

FINDING NEW WAYS TO FIGHT HIV/AIDS

TECHNOLOGY IN HIV/AIDS ORGANIZATIONS

IN THE WESTERN CAPE, SOUTH AFRICA



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Master Cultural Anthropology: Multiculturalism in a Comparative Perspective

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ABBREVIATIONS

AIDS:	Acquired Immune Deficiency Syndrome
AdvaMed	Advanced Medical Technology Association
ARV:	Antiretroviral
ART:	Antiretroviral Treatment
CD4	Cluster of Differentiation 4
CHW:	Community Health Worker
CIDA	Canadian International Development Agency
eHealth:	Electronic Health
HIV:	Human Immunodeficiency Virus
mHealth:	Mobile Health
ZAR:	Zuid-Afrikaanse Rand
SMS:	Short Message Service
TB:	Tuberculosis
TRA:	Temporary Relocation Area

PROLOGUE

On Wednesday February eight, 2012 I visited Delftⁱ for the first time. Delft is a township in the Western Cape Province in South Africa. It is located 30 kilometers outside of Cape Town; next to Cape Town International Airport. The township Delft was created for poor colored and black people during South Africa's apartheid-period. Like any other township, Delft makes a depressing impression. The houses are build closely together on barren sand plains. Although the area consists of officially built government houses, it is very impoverished. It is estimated that Delft had 60 thousand inhabitants in 2001; mostly colored and black people (City of Cape Town 2001; Klein and Wessels 2007:22-23).ⁱⁱ Almost half of these inhabitants has no education and more than half of the economically active persons is unemployed. Income levels in the area are very low (Klein and Wessels 2007:23-24). Crime rates in Delft are one of the highest in the Western Cape. The large inequality in the Western Cape area is said to be connected to this (Gie 2009:4).

An especially troubled area in the township Delft is Blikkiesdorp. During the research for this thesis I spent much time in this area. Blikkiesdorp, officially called the Temporary Relocation Area (TRA) by the government, was established in 2008 to manage illegal occupation in the Cape Town area (Western Cape Government 2010). In the media, Blikkiesdorp is mainly depicted as a concentration camp where poor people from in and around Cape Town were dumped prior to the soccer World Cup in 2010 (The Guardian UK 2010; Times Live 2012; MailEGuardian 2009; NPR 2010). The initial plan of the government was to provide temporary housing for homeless people. However, since its start only ten families have moved to permanent houses (Cape Argus 2012). Blikkiesdorp is currently inhabited by 17 thousand people (Cape Town Magazine N.d.). For these people there is not much hope that they can ever leave.

Entering Blikkiesdorp is like entering a camp. The area is surrounded by a gate, which separates the inhabitants of Blikkiesdorp from the rest of the township. I soon learned why many people call the area Blikkiesdorp. 'Blikkie' is Afrikaans for tin. For as far as I could see I saw rows of four by four meter houses made of tin. There are no trees and no grass in the area; just an almost endless expanse of sand and tin houses. On average, four people live in each of the tin houses. Every four houses shares one tab and one toilet.

The township Delft deals with many problems. One of these problems is the HIV/AIDS epidemic. Delft is part of the health district Tygerberg East where the HIV prevalence rate was 16 percent in 2006 (City of Cape Town 2008). The epidemic causes many societal problems such as poverty and high numbers of orphans. At the beginning of my research, I met a woman named Sarahⁱⁱⁱ who lives in Blikkiesdorp with her two daughters. During her whole life she has been affected by abuse, poverty and disease. Before she got a house in Blikkiesdorp she lived on the streets for years. As a homeless person in Cape Town she was raped, put to jail and worked as a prostitute to get money for food. She was diagnosed with HIV^{iv} a couple of years ago. Sitting next to me on my right side she could show me three big scars on her left arm. Sarah made three suicide attempts after finding out that she was infected with HIV. Now, her disease has reached the stadium where it can be called AIDS.^v This means that the disease has damaged her immune system so badly that it may become fatal. Sarah's main concern is the wellbeing of her children after she dies. There are few government services that can offer her daughters a good life.

Simultaneously, the health services in the country are failing. Delft has one government clinic for its inhabitants. The healthcare in the clinic is free of charge, but the quality is questionable. The corridors of the understaffed clinic are permanently overcrowded and the workload of the nurses is very high. Clearly, a part of the people who arrive at the clinic do not receive the help they need. The government's health services also have trouble reaching all HIV infected people. Because of the stigma attached to the disease many people do not go for HIV-testing at the clinics. Many people do not know their HIV status, because of this. If people do know that they are HIV positive, it is still a challenge for the governments clinics to keep these people on their medication since many clinics do not have the capacity to educate people properly about the need to take the medication.

Many non-profit organizations in the Western Cape try to support government services in their fight against HIV/AIDS and related problems. The organizations have different views on how to do this properly. Some of the organization use technologies to reach their target group. For instance, the mobile phone can be used to send SMSs^{vi} to patients to remind them to take their medication. Other organizations refuse to use technologies in their work and focus more on face-to-face contacts with patients. This thesis explores the use of technology in HIV/AIDS organizations in the Western Cape. It explores if

using technologies such as computers, the internet and mobile phones can contribute to fighting HIV/AIDS.

INTRODUCTION

Technologies such as computers, internet and mobile phones increasingly play an important role in health organizations because of their presumed flexibility and communication power (Castells 2001:131; Stoecker 2002:155, Tyrrell 2002:vii). Organizations have websites, e-mail lists, online campaigns, technology-based health interventions and more. Contacts between people and organizations are increasingly indirect instead of face-to-face (Fortunati 2005:54). This thesis explores how technologies are used in and influence HIV/AIDS organizations in the Western Cape in South Africa. The use of technologies in health organizations might affect the ways in which the organizations can effectively alter the large HIV/AIDS problems in South Africa. The goal of the thesis is to show if, when and which technologies are useful in specific local circumstances. Moreover, the thesis deals with questions about the role of technology in society.

Besides the effects on organizations, the use of technologies also alters the situation for HIV/AIDS patients. Patients can use technologies for information provision and/or contacts with other patients (Castells 2001:129, O'Grady 2008:262). The thesis takes into account technological possibilities of communication with and information provision to patients, but will focus on the point of view of the health organizations. The thesis thus does not look at how technology-based health interventions affect patients; although this is a field that does need to be explored in following research.

The anthropological approach of the thesis adds to literature on the use of technology in healthcare because it explores why people in organizations use certain technologies and how this is influenced by local circumstances. This thesis tries to connect technologies and their users by exploring the meaning that the technologies have for people. Researching organizations is not common in anthropology. However, it is important to do so in order to get a complete image of the use of technologies in healthcare.

The research for this thesis was conducted in South Africa, a very culturally diverse country. The results show that there are many differences amongst users of technology. Therefore, the thesis fits into the multicultural subject of the master *Multiculturalism in a Comparative Perspective*. Trevor J. Pinch and Wiebe E. Bijker (1984:430) argue that different social groups can construct completely different meanings of a technology. Moreover, within groups there can be very heterogeneous users that have a different relation to a technology

(Oudshoorn and Pinch 2005:6). This thesis takes into account the large heterogeneity of users and the different ideas they have about technology.

THEORETICAL CONSIDERATIONS

The Advanced Medical Technology Association (AdvaMed) defines medical technology as '*a wide range of healthcare products that, in one form or another, is used to diagnose, monitor or treat every disease or condition that affects humans*' (AdvaMed 2004). Distinctions can be made between different kinds of technologies in healthcare organizations. Clinical and ancillary technologies are used in the provision of direct healthcare, such as robot capable of performing complex surgery or anesthesiology and radiation therapy (WHO 1997:269). There are also technologies for the coordination, education and spread of medical data. These affect the healthcare more indirectly (WTO 1997:269, AdvaMed 2004). This thesis focuses on these indirect technologies such as the computer, internet and mobile phone.

Halfway the 20th century, the internet started to develop and from the 1980s onward mobile technology was developed (Castells 2001:9-10; Ling 2004:8). In the 1990s, the internet and the mobile phone became immediate successes (Ling 2004:9). The technologies are presumed to give HIV/AIDS organizations a wide variety of new possibilities for the management of health problems that range from finding new donors, supporters and information, to new ways of preventing HIV/AIDS and helping patients.

The use of electronics in health interventions is described as eHealth. mHealth interventions are health interventions with the use of mobile phones. This is an important subfield of eHealth (Vital Wave 2009:8; De Tolly and Benjamin 2012:311; Michael 2010:7). The field of mHealth is an emerging field and not yet established in healthcare. In the literature on mHealth, great expectations about the use of the mobile phone in healthcare are expressed. Authors speak of '*unprecedented opportunity*' and '*great potential*' (Vital Wave Consulting 2009:5; Michael 2010:7).

Technologies are useful in health organizations because they are cheap and fast. Moreover, they have a large geographical reach (Juris 2005:195; Stoecker 2002:157; Juris 2008:12). Many authors emphasize the importance of internet via computer, because this is a fast medium. The organizations are said to be able to react quickly to developments on regional, national and even international level because of the internet (Wasserman

2005:165). Authors emphasize that the internet is becoming the main information source for the prevention, control and treatment of HIV/AIDS (Gómez et al. 2002:75; O'Grady 2008:261). Below, the possibilities of technologies in healthcare organizations are discussed.

Information and Education

HIV/AIDS is a global disease which 33.3 million patients worldwide (UNAIDS 2010:21). Information about the disease need to be available globally. Through technologies, this information can be broadcast to a great number of people. This can save organizations a lot of energy in dealing with informational issues (Gómez et al. 2002:76, Stoecker 2002:148). A limitation of information gathering through technologies is that it can lead to an information overload. There can be too much interesting information on the internet or too many e-mails to read (Juris 2008; Gómez et al. 2002:76). Another disadvantage is that information on the internet can be incorrect. Robert J. Rodrigues and Ahman Risk (2003) explain that it is very difficult to know what information on the internet is reliable. Websites can be profit-driven, promote unproven treatments or contain wrong information.

Technologies give organizations more possibilities to present their own information (Stoecker 2002:147; Juris 2008:12; Castells 1997:129; Rodrigues and Risk 2003; O'Grady 2006; Gómez et al. 2002; Jbilou 2009:276). For instance, organizations which have their own websites can spread information through this. Being connected to a digital network can improve the access of people in remote areas to healthcare and healthcare information (Vital Wave Consulting 2009:5; Hammond 2001:99). An advantage of information gathering via technology is that the online information is always available for the user (O'Grady 2006).

Communication

Besides the informational function, technologies have become essential for the communication in organizations (Castells 2001:137; Jbilou 2009:276). E-mail, mailing lists, newsgroups, web-based message boards and more are used to communicate (O'Grady 2006). Using technologies for the communication with patients is attractive for organizations since it reduces the costs of communication and offers the possibility of fast communication with distant others (Bennett 2003a:144; Bennett 2003b:20; Juris 2008:12; Castells 1997). Because of technologies, some limitations in communication can be overcome. For instance,

people do not have to be present in the same time and space in order to have contact (Fortunati 2005:56; Bennett 2003b:20; Castells 2010; Jbilou 2009:276). Technologies provide health organizations with possibilities of monitoring, motivating and providing information to patients from a distance. As a result, patients do not always have to be present at a clinic for their treatment.

A downside of communication via technology is that the quality of the contacts might be reduced (Fortunati 2005:56). People are not able to read each other's body language and might therefore miss important communicational cues (O'Grady 2006). Marie Préau et al. (2008:467) argue that a trust relationship between the patient and the healthcare provider can positively influence the treatment adherence of HIV patients. A part of the trust in this relationship is dependent on whether the provider takes into account the personal mental and social conditions of the patient (Préau et al. 2008:470). If communication solely takes place through technologies these personal conditions cannot fully be taken into account. Because of this, it cannot be said that indirect contacts replace physical social transactions. HIV/AIDS organizations cannot function solely on indirect communication, because face-to-face contacts generate trust and affective ties that technology-based contacts cannot provide (Juris 2008:97).

