



GÖTEBORGS UNIVERSITET

Institutionen för socialt arbete

Positively positive

- A qualitative study of HIV positive women in South Africa



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Socionomprogrammet
C-uppsats
Bachelor in social work
Spring 2007
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ABSTRACT

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The purpose of the essay was to examine the experience to live as HIV positive and how HIV affects life. The main focus has been the journey from not being HIV positive to the deliberations taking the HIV test, receiving the positive test result and reactions and actions being HIV positive. To examine these questions a symbolic interactive perspective, role exit, turning points and the reaction on crises have been used. Collection of information was carried out through six interviews with South African HIV positive women. During the interviews a semi structured interview guide was used. The result have been analysed and tied to the perspectives, theories and concepts presented. The conclusions that were made are that HIV has affected the women's lives and a change of behaviour has occurred. They handled the fact of being HIV positive in a skilful way through allocating support from their social networks and tried to live positively.

Key words: South Africa, HIV, Symbolic interactionism, reactions, life course

PREFACE

There are many people that I am grateful to and without you this essay would never have come into being. First of all I give my profound thanks to Lorna Yoko, who works at Hope World Wide in South Africa. Before I met you I had nearly lost all my hope of finding people to interview. You really inspired me and I am very happy that we met. Secondly I would like to thank all the ladies that let me interview them and welcomed me in to their homes. Third I thank Bulelwa Mhlwatika for helping me to translate Xhosa into English and Siyabulela Mhlwatika for giving me support and love plus taking me to the rural areas. You know I miss you all. Thank you Bengt Carlsson for supervision, leading me in the right direction and inspiring me to choose symbolic interaction as my perspective. At last but not least I would like to thank my family for supporting and believing in me.

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INTRODUCTION

The thought of writing an essay about how a HIV infection affects the life of the infected came to me after my first visit to South Africa when I went there to do my practical training as social work student in 2006. When we were at a study visit at a Red Cross office a woman that worked there came to introduce her and told us about her work and informed us about the work in general. She told us that she was HIV positive and found strength by working with and supporting other infected people. It felt to me that she was the strongest and most energetic person in the room. So I figured that there are ways to live with HIV and still find a meaning in life and strength to carry on. The motive for this essay is to get an insight and an impression of this issue and one of the reasons why I decided to go back to South Africa.

BACKGROUND

At the end of 2005 an estimated 38.6 million people world wide live with HIV. An estimated 4.1 million were newly infected and 2.8 million lost their lives to AIDS (UNAIDS/06.20E). South Africa is a country that has been hit hard by HIV and it is the biggest challenge socially and economically. About 5.4 million people out of a total of nearly 48 million South Africans were HIV positive in the middle of 2006, giving a total prevalence rate of a little over 11%. Out of these 600 000 were sick with AIDS (11% of the HIV positive) (<http://www.mrc.ac.za/bod/DemographicImpactHIVIndicators.pdf>). HIV is widespread in a sense that can be difficult to imagine for those living in less-affected countries. No matter where in the world a HIV positive person lives the infection does not only impact on him/her, but also those of their families, friends and wider communities. In South Africa the older generation have to carry a heavy load and often take care of the two younger generations.

There are many possible explanations why South Africa has been so badly affected by AIDS including poverty, social instability and a lack of government action. While the work of non-governmental AIDS organisations and civil society groups in South Africa have been widely commended, the government's response has been severely criticised, both domestically and internationally (<http://www.avert.org/aidssouthafrica.htm>) The last years there has been a revolting debate according to the fight against HIV and AIDS, a certain reason for this matter was that President Thabo Mbeki did not want to admit the medical connection between HIV and AIDS. Instead Mbeki blamed the old inherence from apartheid, poverty and social inequalities for the un-normal high death levels. Mbeki and his government has been criticized hard, for not making the antiretroviral drugs accessible to HIV positive, by families and friends to the victim of HIV (www.landguiden.se My translation).

An ending of the AIDS pandemic depends largely on changing social norms, attitudes and behaviours that contribute to its expansion. Top leadership must support the action against AIDS related stigma and discrimination. Every level of society and women's empowerment, homophobia, attitudes towards sex workers and injecting drug users, and social norms that affect sexual behaviour must be addressed – including those that contribute to the low status and powerlessness of women and girls (UNAIDS/06.20E).

With antiretroviral drug treatment, HIV-positive people can maintain their health and often lead relatively normal lives. But only about 33% of the people that need the treatment in South Africa received the treatment in mid 2006. Women seem to get the HIV test more often than men. This could be due to the fear of the stigma that follows a positive result (<http://www.avert.org/aidssouthafrica.htm>).

KNOWLEDGE OVERVIEW OF HIV/AIDS

Research about HIV/AIDS can be divided into several areas and are pursued in different ways. Foremost the medicine field are being researched due to find a vaccine or a cure for HIV/AIDS. There are also several studies according to antiretroviral therapy that has the purpose to keep the virus levels low and make it possible for a HIV positive person to live a normal life. Nowadays HIV is not a deadly disease, as long as you get treatment and as long as you do not get resistant to the treatment but AIDS is. Studies to prevent the virus to be transmitted from pregnant mothers to the child are also widespread. Other areas that are being researched are HIV/AIDS and risks, men who have sex with men, lesbians, preventions, drugs, sex-workers, ageism, traditional healers, body images, how the virus is spread and how many that gets infected and in what ways. I think the medicine research has a high priority since there is a lot of money to be made if a vaccine or a cure is discovered. If a company gets the patent they will earn an incomprehensibly amount of money. At the same time we might get rid of a disease that millions of people are suffering from and have died of. Now some countries have been allowed to produce cheaper copies of the antiretroviral medications, which hopefully makes some HIV positive people's lives easier (<http://www.palmecenter.se/upload/filer/utbildningar/utb2006/hivaidsstudiecirkel.pdf>).

The previous areas of research that have been mentioned are interesting but not exactly in the field that are of high relevance to this study. When searching for HIV in a symbolic interactionist perspective some articles of interest were found. *The role or constructed meaning in adaptation to the onset of life threatening illness* (Fife, 2005) Two central issues are addressed in this article: (1) what influence the meaning that is constructed in response to a crisis, and (2) how does the meaning affect the self and ultimately the adaptation/mental health outcomes as indicated by the level of emotional distress? Three primary findings were made: (1) the meaning constructed in response to a crisis operationalized and its role evaluated as an element of the adaptation process, (2) evidence point out that constructed meaning affects self-perception, which consequently affects adaptation, and (3) the pattern of effects does not differ by illness type. The concept of meaning in the stress experience is a central part of this article and that the meaning is a key factor in the individual's effort to adjust to the event. One article that was found investigates the meaning of spirituality in persons living with HIV and healthy adults (Tuck & Thinganjana 2007). The findings supported that spirituality is an essential human dimension. For the HIV positive people participating in the research it were more prominent being helped or guided and may explain their relationship with God. According to Mak, Cheung, Law, Woo, Li & Chung (2007) is HIV/AIDS among various infectious diseases considered to be one of the most stigmatising conditions. Mak (et. al 2007) have examined attribution model of self-stigma on social support and psychological well being among people with HIV/AIDS. A linkage between the attributions of control, responsibility and blames was confirmed but the relationship of blame to self-stigma was not significant.

Two Swedish essays regarding the HIV/AIDS situation in South Africa were found at www.uppsatser.se. HIV/AIDS as female issue -example South Africa (Lichtenstein & Person 2001) and Partnership and paternalism a study of Sida and the Africa groups development work in South Africa with focus on HIV and AIDS (Carlsson & Lindqvist 2005). Lichtenstein and Person (2001) examines the social situation of HIV positive black women and analyses the data in the perspective of how society looks up on HIV positive people in general and women in particular. Carlsson & Lindqvist's (2005) have the purpose to examine and problemize how

Sida and the Africa groups of Sweden's work with HIV/AIDS in South Africa in view of the post-colonial critique that has been directed this type of work.

