. Patients sometimes borrow money at a 'loan shack', but are not able to refund the money at the end of the month and they are therefore prone to experience even more difficulties. The government provides disability grants for patients with a low CD4 count. However, this grant is only temporary since the CD4 count will rise after taking treatment. Therefore, patients sometimes even stop their treatment in order to keep receiving this grant.

Patients also benefit from spiritual support. It gives them hope and it lifts their spirit up. Support in the form of singing together, praying and discussing bible stories make patients feel happy and relieved. Patients sometimes even believe that you will be healed as long as you believe in God.

## ***2: Who are the main support providers of the different forms of support? (who is doing what)***

Generally speaking, the family of the patients often function as the main support provider, especially when it comes to financial and instrumental support. Also emotional and informative/advisory support is often offered by the family. Close kin relatives are often mentioned as a confidant of the patients in order to talk about their situation or to ask for advice.

Also Tapologo provides a lot of emotional and informative/advisory support, especially during the support groups at the clinics. Professionals often function as confidants, in particular when patients feel they don't have anyone else to rely on. Also, although to a lesser extent, instrumental support is provided by Tapologo via home-based care, as well as spiritual support during counselling sessions. Although Tapologo cannot help their patients financially, they indirectly assist them in applying for a social grant and showing them ways to be self-supplying.

Fellow patients have a great share in the provision of emotional and instrumental support. They share information and openly talk about their problems during the support group. Patients feel most comfortable to talk about their problems in the appearance of other patients. Other forms of support are usually not provided by fellow patients.

Friends hardly seem to provide support in any form, since patients don't even want to disclose their status to them. However, friends sometimes function as a confidant for the patients (emotional support) and it also occurs that they support patients instrumentally, when they don't have their family living around.

Also assistance from partners is rare, especially when it comes to informative/advisory support. Partners are hardly mentioned as confidants and they are normally not the ones whom they ask for advice. However, when it comes to finances the male partners do provide support to their significant other. Female partners, by contrast, are never mentioned as a financial support provider, but they normally do provide instrumental support by the performance of household chores and nursing activities for their sick partners.

Finally, patients' churches, not surprisingly, functions as the main provider of spiritual support and the government tries to help the patients financially by providing a (temporary) disability grant or a pension for patients with a low CD4 count.

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## 4.2 Scenarios of social support shortage

Although some patients receive a lot of support from their social environment, other patients seem to be less lucky. Patients who lack support from their social network in one way or another, tend to rely more on the support from Tapologo. Some patients even solely depend on the help and assistance of Tapologo.

In the previous paragraph some examples have been provided of situations where patients do not always receive (beneficial) social support. These and other situations will be explored in more detail in the subsequent paragraph by presenting different scenarios or pathways of barriers in receiving social support. The typologies are based on the way patients are being withhold or withholding themselves from receiving (beneficial) social support.

### 4.2.1 Scenario 1: No one to rely on

This first scenario can be characterized by the following situation:

*'(...) And unfortunately the place where she stayed was not a place for a person to stay. There was no food and the person who used to take care of her, her sister, went back home in Transkei and she had none to take care of her, no one to give her food or anything. So after a certain time she was no longer coming for treatment. So I just assumed that it is because of financial problems, food, money and everything. So things like this would make you realize that these people are sometimes really suffering'* (Female care worker).

Why didn't this patient have anyone to rely on? Why were there no people to look after her and support her? According to professionals and patients, this scenario seems to occur more often. Although it doesn't necessarily have to be the case that a person is totally neglected, there are quite a few patients who feel that they do not have anyone to rely on. They do not have people in their social network who support them, or whom they can at least approach in order to ask for support. In other words; they have a lack of ties in their social network. This physical absence of potential support providers in their direct environment seems to happen mostly in cases where people are migrated to the Rustenburg area from another country or from another part of South-Africa in order to work in or around the mines.

There are quite some situations where women are migrated from rural areas all over Southern Africa to the townships around the Rustenburg area in order to find a man who will provide her with food and shelter. Sometimes they are even sent to Rustenburg by a family member who promised them that they arranged a job for them, while in fact they only 'arranged' them a boyfriend: *'The reason that I'm here in South-Africa, is that I was brought here by my aunt, who claimed she found a job for me here. But when I got here, there was no job, the only thing that was here was a boyfriend, so I had to live with the guy. But that guy left me, he left the job and this place here to work in another area'* (Female patient, age 42).

It occurs that men easily leave their girlfriend and/or move to another area. This becomes a problem since women often seem to solely depend on their partners when it comes to finances: *'For a person to survive here in Freedom Park, you need to be a man's person, you have to depend on a man to survive'* (Female patient, age 32). And as a female head nurse explains: *'People from Lesotho, it is like they are depending on the men here in the mines. So, that's why they sleep with them, so they can have bread on the table. So, if they don't have men, there's no food'*. Immigrant women are sometimes entirely alone when they are abandoned by their boyfriends. They are left without their families around them and have no friends.

Creating a new social network which contains possible support providers sometimes seems to be extremely difficult for immigrant people in the Rustenburg area: *'It is very difficult to find someone to rely on.*

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*People from Lesotho for example, they might find it difficult to find a best friend or so here in South-Africa. So you might find that most of the time they are alone. They are alone'* (Female care worker). A 33-year-old female patient explains why it is difficult to find new people in order to build a social network: *'You know, nowadays, you become a friend of a person because of what you have. If you don't have anything, I'll say 'no, how can I be a friend with him or her, because he or she doesn't have money'. So, most of the people they go for people who are rich, and, the people who have something. So, if you come from Lesotho, having nothing. So, why must I come to you, because you have nothing. So, nowadays people just make friends while they look for something from a person'*. This statement shows that making friends might sometimes be based on a matter of rational calculation of expected advantages and disadvantages of this possible relationship. Other patients and professionals state that it is just not common to look for people outside of their own families, which might be another explanation for the difficulties immigrants experience in finding new friends: *'People here like to live alone, they like to live on themselves, only with their own family and are only sitting with their families* (Female patient, age 37).

Luckily this 'negative scenario', where immigrants don't have anyone to rely on does not necessarily have to occur. According to professionals, there are also patients who bond with other people and therefore do have friends who, although they are not relatives, support them very much: *'You will be surprised if I tell you that some of the patients, immigrants, do not get support from the family members, but from neighbours. You will find those kind neighbours, who will take care of somebody as they are taking care of one of their family members'* (Female head nurse). Especially immigrants from other countries (compared to immigrants from within South-Africa), seem to have more chances to find new people who substitute the lack of familial support: *'Ehm, with foreigners, I mean those from outside South-Africa it is, I think, it becomes a little bit easier. Because for them, once they realize that you are from Mozambique, and they are finding someone from Mozambique, already you are a family member for them. They look after each other'* (Female care worker). One Tapologo professional even assumes that it actually is quite easy for immigrants to receive support: *'People in Freedom Park are living together, are helping each other. They are friends, they are giving each other support, like family members. Because these people, most of the people living in Freedom Park are not South-Africans. They come from outside South-Africa. And while they are here, they bond, you know. You will bond with your next door neighbour, because it is a poverty place. When somebody doesn't have food, next-door neighbours will offer something for that person to eat. Friends will become sort or relatives while they are here'* (Female professional nurse).

The quotes above might give the impression that patients with friends will have no problems to receive support. However, in case patients do have family members, close friends or other people in their social network, it doesn't necessarily mean that they can rely on them for support in difficult times as will be explained in the upcoming paragraphs.

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#### 4.2.2 Scenario 2: Support refused

Patients who have people in their social network who might be approachable to ask for support are not necessarily guaranteed to also actually receive this. It seems to occur more often that people in their social network refuse to provide support. Both patients and professionals (indirectly) mention several causes for this absence of support in the form of refusal, which will be addressed in this paragraph.

##### ***Prioritising family***

Generally speaking, it seems to be common that the family is assumed to be the main support provider for the patient, especially when it comes to the provision of financial and material support. When asking why some people don't get sufficient support, patients often give statements like: *'Because they don't have their families around to take care of them'* (Female patient, age 42). And: *'Because some live without families, and of course you can't just ask money from your neighbours or friends'* (Female patient, age 33). The statement of a male professional nurse also confirms this general assumption: *'As we all know, blood is definitely thicker than water'*. These statements show that it is generally assumed that family should take care of the provision of support.

When friends or neighbours in the network of a patient refuse support, the simple fact that they are not relatives of the patient is sometimes viewed as a reason for refusing care provision: *'It's because it's everyone for himself here, they choose their own families, they are not going to give to everyone if they are not related'* (Female patient, age 29). And: *'Just because at the neighbours or my friends, they do have their own responsibilities, so I can't just go and ask them for helping me at home or anything. I once tried to borrow money from the neighbours, and they refused to help me because they have their own problems in the family'* (Female patient, age 35).