Privacy and Confidentiality

In South Africa the stigma attached to HIV/AIDS is very big (Vital Wave Consulting 2009:50). Many HIV positive people are afraid of getting their HIV status disclosed, because the large social consequences can negatively affect them. People with HIV/AIDS can experience prejudice, discrediting, and discrimination from others (Herek 2002:595). Successful HIV/AIDS projects must thus take into account the privacy and confidentiality of patients (Vital Wave Consulting 2009:42). HIV/AIDS organizations need to handle information in a confidential manner. Communication and information provision through technologies can meet this need. For instance, people can look for information on the internet alone and in a private environment (Hammond 2001:99; O'Grady 2006; O'Grady 2008:261). Allen L. Hammond (2001:100) describes how people can obtain the information about HIV/AIDS on the computer that they might be too embarrassed to ask a health worker for.

The mobile phone might be a less useful tool since mobile phones are often shared by people in the developing world. Not all people have the financial capacity to buy their own mobile phone. This means that the mobile phone is not always a private tool because others besides the patient could possibly also read the HIV/AIDS-related information (Mechael 2010:34).

Follow-up Appointments and Treatment Adherence

An often described problem in HIV/AIDS treatment in both the developed as the developing world is incomplete treatment and the low number of patients that come for follow-up appointments (Pop-Eleches et al. 2011:826, Gómez et al. 2002:85). Since HIV is a possibly fatal disease, proper management and follow-up of patients is very important. Permanent communication between the healthcare provider and the patient might help keeping the patient involved in the clinical system. The mobile phone can be useful because it is able to send short texts to patients easily. Sending these messages is relatively cheap and in thus useful in underdeveloped settings (Mechael 2010:22). The mobile phone can be used to send reminders to patients about taking their medication (Pop-Eleches et al. 2011:827; Vital Wave Consulting 2009; Mechael 2010). The reminders might help patients with taking their medication at a set time and can therefore increase treatment adherence of patients. The mobile phone can also be used to send reminders to patients about medical appointments. Through these messages, the follow-up of patients might be improved (Mechael 2010:16-20).

E.J. Gómez et al. (2002) explain how a web-based computer system can reduce problems with the follow-up of patients. A computer system can be a solution for patients that do not come to the healthcare facilities. Through the system the healthcare provider is able to follow the progress of the patient's disease. This can be a useful tool in the disease management of a patient.

Digital Divide

When authors speak of a digital divide, they usually point to the low internet availability of the poor in developing countries (Castells 2001; Wasserman 2005:168, Rodrigues and Risk 2003). The digital divide affects healthcare providers that cannot purchase and support

technologies (Schroeder 2001:xi). If the internet and other technologies are not available in an underdeveloped setting they cannot be used for health interventions. Authors explain that since technologies such as the internet are often not available in the Global South, there remains a significant divide in the free flow of information in poorer regions (Juris 2008:13-204; Castells 2010:277-278; Castells 2001:211-262). This means that many people do not have proper access to information about HIV/AIDS and other diseases.

Besides the limited availability of technologies in some parts of the world, technologies often remain inaccessible for some groups of people in a society. For instance, poor people might not be able to purchase the technologies. Also, some people lack the education to properly use technologies (Susser 2009:2). Especially, older people might have difficulty keeping up with technologies (Juris 2008:70).

In general, the expectations about the use of technology in healthcare are huge. Most authors expect that this increases the quality and efficiency of the health organizations (Glaser and Salzberg 2011; WTO 1997; Ellery and Ellery 2012:9; Mechael et al. 2010:5; Vital Wave Consulting 2009:4; Schroeder 2001:ix; Jbilou 2009:276).

Unfortunately, the largest part of the literature written on the use of technologies in healthcare organizations focuses on the developed world. This raises questions about how technologies can be used in healthcare organizations in the developing world. Also, it is unclear which technologies are most useful in the organizations. Finally, it is unclear if and how the specific context of HIV/AIDS affects the use of technologies in these organizations.

This thesis explores the function of technologies in the health interventions of HIV/AIDS organizations in the Western Cape, South Africa. The thesis shows that even though many authors focus on the use of computers in health interventions, this is not the most effective tool in the Western Cape. Because of the low availability of computers it is not a very useful technology. mHealth interventions are more common in the Western Cape. Secondly, the thesis explains that the use of technologies in healthcare is not a solution for all problems. Moreover, some important cultural, economical and technological obstacles that limit the effectiveness of the technology-based health interventions are discussed. Finally, research for this thesis found that the use of technologies is not standard in all health interventions. Although there are interesting possibilities, not all organizations value

technologies in their work. There are organizations that value personal and face-to-face contacts with patients over indirect technology-based communication and information provision.

In the following chapters, different aspects of the work of the HIV/AIDS organizations are highlighted. The first chapter of the thesis explores the research context and methodology of the research for this thesis. The second chapter discusses the advantages of technology-based health interventions. This chapter is mainly build on research of mHealth organization Cell-Life. In the third chapter the main HIV/AIDS related problems in the Western Cape are discussed in connection to the technology-based health interventions. Chapter four explores healthcare interventions without the use of technologies. The presumed need for direct, face-to-face contact between healthcare providers and patients is discussed here. This chapter is based mainly on research of the HOPE Cape Town Association. The chapter is followed by an overall conclusion of the use of technologies in HIV/AIDS organization in the Western Cape. The thesis ends with a discussion on how the thesis adds to larger questions about the role of technology in society.

CHAPTER ONE: RESEARCH CONTEXT

Research for this thesis was conducted from February to April 2012. This chapter discusses the research location, research participants, methodological choices and quality of the research data.

RESEARCH LOCATION

The research for this thesis was conducted in the Western Cape Province in South Africa (See Map1, p.58). Even though South Africa is a relatively developed country in Africa it is still a developing country. In South Africa, the HIV/AIDS epidemic is especially challenging. Because of inadequate government responses the infection rates are much higher than necessary (Epstein 2007). Of all the countries in the world, South Africa has the highest number of people living with HIV/AIDS. Of the 50 million people that live in South Africa, more than ten percent is infected with the disease (SANAC 2011). Simultaneously, South Africa is dealing with one of the world's worst tuberculosis (TB)^{vii} epidemics in the world. TB is a dangerous and possibly fatal infection for HIV positive persons because TB and HIV are infections that reinforce each other (SANAC 2011; Bridges.org 2005). For this reason, many HIV/AIDS organization in the Western Cape focus on HIV and TB simultaneously.

The Western Cape is a relatively prosperous, urbanized area with Cape Town as its centre. However, income inequalities in the area are extremely high. Nearly one-third of the population in Cape Town lives in poverty (OECD 2008:16-64). In the Cape Town region, it is possible to go from a wealthy to a poor neighborhood in ten minutes. Simultaneously, the society is still highly segregated by ethnic background (Klein and Wessels 2007:22). Like other urban regions in South Africa,^{viii} the Cape Town region is facing social problems such as poverty, unemployment, criminality and HIV/AIDS (OECD 2008:44). The Western Cape has 5.2 million inhabitants (SAG 2012). Of this population, 15.4 percent is infected with HIV (Statistics South Africa 2006:35). A large number of these people live in informal settlements and inadequate housing (OECD 2008:16).

RESEARCH PARTICIPANTS

The research for this thesis is a non-standard anthropological research. Instead of researching a group of people, this thesis explores organizations and the people that work in

them. Researching how technologies are utilized by people shows how technologies can be useful in the health interventions of HIV/AIDS organizations. The research for this thesis was conducted at three HIV/AIDS organization located in the Western Cape. All three organizations are established in the 21th century and have therefore from their start been in contact with technologies.

In order to collect data about the use of technologies in HIV/AIDS organizations I did volunteer work at the HOPE Cape Town Association and Cell-Life. Via my contacts at the HOPE Cape Town Association I got in touch with the research institute KidCru. The HOPE Cape Town Association is a non-profit organization founded in 2001 that focuses on HIV/AIDS and tuberculosis in the Western Cape. The organization is connected to the University of Stellenbosch and is located in the Tygerberg hospital. One part of the organization's work consists of providing support in the Ithemba pediatric ward for infectious diseases in the Tygerberg hospital. In the Ithemba ward the organization works with HIV positive children. The goal is to increase the quality of the lives of these children. The organization is also active in different communities in the Western Cape. This work is done by the community health workers (CHWs) that work for the organization (HOPE Cape Town Association N.d.). In the communities, the organization tries to reach people infected and affected by HIV/AIDS. The goal is to increase the quality of life of these people. The 24 CHWs of the HOPE Cape Town Association provide support in 18 understaffed government clinics in the Western Cape,^{ix} initiate community projects for HIV positive and HIV negative persons and provide counseling and support for HIV/AIDS patients (HOPE Cape Town Association N.d.). Map two (p.59) shows the areas where the HOPE Cape Town Association works. The HOPE Cape Town Association does not make extensive use of technologies in its work. My main knowledge about the work of the HOPE Cape Town Association comes from the time I spend in the township Delft and the Tygerberg hospital.

Another part of the research for this thesis was conducted at Cell-Life, an award winning non-profit organization based in Cape Town. Cell-life started as a research project at the University of Cape Town in 2001 and has grown to a leading organization in the field of eHealth. The organization uses technologies such as mobile phones, computer and the internet to fight HIV/AIDS and TB. The main part of Cell-Life's work is information provision and communication through mobile phones (Cell-Life N.d.). The target group of Cell-Life

consists mainly of HIV positive persons in impoverished situations. The goal of the organization is to improve the lives of people infected and affected by HIV in South Africa (Cell-Life N.d.). The organization is not physically present in the townships and clinics, but works together with other organizations to implement its health interventions. The organization does not have direct contact with patients but coordinates projects from the office level.

A small part of the research was conducted at the research unit KidCru, which focuses on HIV/AIDS and TB research in children. KidCru was established in 2002 and is located in the Tygerberg Hospital. With its research KidCru tries to enhance the hospital's capacity to manage HIV/AIDS and TB in children. Besides doing research, the unit provides treatment, education and counseling to patients and family members (KidCru N.d.). Only two interviews were conducted at this organization.

METHODOLOGICAL CHOICES

Kathleen M. DeWalt and Billie R. DeWalt (2002:40) explain that through reciprocity a trust relationship can be established between the researcher and the informants. In order to get involved in the HIV/AIDS organizations, I did volunteer work at two of the three participating organizations. The best way to describe my role in the organizations is '*moderate participation*' (DeWalt and DeWalt 2002:21). This means that I actively took part in some activities of the organizations and in some cases my role was more observational. At Cell-Life I actively took part in the health projects. For instance, I managed the sending of SMSs to patients in certain projects. In the support groups of the HOPE Cape Town Association in Blikkiesdorp my role was more observational. I did not participate in the work of the research institute KidCru. Here, I only conducted two interviews about a SMS-system implemented for the adherence and follow-up of patients.

The volunteer work I did at the organizations had several advantages. First of all, it gave me a great deal of inside about how HIV/AIDS organizations function. Secondly, through the work at the organizations I was able to get sufficient information about the main HIV/AIDS related problems in the Western Cape. Thirdly, through the organizations I was able to get in contact with HIV/AIDS patients. These people gave me an idea about what it is like to live with HIV/AIDS in the Western Cape. They showed me the [health-related]

problems they deal with. Finally, doing volunteer work gave me the opportunity to interview employees of the organizations.