This knowledge overview gives a short introduction to the subject of this essay. What differs is the interest to try to understand how the route to get HIV positive can turn out from the perspective of symbolic interaction. This is important from a social work point of view since it give us an increased possibility to be able to understand how the journey from being well to become HIV positive can take shape and how these persons can manage to find meaning and capacity to live their lives.

PURPOSE

The main purpose of this essay is to analyse (examine or inquire):
The life with HIV

- What is the experience to live as HIV positive in South Africa?
- How does HIV affect life?

To break down this purpose I have put forward the following questions, which hopefully will give the answer to the main purpose

- How was life like before and until the positive test result came?
- Reactions, intentions and actions after receiving test result?
- Orientation of life after receiving the positive HIV test?
- Did a change of life course follow due to being HIV positive?

THEORY AND PERSPECTIVES

The theories, perspectives and concepts that are presented below will be used as a foundation for analysing and interpreting the empiric material. The choice of theories and perspectives are based on the interest to understand the participant's lives before and after the positive HIV test result and how they establish their daily lives.

Symbolic interactionism

The significant thoughts, acts, events, people and encounters that edge our life process affect us all (Carlsson supervision 2007-02-15). Symbolic interaction is an approach, a perspective, and a basis for analyses of the social reality and there is an interest to understand processes, not to predict or explain (Trost & Levin, 1996 my translation). Symbolic interaction regards a careful description of human interaction to be a central goal of social science. The central principle of symbolic interaction is that we can understand what is going on only if we understand what the actors themselves believe about their world. It is the actor that lives and knows his or her world. It is imperative to understand what the actors know, see what they see, and understand what they understand (Charon, 1998). These are reasons why I find the symbolic interaction perspective relevant to the subject matter of this essay.

According to Charon (1998) the symbolic interaction focuses on the nature of interaction. People are constantly undergoing change in interaction and interaction involves human beings acting in relation to each other. The interaction takes place here and now and does not only take place between people but also apprehend what happens inside the person. Symbolic interaction describes the human being as more active and unpredictable than other perspectives do. Instead of focussing of the persons character or how society or social institutions effects human behaviour, symbolical interaction focuses on the social interaction, dynamic and the social activities that occur between people. Anything can become a social object for us. Whatever we use is a social object to us in any given situation.

Self

The self according to symbolic interactionism perspective signifies how the individual acts toward others and how the individual also acts toward himself or herself. It is the actor that acts and not the self that acts, and the actor is able to act back on the environment that exists outside as well as at the self. The self is an element of the actor's environment that he or she acts toward. The self is the internal settings toward which we act (Blumer, 1969). The self should just be understood as a social object that the actor acts toward. It should be viewed as a social object and individual comes to see "self" in the interactions with others. The self is defined as socially and like any other object it undergoes change in interaction (Charon, 1998).

Viewing the self as an object implies that the individual can act toward himself as he acts toward other people. Its social nature means that it is process rather than stable entity. For instance, how I describe myself, how I view myself, how I act toward myself throughout life is highly dependent on the social definition I come across in every day of my life. We are able to see ourselves in the situation as we communicate toward self, to recognize who we are in relation to others and vice versa, as well as to evaluate our own action in the situation. We are able to judge ourselves and to create an identity (Blumer, 1969).

Kinch (1963) mentions that the writings of Mead, Cooley and several others lay the base of the interactionist notions about the self-concept that are well known to social psychologists. The theory attempts to explain the conception that the individual has to herself in terms of her interaction with those about her. Although there have been a variety of expressions used to describe what is meant by an individual's conception of herself, it appears that viewing the self-concept as the organization of qualities that the individual attributes to him/herself could be reached as a definition. In very general terms the basic notions of the interactionist theory can be stated that The individual's behaviour is guided and influenced from the individual's conception of her/himself that in turn emerge from social interaction (Kinch, 1963).

Identity is an important part of self-concept. It is who the individual thinks he or she is and who is announced to the world in word and action. It arises in interaction and is reaffirmed in interaction and changes in interaction. This is important to what we do. The different identities we have are not as important, however some of them matters almost all the time (Charon, 1998).

Mind

For symbolic interactionists, "mind" refers to the processes of behaviour through which a person carries on "transactions" with his/her environment. The process, consisting of description to one by means of symbols, enables the individual to construct his/her acts as he/she executes them and to "carve out" the objects constituting his/her environment. The concept of mind is referred to a mental process or activity, not a physical unit such as his/her brain. Although the activity is covert, it is behaviour that closely resembles the obvious communication between individuals. The inner processes of thought rely on the same symbols used in observable behaviour. Thinking can be viewed as a process of internal conversation-of symbolic interaction between the individual and her/himself (Mains & Meltzer 1972). According to Charon (1998) individuals make indications to themselves. We point out things to ourselves through mind activity. We isolate, label and develop lines of action towards objects around us. We humans are constantly engaging in symbolic action toward the self, alone and in interaction with others. To understand other's minds it is necessary, to make oneself understood by others and to determine lines of action towards objects and situations. Charon (1998) further highlight the importance of mind, it is due to mind humans develop an active relationship to their environment. Now it is obvious that is it thorough symbolic interaction with the self, minded activity, that humans actively participate in the world around them.

Interpretation and action

We interpret the world according to social definitions. It is important to highlight that social scientists operate from the assumption that a physical objective reality does indeed exist independent of our social definition and that our social definitions do respond, at least in part, to something real or physical. We define the situation as "it exists" and that definition is highly influenced by our social life. We interpret the act and decide on a line of action. Even though we define our situation human nature is highly dependent on society for our most basic human qualities, such as conscience, language and the ability to reason. The nature of symbols makes the interdependence clearest. We all depend on society for symbols. We would be without a symbolic life and all the things that symbols make possible if it was not for other people (Charon 1998).

Charon (1998) claims as noticed, that we see the world through perspectives developed socially, reality is social, and what we see “out there” (and in ourselves) is developed in interaction with others. This point of view goes with Berger & Luckmann (1981) that claim that the society exists only as individuals are conscious of it and the individual consciousness is socially determined. Berger and Luckmann (1981) define *reality* as a quality that has reference to a phenomenon that we recognize as being independent of our own choice. (We can't wish them to go away). They define *knowledge* as the certainty that phenomena are real and that they possess specific characteristics.

Reality and knowledge relate to specific social context. We apprehend the reality of everyday as an ordered reality. Reality of everyday life is organized around the ‘here’ of my body and the ‘now’ of my present. This ‘here and now’ is the focus of my attention to the reality of everyday life. What is ‘here and now’ presented to me in everyday life is the realism of my consciousness. The reality of everyday life is not, however exhausted by these immediate presences, but embraces phenomena that are not present ‘here and now’. This means that I experience everyday life in different degrees of closeness and remoteness, both spatially and temporally. In this world of working my consciousness is dominated by the pragmatic motive, that is, my attention to this world is mainly determined by what I am doing, have done or plan to do. The reality of everyday life further presents itself to me as an intersubjective world, a world that I share with others. This intersubjectivity sharply differentiates everyday life from other realities of which I am conscious. I know that there is an ongoing correspondence between my meanings and other people’s meanings in this world, that we share a common sense about this reality (Berger & Luckmann, 1981).

According to Berger and Luckmann (1981) are the analyses of roles important because it reveals the mediations between the macroscopic universes of meaning objectified in a society and the way by which these universes are subjectively real to individuals. Looked at from the perspectives of the several roles, each role carries with it a socially defined attached knowledge. Firm order lays in the typification of one’s own and others performances. Both self and others can be apprehended as performers of objective, generally known, actions, which are recurrent and repeatable by any actor of the appropriate type. This has very important consequences for self- experience. In the course of action there is an identification of the self with the objective sense of the action; the action is going on establish, for the moment, the self apprehension of the actor, and does so in the objective sense that has been socially ascribed to the action. By playing roles, the individual participates in a social world. By internalising these roles, the same world becomes subjectively real to him (Berger and Luckmann, 1981).

Reactions on traumatic events

When we are exposed to traumatic events we react in different ways to be able to deal with the feelings that we experience. According to Cullberg (2003, my interpretation) is it suitable to divide the course of event in traumatic shock reactions in to four stages. These stages cannot be separated but they link together.