It seems that friends and others often have to prioritise the well-being of their relatives above their friends. The (financial) circumstances of families seem to be that difficult that they are forced to make decisions to whom they give support and the general rule seems to be: family first.

##### ***Not willing or not able to support?***

Although the aforementioned implicates that families are forced to make decisions, due to their own difficult financial circumstances, patients often don't agree with this. They state that people outside the family are actually able to give support. According to them it is not a matter of being forced to make decisions who to support (in favour of the family), but they just don't want to give support to people outside of their families. They even feel that they, especially people with enough resources, are the ones who don't want to give support: *'Some of the people who are not suffering and don't have to think about getting enough food or getting money or taking care of the household or other things. These people are just proud of themselves and think that they own the world. They only think about their status in society. If you go to these people and ask for money or for food they will just say they have their own problems at the house and that they don't have time for you'* (Female patient, age 37). And as a 34-year-old female patient describes: *'Some just don't feel like helping others and those people are sitting alone and they don't bother themselves about other peoples' problems. These people told themselves that they won't suffer in life, that they are more important'*. Also a 40-year-old male patient explicitly states that it is not a matter of not being able to give support, but more a matter of not wanting to do so. *'Families, who do have money, don't want to help other people who*

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need money. Because people who do have money think that that money they give they are going to waste that money if they are giving it to other people than their family'. These patients often also feel that their community in general is not close-knit and supportive: *'It is everyone for himself around here'* (Male patient, age 50) and: *'People here don't share with the neighbours or anybody else, they just look out for themselves. Like a family they would just focus on themselves, they won't even give to the neighbour or someone else'* (Female patient, age 32).

However, the opinions seem to differ about this community situation. Some patients even explicitly state that their community is very helpful and willing to support: *'It's like in this community, we are family, we are helping each other and we like to sit together all of us'* (Male patient, age 65). And a 48-year-old female patient: *'People around here are supporting each other, because, like when we have a problem in your house, you can call all the people in the street, and they will come to you and they are listening what the problem is'*. Some also assume that, contrary to aforementioned quotes, it is a matter of not being able to give support: *'Maybe yes, they can help for a shorter period, but they can't help you forever. The thing is they are only sharing with you something small that they have, they can't afford to provide for you and for themselves, because they are struggling themselves'* (Female care worker). And a 48 year old female patient: *'Those who do not have, cannot give'*. Again others notice that it might be a matter of rational calculation. They will not give other people financial support if they assume that they cannot be refunded: *'When it comes to the money story, nobody will lend you money if you can't pay it back, that's for sure'* (Female professional nurse). And a 35-year-old male patient: *'How can someone give you money, whereas they are not sure you will give it back'*. This rational calculation can also be based on not being able to give, since people might just not be able to lend money to others when they are not refunded, without getting financial into difficulties themselves.

### **HIV/AIDS related discrimination**

#### *Blaming the patient*

The previous findings implicate that at least the patients who do have family living near them will receive support from them. However, this doesn't necessarily have to be the case. Some families might refuse to support a relative patient or sometimes even abandon him or her: *'Some of them they are not getting support whereas they are having their families. When you come to their houses as a day visitor, you can find the patient is lying on the bed whereas she was not able to go the toilet, so she just couldn't reach the toilet on time. So then you can find out that the room is not in the good condition, the blankets are not in the good condition, many things are not in the good condition'* (Male care worker).

In case a family is not supporting or even neglecting their sick family member, this can be caused by the families' fear of being judged by other people in their environment. They don't want others to know that they have a sick person in their family and hide the sick person or they blame the patient for assaulting their family status and therefore withhold support: *'People just do such things, because they feel that, as a member of their family, you have degraded them. Their status, you have taken it down, in that community, you have degraded them as a family. Because now, I think people are under the impression that AIDS only affects those kind of families that are the poorest of the poor. So once you come in and you are their family member, and here are you being diagnosed with AIDS, it means that now they are no longer going to be considered on the same level as they used to be'* (Female head nurse).

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In line with the stories of patients and professionals, it can be said that people often are really concerned about what others think of them. Their status is sometimes even more important than the well-being of their sick relative: *'You will find that if my child is sick with AIDS, the family members, even the parents, are scared to take this person to the doctor. They are scared for this person to sit outside, because people are going to see her and they will start talking like 'owh! she is HIV-positive'. And if you come and ask where is Hilda, they will say no, she is not here; she is gone to visit someone somewhere. When at the same time this person is lying in the bedroom sick, very sick (...) People are scared as a mother, I am going to be scared to take my daughter out, because people are going to say 'owh! her child is dying from AIDS'. And as a mother in that community, I don't want to be labelled by the community members. So I'd rather hide my child in the bedroom and look after her by myself and that's it'* (Female head nurse).

Family members can blame the patient for degrading their family status, but they can also blame them for getting infected in the first place and therefore withhold support. They blame them for their behaviour which was not according to their rules of good behaviour; not according the way they were taught to behave: *'There are some people who don't get any support from their family. Even if the patient is lying there, the family just ignore him, don't support him. There are some families who said, 'No, I didn't send you to do whatever what lead you to become like this'. So, there are some families who say these wrong words to the patients. They are blaming them. Families are blaming the patients'* (Female professional nurse).

Other people sometimes also judge their past behaviour and therefore not support patients: *'It depends whether you are known by other people as a person who likes to cheat on your partner. If you cheat on your boyfriend or girlfriend, people will take you badly. So by the time you will be getting sick, they are saying, 'yeah, you have seen this person before, so you were going to be infected, because you were not fair to your partner', so it is your own fault that you became like this. So people won't help you, because it is your own fault'* (Male patient, age 40). A male professional nurse tries to explain why people act this way according to him: *'You know, many people still have got that belief that you know, HIV is associated with somebody who is restless, who is actually reckless, who goes around and sleeps around, and, you know, doesn't actually follow the correct way of living'. And a 28-year-old female patient explains: 'People with HIV are more discriminated than other diseases. It is seen as a disgusting disease and people believe that when you have HIV that means that you are sleeping around or you have more boyfriends or girlfriends'.*

#### *Gossiping and leaving*

It is quite common that people, of whom only mentioned people outside the family, gossip about an HIV-infected person: *'They always like gossiping, and they always would spread your status around. They don't respect HIV-positive people around here. They would swear at you, they won't even eat your food. They look HIV-positive people down'* (Female patient, age 50). Even people who used to be considered as good friends of the patients do so and they often start to behave differently after they find out about the HIV-status of the patient: *'As for friend support, the friends that I used to have in the community they did change, because when my husband is drunk he goes around, telling everyone that we are going to Tapologo. So my friends always come around as if they come to check if we are ok. But this is only to see if it is true. So they can laugh about it, talk about it and start pointing fingers at us'* (Female patient, age 61). And a 37-year-old female patient about discrimination: *'By the time the pimples felt so itchy that I scratched them, my friends said 'you are infected, just go away'. They also didn't want to drink and eat from the same plates and eat the food I was making, they stayed away from me'.*

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Even in public, HIV/AIDS patients are sometimes openly discriminated. A 48-year-old female patient states: *'Sometimes, when we are at the funerals other people say: 'No, don't sit next to this person, because this person is sick, she or he can infect you'.* The general reason for people acting this way has to do with the lack of information about HIV/AIDS according to both patients and professionals: *'It is lack of information, they don't have enough information, or they don't know how to deal with a person with HIV/AIDS'* (Female patient, age 48). And a 40-year-old male patient: *'People will just reject other people, because they think you will go to infect them. Those people are the ones who don't know anything about HIV/AIDS, they don't have information about that'*<sup>19</sup>.

Obviously, this kind of behaviour cannot be considered as support provision. Therefore, patients often experience a lack of support from friends. It even seems to occur quite often that friends don't want to have anything to do with an HIV-infected friend anymore and just run away from them after they find out about their status.: *'My friends thought that I was going to infect them with HIV and they started to turn out'* (Female patient, age 32). And a male professional nurse explains: *'You will be my friend as long as you are healthy. The minute you get sick, I won't care a damn about you. Because I am not related to you, you are not my aunts' mother, you are not my uncles' mother, you are just somebody I just met. I don't even know where you come from'*. This statement shows that friends can easily walk away since they don't feel any responsibility towards them.