Several anthropological research techniques were employed for the research. Data-triangulation was important to get a complete picture of the use of technologies in the HIV/AIDS organizations. Important qualitative research methods such as [participant] observation, open and half structured interviews, informal conversation and media and textual analysis were used in the research. In ethnographic fieldwork, using technologies is very unusual (Fielding 2001:453). Because the research is about technologies, analyses of these technologies needed to be conducted next to analyses of the physical world (Cora Garcia et al. 2009:56; Juris 2005:193). I acquired a lot of knowledge about the technologies by working with the technologies at the organization Cell-Life. Here I encountered the shortcomings and advantages of the technologies. In the township Delft I experienced the reality of HIV/AIDS. In Delft I explored how technologies can support the healthcare system.

The data for this thesis consists of interviews that were conducted with employees of the HIV/AIDS organizations, informal conversation with these employees and the target groups of the organizations, observations done during my work in the organizations, diary notes, statistics about the work of the organizations and informational flyers. The data has several limitations. For instance, I spend little time at the specific sides where the projects of Cell-Life are implemented. Even though patients are not the research object in this research, talking to them would have possibly shed a different light on the research data.

The in-depth interviews with employees of the three organizations give much information about the work of the organizations and how employees experience the use of technologies in this work. Unfortunately, the information that the employees of the organization give might not be very critical about the work of the organization. Employees were sometimes reluctant to share disadvantages of their work. Employees of the organizations might have overestimated the positive aspects and downplayed the shortcomings of their work. This affects the quality of the interviews. I believe that I was able to overcome this shortcoming by participating fully in the organizations. I could see for myself how the organizations work and experience the problems of their approaches.

Even though HIV/AIDS is a sensitive and private subject, I did not encounter any ethical problems, such as not being able to deal with confidential information.

The following chapter discusses the possibilities and contributions of technology-based health interventions. It shows that technologies can make several additions to standard healthcare.

CHAPTER TWO:

CONTRIBUTIONS OF TECHNOLOGY-BASED HEALTH INTERVENTIONS

Technologies such as the computer and mobile phone possibly play a major role in the health interventions of HIV/AIDS organizations. In the literature, great expectations about technology in healthcare are expressed. Technologies in healthcare are supposed to increase the quality and efficiency of the healthcare system while decreasing the costs of the healthcare (Glaser and Salzberg 2011; WTO 1997; Ellery and Ellery 2012:9; Mechael et al. 2010:5-7; Vital Wave Consulting 2009:4; Schroeder 2001:ix; Jbilou 2009:276). The goal of the current chapter is to show the contributions that specific technologies can make in fighting HIV/AIDS.

Since most of the literature about the use of technologies focuses on the developed world, it is interesting to look at the effectiveness of technologies in health organizations in the developing world. Contrary to what most authors suggest, the current chapter shows that not the computer, but the mobile phone is useful in health interventions in the Western Cape. The expectations expressed in the field about the usefulness of the mobile phone are great. This chapter explores the realistic expectations and the contributions technologies are able to make in the health interventions of HIV/AIDS organizations.

EHEALTH INTERVENTIONS

From February to April 2012 I worked at the mHealth organization Cell-Life. The Cell-Life office at the corner of Brandweer and Waterloo streets in Cape Town is a quiet but colorful office. The 20 people in the office are working often on more than one computer at the same time. The atmosphere is filled with enthusiasm and motivation about discovering new and effective ways to fight problems such as HIV/AIDS. The employees of Cell-Life work hard on developing innovating mHealth projects and designing new ways of using technologies. They are changing the meaning that technology has for people and for themselves. Instead of viewing the mobile phone solely as a communication tool, the employees of Cell-Life use it to improve people's health situation and fight HIV/AIDS. This gives the technology a radically different meaning. It can now be seen as a tool that might be used to fight societal and health problems.

My first visit at Cell-Life consisted of a 30 minute talk with the managing director Peter Benjamin. Benjamin has been a socially involved person for most of his life. After coming from the United Kingdom to South-Africa as an anti-apartheid activist, he worked on several developmental projects in the country. His current passion is the development of mHealth interventions with Cell-Life.

During my first conversation with Peter Benjamin, he told me about the many possibilities that mobile phones have to offer in healthcare interventions. In South Africa mobile phones are a form of mass communication; even more so than television and computer. Benjamin explained that when he was working on developmental projects before he came to Cell-Life, he himself made the mistake of overestimating the value of computers. Looking back he sees that the people in the community did not need computers and that he and the people he worked with were blind for the fact that most people in the society had a mobile phone. Benjamin explained that computers are very useful for professionals. However, normal people do not need them. Mobile phones are a much better way to reach the people. Employees of all three organizations I conducted research stated that the most available technology for people in South Africa is the mobile phone. A basic mobile phone costs ZAR100^x and is thus affordable even for poor people.

The field of mHealth is constantly in development in South Africa. Katherine de Tolly is a researcher at Cell-Life who tries to be on top of all the developments. De Tolly is a young and always cheerful woman. One day she came in the Cell-Life office after sleeping only two hours in an airplane after a mHealth meeting in Johannesburg. *'I have done something wrong in a past life. I should have taken a normal job'*, she joked. De Tolly studied informatics and is now involved in many Cell-Life projects. De Tolly explained that the projects are an addition to standard care because the effectiveness of mHealth is not proven yet. Currently, she is conducting and publishing research on mHealth to prove its effectiveness.

De Tolly explained the usefulness of mobile technology compared to other media in health projects: *'With newspapers you get relatively few people. And billboards are fine, but it's quite a limited kind of medium. It's just a short message and image and that's it'*. According to Katherine de Tolly, the mobile phone is the most useful technology in healthcare:

'Because 80 percent of the people in South Africa have a cell phone. And you have got 11 percent of people who have got access to the internet on computers. That is really low. It [mobile phone] is a logical way to reach people. You are going to reach more people through that than through mass media. I mean, TV is good, but it is very expensive where a cell phone is a lot cheaper'.

As stated above, the main focus in the literature is on the use of computers in health organizations (WTO 1997:287; Tyrrell 2002; Rodrigues and Risk 2003). The internet is presumed to be useful because it can transfer information fast (Wasserman 2005:165). However, authors writing about the usefulness of the computer and the internet in healthcare focus mainly on the developed world. In many ways they forget specific characteristics of the developing world. In the Western Cape, as in many other developing regions, internet via computers is not accessible for many people since it is too expensive. Also, internet connections in this region are not always fast: often they fail or are very slow. This supports earlier findings of Manuel Castells (2001) and Herman Wasserman (2005:168) who argue that the internet is not widely available in developing countries.

In South Africa, almost all people have access to a mobile phone. According to the International Telecommunication Union (ITU), mobile phone coverage in South Africa is over 100 percent since 2010 (ITU 2007). Internet coverage is much lower in South Africa. In 2007, 10.75 percent of the people had access to the internet via a computer (ITU 2007). The findings agree with the results of Vital Wave Consulting (2009:7) and Cristian Pop-Eleches et al. (2011:826), who state that the growing accessibility of mobile phones in the developmental world is central to the possibilities that it has to offer. The findings are also supported by Wasserman (2005:166), who states that in South Africa the internet is only widely available to the elites. The mobile phone might therefore be a better tool to reach the masses.

Managing director of Cell-Life Peter Benjamin expects that mHealth has great possibilities. Currently, many mHealth projects are small scale. Peter Benjamin expects that the successful aspects of these projects will be integrated into the standard health system just as previous innovations in healthcare were implemented into standard care. Benjamin explained that the mHealth sector is currently trying to prove that mHealth really works. He

stated: *'When we win the argument, it won't be called mHealth anymore. It's just part of the way the health system works'.*

CONTRIBUTIONS OF MHEALTH

The following part explores the contributions that technologies can make in HIV/AIDS organizations, through the illustration of several HIV/AIDS projects.

Education and Information Provision

On my first day in the township Delft at the beginning of February 2012 I visited the government clinic in the area. Karen Mahada, a hard-working community health worker working for the HOPE Cape Town Association, showed me around in the clinic where she works. The clinic was loaded with people. Everywhere I looked, people were waiting to see a doctor. The atmosphere in the clinic was a mix of sadness and hopelessness. People waited patiently for a doctor, but know that whatever happens their poor living conditions will not improve. Long waiting hours because of a lack of staff are a problem in many government clinics. Often, clinics do not have the capacity to help people the same day they come in. This supports earlier findings of Vital Wave Consulting (2009:6) and Edwin Wouters et al. (2008) who found that the main problem in South Africa's healthcare system is the shortage of health workers at government clinics. There is no lack of available clinics in the Western Cape, but the quality of government clinics and staff shortage are severe problems.

The clinical staff does not have the time to educate people properly about their disease. One Friday I joined Dr. Sandy Picken of the HOPE Cape Town Association in the Delft clinic. During the appointments the doctor tried to find out how much knowledge the patients have about their disease. It became clear that the knowledge levels were very low. Many patients do know their CD4 count^{xi} and often also do not know what this number means. Since HIV is a complicated and chronic disease, not having sufficient knowledge about it is damaging for their treatment.

In some projects, Cell-Life tries to increase the knowledge levels of the patients. During my time with Cell-Life I became familiar with the CIDA project, sponsored by the Canadian International Development Agency. Victoria Nembaware is a researcher working on this project. Nembaware has a background in microbiology, but has now moved in the

direction of health and social sciences. As a healthcare volunteer in the townships of Cape Town she obtained experience and knowledge of the HIV/AIDS reality in the region. As a mHealth coordinator and monitor and evaluation specialist at Cell-Life she works many hours per week dealing with these issues. Her work at Cell-Life consists of writing new ideas, implementing and evaluating these.

The CIDA-project is one of the pilot projects that Nembaware works on. The treatment provided by the project is an addition to standard treatment that patients receive. At their clinic, patients can choose to participate in the project and receive text messages for the duration of one year. The goal is to provide patients with more support and information during their treatment. With use of the computer-controlled Communicate system,^{xii} SMSs can be send to the mobile phones of patients. Nembaware explained that the messages need to be send in several languages to be able to reach as many patients as possible.^{xiii} The SMSs in this project contain information, support, reminders to take medication and medical appointment reminders. If a patient starts using antiretroviral treatment,^{xiv} he or she receives support messages and information on the treatment and disease. During the first two months of the intervention, SMSs mainly provide information about ARVs, the negative side effects of these drugs and other treatment information. After this, the SMSs focus on positive living and encouragement. Examples of SMSs send in the CIDA project are:

Please avoid taking traditional medications with ARVs as it can lead to side effects [bad effects from the medication, like dizziness or sore feet].

Please don't forget to take your ARVs on time. Adherence means taking your ARVs on time, every day. They may not work if you miss doses or take them late.

You've heard it before but it's still important. EVERYONE needs to use condoms. Ask for a box at the clinic!

Victoria Nembaware is positive about the support that SMSs can offer to patients. Recently, she got a phone call from a woman telling her that the daily SMS felt 'like a hug'. Simultaneously, Nembaware wonders rightly if indirect contact between the healthcare

provider and patient can give sufficient support, since direct contact is important in supporting and counseling people. Nembaware expects that because of her counseling background she might overestimate the need for direct contact. However, she did emphasize that *'There are cues that one uses when you are communicating. There are lots of things that are lost in communication via SMSs'*.

The informational function of the SMSs is probably more effective. Through SMSs patients can receive necessary information about their disease that they might not have received at the government clinic. KidCru counselor and researcher Marie Teunissen expects that many patients forget some of the information she or a nurse gave them. On the mobile phone patients can look up this information whenever they want. Moreover, some patients are reluctant to ask for information they do not understand. If patients receive the information on their mobile phones, they can repeat it whenever they want. Because of this, the knowledge that patients have about their disease increases.