Shock phase (lasts from seconds to days)

The affected tend to keep the reality away and cannot adapt to what has occurred. Under the surface of the affected person everything is chaos. Reactions differ from person to person, some might get aggressive and others might go in to regression.

Reaction phase (lasts for about four to six weeks)

The shock- and reaction phase is the most emergent phase of the crises. The affected has to start realising what has occurred and try to find some meaning in what has happened. Feelings of guilt are common and different defence mechanisms are often used to minimize the experience and awareness of danger and threat for (the) me. Feelings of sorrow, abandon, self despise, drug abuse, chaos, meaninglessness, aggression and psychosomatic illnesses are often common during this phase.

Adaptation (lasts for about 1/2 to 2 years)

The affected person starts to live with e.g. the chronically illness and adapts to new social roles. Denial as a defence mechanism decreases when the adaptation starts to increase. Activities that were performed before the incident are getting started again and distance decrease the feelings of guilt.

New orientation (lasts for the rest of life)

New interests are replacing the ones that were lost. The damaged self- esteem has been re-established. A crisis becomes a part of the life (Cullberg, 2003).

A positive result of the HIV test could create reactions that might lead to psychosocial insufficiency. Bernler & Johnsson (2005, my translation) have separated four main characters of psychosocial insufficiently states. *Temporary lack of resilience*; the client has an adequate adaptivitet but because lacking or wrong input is the client in temporary lack of resilience. The problem is solvable through exchange with other systems.

Permanent lack of resilience occurs in systems with lowered adaptivitet. More and more situations are apprehended as problems and these are solved according non-functional stereotyped patterns. The person or family are aware that the solving is not appropriate but are not always conscious about the need for help to structure new habits to solve the problems.

Crises is what we normally call a temporary functional capacity, triggered by radical changes of the demands on the person and are only changeable on a higher level by meta adaptation. At first the person might react with resign and cannot see any possibilities to make such a reconstruction. Inability to transform the system after social and personal disasters, but also in connection with changed demands during development, are the most common reasons for psychosocial crises. *Elimination*, represents the states where the hope about improvement is gone. The state could also be named constant crises. Attentions to help that aims to adoption or reconstruction have no effect, or leads to an adaptation to the psychiatric- or social help it self. The difference between elimination and permanent resilience is that you have both lowered meta-adaptivitet and lowered adaptivitet.

Social relations

Social relations are important when it comes to recovery and persons in the surroundings mean a great deal. There are different functions in the social relations such as: ventilation, material support, motivation, understanding etc. (Topor 2001, my translation).

Social networks consist of horizontal relations between individuals, reciprocal human relations. The actor's position in the social network is decided by social status and resource control. Relations between two individuals are affected by the retaining and strengthening of the relation, this is more important than the action it self. The most central function in the network is the exchange between different individuals; endowment and trust are being exchanged. According the Powell tradition the most vital function of the network is to include or exclude individuals. The relations in the network are constructed of trust and confidence to manage the in built insecurity of life. It is easier to engage in network exchange with

somebody that belongs to the same or a close social group, with similar background-resources, values and norms (Hreinsson & Nilson 2003, my translation).

If you are open with your status as being HIV positive other people might react towards you in a negative way due to fear or pure ignorance. The outcome of this could develop in to stigmatisation. The term stigma comes from Greek and was an expression for bodily signs intended to point out something unusual or disparaging in the person's moral status. Today we do not literary burn mark persons but we tend to categorize people and attribute them with certain characteristics when we meet persons for the first time. If the person have a certain characteristic that differs from the rest of the crowd is not regarded as normal the person can become an outcast of society. Goffman points out that this phenomenon does not have to do with the characteristics but the relations. Stigmatism is always something that takes places in some form of group. The stigmatised person is not always stigmatised in all the group constellations he/she takes part in (Goffman, 1972).

Shifts and changes

Ebaugh (1988) has studied the breaking up as a process and has developed a theory of the process of role exit. According to Ebaugh the mutable self represents a significant shift, for the individual, from orientation toward the stability of self as a process. The shifting self develops as a response to the centrality and frequency of role change in the course of an individual's lifetime. According to Ebaugh role exit is something that occurs over time. Very rarely does it happen as a result of one sudden decision. Rather, role exiting takes place over a period, frequently orientating before the individual is fully aware of what is happening or where events and decisions are leading him or her.

Sometimes during a process an event takes place that leads to a turning point. Turning points can be described as follow:

Interactional moments that leave marks in peoples lives... have potential for creating transformational experiences for a person...they are often interpreted, both by the person and by others, as turning point experiences. (Denzin 1989 p.40 in Carlsson 2005 p. 30)

Denzin (in Carlsson 2005, my translation) identifies four different kinds of turning points:

- *The major epiphany:* an event that totally or suddenly has a major affect in a person's life and never makes it the same again.
- *The cumulative epiphany:* occurs as a result of a series of events.
- *The illuminate epiphany:* an eye-opening event that exposes a problem or an underlying problematic pattern.
- *The relived epiphany:* a previous event is revived and gets its significance as a turning point gradually.

The concept of epiphanies is used to describe significant events that create turning points in people's lives.

Social biography

A way to understand processes or actions is to focus on significant occurrence in a chain of events. If you want a more varied opinion of a process and its complexity it is interesting to examine how the person who acts apprehend these incidents and if the apprehensions are alike or differ. Törnebohm (in Bernler & Bjerkman 1990, my translation) asks, “What is worth knowing?” What is true and relevant at one time is not seldom doubly or irrelevant at a later time. A social biography ought to contribute to the understanding of a human life destiny. The individual life itself is dynamic. It can be understood and studied as a process, a course of event. Life process is a period of time that includes all the logical levels that are included in the system. Within the human actions, perceiving, interactions and reflections takes place. These activities establish the “path” and the life process can be seen as a structure that brakes through, filled with life in the actual process. The live process takes place in three different worlds: in the material world, in the awareness of others and in the own conscious. It includes what happens in these three worlds and beside the relation between these courses of events. I am in the world. I have an image of the world, a conception of the world. My life- process is affected both by what occurs in my interaction with the physical world and social world and this interaction is in its turn affected by my self-image. My process is created by and in the society I live in and me myself constitute a micro cosmos of this society. My process of living reflects not only an event of occurrence in my surroundings but also its structure, its order (Bernler & Bjerkman, 1990).

These perspectives, theories and concepts will help to understand and analyse the participant’s stories. To get a clue of how the journey from pre HIV positive to HIV positive is the participant’s life span will be one of the main targets for this essay, by asking questions that concerns the life before and after and events in-between these periods of time. The figures of the participant’s lifelines will hopefully become illustrated by the questions during the interviews.

METHOD

Choice of method

The purpose of this essay is to look into how the participants experience the reality of being HIV positive. The aim is to describe the interviewee's life world and the subjects in their relations to it. To get this information interviews were made because the participants could give their views from within and from their own perspectives and tell us their own stories. According to Richardson (in Coffey & Atkinson, 1996) we as social actors are all involved in retelling our lives and experiences. We chronicle our lives in terms of series of events, happenings, decisions and influences. In this essay the women's histories will have significance for me as a researcher as well as a private person. According to Kvale (1996) may a journey like this not only lead to new knowledge but the traveller might also change. The insight of a reflection process might lead the interviewer to new ways of self-understanding, as well as uncovering previously taken for granted values and customs.

Design of interview guide

The qualitative research interview focuses on certain themes in the interviewee's life world. Neither strictly structured with standardized questions nor an entirely nondirective interview will be carried out. The interview guide that was used has semi structured questions, which can be seen as themes (See attached interview guide) that cover a perspective from the time before the participant knew about their status and to the interview day. I tried to construct the interview guide so it would come together with the theories that were chosen for this essay to facilitate the analyse. I wanted to keep the questions as open as possible e.g. not ask if they find support in friends, family or God or since I wanted the answer to come from the women without me giving clues to what they could answer. The purpose is to make a mini travel in to chancing others personal experiences and feelings. The journey starts letting the women looking back at how they understand the lives they had previous discovering their status. Then they look into the time before, during and after taking the test and receiving the result. Their reality of re-establishing and living life as HIV positive is also being explored and finally they are asked to share their thoughts of the future. In this way the participants are looking at the past, the present and the future. It is important to observe if the previous is affecting both the way we look at the past and the future.