Also boyfriends, especially those who are married to a woman who lives in another country, often don't feel to have responsibilities towards a second girlfriend. Therefore, some (mainly immigrant) patients will find that their boyfriends run away after they find out about their status: *'And when they tell their boyfriends that they tested HIV-positive, a married man will definitely leave this girlfriend and say 'no, I don't want to get involved in this, my wife is at home, my children are at home, so why should I suffer and help you'. They go and dump this girlfriend for another girlfriend'* (Female head nurse). The same can occur to male patients: *'(...)So the girlfriend saw him coming here for treatment, and then the girlfriend left and the boyfriend is now taking treatment. But the girlfriend has left, she is living another life now, she didn't even come for a test* (Male care worker). However, patients and professionals argue that it occurs more often that boyfriends are the ones who leave.

A reason for the unwillingness of men to provide support in these situations is often the result of HIV/AIDS related stigmatisation: *'They don't want to be associated with somebody with HIV, because that will actually stop them from having extra affairs, because everybody is going to say he had a relationship with so and so who had AIDS. They know that they slept around, but they will always blame the woman. So that's why they'll kick you out'* (Tapologo professional 30). This statement shows that besides or instead of stigmatising their own partner, they seem to be afraid that they will be discriminated themselves if others find out that their partner is HIV-positive.

### **Gender rules and gender inequality<sup>20</sup>**

The absence of support from (especially male) partners also often has to do with gender inequality. General norms and values according to the way women and men need to behave including the dominant power of men in a relationship seems to influence the support provision for the patients. Men tend to decide and

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<sup>19</sup> However, some patients and professionals think that is also has to do with being stubborn, as will be described in paragraph 4.2.4: Scenario 4: Wrong or contradictory support.

<sup>20</sup> In-depth information about condom use and gender inequality falls beyond the scope of this study. See for more information the master thesis of Marielle Lunenburg: 'You cannot eat a sweet with a paper on it'.



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determine important aspects of the lives of their wives or girlfriends. Women often have to ask permission whether they are allowed to test and follow treatment and sometimes the man decides that she is not allowed to go: *'Some women you will find them very sick and you say 'why didn't you come to the clinic' and they say 'my husband didn't want me to come and he is sleeping on'. But this man doesn't see anything, it's his ego, he has the power to say yes or no and I think we need to pass that stage now'* (Female head nurse). Some women whose husbands refuse to give permission for an HIV-test, secretly visit the clinics and secretly take their medication, or don't take it at all, because they are afraid of their partners' reaction: *'Sometimes the men even refuse that their woman takes treatment. Some patients are taking their treatment secretly, one at a time and they have to go quickly. Or when you visit them in the afternoon, you will find that they supposed to take their treatment but didn't, because they are scared of the man. That's because they are scared of being kicked out of the house, they are scared'* (Female professional nurse).

The power of a man in a sexual relationship is also visible in the absence of the support of consequent condom use. Although some patients state that their partners don't have any problems with the use of a condom, there are also male partners who are not supportive at all to the promotion of condom use and sometimes even refuse to use a condom: *'men don't like condoms, they want flesh-to-flesh sex'* (Female patient, age 33).

Gender inequality within a relationship is also visible in the strict division of labour, which is another source for a man to withhold himself from providing support to his partner. The absence of a supportive male partner is already mentioned in paragraph 4.1.3: instrumental support. This absence can be explained by the strict division of chores between men and women in traditional African families: *'The job of the woman is to just do the cleaning in the house, wash dishes and wash clothes. And the man is the one who is looking after the garden'* (Male patient, age 35). Because of this strict division of tasks, men will normally not do tasks they consider to be a women's job: *'If the woman is sick and in the house, the men, some of them, will find that they literally can't cook for themselves, let alone for the children. And in the traditional villages they will call somebody, one of the female family members. It could be the women's mother or somebody to come and take care of the sick woman and prepare the food and do the cleaning of the house. No, the man can't do that. Even when you see a female patient comes in [in the clinic], the husband might be there, but you won't see him holding. There will always be elderly ladies, grannies or whatever who will have to support this woman, not the man'* (Female head nurse). Both men and women have their own tasks which seems to be embedded in their cultural beliefs. In cases of providing instrumental support, especially when it comes to direct nursing, it is even considered to be inappropriate for a man to provide care for a woman.

#### **4.2.3 Scenario 3: Obstacles in asking support**

A third pathway which facilitates a lack of support can be the patients' own difficulties to ask people in their social network for support. Patients often don't feel like asking support, which can have several reasons as will be addressed in this paragraph.

##### *Burden*

Some patients express that they feel have the feeling they are a burden to others when they would ask for support and therefore withhold themselves to do so: *'Sometimes I feel like a burden to ask money and that makes me feel really sad. I don't want to bother other people with my problems. Then I just accept that I don't have the money and that I can't go anywhere'* (Female patient, age 37). And a 65-year-old female

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patient explains: *'Sometimes I feel like a burden, and I also pray to god to give me a job every day. I have tried to find a job, but with no luck. It's just that I am sometimes scared to ask for money because I feel like a burden. And then I just give up and leave everything to god'*.

Some are afraid to ask for support, because experiences in the past makes them believe that they bother other people when they ask for support: *'I'm afraid to ask, because I once tried to borrow money from the neighbours and they refused to help me'* (Female patient, age 35). The reaction of potential support providers on a support request also influences the support-asking behaviour according to a female professional nurse: *'You might ask for the first time, and a second time, but maybe when you ask for a third time they won't give it to you. And they will give you bad feelings by saying something bad about you asking for something, which will hurt you in such way you don't want to go back and ask again'*.

#### *Not disclosed*

It often occurs that patients have not disclosed their HIV-status, which creates a support receiving barrier for themselves. They don't want others to know about their status, because they are afraid of others' reaction or they just don't accept their own status in the first place. A female professional nurse explains: *'They've been denying, they don't come out, they don't tell they are sick. You will see her along the road, moving like that [moves like a disabled person], but when she comes in home, she brings up herself, she tries to bring up. Because she does not want to be known. And then if you would tell someone, they will be supporting me here and there. To say 'no, hold on like that'. But if I don't say anything, I will end up dying, I will die, with no help. As a result, at home you will find a parent who will say 'you are lazy' to someone who is sick. But if she knew you are infected, she would know that it's a long process, that sickness goes a long way. And then she would give a good support'*. A male professional nurse also assumes that some patients would have received help if they would have disclosed their status. He gives an example about his own experiences: *'We have a case of a patient on treatment here who didn't tell her mother she was in this clinic (...) So the mother took her to the traditional healers, because the mother didn't know she was on ART<sup>21</sup>. And then she died, it is bad. She died, it was only then that the mother knew that she has been attending at our clinic and being on treatment. Had she informed the mother, I'm sure she wouldn't have taken her to the traditional healers'*. A 61-year-old female patient also expresses her realisation that people cannot support someone if they don't know about their status: *'Spiritually we do get support here at Tapologo. We usually pray in the morning and sing and read the bible. But at the church we don't get any support, but I think that's because they don't know our HIV-status'*.

#### *Afraid of gossip and being blamed*

Patients are often afraid of the opinion or reaction of people in their environment. They are concerned what others will say about them, when they find out that they are HIV-positive: *'People are gossiping about persons who are infected and they are not visiting them anymore, they don't want to enter their house, because they think they will be going to be infected. So that's what would happen if I tell my friends. The only other ones who know are the people around here at the clinic'* (Female patient, age 48). A 40-year-old male patient also claims that he will not ask for support, because he is afraid that people will gossip about him: *'If you need help from other people, like financial support, people will just help you with financial support. But inside they will just go around and tell people you were asking for help. Like after you just left him and go to*

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<sup>21</sup> ART is not working in combination with some traditional medicine and can therefore not be taken together

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*your home he will just go and tell other people that you were asking for money. So then I decide if weather I will ask this person or another person. But in the end, I will not ask anybody anymore, I can't trust them'. And a 65-year-old female patient: 'Sometimes, when you are here, it usually feels that you are hiding, because you are afraid that maybe someone sees you and starts telling around'. Also professionals acknowledge this fear of patients: 'Some people think that if they will ask help from you they will just tell other people that you asked help from them, they are afraid of other people's reaction and will not ask for help' (Female professional nurse).*

A female head nurse explains why people are concerned: *'I think it's because of the stigma, it's still there much there. And people are scared of being rejected by society, rejected by family members and by friends. So I think that's why they don't disclose and ask for support. And because they are scared to be labelled, you know. The first thing if you say you are positive in our community the person is looked upon as been having immoral sleeping around, having a lot of partners'. And a 38-year old female patient explains: 'Given the fact that everybody thinks that HIV is the worst disease that could happen to someone, people don't take it like any other disease. I think the problem is people are always afraid of 'should I be positive, what will other people say about me'.*