Cell-Life researcher Katherine de Tolly expects that these projects also have positive effects on the government system: *'The clinic workers say that they get less calls'*, De Tolly stated. The information provision via mobile phones might lighten the burden on the understaffed government clinics because fewer people come back with questions or medical problems.

Follow-up Appointments and Treatment Adherence

With proper treatment, HIV can be transformed from a deadly to a chronic disease. However, the weak and overloaded health system in South Africa is threatening the success of HIV/AIDS treatment (Wouters et al. 2008; Dahab et al. 2008). Anti-retroviral treatment (ART) is available in government clinics in South Africa for HIV/AIDS patients with a CD4 count below 350. Adherence to ARV medication is a strong predictor of treatment success for HIV patients (Dahab et al. 2008; Nachega et al. 2012:128). Almost all of the employees of the organizations in this research emphasized that many patients have problems in adhering to their medication. This supports earlier findings about treatment adherence. Jean B. Nachega (2012:130) found that almost half of all HIV patients worldwide miss at least one dose of their medication each month. This has major effects on further treatment. If medication is not taken regularly and at the same time each day, the virus may develop

resistance against the drugs. If the HIV is resistant against the medication, treatment becomes much more difficult.

In order to keep patients on the right medication, having follow-up appointments with healthcare providers is of main importance. Unfortunately, almost all participants in the research stated that many clinics have problems with the follow-up of patients.^{xv} HOPE Cape Town Association director Noëline de Goede explained that the government clinics do not have the staff to take care of follow-up. If patients do not come back to the clinics for follow-up appointments, they simply do not come back. This finding supports the research of Gómez et al. (2002:85), who state that there are many problems with the follow-up of HIV/AIDS patients.

Cell-Life researcher Victoria Nembaware explained that it is very easy to send an SMS to a patient to remind them about medication and medical appointments. This makes the mobile phone a very useful tool in healthcare. Besides mHealth organizations such as Cell-Life many other health organizations in the region send SMS reminders to patients. In 2008, the research unit KidCru installed a SMS service to deal with the lost of follow-up and insufficient treatment adherence. In the SMS service, patients are reminded of their medical appointments and medication.

Marie Teunissen works as a counselor and researcher at KidCru. In her studies she explores the effect of different medication in children infected with HIV/AIDS, TB or both diseases. Teunissen noticed that in her studies the lost of participants was very high. Many patients did not take their medication properly or did not come back for follow-up appointments. Teunissen views the implemented SMS service as a success. Teunissen stated that the SMS service made a *'significant difference in patient retention and patient follow-up'*. The main achievements of the SMS service are that the number of patients that stay in KidCru's studies has increased, that patients miss fewer medical appointments and that the communication between the patient and the medical staff of the research unit has increased. The treatment adherence of the patients in the SMS service also improved. *'If I would write the use of SMSs for adherence, I would give it a thumbs up'*, Teunissen stated.

Teunissen expects that the mobile phone is successful because patients are very attached to it. *'People are constantly on their phones. And I am talking from experience. If I am sitting in a bus or taxi and I am kind of bored with myself, the first thing I do is grab my*

phone,' Teunissen explained. *'And even though I don't have any new messages, it keeps me preoccupied. I am going to sit and go through all my old messages'*. Jean B. Nachega et al. (2012:301) found that the most common reason for not taking medication is forgetfulness. SMS reminders can thus be a useful tool to remember taking medication properly.

CONCLUDING REMARKS

This chapter explored what contributions technologies can make in fighting HIV/AIDS and showed that the mobile phone can be a very useful technology in HIV/AIDS organizations. This contrasts with much literature on the use of technology in healthcare, because many authors focus on computers and the internet. The mobile phone is a highly available technology for the poor in the Western Cape and can therefore be seen as the most useful technology for healthcare projects.

The mobile phone can be used to deal with several problems in HIV/AIDS treatment. Many patients do not have sufficient knowledge of their disease because the nurses in the overloaded government clinics do not have the capacity to educate the patients properly. The mobile phone is found to be a successful tool to send treatment information to patients. Simultaneously, the mobile phone can be used to send SMS reminders about medication and medical appointments. These SMSs can increase the treatment adherence and decrease the lost of follow-up in patients. Cell-Life researcher De Tolly explained that the government clinics get fewer calls from patients about their treatments. In this way, the use of the mobile phone could possibly lighten the burden on the government clinics.

Besides the possibilities there are several limitations of technology in HIV/AIDS organizations. The following chapter discusses some HIV-related problems that limit the effectiveness of technologies in health interventions.

CHAPTER THREE:

LIMITATIONS OF TECHNOLOGY-BASED HEALTH INTERVENTIONS

It has been argued that in studying technology, the cultural context needs to be taken into account because this determines the functionality of the technology (Oudshoorn and Pinch 2005:12). In this chapter cultural, economical and technological factors are discussed that limit the effectiveness of technology-based health interventions. This tempers some of the enthusiasm and expectations expressed in both the literature and the field about the usefulness of technology in healthcare. The goal of this chapter is to show that the use of technologies in healthcare should not be seen as a miracle solution to the HIV/AIDS epidemic. Three cultural and economical obstacles are explored in this chapter. After these, two shortcomings of technology as an instrument in healthcare are discussed.

THEORETICAL CONSIDERATIONS

There are various HIV/AIDS related problems in the Western Cape. These problems vary from the stigma attached to HIV/AIDS to the poverty that both causes and is caused by HIV/AIDS. This section discusses some theory on the issues that might limit the effectiveness of technologies in health interventions.

Stigma

A main HIV/AIDS related problem in the Western Cape is the stigma attached to the disease. Gregory M. Herek (2002:596-597) describes three factors in social psychology that result in an increased stigma attached to a condition. HIV/AIDS meets all these demands. First of all, the stigma attached to an undesirable condition tends to be larger when it is assumed to be the bearer's own responsibility. For instance, HIV/AIDS is said to be connected to promiscuous behavior. Second, more stigma is attached to conditions that are lethal and incurable. Thirdly, the stigma tends to be bigger if the condition poses a risk to others. Many prejudices exist about HIV/AIDS. Brendan Maughan-Brown (2007:2) describes that people associate HIV/AIDS with homosexuality, ethnicity, prostitution and poverty.

Government denialism by former governments of South Africa enhanced the stigma, slowed down proper reactions to tackle the HIV epidemic and still affects societal views on HIV and AIDS in the Western Cape. Especially statements by former president Thabo Mbeki

and former health minister Manto Tshabalala-Msimang are damaging (Grebe 2011:850). By 1999, research had already shown that HIV causes AIDS (Epstein 2007:107). However, former president Mbeki, in the office from 1999-2008, kept denying the link between HIV and AIDS and stated that South-Africans were dying of non-AIDS related diseases. With this, he supported the view that HIV/AIDS is not a real and damaging disease. Health minister Tshabalala-Msimang, in the office from 1999-2008, also denied the link between HIV and AIDS. Moreover, as a cure for HIV she suggested eating healthy. According to her, lemon and garlic serve as a proper treatment. The Mbeki government refused to use ARV's for treatment and prevention of HIV (Grebe 2011:850). Damaging commands are not only made by former government officials. The current president of South Africa, Jacob Zuma, stated during a rape trial several years ago that he had participated in unprotected sex. He explained that taking a shower after sex significantly decreases the chance of getting infected with HIV. It is difficult to expect that people have correct knowledge of HIV and AIDS if government officials provide insufficient and incorrect knowledge about the disease.

Sexual behavior and Gender

People mainly get infected with HIV through unprotected sex. Unsafe sexual behavior such as having multiple partners increases the chance of being infected with HIV (Whiteside 2002:317). In South Africa, unsafe sexual behavior is often connected with gender inequality. Women are often seen as subordinate in the country. Many women in South Africa deal with gender-based violence, including rape and sexual abuse. The inequality results in women getting infected with HIV more often than men (Mills et al. 2009:3). Elizabeth Mills et al. (2009) do point out that it is important to create a nuanced understanding of gender relations and to move beyond the victim-perpetrator dichotomy. Not only men initiate unsafe sex. In their research in Cape Town South Africa, Mills et al. (2009:3) found that because of the fear of disclosure women often do not have safe sex. This could be very damaging for the their sexual partners.

Poverty

Poverty and inequality are large problems in South Africa. In the Cape Town region nearly one-third of the people lives in poverty (OECD 2008:16-64). HIV can be both caused by and

cause more poverty (Whiteshed 2002:317). For instance, poverty can force women to become a prostitute. This makes them vulnerable for HIV infection. Simultaneously, not being able to work because of the disease can lead to poverty amongst patients and their families (Whiteshed 2002:320).

It remains a question if and how these problems influence the effectiveness of technology-based health interventions. Both the literature and some health organizations in the field express great expectations about the use of technologies in healthcare. Technology is presumed to be able to increase the quality and efficiency of healthcare significantly (Glaser and Salzberg 2011; WTO 1997; Ellery and Ellery 2012:9; Mechael et al. 2010:5; Vital Wave Consulting 2009:4; Schroeder 2001:ix). This chapter shows that these expectations need to be alleviated. Technologies in healthcare do not provide solutions to all problems and should therefore not be seen as a miracle solution. When technologies are implemented in healthcare, many practical and cultural issues arise. This chapter presents five cultural, economical and technological obstacles that limit the success of eHealth in HIV/AIDS organizations in the Western Cape.

OBSTACLES IN MHEALTH

Culture, background and religion affect how people think about HIV and AIDS. However, because of the rich diversity of cultural practices in the Western Cape, it is difficult to write a comprehensive description of it. The following part consists of the main myths, traditions and practices encountered during the research for this thesis.

Obstacle one: Stigma

The stigma attached to HIV/AIDS can have devastating social consequences for HIV positive persons in the Western Cape. One day I met a mother of three who had two HIV infected daughters. She told me about a discriminating experience that the girls encountered. During a holiday break, the girls were sleeping at their aunt's home. After the weekend, the mother found out that the children had to sleep outside on the dog's blanket because the aunt did not want the HIV positive children sleeping in her house. The mother, however, does not speak with her daughters about their disease, because she is afraid that knowing their

positive status will damage their lives. As a result, the daughters do not know why they are unwanted in their family's house.

Examples such as this one show the magnitude of the stigma attached to HIV/AIDS. There is great consensus amongst the participants of this research that the stigma attached to HIV/AIDS is still very big. Cell-Life researcher Victoria Nembaware explained: *'People distance themselves from HIV. They don't think it can happen to them. Even some people high up in society are HIV positive. But people distance themselves because there is this whole stigma attached to it and this notice that if you are HIV positive you are promiscuous'*.

HOPE Cape Town Association director Noëline de Goede called the phenomenon of people having unsafe sex despite their knowledge about HIV the *"It can't happen to me-syndrome"*. Regardless of their educational level, religion, ethnic background, economic situation or age, many people believe that they cannot get infected with HIV. Many colored people believe that HIV/AIDS only exists amongst black people. Many rich people believe only poor people get infected with HIV. Many educated people say that only uneducated people get infected with HIV. Having more knowledge and information about HIV does not necessarily lead to safe sexual behavior or decreasing stigma.

A major problem in the management of HIV and AIDS is the large group of people who does not want to know anything about it and refuse to go for HIV testing. It is very difficult to get these people involved in health projects or health education. Even the use of seemingly accessible technologies cannot change this.

Generally, the people participating in technology-based health services have to sign up for this because it is a voluntary addition to standard treatment. The people who refuse to get involved in the clinical system will therefore be very hard to get into these programs. This significantly reduces the effectiveness of the projects, since this group of people is very important to reach. Cell-Life sporadically tries to deal with this problem by initiating campaigns where large groups of people receive SMSs about HIV/AIDS. However, for the receiver of this SMS it is easy to ignore these messages. Contrary to what many employees of Cell-Life expect, reaching all people in health interventions through technology is very difficult.