Literature

I searched for relevant literature at Gothenburg University's library database and the search motor for articles. Words as symbolic interactionism, interaction, HIV, support for HIV positive and qualitative interviews were used. I also used the library at Växjö University to find some of the books that I could not get hold of at the University library in Gothenburg. My supervisor Bengt Carlsson PhD at Gothenburg University gave me ideas and suggestions to literature and perspectives such as the social biography, turning points and resilience. When using the Internet to find sources, the search motor Google was used. Words like: South Africa, HIV/AIDS, UNAIDS, Red Cross. A search motor, uppsatser.se to find essays written at Swedish Universities was also used.

Contacts, participants & procedure

Two contacts were taken before leaving Sweden but apparently they did not turn out well in South Africa. One of the contacts is a professor who works at a university in South Africa and the other one is the branch manager at a well-known international organization. The persons said that they were willing to help but apparently they were too busy, because they could not help me when I called and emailed them in South Africa. I searched at the internet to see if I could get hold of other organizations that were situated close to where I was staying, no results. I looked in the yellow pages and found a support centre for HIV positive. When I called them the number was not in use any more. I visited a hospital and asked to talk with the people in charge to see if they would agree to let me ask patients if they wanted to participate in the interviews. I was told to call back the next day. The next day everyone was busy because they were reorganizing the staff and they could not help me. Luckily a person that works at the hospital's reception gave me a number to a lady, Lorna Yoko who works for HOPE WORLD WIDE an organization that supports people that are HIV positive and inform about HIV/AIDS. I called her but was worried that the history would be repeated however this time we made an appointment and everything turned out well.

How many participants should be interviewed? According to Kvale (1996) you should interview as many as you need to get to know what you want. There is a major critique against qualitative interviews because they are hard to generalize when you use too few subjects. Statistical generalisation is not a central aim in the qualitative method but the choice of participants will still have a decisive part of the research. If we get wrong persons to participate it can jeopardize the outcome and the research will be useless. The choice of participants will be made after certain reasons. This means that a random or occasional selection do not take place (Holme & Solvang, 1997 my translation). In this essay generalization will not be made because the interest lies in how the participants experience their life and a generalisation would not be fair to them after they have given an insight to their life or to other people that also experience the fact of carrying the HIV infection. It was difficult to find participants for the interviews. At first the goal was to interview as many persons as possible, but now I had to settle with six participants due to the difficulties getting hold of participants. Since there are more women than men in South Africa that are HIV positive I thought it would be interesting to hear the voices of the ordinary adult HIV positive South African woman.

Lorna Yoko and I met and she helped me to find the six women that were interviewed. All the women lived in the same district. All the women except one belonged to the same support group. They did not know that the other once were interviewed except in one case when mother and daughter lived in the same house. Each and every one of the participants is open with their status. The names that are used in the result and analyse section are not the women's real names. Five of the interviews were held in Xhosa, one of the eleven official languages in South Africa. Bulelwa Mhlwatika who has Xhosa as mother tongue and speaks fluent English helped me to interpret during the interviews. I found it a little bit difficult because the follow up questions did not come naturally and the flow was interrupted since I needed to write and understand what was said at the same time. The interviews were not recorded. It did not feel right to ask the women if I could record them and since they spoke Xhosa it would not be much of a help to me any way. Bulelwa helped me to go through three of the interviews, the other three I went through by my own. None of the woman got paid and all of them wanted to participate by own free will. Before the interviews started, Lorna from

Hope world wide told the woman who I was, the purpose of the interviews and that everything that were said in confidence and the material would only be used in this essay.

It is important that the interviewer is aware of interpersonal dynamics with in the interaction and takes them in to account in the interview situation and the later analysis of the finished interview (Kvale, 1996) After the interviews took place I was filled with many different emotions and I felt amazed how strong the woman were. The atmosphere during the interviews were friendly and I experienced that the women spoke from their hearts and did not get affected even though there were more people that just me, the interpreter and the interviewee in the room.

Validity & reliability

The qualitative method is not as demanding as the quantitative methods concerning the representatives of the information. The problem with getting valid data is less in the qualitative method because the closeness to what is being studied is more advanced. Anyhow the researcher might miss -interpret the situation so the problem is not completely out of the picture (Holme & Solvang, 1997 my translation). The reliability is decided of how the measures are carried out and how precisely the information is adapted. The validity is depending in what we measure and if this is made clear in the purpose. It is not enough to have reliable information. If we measure something else than we want or think that we measure, the information can be how ever reliable, but it cannot be used to answer the inquiries. A necessity for this is that we have valid information. Reliability is a necessary but not a condition enough. Except from being reliable the information needs to have a definitional validity. According to Ejvegård (1996, my translation) is it more difficult to test the validity than the test reliability. It can only be made if you have another measure of what you measure to compare with. *Internal validity* concerns the level of which we are able to eliminate the rival hypotheses or potential alternative explanations of our findings. As such, the concern with random selection in relationship to internal validity is limit biases in research designs that are attempting to support explanatory. *External validity* is limited to the degree that findings within a study are not able to be generalized (Cournoyer & Klein, 2000). Further on Cournoyer and Klein (2000) mean that we must be concerned with external validity whenever descriptive, predictive or explanatory inferences are being made. Although external validity may also be limited whenever the study conditions differ from those that are found in the nonstudy environment, failure to randomly select from the population is probably the most common limiting factor in generalization.

Ethical considerations

There are some important ethical questions that have to be considered before the research starts. The research should be aiming at important questions and have a high quality. The individuals that participate shall not be exposed to physical or psychological hazard, humiliation or violation. These two demands are called research-and individual security demands. The value of received knowledge shall be measured against the risks of negative consequences for the participators. In this essay the aim is to improve the understanding of the experience of being infected by HIV and the participants gave the data by their own free will. The basic individual security demands can be concrete in to four demands on the research. Information before the decision to participate is taken. As mentioned earlier Lorna made a presentation of me and the purpose of the interview before the women agreed to participate. *The information demand*, the participants were told that I was interested to interview them

because of their HIV status. They were informed that some questions concerning live as HIV positive were going to be asked. *The demand of agreement*, the participants were free to interrupt their assistance and stop the data from being published. *The demand of confidentiality*, nothing that were said during the interviews will be outspoken, the only ones take part of the information as a whole are the interviewer, the interpreter, the other people that were present during the interviews and my supervisor. The interviews will not be published in a way that identity of the participants will be relieved; names and places have been changed. In this essay the interviews will not be published as a whole, quotes will be made and they make the foundation for the coming analyse. *The demand of use*, the collected data will not be used elsewhere than in this essay, and the personal data will not be used as a base for decisions or to attends that concern the persons that take part (Vetenskapsrådet, ISBN: 91-7307-008-4 my translation)

Analyse

Analysing is not simply a matter of classifying, categorizing, coding, or collecting data. It is not simply a question of identifying forms of speech or regularities of action. Most fundamentally, analysis is about the representation or reconstruction of social phenomena. We do not simply “collect” data; we fashion them out of our transactions with other men and women. Likewise, we do not merely report what we find; we create accounts of social life, and in doing so we construct versions of the social worlds and the social actors that we observe. It is therefore, inescapable that analysis implies representation (Coffey & Atkins, 1996 page: 108).

According to me Coffey and Atkins (1996) highlight a very important phenomena. I can never represent exactly what happened and was said but I will give a retrospective representation of what the interviewee's said. Coffey and Atkinson further on emphasizes the importance to enquire what unit of analyse we are dealing with: the individual social actor, the household, a particular social group, and so on. They also request that we consider what level of social analysis our texts will convey. In this case the analysis will deal with the individual actors and a particular social group. The women have only spoken about their own experiences and not of the experience as a social group. When writing the interviews I first wrote them separately word-by-word. After that I chose to give the participants fictitious name and took out parts that give a relevant presentation of the women's experiences, opinions and actions for the specific theme. The collected data will be presented in themes to facilitate analysing and reading. First a short presentation of the theme will be handed then quotes and descriptions of the women's sayings will be given and finally an analyse that attach the data with the perspective, theories and concepts will be made.