#### *Not common to ask*

The fear of asking other people for support can also be caused, or at least enhanced, by the general view that it is not common to ask for support from others outside the family as explained in scenario one. It is, so to say, against the moral codes of behaviour and hence, patients do not always feel comfortable asking support from others: I: *'And why don't you ask money from other people?' P: 'I'm not used to that. I'm not used to ask money from other people, I'm only used to ask from my family, because my parents taught me not to ask other people for money' (Female patient, age 34). And a 35-year-old female patient explains: 'I am afraid to ask for money from neighbours, but as for my family I can'. I: 'Why do you think you can ask for money from your family and not from the neighbours'? P: 'Just because at the neighbours they do have their responsibilities, so I can't just go and ask them for money or anything'.*

#### *No need to talk or ask advice*

Some patients point out that they don't feel the need to talk with others and therefore don't ask for support: *'The thing is I'm not too much of a people's person, I usually sit at home alone (...)'. However, later on in the conversation this patient seemed to have some difficulties talking about her situation, rather than not wanting to talk: '(...) The thing is, people that are affected, infected and affected, usually they never talk about it, so it is a bit difficult to even say something about it, because it feels like that people are surprised at you that what is it you are talking about. People turn to rather keep it to themselves than talk it out.' (Female patient, age 65). And an 69-year-old female patient: 'I find it difficult to talk about it, it is my secret (...) even if I get very sick, I won't tell anybody anything, I just don't feel like talking' (Female patient, age 69).*

Some patients notice that they don't want to approach anyone in order to ask for information or advice; they rather search for information themselves without personal contact. *'I have never been to anyone before, I don't need advices from others, I can find them out myself. But usually magazines and pamphlets do help. Like my son is working in the mines and then there they usually give out those pamphlets, so I usually read the information from the pamphlets and magazines, because magazines tell the story every week about HIV' (Female patient, age 48).*

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#### 4.2.4 Scenario 4: Wrong or contradictory social support

The previous scenarios all relate to the absence of social support. Having no one to rely on due to the physical absence of possible support providers, being excluded from support provision and patients withholding themselves from asking support, all lead to the absence of support provision. In this last scenario, by contrast, it is not a matter of not receiving support, but of receiving wrong or contradictory social support.

##### ***Misconceptions about HIV/AIDS<sup>22</sup>***

###### *Traditional medicine*

Patients often have people in their social network who believe that traditional medicine is the answer to HIV/AIDS related complaints. They don't believe that ARV-treatment will benefit the patient and therefore advise the patients to use traditional medicine instead: Patients even get the advice to quit their treatment: *'The community people sometimes they say 'you should leave the treatment, the treatment is waste of time, we should go to the bushes to find traditional medicine, just to heal ourselves, this medicine is waste of time'* (Male patient, age 65). And as a 33-year-old year old female patient explains: *'The people who are passing on the street they will go to the community and tell: 'we saw whoever and whoever at the clinic, that means that person is sick' and they say that we should leave the treatment, we should go to the bushes and find a cure'*. Both patients and professionals assume that a lot of people still believe in these traditions and are therefore not capable of giving beneficial informative/advisory support.

The negative consequences that arise when family members, friends or other possible support providers believe in traditional medicine takes shape in the absence of beneficial informative/advisory support. However, the statements of patients also indicate that advice concerning traditional medicine has a negative impact on the emotional well-being of patients as well: *'I'm getting very angry and frustrated and say to them that they should leave that things about traditional medicine and that they don't know about it'* (Female patient, age 37). And: *'I feel sad if people tell me all of these wrong things, because they don't understand the situation, then I feel like I'm totally alone'* (Female patient, age 50).

###### *Worrisome stories about HIV/AIDS*

Besides the belief in traditional medicine, patients are also confronted with worrisome stories related to HIV/AIDS. People in their environment provide information and advice about HIV/AIDS which will not benefit the (emotional) well-being of the patient: *'Some people don't usually give you the right information. Like when you are sick and you are at home and want to go to the clinic and you know that when you are at the clinic they will take you to the hospital. Some people will say 'Owh no, hospital, people go to hospital, they go there for two days and then they will die'. So you are getting a state of 'I don't want to go to the clinic, because the clinic will take me to the hospital and then I will die'* (Female patient, age 26). These stories might be told with the right intentions, but this will obviously not benefit the patient, for example by hindering the acceptance process of the patient: *'What they always say is that a person living with HIV will die. That HIV is a killing disease. So then people get scared and don't want to know about their status. They don't want to be a person who dies'* (Female patient, age 32).

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<sup>22</sup> In-depth information concerning misconceptions about HIV/AIDS falls beyond the scope of this study. See for more information the master thesis of Linda van der Kevie: "HIV is definitely not the end of the world!?"

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### *Lack of knowledge or stubborn culture?*

As mentioned in the previous paragraphs, people in the informal social network of the patient often lack the knowledge when it comes to HIV/AIDS related information. When it comes to the provision of wrong advices, this is also due to a lack of information. As a 42-year-old female patient states: *'They don't know any better it's because they have never been giving lessons or being told about HIV'* (Female patient, age 32).

However, some patients and professionals assume that this is not due to a lack of information provision, but just because they are 'stubborn': *'The thing is, they don't want to accept that HIV is there, they are denying'*. And a female care worker explains: *'Well, when it comes to us black people, we are just too stubborn. If you belief something it's not easy to change your belief or anything'*. And: *'People will say to a patient: 'We are Africans, we have to follow our roots''* (Female professional nurse). Sometimes people indeed receive information, but they just don't want to know about it. The experience of a 32-year-old female patient: *'Here in Tapologo they have some pamphlets. And the patients are supposed to take these pamphlets with them and give them to the people who live in the community. So that people should be aware that Tapologo is here and that Tapologo can help them. And when I'm giving the pamphlets to them, they say I have to go to the bushes and find the traditional medicines. And they say 'no, I don't need the pamphlets, you should take the pamphlets back to Tapologo and tell the nurses that we don't need it'*.

### **Contradictive signals of Tapologo**

#### *Accepting HIV/AIDS?*

The support of Tapologo often benefits the well-being of patients in various ways, via different forms of support provision. However, their actions are not always in line with their advice. Although Tapologo preaches about accepting HIV/AIDS, even care workers sometimes gossip about patients within the community: *'Even some care workers are sometimes doing that, gossiping about the patient and they know that it is wrong'* (Female care worker). And a 39-year-old year old patient states: *'Sometimes when they [the caregivers] get drunk or maybe they have an argument and they start arguing, that's when they start talking about it, about who has HIV or stuff like that'*.

The same applies to information about infection and re-infection. Tapologo informs patients that you cannot get infected with HIV by sharing cups and by eating from the same plates and so on, but the nurses and care workers only want to use their own dishes at the clinic: *'We [4 female patients in a focus group discussion] have all experienced it, even here at the clinic. The nurses have the tendency of like say for instance, we have our own water, like this water is for people that are positive and the cups, you are the only one who uses them, other people won't use it. You can just see that you are not accepted, not even here at the clinics, by the nurses. And it really hurts, especially when you get discriminated by nurses who should know better'* (Female patients, age 46).

Furthermore, some nurses and care workers advise their patients to hide their disease from others and treat their disease as a secret: *'We are just telling the patients during the counselling, it's our secret, you don't have to tell everyone. You don't have to just tell everyone, because some people will just start discriminating you and saying you have HIV/AIDS'*. Although these recommendations are provided with the best intentions, namely to protect the patient from negative reactions in his or her community, this will often only enhance the (self) stigmatising of the patients. Above all, this type of advice is contradictive to the emphasised importance for patients to talk about their disease.

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### *Advising condom use, but not providing them*

Support provision from Tapologo concerning the use of condoms sometimes also is contradictive. Although nurses and care workers at the clinics advice their patients to use a condom<sup>23</sup>, and condom use is not a problem for Tapologo ‘founding father’ Bishop Kevin Dowling, condoms are not always available at the clinics and some clinics don’t provide condoms at all. In these cases, Tapologo gives the advice, but not provide the necessary ‘tools’. Policy about condom provision seems to differ per clinic or individual Tapologo professional. In Freedom Park, there are condoms available, but patients need to ask for them or secretly sneak away and get the condoms which are stocked in a separate room: *‘We put them in a box in counselling room in here. They know we educate them who ever need a condom come and get a condom. You know, because you can’t give me a condom while I don’t want it’*. And: *‘We respect them, there are those who will ask for condoms and there are those who will tell you that I don’t use a condom, because I don’t have a boyfriend, I dropped my boyfriend. Meanwhile the patient is lying, but I don’t push them and say ‘take, take, as if I encourage them to go and sleep around’* (Female professional nurse). In Kanana, patients notice that condoms are not available: *‘No, I don’t think I ever saw a condom here, I normally go and get them from the mines’* (Female patient, age 26).