The stigma attached to HIV/AIDS has several consequences. In Blikkiesdorp I met a woman who was surprisingly open about having AIDS. I talked with her about the issues that

she encountered in her daily life. Mainly, she explained, she is worried about people who do not get tested for HIV. People are so afraid of having the disease that they do not go to a government clinic, even if they are very sick. The week before I met her she tried to convince a sick couple that they should go to the government clinic. The couple was very afraid to do this and never went for HIV testing. There are many like this couple who refuse to go for HIV testing for reasons such as fear and prejudice.

Policies at the government clinics also make people reluctant to go for HIV testing. *'If you are HIV positive you are given a different color folder and there is a specific door that you have to go to. So everyone can already see that you are HIV positive'*, Victoria Nembaware explained. During my research I also found that most government clinics have a separate HIV wing. If people go to this section, their status is revealed to others. Since many people are afraid of being disclosed to others they will not go to the clinic. These findings support Mison Dahab et al. (2008), who showed that the stigma attached to HIV can result in people not starting or stopping their HIV treatment.

At Cell-Life the mobile phone is used in health interventions because it is a personal technology. This means that only the owner of the phone gets the information. When health information is sent to a mobile phone it is not visible to others if a person is HIV positive. Cell-Life researcher Victoria Nembaware explained that *'Given the stigma and discrimination in South Africa, especially with things like HIV and AIDS, I think SMSs and text-based interventions have a large part to play in trying to improve people's health'*. However, Nembaware does expect that there can be privacy problems with mobile phones when people share one phone: *'Their family or friend could read a message. That could be a problem because we [sender of the message] could expose their [the patient's] status to some people'*. Cell-Life has experienced that patients opt out of projects because of this.

In the townships I have seen that people sometimes share mobile phones because of financial problems. This might result in the disclosure of someone's HIV status. The mobile phone is thus not a 100 percent private technology. Concerns about privacy, stigma and disclosure are also found in other research on the use of mobile phones for sensitive diseases such as HIV/AIDS (Déglise et al. 2012:16).

Obstacle two: Sexual Behavior and Gender Inequality

Noëline de Goede recently became director of the HOPE Cape Town Association. She is an ambitious woman with much experience of working with people at the bottom of society. She sees the moral decay that is found in the whole society as a main problem in today's world. The main problem in HIV/AIDS prevention is having unsafe sex, de Goede explained. In the Western Cape, both men and women initiate unsafe sex and often have different sexual partners at the same time. This leads to a fast spread of HIV. Helen Epstein (2007:55) explains that having more than one sexual partner at the same time creates a giant web of sexual relationships that results in the fast spread of HIV.

Noëline de Goede explained that women are especially vulnerable for HIV infection because of their subordinate position in society. Gender inequality is found everywhere in the society, but is most severe if the partners do not have the same income, De Goede explained. Often, women are not able to provide their own income. This makes them dependent on the income of the man. The dependent relationship between women and men results in the women having no power to say and do what they want. *'Definitely men say "I refuse to have sex with a condom". And females don't have, in many relationships, the right to say no'*, De Goede stated. Since many men refuse to use condoms during sex, the chance that women are infected with HIV increases. With a low educational level and no income, few women have the power to negotiate for safe sex.

The gender inequality also has negative effects on men. Many participants of this research note that many men do not go to a clinic to get tested for HIV until they are very sick. *'One of the things that we have been noticing in the clinics is that the gender inequality is actually not good for men on ARVs. Because for men to be seen at a clinic is a sign of weakness,'* Cell-Life researcher Victoria Nembaware explained. *'In adherence studies that we are doing there is a very small proportion of men compared to women'*. Not knowing their positive HIV status affects the health situation of men but also endangers the health situation of the women that these men have sex with. This supports findings of Mill et al. (2009), who found that constructions of masculinity deter men from getting tested for HIV.

Cell-Life tries to incorporate gender into its projects. For instance, the organization tries to make SMSs gender sensitive. However, since the gender relations are so deeply

rooted in the South African society they are very difficult to change. Unsafe sexual behavior limits the effectiveness of any HIV/AIDS program in the Western Cape.

Obstacle three: Poverty

During one of the support groups of the HOPE Cape Town Association in Blikkiesdorp I talked with a woman about the healthcare she received at the government clinic. In the clinic she often had to wait many hours before she got help. She was very afraid that the help she received was not sufficient. She told me that she realized that the healthcare she received was not as good as the private healthcare. Unfortunately, she had no other choice than to go to the government clinic. Private clinics are very expensive and unaffordable for most people in the townships, while government facilities are free of charge. One appointment at a private clinic costs a person ZAR150 and this does not include medication or further treatment.

Poverty is a big problem in the Western Cape which is related to HIV/AIDS. Besides not being able to pay for the best medical care, poverty affects HIV infection and public health in other ways. Poverty leads to problems such as not having money for transport to ARV-providing government clinics,^{xvi} having no money for healthy food to support the immune system and living in bad living conditions. In the townships surrounding Cape Town living conditions are generally bad. Sanitary is missing or unhygienic, houses are of low quality and badly maintained and there is a lot of garbage on the ground. A lot of people live in one space at the same time. This results in a quick spread of infectious diseases such as TB. TB is a very dangerous infection for people infected with HIV and can result in severe illness or even death.

Research for this thesis showed that poverty can result in problematic sexual behavior such as prostitution. One day I met a woman who used to work as a prostitute on the streets of Cape Town. She explained to me that she had unprotected sex as a prostitute, since many men do not want to use a condom. Since she had no other options to get money for food, she did not use a condom while she was working. Problematic sexual behavior such as not using condoms results in a high spread of the HIV.

HOPE Cape Town Association director Noëline de Goede recently started her work at the organization but has a lot of experience with the main societal problems in the Western

Cape. She connects many HIV-related problems with other societal problems. In an interview, De Goede pointed to Maslov's hierarchy of needs^{xvii}. She rightly asked: *'If you don't have your basic services and needs covered - like food, shelter - how can you function on a level where you make correct cognitive decisions?'* If people are worried about getting money for food, HIV prevention is not their main focus. De Goede explained that educating people about what is the best thing to do is not a solution. HIV and AIDS services need to function properly, but in order to change behavior an alternative must be offered to people, so that they are able to make good decisions. As Noëline de Goede pointed out, an all encompassing developmental approach is needed. Using technology in health interventions cannot change behavior if people have other more urgent problems.

Also, focusing on technology could exclude the ultra-poor in the society. The poorest people that do not have a mobile phone are excluded from the projects. Simultaneously, many mHealth projects focus more on literate people. Cell-Life researcher Victoria Nembaware explained that many people in South African are illiterate. According to UNESCO (2010), 87 percent of the women and 90.7 percent of the men in South Africa can read properly. This means that focusing on text messages excludes a relatively large and vulnerable group in the society.

Obstacle four: Need for Direct Contact

The following two obstacles reveal limitations of technology as a tool in healthcare. First of all, there is a debate on whether the technology-based contacts that patients have with healthcare provider are sufficient. As I was spending time with the people in the support groups of the HOPE Cape Town Association I realized that HIV positive persons need the personal contacts to be able to deal with the issues they encounter in their lives. A limitation of technology-based health interventions is that this direct, personal contact is removed. Victoria Nembaware from Cell-Life has experienced that patients still look for the personal aspect in the contacts with health providers. One day she got a call from a patient who she expected wanted to stop receiving text messages about her HIV treatment. However, this patient turned out to have a need for more personal contact, stating *'I was getting very lonely'*. The patient called because she *'Just wanted to speak to somebody'*.

Nembaware explained that, possibly because of her counseling background, she expects that patients still have a need for direct contact with healthcare providers, because this results in more understanding and support. *'I think technology is great,'* she stated *'For me I think it should supplement person-to-person contact, because there is no way that you can replace human contact. And technology can never respond.'* Technologies cannot provide the affective ties, trust and support that direct contacts can. Moreover, non-verbal communication is lost when technologies are used. *'If you are a person you can see gestures of a patient,'* Nembaware explained. *'Maybe you've got a personal story to it or a personal question to it. that will not be addressed in such a mass kind of way.'*

Research found that a good relationship between the healthcare provider and patient leads to more successful treatment (Johnson et al. 2012:401). This relation can only be established when there is trust and understanding between the patient and the provider. Only direct contacts can provide this trust (Juris 2008:97). Although many employees of Cell-Life emphasized that personal contact is important in treatment it is difficult to integrate this into the technology-based health projects.

Obstacle five: Failing Technologies

Failing technologies are part of the daily life in the Western Cape. During my research, I have encountered technological problems at the organizations I volunteered. During my time at Cell-Life I encountered several technical problems that affected the health interventions. Sometimes too many and sometimes too few text messages were sent to patients. At the end of February 2012 there was a serious technological problem from outside the organization. Around 70 text messages were not sent to patients because of this. The SMSs were reminders to educate patients how and when to take their medication. Katharine de Tolly, the project manager of the project, found out by accident that the messages were not sent. Not receiving messages can seriously affect the patients' health. While trying to fix the problem De Tolly realized: *'I am messing with someone's health procedures'*.

I also encountered technological problems at the HOPE Cape Town Association. Here, the internet connections are very bad. Even though the organization does not use technologies in its health interventions it could still seriously affect the work of the organization. In February 2012 there was a major internet failure at the organization's office.

Noëline de Goede explained that she could not receive or send any e-mails for five days. Since the organization does use technologies at the office level, technological problems still affect the organization.

Non-functioning technologies can be damaging for the health situation of the patients. Unfortunately, failing internet connections or malfunctioning mobile phone networks are not rare in the Western Cape. Technologies lose some of their usefulness because of these problems. These findings support Carole Déglise et al. (2012:15) who state that mobile network connection fluctuation can be a serious barrier to the usage of mobile phones in healthcare in developing countries.

CONCLUDING REMARKS

This chapter showed that it is very important to take into account the local situation when designing and implementing health interventions. Both the literature and the field express great expectations of technologies in healthcare. Contrary to this, the chapter showed that there are several obstacles that limit the effectiveness of technology-based health interventions. The stigma attached to HIV/AIDS can limit the effectiveness of the technology-based health interventions, since it results in people being reluctant to get involved in HIV/AIDS projects or go for HIV testing. Simultaneously, unsafe sexual behavior such as not having safe sex is very common in the Western Cape. These patterns are sometimes reinforced by the gender inequality in the society. Also, poverty in the Western Cape supports the spread of HIV. The effect of technology-based health interventions is limited because they cannot change the underlying factors that support these unsafe behaviors.

Besides these cultural and economical factors, this chapter discussed two disadvantages of technology as a tool in healthcare. First of all, there is always a need for direct, personal contact amongst patients. Technologies-based health interventions cannot provide this and might therefore have less effect. Secondly, organizations in the Western Cape deal with failing technologies. Internet connections and mobile phone networks often fail. This seriously limits the usefulness of technology in health interventions. In fact, failing technologies can even be dangerous for the health situation of patients.

The obstacles presented in this chapter show that technology should not be seen as a solution to all problems in HIV/AIDS healthcare. In fact, some HIV/AIDS organizations do not

see technologies as a useful tool in their organizations at all. The next chapter explores the work of the HOPE Cape Town Association, an organization that does not make extensive use of technologies in its work. The chapter discusses the importance of face-to-face contacts between patients and healthcare providers.