Methodological reflection

The first question that should be asked is if other methods would have been more appropriate to use? A survey would have been good to use in the perspective of anonymity and more people could have been reached. I think it can be difficult to get people to answer a survey if they do not feel interested in the subject of matter and that the fact that personal interaction will not occur makes it easier for the respondent not to answer the questions. If a survey with multiple choice answers is used the participants will not be able to express their own thoughts and feelings. I consider that there are several advantages with the qualitative method that was used. The participants answered the questions with their own words and were free to express

them self. Closeness between the interviewer and the interviewee that gives the possibility to create an atmosphere and a feeling of confidentiality that can make it easier for the interviewee to open up can be created (and reversed if the respondent does not feel fine in the situation). I wanted to get a down to earth relation and get near the person that was interviewed since the subject matter is personal. In this case the interviews all took place in the women's homes I got the feeling that it was good because the ladies were all relaxed in their own environment and it was convenient since they did not have to go any were. As mentioned before there were more people in the room when the interview took place than just the once that were concerned. This could have affected the way the women answered the questions but I am not sure since all the women were open with their status and the culture differ from the one I am used to. Cultural phenomenon differs from South Africa and Sweden. In Sweden we are more individualistic and sometimes I get the feeling that you should mind your own business and not bother others with your problems. In South Africa I get the feeling that you care more about your family and have a more collectivistic way of thinking. I think this have to do with the tradition of Ubuntu, which implies that you should take care of, help and share what you got with your family and friends. I think the fact that they all belonged to the same support group can have affected their answers because they all share similar values and ideas and have shared the same information during the sessions. As already mentioned five of the interviews were held in Xhosa. This affected my ability to get the slight differences and how the women expressed them selves. Since the body language differ a bit from what I am used to this was also a minor difficulty even though it feels like I understood the major parts thanks to my interpreter. Some of the questions in the interview guide were apprehended as very similar. It was the questions concerning changes of organizing the life and the question about changes of life course. The participants were confused and some of them gave the same answer on both of the questions.

RESULT AND ANALYSE

In this part of the essay the result of the interviews will be presented and analysed. First a brief introduction of the women that participated in the interviews will be given. After that a short introduction to the current topic will be made, then the women will be quoted to get a more living picture and the collected information from the interviews will be summarized. Finally analyses will be made where the perspectives, theories and concepts earlier presented will be attached to the material.

Presentation of participants

- Joanne received her positive test result in July 2005. She is the mother of a son.
- Nicky got to know about her status in 2001. She had lived with her husband who also was HIV positive. He passed away in an accident 2001 and she was left with three boys support.
- Julia is the youngest participant. She finished senior high school in 2002 and found out that she is HIV positive two years later.
- Mary got to know that she is HIV positive in 1997. She has two children.
- Patricia got to know about her status in year 2000. She used to work as a domestic worker. She is the mother of Julia.
- Sarah found out that she is HIV positive in early April 2006. She has three children.

Life and self-image before positive test result

We start the journey from the beginning by going back in time and looking in to the women's life before the infection. It is important to be aware that the women look back at their lives in the light of HIV and that this fact can affect the way they view their previous life. It seems that they all lived quite normal lives. All of them but the youngest, Julia had children and lived with a man. Some of them were out partying and drinking others preferred to stay at home with their families.

” We were a happy family. Me and my husband were going out together and went for drinks” (Nicky)

“ I lived a normal life. I was a family person and not a party person”. (Julia)

According to their stories all of the women were living happily except Sarah.

“ The life I lived before the positive test result was not all right. My first husband had passed away and I lived with my new boyfriend who abused me and never came home on pay days.” (Sarah)

Comments and reflections

The reason why I wanted the women to tell about their lives before the infection was to see if there had been any change in the way they view their previous lives compared to how they experience their lives now. This question was asked because it is important to understand what the actors believe about their world (Charon 1998) and so we can get an insight in their past. Törnebohm (in Bernler & Bjerkman, 1990) states that it is important to try to see the chain of events and if apprehensions are like and differ. I tried to make the women create a life course and where would be better to start if not before the awareness of the infection. Before getting infected five of the women identified their lives as happy this sensation is likely developed through the interaction with others since our perspectives are developed socially (Charon, 1998). This gives an explanation to why Sarah did not experience an all right life.

Decision to take the test and waiting for result

Before taking a test like this there could be some deliberations since a positive result involves different changes such as becoming a patient, a HIV positive and reconsideration of previous life could take place etc. On the other hand if the test turns out negative you know that you are well and can keep on living your usual life, maybe more carefully than before. Changes according to being HIV positive that might arise out of your control will not occur. There could be things pro and against taking the test that make you deliberate concerning the procedure. For the women this was not the case, their decisions to take the test came after a period of not feeling well and all the women except Sarah decided to take the test because of feeling ill. They had different kinds of symptoms such as; vomiting, swollen glands, weight loss, fevers and boils.

Sarah decided to take the test because she could see the signs that her boyfriend was sick. Julia did not want to take the test at first but her family encouraged her to do it. At the time she was already in hospital.

“ I signed the forms myself.” (Julia)

Nicky went to see the doctor several times before taking the test. She was given injections and tablets and she felt better for a while but then she felt sick again and the doctor asked her to take the test. After she found out that she was positive her husband that had children on the side also took the test. Mary did not hesitate to take the test; she wanted to know her status. Nor Joanne had any deliberation to take the test. She was so sick and wanted to know what was wrong with her. It was the same for Patricia; she decided to take any test just to get better.

Comments and reflections

All the women decided to take the test of on free will due to feeling sick or because of the awareness that the partner were sick. This can be attached to the individual's self-concepts; they attributed qualities that could be interpreted as signs of having HIV. They were feeling sick and their doctors offered them to take the test. From a symbolic interaction perspective this can be viewed as their behaviour, to take the test, were guided and influenced by the social interaction with the doctors (Kinch, 1963). The symptoms that the women were familiar with were independent of their own choice and they could be put together as a sign or a symbol that could indicate that they were HIV positive (Berger & Luckmann, 1981). For Julia it was important to emphasize that she signed the form to get the test herself this can be seen as symbol of power in the situation when executing action (Mains & Meltzer, 1972).

Waiting for a test result can be difficult. The not knowing of the out come can be complicated to handle. Worrying and thinking about being infected and the outcome of a positive result takes a lot of energy from the individual. The time of waiting for the test result differed from three days up to one month for the women.

Julia was very nervous before the result came. Mary, who has been aware of her status longest since 1997, does not remember for how long she had to wait for her result, since she had so many tests taken.

“People did not speak that much about HIV at that time” (Mary)

Sarah was fearful and scared of the out come of the test. She had lost weight and got scared and worried for the kids and her family.

“I was not fooling around” (Sarah)

Comments and reflections

The fact that the women did not talk much about how they felt during the waiting can have to do with defence. It can be hard to think back and rediscover the old feelings. Sarah emphasized that she had not been fooling around this can be interpreted as a sign of taking distance from the dissolute living that some people associate with HIV. The time of the waiting for the result differs form woman to woman and the fact that it was several years since they found out about their status can affect their memories. Another reason that some of them did not talk about how the time was can have to do with their reeling health. According to Berger & Luckmann (1981) it is the certainty that phenomena are real and possess specific characteristics that makes knowledge. The lack of sureness can make it difficult to remember the feelings that were felt and the fact that they differ from time to time can make it hard to pin point them. I think the fact that it is easier to remember the emotions felt when receiving the test since it is a much more crucial moment.

Reactions

When receiving a positive HIV test it is likely that you react in some way. Even if you have the feeling of being sick and might even concern being positive I think it is common that a reaction of chock occurs. Cullberg (2003) offers four stages of the reactions to traumatic chocks. The stages link together; chock phase, reaction phase, adaptation and new orientation. The first reactions that are seen are the chock- and reaction phase. When a HIV positive test result reaches you the possibility of getting into an insufficient psychosocial state is likely. Bernler & Johnsson (2005) have separated four different states of this phenomenon: temporary lack of resilience, permanent lack of resilience, crises and elimination. This model has been chosen to deal with the psychosocial side of handling the result of being HIV positive.