Irrespective to the different condom policy per clinic, condoms are never provided by Tapologo as an institute. Individual care workers or nurses have to go to governmental clinics or the mines in order to ask for condoms: *‘We actually asked for condoms from the government clinics, and then we take them to our clinics’* (Female professional nurse). A female head nurse explains why the standards with respect to the provision of condoms differs per clinic: *‘You have to go as an individual to the government clinic and say, ‘can I have condoms, because I have patients that need condoms’, just to make it easier for the patients’*. I: *‘So you can’t get them from Tapologo?’* P: *‘No, because it is Catholic based’*. I: *‘But the Catholic faith does allow you to advice or doesn’t it?’* P: *‘Yes, you can advice, but you cannot provide. But the professional nurse there [in the clinic] can go out and ask for them from the government, they would give us boxes with condoms’*. I: *‘But if the government would give the boxes, why are they not everywhere at the clinics?’* P: *‘Again like I said it’s not policy that we give them out. They must go and get it wherever, but not at Tapologo. Tapologo is Roman Catholic, so there are individuals [nurses] who might also feel strongly that ‘I can’t give out condoms because of my religion’ so it’s individual (...) ‘The Catholic religion says no condoms, no contraceptives. But again, those nurses who want to give them can get them from the government to make it easier for the patients’*.

This fragment explains why some clinics do provide condoms and others don’t. It all seems to depend on the ideas of individual nurses in charge of the clinics, since the provision of condoms is not part of the policy of Tapologo. However, some give other signals about this ‘condom policy’, since another female head nurse even reacts surprised when she hears that condoms are not always available: *‘I’m sure that by the time you were there they were finished. We do try to supply them, because we cannot encourage them to use them, while we don’t supply them, neh?’*

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<sup>23</sup> See paragraph 4.1.2: Informative/advisory support

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#### 4.2.5 Conclusion: Answer sub-questions 3-4

Based on the aforementioned analysis in paragraph 4.2, the remaining two sub-questions 3 and 4 can be answered.

##### **3: Do patients experience and Tapologo professionals notice a lack of (beneficial) social support?**

In general, patients seem to be very happy about the support they get from their social environment. The way they tell about the support they get, for example their enthusiastic stories about the Tapologo support group sessions and their fellow patients, implies that they feel the support is beneficial to them. Also the support of family members who take care of them while they are sick, who give them money or who function as a confidant is very much appreciated. Some patients have a supportive network and feel loved and cared for by their social environment. They feel accepted and understood, they have a confidant to discuss their problems with and they expect that there will be people in their network (mainly relatives) who will take care of them in case they will get sick.

However, patients and professionals indeed notice a lack of social support. It often occurs that patients don't get support from their social environment, at least not from every of the distinguished support providers. Friends of the patients are generally not supportive at all and even gossip about the patient. Partners sometimes leave when they find out about the HIV-status of their partner. When it comes to instrumental and financial support, patients can usually only receive this from family members or male partners and not from other ties. And even these family members, who are generally viewed as the main support providers, sometimes withhold support. Besides having one or more ties that are not supportive, it even occurs more often that patients are totally abandoned with no one who takes care of them. They are left alone in their houses and sometimes even die alone in the house. These patients rely more on the support Tapologo offers, but even Tapologo sometimes provides wrong or contradictory social support, which is not beneficial for the patient.

##### **4. What might be barriers (and enablers<sup>24</sup>) in asking and receiving (beneficial) social support?**

The negative consequences of the aforementioned absence of (beneficial) support finds expression via four different scenarios: (1) patients don't have anyone to rely on (lack of network ties), (2) potential support providers refuse to give them support, (3) patients withhold themselves from asking support and (4) patients receive wrong or contradictory support.

The first scenario occurs when patients don't have anyone who can be approached for support, or put differently, when patients experience a physical absence of possible support providers in their social network. This scenario occurs when people are migrated to the Rustenburg area in order to work in the mines or, concerning women, to find a man who will provide her with an income. These people lack extended family, who would normally be approached to provide support. When it comes to the women, their boyfriends who often have a wife in another country, often already left her. Creating a new social network is sometimes difficult for immigrants, since patients often experience that it is just not common to look for people outside of the family. Friendships are based on rational calculation and 'it is everyone for him or herself'.

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<sup>24</sup> 'Enablers' is put between parenthesis, since this was not part of the original formulated sub-question, but is included to create a 'complete picture' of social support provision.

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In scenario 2 potential support providers refuse to provide support due to various reasons. In general, people give priority to their family members above their friends; it is not common to give support to people outside of the family. Their (financial) circumstances are that poignant that they are forced to make decisions and the general rule is family first. However, this can be a matter of not being able to give support, not willing to give support or a rational calculation based on whether the patient can refund financial support. Support is also refused due to HIV/AIDS related discrimination. Families blame their sick family member for their past behaviour or for degrading their family status. Families are often extremely concerned about what others will think of them, having an HIV-infected family member. Their status in society is sometimes more important than the well-being of their relatives. Friends and partners (if not married) are normally weak ties and therefore often don't feel any responsibility to provide support. They often easily leave when finding out about the HIV-status, discriminating the patient themselves or being afraid of being associated with someone with HIV/AIDS and therefore being stigmatised themselves. This stigmatising behaviour is addressed by a lack of information and education about HIV/AIDS. Finally, gender roles form a barrier as well. Men will usually not do 'female tasks' like cleaning and nursing, which even seems to be inappropriate.

Obstacles in asking support (scenario 3), occur when patients don't feel comfortable asking for support, or in other words when they feel like a burden. However, the main reason for not asking for support is the fact that they don't want to disclose their HIV-status, since they are often afraid for the (negative) reactions of their environment. They stigmatise themselves by being afraid of gossip, discrimination and accusations of others. Patients also don't ask for support because they feel it is not common to ask and it is against the moral codes of behaviour to ask for support outside of the family.

While the aforementioned scenarios all lead to the absence of social support, scenario 4 includes wrong or contradictory social support. Sometimes patients receive support that is not useful to them. They get, for instance 'wrong' advice concerning the use of traditional medicine and worrisome stories about HIV/AIDS are revealed to them. Although this type of advice might be provided due to a lack of knowledge about HIV/AIDS, some assume that it is more a matter of 'being stubborn'. Tapologo gives contradictive signals as well. They preach about accepting HIV/AIDS, but even Tapologo care workers sometimes gossip about the patient. They give information about how you can get infected, but at the same time nurses don't want patients to use the same cups as they do. They also recommend patients to keep their status secret to community people. Furthermore, they advise their patients to use a condom, but they don't (always) provide condoms, due to their Roman Catholic religion. These results show that even Tapologo, although probably unintended, contributes to the conservation of HIV/AIDS related stigmatisation.

Within these barriers of the four scenarios, there are some general barriers notable that capture all the scenario specific and support provider specific barriers. HIV/AIDS related stigma and discrimination is a ever-recurring factor that forms a barrier for support provision. Not only the actual performed stigmatising actions from the support providers themselves, but also the fear of patients and possible support providers to be stigmatised influence the support provision. Also the socio-economic context of the Rustenburg area, including a lack of resources (finances and information) and a lack of social network, or at least strong ties in the social network, form a dominant barrier for the provision of support. People lack the information to give the right advice and when it comes to the money story, they are forced to set priorities with respect to who they will support. This is usually in favour of a relative. A lack of information also results in the conservation of HIV/AIDS related stigmatisation. Furthermore, the cultural norms and values function as a general barrier, including traditional gender roles and the common view that family is supposed to be the main support



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provider. Last but not least, the continuing believe in traditional medicine against western medicine is an ever-recurring general factor that forms a barrier in the provision of support.

*Additionally: Enablers (the other way around)*<sup>25</sup>

The assumptions on beneficial support and the stories about barriers automatically refer to, besides support needs and support barriers, the enablers of social support as well. Some of the mentioned barriers can function as an enabler as well. The negative aspects of the barriers for one person can function as a positive enabler for the other. Family members, for example, are generally considered as strong ties of the patient. It is culturally determined that they take care of a sick family member which is therefore an enabler to receive support from a relative, but a barrier to receive support from a non-relative. Although gender inequality can form a barrier to provide support, this can also function as an enabler. Male partners are culturally determined to provide financial support and female partners are determined to provide instrumental support. Within these findings, some general features of a possible support provider that enables support provision noteworthy. A potential support provider who accepts HIV/AIDS (no stigma), who has resources (money and knowledge) and who has a strong network tie with the patient (normally a relative) and who is culturally determined to take care of the patient or not culturally restricted to do so, will, according to these findings, facilitate or enable the support provision.