CHAPTER FOUR:

EXPLORING THE NEED FOR TECHNOLOGY IN HIV/AIDS ORGANIZATIONS

Most authors assume that implementing technologies in healthcare organizations is always better than not doing it at all. Authors agree that enhancement in healthcare can be made through the use of technologies and that essential problems will remain if technologies are not implemented (Ellery and Ellery 2012; Mechael 2010:69; Vital Wave Consulting 2009). The question that is relevant to these authors is how and not if these technologies should be implemented. The goal of this chapter is to explore if this is true for all HIV/AIDS organizations and if using technologies is at all times an improvement of the work of the organizations.

This chapter shows that some healthcare workers in the field do not find technologies a useful tool at all. Some emphasize the disadvantages of technologies over the advantages. This undermines the statements made by many authors about the usefulness of technologies in healthcare. Secondly, the chapter shows that face-to-face contact is important in dealing with HIV/AIDS.

FACE-TO-FACE HEALTH INTERVENTIONS

The HOPE Cape Town Association is very active in Blikkiesdorp.^{xviii} Before the soccer World Cup in 2010 many poor and homeless people from Cape Town were relocated to this area. It is a very impoverished area in the already poor township Delft (The Guardian 2010; Times Live 2012; MailGuardian 2009; NPR 2010; IOL News 2012). At the entrance of Blikkiesdorp, the HOPE Cape Town Association placed three containers where projects and support groups^{xix} take place. During the months I spend in the Western Cape I regularly visited the nutrition group that takes place on Wednesdays. This support group is directed by CHW Karen Mahada. Mahada used to live in the area she works in and knows the issues that the women^{xx} deal with. Mahada explained that with every new group she builds a strong relationship. She both teaches and learns from the women in the support groups. During my time with the HOPE Cape Town Association I got to know Mahada as a hard-working woman who is driven to develop new ways to support the community. Recently, she founded a homework class for children in Blikkiesdorp that are struggling with their education.

In the nutrition group, Mahada explains to the women how to eat healthy while cooking some food. The nutrition group has very limited means. There is one stove, a table and very few kitchen supplies. There is no water available in the container. During the cooking, life and health issues are discussed. The women in the support group mainly struggle with issue such as poverty, unemployment, violence, diseases such as TB and HIV/AIDS and malfunctioning government health services. Through talking about the problems they encounter, the women in the support group learn how to deal with the problems in their lives.

Employees of the HOPE Cape Town Association think that this face-to-face contact is the strength of the work they do. Talking directly with people about their problems is seen as the most effective way to educate and counsel them. This does not mean that communication is not mediated at all. For instance, important things are written on paper.

CHW Karen Mahada explained why it is not necessary to use technologies in her work. She stated that she does not have to give her phone number to her clients. Important issues are discussed during the weekly support group. If somebody encounters a problem during the week she can contact somebody else from this support group. In this way, people deal with problems by themselves. This strengthens the trust and sense of community between people. The goal is that the people in the community learn to deal with their issues by themselves while not being dependent on other people.

CONTRIBUTIONS OF PERSONAL CONTACT

As stated above, the HOPE Cape Town Association does not regard technologies as a necessary tool in its health interventions. The following part shows the contributions that this direct, face-to-face approach can make.

Reaching the Target Group

The HOPE Cape Town Association is active in 20 different communities in the Western Cape. The work in these communities is done by 24 community health workers. The most important task of the CHWs is providing support in the overloaded government clinics. Besides their work in the government clinics, the CHWs go to schools and other places to

educate people about HIV/AIDS and develop community programs for the people in the neighborhoods.

It is argued that technologies significantly increase access of people to health services (Mechael 2010:7). Employees of the HOPE Cape Town Association state that with their approach this is not the case. HOPE director Noëline de Goede explained that while doctors and nurses stay in the clinics, the community health workers go into the communities to bring the healthcare to the people. For the HOPE Cape Town Association it is very important that the community health workers come from the communities they work in. The organization hires only people that come from the communities because these people have sufficient knowledge about the issues and problems in the areas and are able to relate to the people they work with. An advantage of this is that the personal networks of the CHWs can be used to reach the target group. Participants of the support groups in the communities are found through face-to-face contacts and the personal networks of the CHWs. The CHWs know which people to approach for support groups because they know the main problems in the communities and see who is most in need of support. Community health worker Karen Mahada explained that people trust her because she knows the problems that people deal with. This trust relationship between the provider and client results that people come to the support groups.

A downside of using the personal networks of community health workers to reach the target group is that it can result in a selection of a specific group of people if the personal network of the CHW is biased. The CHWs cannot reach people they do not know. People who rarely get in touch with health organizations have a smaller chance to be part of the projects of the organization. This is problematic since many people need to be involved in health projects if HIV/AIDS is to be fought effectively.

In summary, employees of the HOPE Cape Town Association argue that they do not need technologies to reach its target group. Going out to the community and building trust is important for the organizations in involving the people in the health interventions.

Counseling in the Ithemba Ward

Besides HOPE's work in the communities, the HOPE Cape Town Association works in the Ithemba Ward in the Tygerberg hospital. The HOPE Cape Town Association was founded in

2001 to support HIV/AIDS treatment of children in the Ithemba Pediatric Ward for Infectious Diseases in the Tygerberg hospital. The hospital is located 30 kilometers outside of Cape Town. The hospital is old and poorly maintained. In order to walk from the office side where the HOPE Cape Town Association is located to the Ithemba ward I needed to cross the entire hospital. In the hospital, paint is falling off the walls and floors are crooked. A bucket was placed in the middle of one hallway to catch leaking water droplets. Luckily the Ithemba ward is in a better state.

The name Ithemba was established by Rev. Fr. Stefan Hippler, one of the founders of the HOPE Cape Town Association, and means "HOPE" in isiXhosa. The ward consists of one long corridor with rooms on both sides and one playroom for the children. The ward has a total of 24 beds. The ward is silent and the air is stale. Most of the children in the ward have HIV, but some of them are infected with TB. The children are small, thin and some of them have sunken faces with bulging eyes.

At its establishment in 2001, the goal of the ward was to provide medication for HIV infected children since there was no treatment available for them. In 2007, the South African government started providing this treatment for the children. This changed the organization's role in the ward. Currently, the HOPE Cape Town Association tries to improve the lives of the children and their families in the ward while at the same time providing education and counseling.

Sonia Daniels, a cheerful and motivated woman, is HOPE's main point of contact in the ward. The families of the children staying in the ward can always come to her with questions and problems.^{xxi} Sonia Daniels is a fashionable woman who matches the colors of her outfits, bracelets and eye shadow. Although she must be in her forties I estimated that she was much younger. Working with the children in the ward keeps her young. She clearly has a passion for working with the children. Before coming to the HOPE Cape Town Association, Daniels worked in the textile industry. Now that she is working for the HOPE Cape Town Association her life goals are being fulfilled. Daniels explained that all people should make a contribution to society and this was her way to do this. Daniels explained that in the past she had difficulty letting go of her work while she was at home. This is no longer the case today and because of this she her work is more effective. She is proud at what she does. Her work gives her great satisfaction.

Sonia Daniels' main interaction is with mothers who stay with their children in the hospital permanently. These mothers sometimes stay in the hospital for months. Most of these mothers are infected with HIV and gave the virus to their children. Some of them found out about their positive HIV status just recently when their children were diagnosed. Talking to these mothers is very important. They need to learn how to deal with their and/or their children's disease. Receiving support is very helpful in this process. Daniels provides the mothers with food, support and education. Sonia Daniels explained to me that talking with the mothers about the stigma attached to HIV/AIDS is '*Key number one*'.

At the HOPE Cape Town Association it is believed that providing support and education is most effective when the contacts between the healthcare provider and patients are face-to-face. This contradicts with authors who state that this can be performed online (Rodrigues and Risk 2003; O'Grady 2006; Gómez et al. 2002). Daniels explained that in order to give of counseling, support and education to the mothers in the ward, she needs to build a trust relationship with them. The face-to-face contact that Daniels has with the mothers facilitates this trust and stability. A large part of the knowledge transmission depends on good communication between the health worker and the client. Daniels explained to me how the mothers trust her and ask her questions that they do not ask the doctors.

Because of the wide variety of cultural practices and ethnic backgrounds in the Western Cape it is very difficult for organizations to create a comprehensive approach for their fight against HIV/AIDS. HOPE director Noëline de Goede explained that organizations can only appropriately educate and treat people if they realize that they need to take into account the variety in the Western Cape. It is important to approach every person different since the wide cultural, educational and economical variety in the Western Cape results in people having very diverse problems. It can be very difficult for healthcare providers to have proper understanding of someone's cultural background if the contacts only take place indirectly via technology. Hubert Dreyfus and Stuart Dreyfus (2004:403) state that this is the fundamental shortcoming of technology in communication. Technology, they say, cannot be programmed for context. Technologies do not understand human life. The findings also support Préau et al. (2008:467) and Demetria Cain et al. (2011:476) who state that a good relationship between the healthcare provider and patient and face-to-face communication are very important in successful counseling. The insides of the employees of the HOPE Cape

Town Association also support findings of Mallory O. Johnson et al. (2012:401) who state that health interventions aimed at improving the patient's skills in problem solving and assertive communication result in higher treatment knowledge and understanding about the need of the treatment. The patient has more knowledge about the disease and is more involved in the healthcare system. This might result in a higher treatment adherence of HIV patients (Johnson et al. 2012:401).

Checking on Patients

Since HIV/AIDS is an incurable disease checking on patients regularly is mandatory. Technologies offer the possibility to monitor patients from a distance and can be useful since some patients do not want to come back to the clinics for follow-up appointments. The HOPE Cape Town Association does not work with these kind of technology-based systems. Also, checking the health situation of patients happens face-to-face.

Dr. Sandy Picken recently started working as a doctor for the HOPE Cape Town Association. She works at the Tygerberg Family Care Clinic, the Ithemba Ward in the Tygerberg hospital and the Delft ARV clinic. Picken is a very friendly and patient person. Being a young woman who just started a family she is very good at working with children. On Fridays, Dr. Picken works in the HIV wing of government clinic in Delft. One morning I joined her during her appointments. The HIV wing of the clinic is in a much better state than the rest of the clinic. Still, waiting hours are long. Early in the morning, people are already waiting to receive medical help. In the Delft clinic Dr. Picken treats HIV positive children.

One mother did not join her nine year old daughter in the clinic because she needed to work. A neighbor joined as the guardian of the girl. The girl was so sick that she possibly needed to go to the hospital. During Dr. Picken's conversation with the guardian it became clear that she did not know what disease the child has or at least did not want to mention it. While trying to explain that the girl needed medication the word HIV was never used. This example shows that the personal context needs to be taken into account. Dr. Picken always needs to access the extent to which the people openly speak about HIV/AIDS. This estimation can only be made if there is personal contact between the provider and patient. It determines how Dr. Picken approaches the patient and the guardian.

An advantage of seeing patients at the clinic is that Dr. Picken can also explore the life and family circumstances of the patient. While checking the children's health situation, Dr. Picken talks to the guardian of the child. Many parents of HIV positive children are infected with HIV, but the focus is often only on the children. Dr. Picken explained: *'A lot of the time the focus is not on the moms and we are often forgetting about asking the mom if she's on treatment or if she has had a CD4 count done recently. That [not taking into account the health situation of family members] is a problem that is contributing to HIV orphans and all these social issues, because the moms actually get quite sick without knowing it'*. If a check-up is done via technology Dr. Picken might get information about the child's health situation, but not about the living circumstances and health situation of the parents. An advantage of direct contact is that can be taken into account. During her appointments with the children Dr. Picken makes an overview of the family-situation by making an overview of the people who lives in a house. She asks about the home situation and school of the children. The effectiveness of this personal approach is supported by Johnson et al. (2012:401) who found that healthcare providers who make efforts to get to know the patients, who strive for patient autonomy and make concrete efforts to involve the patient in the decision-making process are better able to achieve these results with patients than providers who do not look beyond their patient's clinical presentation.