After receiving the result Nicky was scared and chocked. She thought that she was going to die and became very thin. She was out drinking with her friends and left her kids home alone. Joanne reacted strongly to the result and got very worried. A car almost hit her on her way from the hospital.

“ I got mentally ill and started to hallucinate. I could not believe that I was sick”
(Joanne)

At first Julia reacted with denial but eventually she accepted her status. Though she did not want to talk about it and was not open with her status at first. When Sarah found out that she was positive she told a friend who supported her and let her stay over the weekend.

“Now everyone knows about my status” (Sarah)

Mary was a bit worried after receiving the result. She cried about it but then she accepted the situation. After the positive test result Patricia did not want to visit her family the following time and it took her time to face them.

Comments and reflections

As seen the women went through a form of crises when receiving the test result but they acted in different. They were scared, shocked and worried. Some of the women acted with denial, which is a defence that often is used in the reaction phase of crises (Cullberg, 2003) because the fact that of being HIV positive was too difficult to handle. The next phase in the symptoms of crises is the reaction phase. Joanne became mentally ill and started to hallucinate and could not believe that she was sick. Nicky was drinking and neglecting her children. These are ordinary responses in the reaction phase and probably occur because the awareness of the HIV infection was such a big threat for the women who acted like this to be able to cope with the situation. Sarah's way of acting differ from the other women and told a friend from the start the reason for this might be that she did not feel that she could get support in her own house since her boyfriend at the time was abusive. Looking from the different states of psychosocial insufficiently (Bernler & Johnsson, 2005) she suffered from temporary lack of resilience and solved the problem through seeking support and comfort at a friends place. I think Mary fits in to this category as well she was sad but then accepted the fact that she was HIV positive. Nicky who was drinking had a lowered adaptivitet and solved her problems with non-functional activities and needed to structure new habits to solve her problems. Her status could be called a permanent lack of resilience. For Joanne, Patricia and Julia crises as the state of resilience occurred because they needed to work with and reconstruct and brake down their fear of facing the family and talking about the fact of being HIV positive. Joanne came to suffer from a mentally illness due to the crises also needed to adapt on a meta level. According to Charon (1998) we interpret the world according to social definitions and defined the situation as it exists but when you get the information that you have a severe infection it can be hard to find realize this knowledge as real and difficult to know how to act.

Social relations

After receiving information that tells you that you suffer from a chronically and sometimes deadly decease you need support and comfort to be able to move on. I think it is common that you turn to someone that was close to you and you trusted before the harrowing event took place. This person is most likely included in your social network, since exchanging of endowment and trust takes place between included persons (Hreinsson & Nilson 2003).

The whole family knows about Patricia's status. She can talk about her situation with her counsellor, sister and daughter. She feels that she gets the support she needs especially from her sister. Patricia's mother who recently passed away was worried about her. The strength to carry on Patricia finds in her counsellor. At first Nicky could only talk about her situation with a nurse that counselled her at the hospital where she took the test. After knowing her

status for six months Nicky told her sister thanks to support from the nurse. Now Nicky feels that she is given a lot of support from church, work and friends.

“My friends took care of me when I was in hospital suffering from meningitis. They washed me, fed me and kept me company.” (Nicky)

The fact that Nicky helps others helps her and gives her strength.

“I find the strength to carry on in God, because I pray much” (Nicky)

Sarah feels that her friends are very supportive. They give her food and help her out. Sarah feels that she finds her strength in her counsellor and the church fathers. The priests come to visit her at home and give her the communion. Mary found comfort in her sister and gets support by her family, her brother and sister and the support group she takes part in. The strength to carry on Mary finds by going to church, pray and take the treatment. Joanne feels that she gets the support she needs. She finds comfort in her mother and the whole family. She gets the strength to carry on by going to church, the support group and the needlework group. Julia gets supported by and talks to her mother, who is also HIV positive and her aunt.

“It feels like I am being spoiled because everyone takes care of me. My mother does all the washing and cooking. Sometimes it feels that it is a bit too much” (Julia)

Julia finds her strength to carry on through her counsellor. She likes church.

“Jesus and my mother help me to find the strength” (Julia)

Comments and reflections

The network might look different depending on who you are if you are out going you might have a big network but the persons that you chose to include might not be that close to you. Sometimes the network might look undersized but the persons are very close to you and you feel that you can entrust the individuals that are included. Finding strength in others and yourself is also a curative factor that the women use. All the women feel that they get the support they need. They mention mothers, sisters and their family as supportive, which shows that a great deal of the support comes from nearby, from their social network. Nicky was supported by the nurse who came to be an important person for her and was included in Nicky’s network. Even if some of the women hesitated to face and tell their families at first they turned out to be the major support. Friends also stand for a vast deal of the support. The women also tell that their support is not only passive listening and being there for you but also more practically such as helping with food and nursing you when you are at hospital. This can be considered as forms of material support (Topor, 2001). Julia experience that she almost gets too much of this kind of support and feels spoiled. These feelings can have to do with her knowledge that she herself would have done some of the household chores if she were well. All of the women except one are attending the support group and see a HIV counsellor that supports them. The women all have a religious belief and also feel that they find strength to carry on in the church and Jesus. They pray often and that is also an important element in the support group. All of the members are saved and it seems to me that this means a lot to them. This can be compared with the previous research that clamed that HIV positive persons were more prominent being helped or guided spiritually (Tuck & Thinganjana, 2007). Nicky differs a little from the other since she works with helping others in the same situation and this gives

her strength. I believe that working in this altruistic way can give you a form of satisfaction that make you feel strong and give meaning to your life. I think that the fact that you have people around you that are supportive and give you strength affects the way you come to view yourself. Since the interaction with others affects how we view ourselves and roles we play when participating in the social world (Berger & Luckmann, 1981). All the women find hope and strength through participation, presence and help from others.

The women are open with their status and this might lead to that other people stigmatise and discriminate them. As Goffman (1972) states does not the stigma have to do with the characteristic but the relations. I think this corresponds here since the fact that you are HIV positive not necessary shows but you get discriminated because you carry the virus. Goffman further states that stigmatised persons are not always stigmatised in all the group constellations they participate.

Mary has not experienced nor discrimination or stigma because of her being HIV positive.

“I am always around people that are HIV positive” (Mary)

Joanne first got discriminated people. Her neighbours did not allow their children to visit her. Now things have changed due to more information. The children are visiting her again and she does not feel discriminated or stigmatised. Sarah has not felt any discrimination or stigma since she is HIV positive. People support her and she only had close friends. Before Nicky was discriminated by her family and some of the church members because they were in denial. Her in-laws blamed her for infecting her husband. Some of the people in society call her names and gossip around. Julia has felt discriminated because of her status. Especially by the neighbours,

“They come to visit as if they want to see how I am doing and to support me, but all they really want is to get information so they can gossip and spread rumours.” (Julia)

Julia’s mother Patricia has also felt discrimination and stigma from society. But she does not get as bothered by the neighbours gossip as Julia does.

Comments and reflections

Two of the women have not been endured discrimination and tend to normalize the situation through avoid discrimination through just being in the company of other HIV positive or with close friends. This correlates with Goffman’s statement that the stigma does not have to do with the characteristic but the relation. I do not know if this strategy is a deliberately act from the women. The other four women have been exposed to stigmas and discrimination of different degree. In one of the cases this has stopped through education and information. Which I think is a good sign that people’s attitudes can be changed through education.

Turning points

Events that leave marks in a person’s life are considered as being a turning point (Denzin in Carlsson, 2005). As mentioned previously there are four major kinds of turning points. When it comes to receiving a positive HIV test I would like to call this a major epiphany, an event that totally has a major effect in a person’s life and never makes it the same again (Denzin in Carlsson, 2005). The awareness of being HIV positive will be with you for the rest of your

life even if the fact is not constantly on your mind. The incidence that takes place can be seen as a process. The event takes place and a process of adaptation to the new situation starts. You could call it a start of normalisation of the new situation. A turning point affects your life on many levels and can lead to a change of behaviour and new habits can be created. I would like to say that this event started already when they found out about their status.