#### **4.3 Answer to the main research question: support provision model**

*What are the assumptions on (beneficial) social support for black HIV-positive individuals and why might support be lacking, according to patients and professionals of the Tapologo ARV-outreach programs around Rustenburg, South-Africa?*

By answering the four sub-questions as described in paragraph 4.1.6 and 4.2.5, the overall research question has already been answered. To avoid repetition, this paragraph focuses on portraying a an overarching summary via the presentation of the completed social support provision model in figure 2.

The results show that patients have various social support needs, for example emotional support, such as being accepted and informative/advisory support such as getting advice concerning infection, re-infection and living a healthy lifestyle. The left column of the model includes these considered beneficial support needs, per type of social support. The right column contains the most outstanding support provider specific<sup>26</sup> enablers and barriers retrieved from the data. Kin relatives, for example, are normally a strong tie which facilitates support and therefore functions as an enabler. However, families sometimes also blame the patients for their past behaviour and/or are afraid of the damage of their family status in society (due to stigma), which forms a barrier.

There are some general barriers and enablers visible which capture and supplement all the support provider specific barriers. General enablers include accepting HIV/AIDS and having strong network ties. Examples of general barriers are HIV/AIDS related stigma and cultural norms and values. These general enablers and barriers are presented in the middle column of the model. Sometimes the same factor is both mentioned as an enabler and as a barrier due to the fact that some of the mentioned barriers can function as

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<sup>25</sup> Although enablers are not explicitly mentioned in the research question, it does give a more complete view to include them and are therefore included in this paragraph and the upcoming support provision model.

<sup>26</sup> Colleagues/fellow patients are deleted in the completed support provision model, since they were never mentioned as a support provider, which can at least partly be explained by the high unemployment rate and lack of education.

an enabler as well and vice versa. The negative aspects of the barriers for one person can function as a positive enabler for the other, depending on the type of relationship. For example traditional gender roles (as part of traditional norms and values) function as an enabler when it comes to a male patient who needs to be nursed, but a barrier in case it concerns a female patient who, due to these gender roles, won't be nursed by her partner. Furthermore, the arrow from socio-economic resources to HIV-related stigma shows that a lack of resources (information) results in the conservation of HIV/AIDS related stigmatisation.

The presence of enablers will normally lead to the provision of beneficial social support; the presence of barriers (or the absence of enablers) will often lead to the absence of (beneficial) support provision. This absence of (beneficial) social support finds expression via the four different support lacking scenarios: (1) patients don't have anyone to rely on (lack of network ties), (2) potential support providers refuse to give them support, (3) patients withhold themselves from asking support and (4) patients receive wrong or contradictory support.

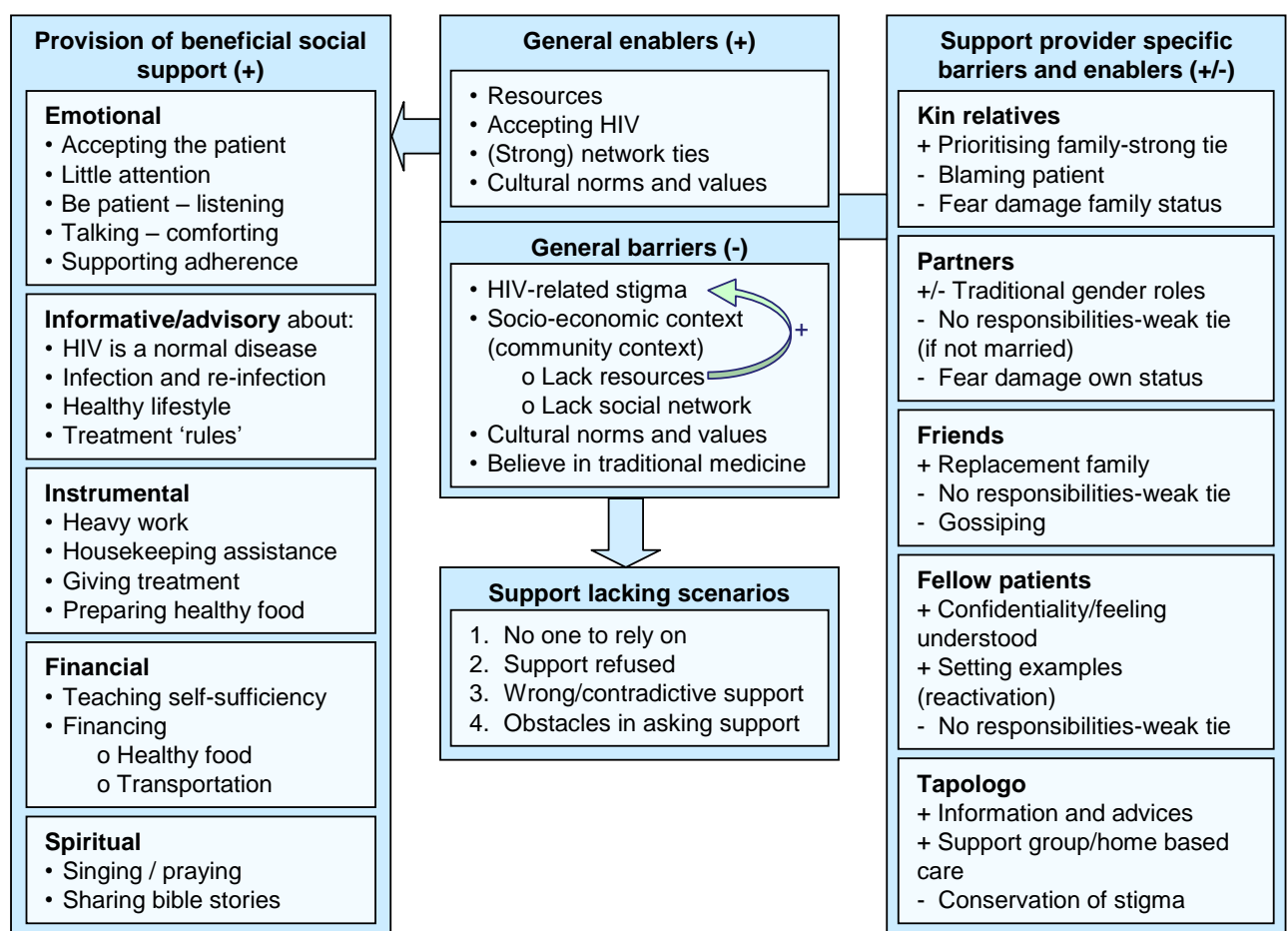


Figure 2: completed support provision model

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## Chapter 5 Conclusion and discussion

### 5.1 Theoretical reflection on findings

This paragraph elucidates how the research findings relate to some starting points derived from the literature review, by linking and comparing the results to the theoretical framework. The findings of this study are often in line with existing theories in the literature. Patients and professionals of the Tapologo programs thereby confirm these existing empirical findings and theories. However, as will become obvious, some of the findings add to the existing literature or are more or less contradictory.

#### *Beneficial social support*

The findings of this study give more insight in the support for HIV-positive individuals that is considered to be beneficial. These results are schematically presented per type of support in the left column of figure 2.

This study adds to the existing literature by providing new information about beneficial social support for HIV/AIDS patients in this specific context that was not yet explicitly mentioned as such within literature. Although the findings are often in line with existing literature (in case there was literature available), this study adds a complete overview instead of separate fragments indirectly derived from different studies. The results are in line with other studies focusing on black HIV/AIDS patients in South-Africa. Moratioa (2007), for example, concludes that religion plays an important role for patients, it gives them hope and a feeling of relief, which is in line with the findings of this study. Also the ideas of Feitsma et al. (2007), concerning the need for provision of healthy nutrition as a part of their instrumental needs are in line with the findings of this study.

The results of this study show that all the different types of support seem to be of importance, but in this context, financial support is of substantial importance, since the financial circumstances of patients in this context are extremely poignant. Furthermore, since people in this context often lack education, informative/advisory support is also extremely necessary. HIV/AIDS patients are often discriminated in this context (which can also, at least partly, be caused by a lack of information). This enhances the wish of patients to just be accepted by others. Therefore, beneficial emotional support is extremely relevant as well. It can be concluded that the specific support needs of HIV/AIDS patients in this context are, at least partially, determined by the poor socio-economic context of this area.