The communication between patients and healthcare providers can be facilitated through technology (Jbilou 2009:276; O'Grady 2006). However, the usefulness of indirect contact through technologies in the provider-patient relationship is debated. Laura A. O'Grady (2006) states that indirect contact cannot replace direct contacts, because through technology important communicational and physical cues might be missed. Dr. Picken explained that in the Western Cape the focus on personal contact is the best. She explained that there are very few technologies available in the communities. In Blikkiesdorp there are very few computers. Mobile phones are available but since many the people are poor they do not always have airtime to use their phone. It is very difficult for the patients to communicate their health situation to the health worker via technology because of this. Dr. Picken explained that contact via technology has negative consequences for the quality of the contact: *'It [technology] takes away from a personal one-to-one contact'*. Talking on the phone does not provide a sufficient overview of the patient's health situation. Dr. Picken

cannot know if people understand her by talking to them on the phone. If the patient is physically present at the clinic Dr. Picken can actually see how the patient is doing.

OBSTACLES OF REFUSING TECHNOLOGY

As explained above, technologies are not always needed in HIV/AIDS organizations. However, there are some disadvantages of focusing solely on face-to-face contact. This section discusses some disadvantages of not using technologies in HIV/AIDS organizations.

Obstacle one: Reaching all People

Sometimes parents are not present in the Ithemba ward to support their child. As I was walking with the German volunteer Olaf Schmitz through the ward, I noticed one child that was alone in a room. The parents of this child do not believe that the child has HIV. '*The parents never come*', Olaf said. '*I always play with her a little more, but she looks kind of sad sitting alone in her room*'. Not being supported by the parents can have very negative consequences for the health situation and development of the child. Both at the hospital and at home the child does not receive the needed support.

The HOPE Cape Town Association tries to reach as many people as possible so that many people can benefit from their work. However, the organization is not able to make much efforts to reach people who distance themselves from HIV/AIDS. These people will be able to continue to distance themselves from the organization because no efforts are done to reach these people in other ways than through face-to-face contact. This has negative consequences for the fight against HIV/AIDS, because this makes it difficult to change the behavior of all people so that the transmission of HIV can be stopped. Simultaneously, in order to reduce the stigma attached to HIV/AIDS all people need to be educated. Information and education about the disease could possibly reduce the stigma.

Obstacle two: Follow-up of Patients

Very important in the treatment of HIV/AIDS is the follow-up of patients. Some authors state that using SMS reminders for taking medication can be very successful (Pop-Eleches et al. 2011:827; Vital Wave Consulting 2009; Mechael 2010). SMSs can also be send to patients to remind them of appointments with the clinic or hospital (Mechael 2010:16). Because of this,

fewer patients miss medical appointments and the lost of follow-up decreases (Mechael 2010:20). The HOPE Cape Town Association does not use this kind of technological tools to increase the follow-up of patients. Dr. Picken explained that many people do not have access to technologies. She stated: '*Seeing the person is practically easier in follow-up*'. Dr. Sandy Picken explained that '*It's a very first world type of thing to phone a patient afterwards*'. Many mothers of patients that leave the ward do not have a mobile phone or rely on a neighbors phone. Dr. Picken explained that from a feasibility point of view it is easier for the patients to come back to the hospital or clinic. If patients do not come back to the hospital or clinic, they are lost. This is very negative to the treatment of the patient and further transmission of the virus.

CONCLUDING REMARKS

Sally Wyatt (2005:68) wonders if the non-use of technology can be voluntary or that this is always based on inequality and deprivation in society. Often, it is argued that all people should have access to the internet. Internet is viewed as a desirable technology. Many authors assume that access to the internet is the problem, instead of necessity (Wyatt 2005:69). This chapter explored not which but if technologies are useful in all HIV/AIDS organizations. Wyatt (2005:69) argues that some people will not use the internet because they do not want to. This chapter supports the view that technologies are not always wanted. Contrary to many expectations, it showed that technologies are not wanted in all health organizations. Research at the HOPE Cape Town Association showed that in some circumstances technologies are not useful at all. The HOPE Cape Town Association chooses to have direct, face-to-face contacts with its target group. This contradicts with authors who believe that implementing technology in health organization is at all times better than not doing this (Ellery and Ellery 2012; Mechael 2010:69; Vital Wave Consulting 2009).

The HOPE Cape Town Association does not use technologies in the contacts with its target group for several reasons. First, technologies are not needed to reach the target group. Face-to-face networks of the CHWs are utilized for this. Second, the counseling of clients is presumed to be more successful if a trust relationship between the provider and the client is present. A good provider-patient relationship is build easier through face-to-face than technology-based contact. Thirdly, it is difficult to check the health status of patients

when they are not present at the hospital or clinic. Direct contact is needed to see how the patient is doing and to get sufficient knowledge of the life circumstances of the patient. Fourthly, employees expect that many clients do not have access to technologies. Technologies are therefore not regarded as a useful tool in reaching the target group. Technologies are not a necessary tool for the HOPE Cape Town Association and can make contacts impersonal. They are therefore viewed as undesirable by employees of the organization.

Not using technologies does have some disadvantages. For instance, the organization does not have much tools to reach people other than through personal networks. Simultaneously, few efforts can be done to involve people distance themselves from HIV/AIDS. Secondly, if patients do not come back for follow-up appointments they are often lost. Unfortunately, the organization does not have possibilities in reaching these people, such as SMS reminders to keep patients involved in the medical system.

CONCLUSION

This thesis explored the use of technologies such as the internet, computer and mobile phone in HIV/AIDS organizations in the Western Cape Province, South Africa. The research for this thesis was a non-standard anthropological research, because of its focus on organizations instead of people. The original focus of the research adds to anthropological literature because it broadens the scope of the field. Simultaneously, the anthropological focus of the research adds to literature about the use of technologies in healthcare. Research on this subject is often statistical and views the technologies and their users as separate entities (Oudshoorn and Pinch 2003:2). The current thesis explores how technologies can be useful in a local context while looking at the meaning that the technologies have for its users. Because the organizations that participated in the research have very different attitudes towards technologies, a comprehensive overview of the meaning of technologies in HIV/AIDS organizations was presented in this thesis.

The goal of the thesis was to find out what function technologies have in HIV/AIDS organizations by showing if, when and which technologies are useful in specific local circumstances. The thesis shows that the usefulness of technologies in health interventions depends strongly on the local context. It showed that some factors make the implementation of a [certain] technology easier while other obstacles limit the effectiveness of technologies in healthcare. This means that when organizations want to implement technologies in health interventions they should look properly at the possibilities in the society instead of solely looking at the opportunities that technologies are presumed to offer.

The thesis adds to literature on eHealth since it gave important insides and made corrections to earlier findings. A main flaw in earlier literature is the focus on the computer in health interventions. Many authors emphasize that internet on the computer is useful because it is a cheap and fast technology (Juris 2005:195; Juris 2008:12; Stoecker 2002:157; Wasserman 2005:165). Many of these authors based their statements on findings in the developed world. This thesis gave inside on how technology can be useful in healthcare in the developing world. It showed that in the Western Cape the computer is rarely used in health interventions since the people in the society have very little access to computers. Computers are too expensive for most people in the society. In the Western Cape, not

computers but mobile phones are a widely available technology and therefore much more useful in HIV/AIDS organizations.

Authors writing about technology in health organizations have high expectations of the use of technology in HIV/AIDS healthcare. They state that technologies will significantly increase the quality and efficiency of health organizations (Glaser and Salzberg 2011; WTO 1997; Ellery and Ellery 2012:9; Mechael et al. 2010:5; Vital Wave Consulting 2009:4; Schroeder 2001:ix; Jbilou 2009:276). The enthusiasm about eHealth in the field is also great. Employees of the organization Cell-Life expect that technology can make a big difference in fighting HIV/AIDS. Technologies are valued by the employees of the organization as more than just communication tools. Technologies have a greater significance since they can be used in solving societal problems.

The thesis showed that expectations about eHealth should be attuned to local circumstances. Technologies in healthcare should not be seen as a solution to all HIV/AIDS related problems. Chapters one and two showed that technologies can contribute to the fight against HIV/AIDS, but that local circumstances can limit the usefulness of technologies in HIV/AIDS organizations. Cultural, economical and technological obstacles can severely limit the effectiveness of technology-based health interventions. Simultaneously, technology can make several contributions in HIV/AIDS organizations. For instance, technologies can increase follow-up, treatment adherence and knowledge levels of patients about their disease.

Besides looking at when and which technologies are useful in health interventions, the thesis showed that it is important to ask if technologies are useful in healthcare. The results support Sally Wyatt (2005:69) who argues that some people do not use technologies because they do not want to, not because they do not have access to them. The fourth chapter of this thesis showed that employees of the HOPE Cape Town Association value direct, face-to-face contacts over indirect, technology-based communication. Technologies are unwanted since they have the power to make contacts between the healthcare provider and patient impersonal. Moreover, using technologies in communication might lead away from real understanding. The findings contradict with authors who believe that implementing technology in health organization is at all times better than not doing this (Ellery and Ellery 2012; Mechael 2010:69; Vital Wave Consulting 2009).

The greatest challenge in the evolution of healthcare, Eike-Henner W. Kluge (2008:86) states, is not the technological development but identifying the ethical bridge that binds different views about technological use together. Cell-Life and the HOPE Cape Town Association have different approaches in increasing the quality of the healthcare in the Western Cape. Both approaches make contributions and have shortcomings. Combining the two approaches can lead to a more successful and comprehensive approach. This thesis showed that technologies can be useful in increasing treatment adherence, follow-up and information levels in patients. The mobile phone is presumed to be a good tool because most people are very attached to their phones. Besides encouragement, reminders and information that can be send to the mobile phone`s of patients, there is still a strong need to personal contact. This means that organizations can never function solely on indirect, technology-based contacts with patients. When people are diagnosed with HIV they need to learn how to cope with this complex disease. Since South Africa is a very diverse country, people have different cultural backgrounds and personal problems they have to deal with. Many research participants emphasize that personal contact leads to trust that is needed in order to educate and counsel people properly. Offering both personal and technological support to patients will lead to successful treatment of HIV patients.

In my view, technologies should have a supporting role in HIV/AIDS organizations. The core of the work of these organizations should consist of direct and personal contact with patients. Only through this patients can be educated and supported properly. Technologies can be fantastic supporting tools to remind patients of medication, medical appointments and giving extra information. However, I expect that patients can be supported in the best way when they have a good relation with the healthcare provider instead of having communication through technology.

However, there are important shortcomings that limit the effect of a comprehensive approach that combines both personal and technology-based contacts. It is important to remember that we are dealing with a developing country. This country has limited means and might not have the money to properly support these improvements in healthcare. It might be difficult to find funding from the government or other organizations or individuals. Besides funding, the underdeveloped state of the country can lower the effectiveness of the approach. As explained above people might not prioritize HIV/AIDS prevention because of

other needs that are not fulfilled. HOPE Cape Town Association director Noëline de Goede explained that if people do not have enough money for food, HIV/AIDS is not high on their agenda because this is a less immediate problem. In order to make the fight against HIV/AIDS successful a broader developmental approach is needed. Thirdly, a main problem in fighting HIV/AIDS in the Western Cape is the stigma attached to the disease. There is a large group of people that do not want to have anything to do with the disease even if organizations try to reach them through both personal and technology-based contact. It remains a challenge to involve these people in health interventions and HIV prevention.

In summary, the usefulness of technology in HIV/AIDS organizations is not straightforward. The thesis showed that technologies might not always be as useful as many claim them to be. However, technologies can play a large role in the fight against HIV/AIDS in the developing world if they are implemented correctly and according to local needs and circumstances.