Joanne experienced HIV as a changing point of event in her life. Her husband left her and she was hallucinating. Now she says:

“HIV does not affect my life. I view HIV as any other illness. I take life very easy and as it comes. I am not stressed.” (Joanne)

Now she views life very differently, because now she is ready to work again. Patricia also experienced HIV as a turning point in her life. At first she felt very small.

“I felt that I infected others and my family. Now I know that I will not infect others and I feel fine thanks to more information and knowledge.” (Patricia)

The awareness of her HIV infection made her life easy. When she found out that she was positive she had a boyfriend and they are still together as before. She views her life differently after the result and is living positively and healthy with her boyfriend and daughter. Nicky sees HIV as a turning point.

“Now I know how to take care of myself. I know how to prolong life and feel that I know more about myself.” (Nicky)

At first she lost hope and pride, because everyone was blaming her for the infection especially her in-laws that came from the rural areas. Nowadays Nicky wants to gain her goals and give other people who are HIV positive hope.

“I am just myself and I believe” (Nicky)

Mary experiences the HIV infection as a point of change, because she does not drink any more and has changed her habits. She views life differently, now she wants to protect her self and her family and raise her kids. The fact that she is HIV positive has entailed alteration for Julia. She has no old friends in her own age anymore. They all left after they found out about her status. Her friends are now her family, the support group and her counsellor. The awareness of the infection has changed her life. At first she could not talk about it, but now she talks about it openly. The same month we met she had told her uncle about her status when she was admitted to the hospital. She feels as she has disappointed him. She views her life differently now. She is looking after her health and takes everyday as it comes. For Sarah HIV is also experienced as a turning point.

“At first I was scared that I would die but now I deal with it. It has changed” (Sarah)

She got to know everything about the infection from a centre and her counsellor. Her life is very easy. After the result she viewed her life differently. She was very scared and did not want to mingle with people. Now she goes out and has supportive friends and neighbours.

Comments and reflections

The affects of turning point that has taken place in the women's life can be viewed in different ways. I would like to say that the event has effect on emotions, habits, reconstructions, and practicalities. The result has affected the family situation in at least three cases, Joanne's husband left her, Sarah took the decision to end a destructive relation and Patricia sees her daughter being affected by the HIV infection. Julia lost all of her friends in her own age because they decided to turn their back on her when they found out that she was HIV positive. It seems to me that the family and friends that stay and continue to support and comfort you are faithfully and will be there for you no matter what. All of the women have changed their habits in different ways and have adapted to the situation. The once that were drinking have stopped and the once that had problems interacting with others have over come the fear. All of them take good care of their health and try to live positively. They tend to take everyday as it comes and live their lives easy. Nicky lost her pride and her self-esteem was lowered due to the blame of her in-laws. Now she is regaining her self-confidence by helping other in the same situation. When it comes to seeing the turning point out from the symptoms of crises (Cullberg, 2003) I believe that all the women are in the adaptation- or new orientation phase. No one of them longer lives in denial and they have adapted and re-established their lives. The resilience has been solved and the insufficiency has been restored. They have been able to create meaning in their lives as HIV positive. Some of the women mention that they live and take their lives easy after they got to know their status. This can have several explanations, now they know how to take care of them selves and have a goal to stay healthy, take care of their children and take life as it comes.

Life changes

The reality of everyday is organized around the here of my body and the now of my present. It is the here and now that is the realism of my consciousness (Berger & Luckmann, 1981). Since the HIV affects both the body and the present a change in organizing the everyday life might occur. According to Charon (1998) we interpret the world according to social definitions. We identify the situation as it exists and that definition is very influenced by our social life. We interpret the act and decide on a line of action. After getting the information of being HIV positive the definition of life might change. The way of organizing the life and the way of looking at you could change due to adaptation to the new situation. A new role of being HIV positive is included in the person's life and this could lead to adjustments of the way of acting. Ebaugh (1988) has developed a theory of role exit. In this case we can use the theory both as form of exit, from being HIV negative but also as a from of role entering in becoming HIV positive. She implies that the changeable self represents a shift from orientation toward the stability of self as a process. Blumer (1969) states that we judge ourselves and create an identity and that it is the self that acts toward others. How I describe myself, how I view myself and how I act toward myself is highly depending on social definition.

The major change for Sarah is that her boyfriend took off.

"I kicked out my abusive boyfriend and now I feel that we are a happy family"
(Sarah)

The HIV infection has made her stronger and she had the power to kick him out. She did not really change her life course after the positive result. She did not drink before. After she got to know her status Sarah changed everything about the way she organized her life.

“I am still the same but happier.” (Sarah)

At first when she found out that she was sick Joanne did not want to be around other people, because she did not want them to see her sick. Now she has no problem being around other people and likes it. She has changed her life course to adjust her role.

“Now I am looking after myself and are positive at heart” (Joanne)

The infection made her weak but now she does not feel sick. She works and the positive thinking and the treatment make her strong. Joanne encourages others to get tested and to view HIV as any other disease. For Mary the life has changed and she is more carefully and decided to care more about her kids than she did previous. The infection has changed the way she looks at herself in a way that she now values herself more than before. Mary has changed the way of organizing her life in the ways that she is more carefully and wants to live longer. Patricia has changed the way she organize her life because now she cannot do the things she had planed to do due to the infection. She cannot work anymore and gets grant. Patricia does not think she has adjusted or changed her role that much since being HIV positive.

“I was a caring mother and a family person before, but I am still the same”.
(Patricia)

The infection changed the way Patricia looks at herself since now she is looking after her weight and worries that she is getting thinner. Nicky has changed her life a great deal. After her husband passed away she drank too much and left her kids alone at night. Now she does not drink any more or goes to parties. She takes care of her children, her sister and the sister’s children. When Nicky found out about her status she started to adjust her role self to become a better mother, a HIV counsellor and a public speaker. She decided to help other in order for her to feel strong. The infection has changed the way she looks at herself.

“I was thin and thought I was going to die. Now I am taking care of myself and look very healthy” (Nicky)

Now Julia organizes her life the way she wants to because of her status. Julia has changed the way she interacts with others. She no longer has her old friends. But she is no longer afraid to interact with others as she was in the beginning when she found out about her status. The infection has also changed the way she looks at herself.

“I see that I am very thin” (Julia)

Comments and reflections

A change of life habits can be seen in all the participants. Patricia expresses strongest that she had to change her life due to the infection since she can no longer do the things she did before. The tendency is to organize the life in a healthier way and looking after them selves due to live longer can be seen in their descriptions of behaviour. This can be perceived as a change in how the individual acts toward herself and might have to do with the interaction of others (Blumer, 1969). The participation in the support group and the meetings with the counsellor might have inspired the women in new ways of proceeding and valuing their well-being. The individual’s behaviour is influenced from the individual conception of herself that emerges from social interaction (Kinch, 1963). Joanne, Sarah, Mary and Nicky claim that the

fact of being HIV positive have made them more powerful, stronger and higher self value. I guess this can have to do with the fact that they realized that they now speak up in a different way since the experiences they have been through. There can also be other reasons for this change such as the social definition, they define themselves differently, which affects the way they describe themselves and involve a change in how they behave (Blumer, 1969). Some of the women have noticed bodily changes such as being thinner and this has affected the ways they look at themselves. This could have to do with worries of becoming sick and the fact of others noticing that you are ill. Which probably will reinforce the role as being HIV positive since the reflection of the interaction has consequences for self-experience (Berger & Luckmann, 1981). The ways of interacting with others has also changed for some of the participants. Joanne and Julia did not like interacting with people at first. This could be a sign of defence but after adaptation and finding new groups to interact with they both meet people again. The women's view on role adjustment varies. Patricia and Sarah clearly states that they still are the same have not changed their ways of acting that much. The other women have changed their ways of acting in behaving more responsible towards themselves and others. They started to question how they were acting as mothers and changed their behaviours. A conscious behaviour shift like this could be seen as a course of action they changed the identification of the self through change the way they act (Berger & Luckmann, 1981).