#### *Role different support providers*

Derlage et al. (2003) state that the social support patients receive, depends on the type of close relationship the patient has with the potential support provider. Berkman (2002) adds that some ties within the network provide just one type of support, while others provide different types of support. The results of this study confirm this theory. For example family members, who are generally considered to be a strong tie with a close relationship, often function as the main support provider, while friends, who appear to have a weak tie and easily leave, often withhold support. Fellow patients normally only provide emotional and informative/advisory support, while family members often offer more types of support.

Subsequently, in line with the findings of Thoits (1995), the role of fellow patients is extremely important. Fellow patients are indeed often considered as the most effective support providers since they have, due to their own experiences, the ability to offer beneficial support in line with the actual support needs

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of the patient. In addition to these previous findings, this study shows that fellow patients are also often more trusted than other possible support providers. Patients feel free to talk openly about their situation, which can be the effect of the absence of fear for stigmatisation, because fellow patients are in similar situations.

Friends have a more subordinate role as a support provider than the literature review suggested. Derlaga et al. (2003) conclude that it is more difficult for HIV/AIDS patients to seek and receive support from family members than from friends, due to the more voluntary character of relationships between friends compared to family. Although the results of this study show that relationships with friends are indeed more voluntary, the results show that this functions as a barrier instead of an enabler. Their ties are, due to this voluntary character, often weak, causing them to hardly feel responsible to provide support and in some situations even terminate the friendship. The trusting aspect of friends as mentioned by Derlaga et al. is also absent in these findings. Friends are often not trusted at all and patients therefore often don't even disclose their status to them, which automatically creates a barrier for support provision. The same goes for partners. While the literature assumes them to be very supportive, due to mutual attraction, trust and common interests which are the main characteristics of partners (Derlaga et al (2003), the findings of this study don't support this theory. This can be argued by the findings that (sexual) relationships are in this context not always necessarily based on these characteristics, but on the base of exchange of money and sex instead.

Family (in case they live nearby) normally function as the main support provider (in case other barriers are not present). This is in line with the theory of Sagner & Mtati (1999) that the nature of kinship regarding to social support is associated with morality, including mutual responsibility between kin, also in situations in which these responsibilities are actually a burden.

#### *General enablers and barriers*

The middle row of figure 2 reveals some general barriers and enablers of support provision. Most of these elements are already (indirectly) mentioned in the literature review. The results of this study show for example that socio-economic contextual factors function as a barrier for support provision. These factors include a lack of resources (finances, information), which is in line with the findings of the Department of Health (2003) and a lack of ties within the network, in line with the findings of Marais (2005). In addition, Moratioa (2007) states that networks can spread wrong information by encouraging traditional medicine instead of ARV-treatment, which was also evidently visible in the result of this research.

However, this study also adds something to the factors that function as a general barrier or enabler. First of all, the results of this study show that cultural norms and values function as an important general barrier (or enabler) of support provision. Traditional gender roles enable the provision of material support from a female partner to a male patient, but form a barrier to provision of material support from a male partner to a female patient. Furthermore, the norm that it is not common to ask for support outside of the family forms a barrier to ask and/or receive support from non-relatives. Cultural norms and values as a barrier are not mentioned in the literature as such and therefore supplement the existing theories.

Subsequently, the results of this study provide more in-depth information about HIV/AIDS related stigmatisation as a general barrier. The literature review suggests that possible support providers might stigmatise the patients and therefore withhold support (Heyer and Ogunbanjo 2006) and that patients sometimes stigmatise themselves which forms a barrier to ask for support (Nachega et al. 2004). Although these literature suggestions are in line with the findings of this study, the current study reveals that possible support providers are not only directly discriminating to a patient themselves, but are afraid of other peoples'

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reaction when they know their partner, child or friend is HIV-positive. The results show that possible providers are often extremely worried of what others think of them and afraid of the violation of their own status in society. They are afraid to be stigmatised themselves when they are associated with someone living with HIV/AIDS and therefore withhold support.

## **5.2 Reflection on this study**

Looking back on this study, there are some critical points which are noteworthy to mention. First of all, the recruitment of respondents was, at least in Kanana and Tlaseng, on voluntary bases. Therefore, one needs to consider that only the most self-confident patients participated in this study, while less confident patients, who possibly have another view on the topic, are not included. Furthermore, the opposite also occurred. The interpreters mentioned that they had the idea that patients in Freedom Park felt more or less obliged to participate. If this is true, it might be that these patients did not feel like talking and therefore gave a biased opinion during the interviews, lacking confidence with respect to their own stories. For future research it might be of importance to discuss the participation process in more detail with the professional nurses.

Subsequently, patients often literally copied the words or sentences professionals use in their support sessions to express their thoughts. The phrases '*HIV is not the end of the world*', '*you can still live a longer life*' and '*you have to accept your status*', are cited by several patients and professionals. Although it doesn't necessarily have to be the case, this might imply that patients were giving 'politically correct answers', namely those in line with the advice they get from Tapologo. This indicates that patients probably didn't feel completely free to talk, which might be attributed to a lack of confidence concerning the confidential character of the interviews. For future research it would be better to interview the patients outside the clinics, for example at their homes, so they might not directly associate the interviewer with Tapologo and feel more comfortable.

Furthermore, the provision of support by the different support providers is investigated via interviews with the patients and professionals. For a better understanding of the motives behind the decision to provide or withhold support provision, it is recommendable to interview these potential providers as well. By including their points of view, the results of this study might be more inclusive. The same applies to the inclusion of the points of view of male patients. Only one of the four interviewed male patients had a partner at the time of the interviews and also only two of the interviewed professionals are male. Therefore, the information about traditional gender roles and the dominant power in a relationship which is argued to form a barrier for support provision is practically only based on the opinions of women. Although interviewing few male professionals could not be avoided, since hardly any Tapologo employee is male, it is advisable for future research to discuss with the nurses in charge how to recruit more male patients. Furthermore, it can be expected that patients who are enrolled in the ARV-programs receive relatively more support than patients who stopped the treatment or potential patients who didn't even come for a test yet. For future research it is recommendable to find ways to get in contact with this 'lost' group and include these individuals well.

Finally, the fact that local translators are used during the interviews causes some difficulties during the interviews. First of all, having a mediator makes it more difficult to interact with the patient on the right moment (timing). Although the use of interpreters could not be avoided, we have to consider that possible 'bad timing' have resulted in the loss of important information. Secondly, it is unverifiable whether the interpreters indeed gave the same answers as the interviewed. Looking back, it would have been a good

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idea to let an unprejudiced (non-Tapologo) Tswana-English expert listen to the recorded tapes of the first interviews in order to judge the translations.

### **5.3 Recommendations**

#### *Future research*

In general, this qualitative research provides a lot of information about the situation of HIV/AIDS patients in the Rustenburg area regarding social support provision. This knowledge can be used in different ways during future research, for example by composing questions for a quantitative research to gather data of a larger research population, which makes it possible to generalise findings. However, the results of this study also generate some interesting starting-points for future research.

The support provision of the different support providers is investigated by interviewing the patients and professionals. Therefore, actions of support providers are only based on the views of these two groups. In order to get a better understanding of support provision, it is also interesting to investigate their views related to the topic.

Moreover, barriers to support provision in this research are only based on the way the potential support providers reacts on a support request, what support they give or why patients don't want to ask for support. However, for a more complete view of the process of support provision, it is also interesting to consider the way the patients communicate with possible support providers. How do they ask for support, or in other words, how do they approach the potential provider? Does the way a support request occurs, influences the provision of support?

Subsequently, the results show that the opinion about whether the community is close-knit and supportive or not, varies from person to person. Although there were different clinics (traditional villages versus informal settlement) investigated, the scope of this study didn't allow to make a clear division between the situation per clinic. However, it became evident that patients in Freedom Park (informal settlement) often lack extended family, compared to the other areas, which, according to the findings, causes difficulties in generating support since family is usually the main support provider. Nevertheless, some individual patients in Freedom Park mentioned that people easily bond, while others say 'it is everyone for himself'. Future quantitative research can investigate whether there are indeed significant differences between the different areas when it comes to community bonding and support provision. Future qualitative research can also find out how immigrants integrate in the community.

Furthermore, the results show that friends are often not supportive, which is contradictive to the findings in the literature which were based on research in the developed countries. Friends are often not trusted in this area, while trust was mentioned in the literature as a typical characteristic within the relationship between friends. Future research can investigate the relationship between friends in this area, such as on the basis of which characteristics do individuals become friends?