DISCUSSION

Questions about the use of technologies in HIV/AIDS organizations add to larger questions about the role of technology in society. Today's world struggles with questions such as: How big is the role of technologies in people's lives? Do technologies determine how people organize their lives? And should the use of technologies be seen as a route that all societies inevitably take?

David M. Kaplan (2009:1-2) describes that in determinism social change is said to follow technological change. This means that if a technology is developed the society changes accordingly to the possibilities that the technology has to offer. This thesis shows that even though technologies are becoming important in health interventions, not all people follow these developments. There is debate about how useful the technologies actually are in healthcare. Trevor J. Pinch and Wiebe E. Bijker (1984:430) were the first to describe that different groups in society have a different view of what a technology is. This view partly determines the functionality of the technology, because people will not use a technology that they do not value. I believe that the function that technologies have for people is important in shaping the usefulness of the technology. The value of a technology should perhaps not be determined by its innovation and possibilities, but by the meaning that it has for people. This determines how big the role of the technologies in society will become.

Ronald Kline (2005:51) argues that resistance is a common aspect of the process of creating technological and social change. He does however state that resistance does not mean that the technologies will never be adopted by a certain group (Kline 2005:53). The question is if it is possible not to use technologies in a society that is based more and more on technology? I do not believe that people and organizations are eventually left without any choice of using a technology. The case of the HOPE Cape Town Association supports this view. However, if the advantages of technology in healthcare are irrefutably proven it becomes almost impossible for the organization not to participate in this. Not-participating will result in the organization being accused of using old-fashioned and inefficient methods.

If technologies are eventually adopted by all organizations, what is the use of the resistance against the technological developments? I argue that this resistance emphasizes the disadvantages and shortcomings of the new developments. This is necessary since

developers of the technologies usually focus in their enthusiasm solely on the positive sides. Resistance raises ethical questions about the use of technologies. Is it ethically right to use technologies in healthcare? Is the effectiveness of the healthcare more important than human relations? As David M. Kaplan (2004:227) notes: *'The crucial ethical issue with technology is not whether we can make or use something but whether we should make or use something'*. To what extent should people allow the developments in their lives? Can people demand human contact? On the other hand, refusing technological development is also unethical. If the use of technology in healthcare results in better health services how can it be seen as unethical?

Eike-Henner W. Kluge (2008:85) presents some ethical issues regarding eHealth. He describes that fewer personal contacts in healthcare result in lower responsibility of people for the patient's health and lower ownership of medical information. He describes the fear that because of the increased use of technologies in healthcare, patients might in the future rarely meet with healthcare providers in real life. In comparison to direct contact between the healthcare provider and patient, the use of technology in healthcare raises questions about privacy, ownership, control and responsibility (Kluge 2008:79).

If technologies play a big role in our health situation, they take over a main part of our lives. In the following years, many new technological developments will be implemented in health interventions because of new technological developments and increasing evidence on the effectiveness of current methods. It is clear that technology has a strong place in society and that it will not leave soon. I have noticed during the research for this thesis that some people value technology almost like they value other people around them. This makes technology powerful. However, a society is build by humans and only their actions can determine the role that technology will have in society. The people in a society determine the value of a technology and with this that place that it will have in society.

ATTACHMENTS

Map 1. Western Cape Province, South Africa.



Source: License Plates of the World

Map 2. HOPE Cape Town Association working area



Source: HOPE Cape Town Association

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NOTES

PROLOGUE

ⁱ Delft is a township created during South Africa's apartheid period for the Cape Town's poor inhabitants. Inhabitants of Delft are mainly black and colored people. Delft is divided in five sections: The Hague, Roosendal, Voorburg, Eindhoven and Delft South. Delft is growing fast. After 2001, two new areas have been developed, namely Leiden and Tsunami (Klein and Wessels 2007:22). The Tsunami area got its name because it gets flooded on a yearly basis. It is unclear how many people live in Delft. During the 2001 census it was estimated that Delft had 60 thousand inhabitants (City of Cape Town 2001). Blikkiesdorp is located in the south of Delft.

ⁱⁱ In the Western Cape society, a distinction is made by both the inhabitants and the government between white, colored and black persons. White people are the descendants of the European colonists and constitute 18.4 percent of the population in the Western Cape. The black inhabitants are the descendant of the original inhabitants of South Africa before the arrival of the Europeans in 1652 and consist of 26.7 percent of the population. Colored people are a mix between the two groups and are the largest group in the Western Cape with 53.0 percent (Statistics South Africa 2006:1).

ⁱⁱⁱ The names of the participants in this thesis have been used with their permission or changed into fictive names.

^{iv} The Human Immunodeficiency Virus (HIV) is a virus that damages the immune system of the carrier. The virus does this by attacking the CD4-cells of the immune system, so that the carrier can no longer protect her- or himself against other viruses and bacteria properly. HIV is a sexually transmitted disease, but can also be transmitted via blood, injection needles and breast milk. There is no cure against the disease. HIV is responsible for causing AIDS. In 2010, 34 million adults and children were living with HIV worldwide (UNAIDS 2011:11). In South Africa, 5.3 million people are infected with HIV (SANAC 2011).

^v The Acquired Immune Deficiency Syndrome (AIDS) is caused by HIV. The disease can be called AIDS when the carrier has a CD4 count below 200 and a stage-four defining illness. Stage-four illnesses are opportunistic diseases that might be fatal for the carrier. In these cases, the virus has damaged the immune system of the carrier to the extent that it can no longer fight other diseases. Many AIDS patients die of opportunistic diseases, such as TB and pneumonia. In 2010, between 1.6 and 1.9 million adults and children died of AIDS worldwide (UNAIDS 2011:11). In South Africa, 310.000 people died of AIDS in 2009 (UNAIDS N.d.).

^{vi} Short Message Service (SMS) is a service which short messages can be sent from and to mobile phones. One message can contain around 160 characters.

CHAPTER ONE: RESEARCH CONTEXT

^{vii} Tuberculosis (TB) is an infectious disease caused by bacteria. The bacteria generally infects the lungs, but can also infect other organs in the human body. Symptoms of TB are coughing, sweating, fever and weight loss. TB can be a deadly disease and especially dangerous for HIV infected persons. The disease is the main cause of death of HIV positive persons, causing a 25 percent of its deaths (WHO 2012:1). In South Africa, drug-resistant TB is a serious problem. This bacteria is resistant to many drugs. The prevalence rate of TB in South Africa in 2010 was 795 per 100 thousand people. At least 54 percent of these people was HIV positive (WHO 2012:2).

^{viii} The main urban regions in South Africa are Gauteng-Johannesburg, the Cape Town region and eThekweni/Durban.

^{ix} The community health workers of the HOPE Cape Town Association work in: Belhar, Bellville South, Bishop Lavis, Blikkiesdorp, Bloekombos, Brackenfell, Delft, Delft South, Durbanville, Elsies River, Goodwood, Grabouw, Hermanus, Mfuleni, Paarl, Scottsdene, Valhalla Park and Wallecedene (HOPE Cape Town Association N.d.).

CHAPTER TWO: CONTRIBUTIONS OF TECHNOLOGY-BASED HEALTH INTERVENTIONS

^x The exchange rate of the Euro and South African Rand is E1 - ZAR10.044 in July 2012 (IEX 2012).

^{xi} The CD4 (Cluster of Differentiation 4) count measures the number of white blood cells (also called T-lymphocytes) in the blood. These cells are important in the immune system of human beings. HIV attacks the CD4 cells in the carrier's blood and decreases the working of the immune system of its carrier. In South Africa, ARV's are available in government clinics for HIV patients with a CD4 count below 350.

^{xii} Communicate is one of four services that the organization Cell-Life offers. The other services are iDart, Capture and Research. Communicate is a software that is able to send SMSs to mobile phones. Users are able to send as many or few SMSs as they want, with varying content. The iDart system is a pharmaceutical dispensing system used in health clinics. The system is used by pharmacists to manage drug supplies, print reports and manage the collection of drugs by patients. Capture is a mobile and web-based data collection system that enables the user to collect data remotely. It is developed as a monitoring and evaluation tool for NGOs using community health workers. Finally, Cell-Life conducts mHealth research to decrease the lack of knowledge in the field (Cell-Life N.d.).

^{xiii} The Republic of South Africa has 11 official languages: isiZulu (23.82 percent), isiXhosa (17.64 percent), Afrikaans (13.35 percent), Sepedi (9.39 percent), English (8.2 percent), Setswana (8.2 percent), Sesotho (7.93 percent), Sitsonga (4.44 percent), isiSwati (2.66 percent), Tshivenda (2.28 percent) and isiNdebele (1.59 percent). The main languages spoken in the Western Cape are Afrikaans (55.3 percent), isiXhosa (23.7 percent) and English (19.3 percent) (Statistics South Africa 2006:14).

^{xiv} Antiretroviral (ARV) treatment is the standard treatment against HIV/AIDS. The drugs lower the viral load in the carrier's blood, but cannot cure HIV. Currently, the South African government offers ARV's to all patients with a CD4-count below 350. Prevention of Mother To Child Transmission (PMTCT) treatment can prevent the transmission of the HIV from pregnant women to their children and was introduced in the Western Cape in 2001. Highly Active Antiretroviral Treatment (HAART) is a treatment in which the patients uses a combination of three or four different drugs and is available in the Western Cape since 2000 (Western Cape Government N.d.). The Western Cape Government states that in 2005 these treatment were available for respectively 90 percent and nearly 60 percent of the HIV patients in the province (Western Cape Government N.d.).

^{xv} It is difficult to measure the actual lost of follow-up. Some patients choose to go to other clinics than where they took their initial test. Because this is not recorded in the clinical system these patients are seen as 'lost', while this is not the case. People may choose to go to a different clinic because this is closer to their work and therefore reachable during the clinic's opening hours or to avoid disclosure by others who visit the same clinic.

CHAPTER THREE: LIMITATIONS OF TECHNOLOGY-BASED HEALTH INTERVENTIONS

^{xvi} Not all government clinics in the Western Cape provide ARVs. This means that some people have to travel further to get their medication.

^{xvii} Abraham Maslov (1908-1970) created a theory of human needs and explained how these influence human behavior. According to Maslov, the human needs are hierarchy organized from basic needs to needs of self-actualization. People will not focus on higher needs if the lower needs are not met. People cannot make conscious choices that affect higher needs if the lower needs are not met (Glassman and Hadad 2004:271-274).

CHAPTER FOUR: EXPLORING THE NEED OF TECHNOLOGY IN HIV/AIDS ORGANIZATIONS

^{xviii} Blikkiesdorp is officially called the Temporary Relocation Area (TRA) by the government and is located in the south of the township Delft (Western Cape Government 2010). The area was originally meant as a temporary shelter for homeless people in the Cape Town region. However, it has become a permanent home for many poor and vulnerable inhabitant. Blikkiesdorp is currently inhabited by 17 thousand people (Cape Town Magazine N.d.).

^{xix} The HOPE Cape Town Association works both with HIV negative and HIV positive people in the support groups. The organization made this decision because prevention is important in combating HIV. Director Noëline de Goede explained that because the government spends more money on HIV/AIDS treatment than prevention it is important for the organization to focus on this. Simultaneously, the stigma attached to the

disease forces the organization to work with both HIV positive and negative persons. If the organization is solely known for its focus on HIV/AIDS very few people would go to the support groups because of the consequences of getting disclosed.

^{xx} The support groups focus mainly on women, since men often do not want to get involved in health organizations. The reason for this is that many men feel like asking for support is a sign of weakness.

^{xxi} Although both fathers and mothers are welcome to stay in the ward, fathers rarely come to visit their children. The reason for this is that in many families the fathers are not present.