Wishes for and thoughts of the future

The fact that the women are infected with HIV does not mean that they do not have thoughts of the future. All of them except one has children and like most parents they will probably pass away before their children. What differs in these cases is the fact that they probably are more conscious of their immortality than other mothers since they are HIV positive. All of them are single mothers, which is another fact that influences their concern of the children.

Nicky's plan for the future is to live longer and to see her and her sisters children get the education that they need. So they can take care of themselves when she passes on. She is going to night school to get the certificate to become a nurse. Sometimes Nicky thinks that things are meant to be, like the fact that her husband was killed in the car accident. If he was still alive she might not be allowed to take care of her sister and her children and work as she does.

“Positive thinking leads to positive living.” (Nicky)

The youngest participant Julia had plans to and wanted to work for her mother. But when she was hospitalised recently she found out that she cannot work or go out any more. Julia's mother Patricia thought that her future is to look after her daughter. She wishes that Julia could be strong; she is Patricia's only child. She wishes that her daughter could do things like other young people. Patricia also wishes that she could be in a better place so that she could give Julia the strength she needs. Mary wishes for a brighter prospect for her children. For the future she wants to live longer so her kids can take care of themselves and be educated. For the future Joanne wishes her son to feel the same way she feels if he finds out that he is HIV positive. She does not want him to think it is the end of the world like Joanne did at first.

“Now I am happy.” (Joanne)

Sarah wishes in the future to rebuild her house and that her children will be educated and in a better position to take care of themselves.

Comments and reflections

The women with younger children all wish for them to get educated so they can take care of them selves. I think this is a common wish that parents for their children but that is more important to see to that it is fulfilled since they all know that they are suffering HIV. The situation differs for Patricia who wishes that she were in a better place to be able to give her daughter the strength she needs. This situation is stressful and affects Patricia very much. For Joanne have journey from being mentally ill due to chock from receiving the positive test turned out fine and she sees herself as happy which is an example for that you can live a happily life even though you are HIV positive. The creation of meaning to difficult situations has helped Nicky to live positively and finding strength for the future.

DISCUSSION

The purpose of this essay is to examine how the experience of living as HIV positive is and how HIV has affected life. As we have seen HIV has affected all the women and they all went through a crisis when receiving the positive result. Becoming HIV positive can be seen as a form of medical drama with both medical and psychological consequences. The women who participated in this study handle the fact of being HIV positive in a skilfully way. All of them allocate support in their social network and defuse being HIV positive. The most outspoken example of this is Joanne who said that she views HIV as any other illness. I would like to make the conclusion that the women are trying to make the best of their situations and that is where the name of the essay: Positively positive came out of. They try to think and live positive.

The fact that they all have started to look after their health to keep well and try to prolong life can be seen as a major change. Now when the fact of being mortal is obvious the women try their best to stay healthy. One thing that could have been pinpointed stronger is the necessity of finding meaning in what takes place. How can you see a meaning in getting HIV positive? The women were not asked questions according this matter but I think that in some of their stories you can see that fact of being HIV positive have given them strength and a new perspective of life. They have all adapted to the circumstances and started to live a new life with HIV. They take life as it comes. Which factors have made it possible for the women to adapt to the situation? I think it has a lot to do with the support they get and the fact that they all have people that rely on them e.g. their children and mothers. They have to stay strong to make sure that their children get what they need. All of the women believe in a higher power which gives them support and strength. I would like to see this out of a holistic point of view, psyche and soma, body and soul are connected and their believe make them stronger. You can get stronger by positive thinking, seeing the options and potential in things and situations instead of focusing on the negative and depressing parts of life. This could sound simplifying and absurd when you are in such a difficult situation as these women have been but according to some of them this is one of the strategies they use. I would like to describe the fact that all of the women have chosen to be open with their status a form of role exit. Ebaugh (1988) states that the role exit process gets started by doubts and questioning of the initial social role. In the women's case I would like to describe the decision making to be open with their status as a form of role entrance. They had the choice to keep their status a secret but decided to be open with it. For some of them it took time to reach this decision and this could be seen as a period of reconsideration and costs and benefits by coming out might have been evaluated.

According to symbolic interactionism we create our understanding of our daily life through interaction with others. The way we act depends on how we view our selves and is affected by interaction. The women all interact with persons in diverse situations and are affected differently depending on how they are treated. In some cases discrimination and stigmatisation have occurred and this have affected the women in different ways. They tend not to be bothered and try to be together with close friends or other persons with HIV. All of them were part of the same support group. I can see that some of the answers are alike and this might have to do with the participating in the group. This can be taken as a sign that the interaction in the group has affected the women's way of thinking and viewing their world.

The future might become brighter for the HIV positive persons in South Africa since the access to treatment hopefully will increase. HIV has become a part of many persons daily life and can be seen as a collective illness since it affects more persons than the one that are

infected. HIV/AIDS was and still is a private and shameful disease that now gets more and more out in the open. I think this openness and normalization of HIV/AIDS is a must for us being able to fight it. One of the women that participated in the interviews had been a victim for discrimination but after the people discriminating her received information about HIV/AIDS the discrimination stopped. In other words people need to be educated and informed to stop discriminating and get to know how the infection spreads and how you can protect your self and others from being infected. As seen in this essay the women knows how important it is to live healthy and try to be positive which is also an important part of saying well if you are infected.

It has been very interesting to meet these women and take part of their stories. I have been taking part in the journeys of six women who have made the travel from not being HIV positive to being HIV positive. From the start I did not know what to expect. I had met the HIV positive woman at the Red Cross last year and remembered her in that context. During the time of interviewing the women she was not on my mind. I thought the women I was going to meet would be more bitter and miserable due to their situation. The women I meet were strong and proud and tried to make the best out of their situation. This have shown me that even if you are infected and affected by HIV you can still live positively. I am very touched by what they told me and how they find the strength to carry on. During the writing of the result and analyse section I can admit that I started crying because of I got so touched. I have learned that it is important to value the life we have been given and try to make the best of our situations.

FURTHER RESEARCH

There are several new ideas that have appeared in my mind that would be interesting to dig in to. One thing I have been wondering is where are the HIV positive men? In South Africa more women than men are HIV positive and it seems to be more common that women take the test and are more concerned about their health. I asked Lorna Yoko if it was more common that women came out with their status. She said that it was the case and I asked her why she thinks it is like that. She thought it had to do with the fear of stigma and being discriminated and she also said that women are stronger and can handle the situation better. I think this might have to do with their net works and the closeness between women. It would be interesting to try to investigate if this is the case.

The relation between the client, the HIV positive person, and their consular is another area that can be researched. How did they get in contact, how does the client versus the consular interpret the relation, what does the relationship look like, what are the purpose, is the purpose reached, what does the help, support strengthening consist of, how and when do they meet, etc? This would be a relevant study to get to know what the HIV positive person need and wants from their consular and it would be interesting from a social work point of view.

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Dictionary

Nordstedts Stora svensk – engelska ordbok (1993)

Nordstedts Stora engelsk – svenska ordbok (1993)

ENCLOSURE

Interview guide.

- What was your life like before the positive test result?

Why did you decide to get the test?

Did you have any deliberation not taking the test?

What was the time waiting for the test result like?

When did you get to know that you are HIV positive?

- Reactions, intentions, actions, what did you do when you got the test result?

Do you have anyone to talk to and get comfort by?

Do you feel that you get the support you think you need?

Have you experienced the HIV as any kind of turning point?

- How does the awareness of the infection effect the way of life and the sparkle of life?

Do you view your life differently after the result?

Have you changed the way you organize your life?

How and where do you find the strength to carry on?

Are you open with your status?

Have you felt any discrimination or special treatment since you are HIV positive?

Do you experience any form of stigma from the society?

- Did a change of life course occur and role adjustments in to the role of being HIV positive take place?
What happened?
Which decisions did you take?
- Has the infection changed the way your look at your self?
The way you interact with others?
- What are your thoughts of the future?