Finally, the results show that patients and professionals experience a lack of social support. However, it remains unclear how big this 'support lacking group' is. In order to investigate how serious the situation concerning lack of support provision is, this can be investigated by future quantitative research. Quantitative research can also be used to confirm or reject some hypothesis deriving from this study concerning which type of support provider is engaged in the provision of which type of support.

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## *Tapologo*

Although the aim of this study does not include an evaluation of the current Tapologo ARV-programs, the results of this study give rise to some recommendations to Tapologo.

Since support of fellow patients is considered as extremely beneficial, it is recommendable to expand the opportunities for patients to talk with each other. At the moment, Tapologo clinics only provide a counselling session/support group at the beginning of the clinic day, with all patients together, and it varies from clinic to clinic whether there is room left for interaction among the patients. Some patients didn't even experience the 'support groups' of Tapologo as such and reported that they would be interested in a fixed small discussion group of patients. It is advisable for Tapologo to arrange such support or discussion groups for their patients, independently of so called clinic days.

At the moment, Tapologo already often informs the family members of the patients about HIV/AIDS. However, community members and friends often appear to gossip about the patients and they often lack knowledge about HIV/AIDS. Therefore, it is recommendable to try to involve friends and community members as well by providing information sessions within the community, placing HIV/AIDS related billboards in the area or invite them to visit the clinics (which is currently not allowed during clinic days).

The poverty in the Rustenburg area is tremendous: almost all patients are unemployed and especially immigrants without a South-African identification card lack the opportunity to find a (legal) job. Although Tapologo doesn't have the financial resources to support their patients financially, they sometimes advise them to be self-supplying, for instance by planting seeds and growing vegetables. Patients appreciate these suggestions, but they never mentioned that they actually follow up with them. Therefore, Tapologo can consider initiating programs to set up vegetable gardens with and for patients, which they can maintain themselves.

At the moment, the distribution of condoms is not accomplished on a structural basis. Some clinics don't provide them at all and others get them from the governmental clinics, but only put them somewhere in a corner so that patients can secretly get them. There seems to be some vagueness about the condom provision policy of Tapologo, even among the staff of Tapologo (head nurses). Nevertheless, all professionals state that they do advise their patients about the use of condoms. Since even the 'founding father' of Tapologo (Bishop Kevin Dowling) promotes condom use, it is remarkable that some clinics refuse to provide them. It is undesirable that the ideas of individual nurses determine the use of such an important aspect of the fight against AIDS. It is advisable to Tapologo to review their 'condom policy' and to communicate this to every Tapologo employee.

Finally, the results show that Tapologo provides, besides this 'condom issue' other contradictive signals to their patients. They preach about accepting HIV/AIDS, but even Tapologo care workers sometimes gossip about the patients. They give information about how you can get infected, but at the same time nurses don't want patients to use the same cups as they use. They also advise patients to keep their status secret to community people. It is important for Tapologo to be aware of the fact that these contradictive signals might contribute to the conservation of HIV/AIDS related stigmatisation and to find ways to avoid this.

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## Appendices

### Appendix 1 Statistics Tapologo 2004 – 2009

Tapalogo started ARV roll-out in March 2004 (de Waal 2008).

February 2004 – January 2009		
	Started ARV treatment	Stopped ARV treatment (lost to follow up)
Freedom Park	253	60
Tlaseng	204	31
Kanana	300	45
<b>Total</b>	<b>757</b>	<b>136 (= 18%)</b>

Tapologo current patients at outreach clinics (February 2009)		
	Male	Female
Freedom Park	21	112
Tlaseng	38	76
Kanana	95	171
<b>Total</b>	<b>154 (=30%)</b>	<b>359 (= 70%)</b>

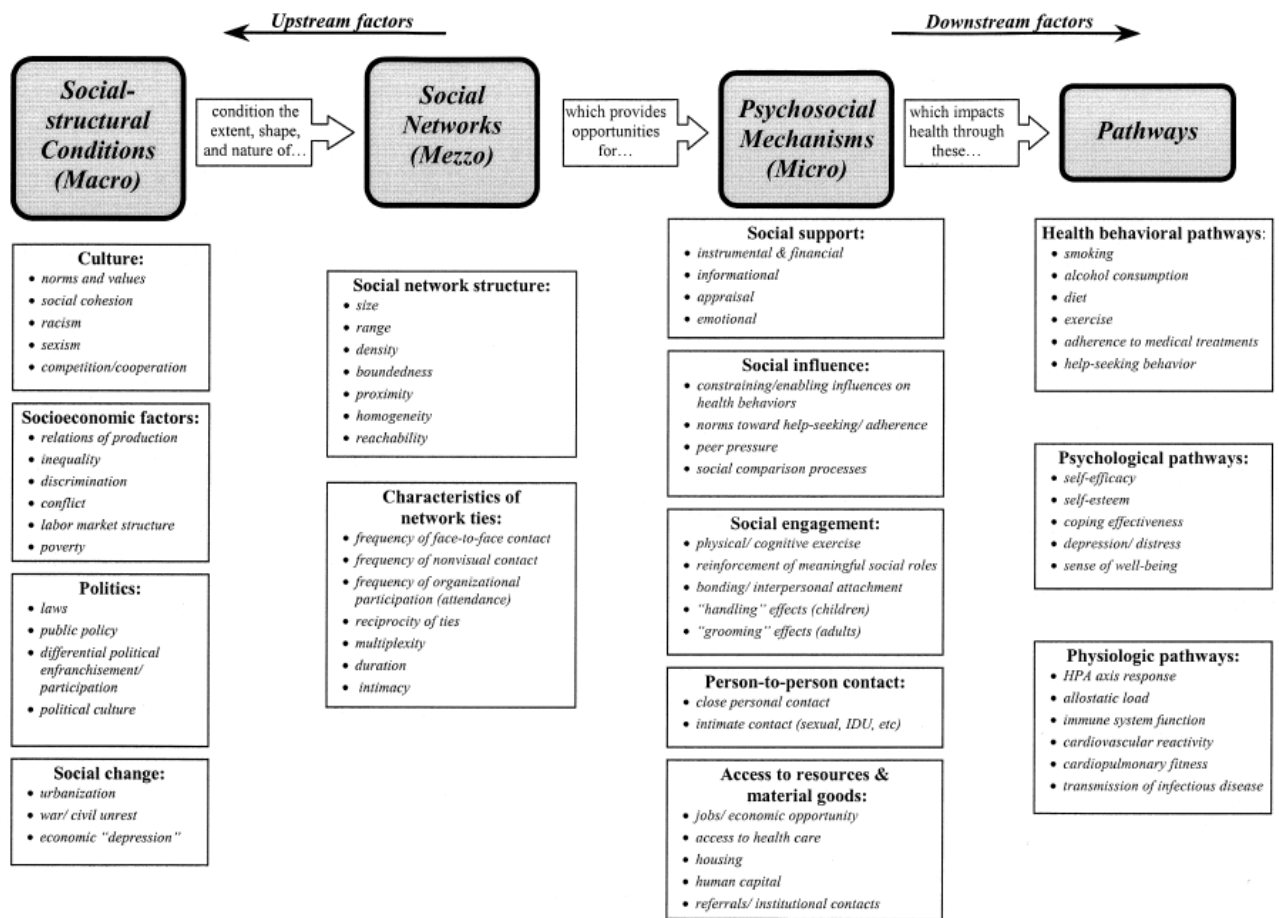
## Appendix 2 Statistics participants and research methods

Patients						
	Male	Female	Total	# individual interviews	# focus group discussion	Total interviews / discussions
Freedom Park	0	10	10	6	1 (1x4)	7
Tlaseng	4	6	10	10	0	10
Kanana	0	4	4	4	0	4
<b>Total</b>	<b>4</b>	<b>20</b>	<b>24</b>	<b>20</b>	<b>1</b>	<b>21</b>

Tapologo professionals						
	Male	Female	Total	# individual interviews	# focus group discussion	Total interviews / discussions
Care worker	1	9	10	2	3 (2x3, 1x2)	5
Professional nurse	1	3	4	2	1 (1x4)	3
Head nurse	0	2	2	2	0	2
<b>Total</b>	<b>2</b>	<b>13</b>	<b>16</b>	<b>6</b>	<b>4</b>	<b>10</b>

Age of patients interviewed			
	Male	Female	Total
< 35	1	6	7
36 – 50	2	11	13
> 50	1	3	4
<b>Total</b>	<b>4</b>	<b>20</b>	<b>24</b>

## Appendix 3 Conceptual model of how social networks impact health



(Berkman et al. 2000: 847)